

Long-term Outcomes of Services in Inclusive and Self-Contained Settings for Siblings with Comparable Significant Disabilities

Diane Ryndak
University of Florida

Terri Ward
College of St. Rose

Sandra Alper
University of Northern Iowa

Jill F. Storch and
Jennifer Wilson Montgomery
University of Florida

Abstract: A major goal of special education services is to prepare graduates for productive and rewarding lives as adults in the community. Follow-up studies, however, consistently have indicated very poor post-school outcomes for special education graduates. While there has been a wealth of research related to the effectiveness of services in inclusive general education settings for students of school age, few studies have investigated the impact of inclusive educational services on long-term outcomes for students with significant disabilities. The purpose of this study was to describe how two brothers with similar diagnoses involving significant disabilities and who had a 10-year age difference functioned in their natural settings as young adults after receiving services in the same rural one-building district. The older brother received special education services in self-contained settings throughout his school career, while the younger brother received special education services in inclusive general education settings. Qualitative data were collected through records, interviews, and field notes of observations. Findings suggest that the brother who received special education services in the school's inclusive general education settings achieved more positive long-term outcomes. Implications are discussed for future research and provision of educational services.

Many benefits of inclusive education for students with significant disabilities have been documented. A comprehensive list of the research in support of those benefits would be lengthy and reveal increases in appropriate social behaviors, increased interactions with others, more positive affect, increased friendships, and improved communication skills, as well as improved acquisition and use of academic content and an increased likelihood of participation in other inclusive settings (McLaughlin, Ryndak, & Alper, 2008). In contrast, although we have found literature that presents critiques of various studies about inclusive education and arguments that suggest

that inclusive education may have a negative impact upon learners (e.g., Sandler, 1999), we have found no research related to inclusive education for students with significant disabilities that provide learner performance data in support of those arguments. (For a summary of research regarding inclusive education see Fisher and Ryndak (2001); McGregor and Vogelsberg (1998); Ryndak and Fisher (2003).)

Fisher, Sax, and Jorgensen (1998) noted that in the United States the education system is expected to contribute to the preparation of children for the demands of adult life (p. 30) (see also Lipsky & Gartner, 1997). The expectation is that when students with disabilities exit school they will be prepared for successful and rewarding lives as adults, as consistently has been reflected in the literature (Alper, 2003; Fisher et al.; Karagiannis, Stainback, & Stainback, 1996; Kliever, 1998; Ryndak, Morrison, & Sommerstein, 1999).

Unfortunately, the results of follow-up stud-

Correspondence concerning this article should be addressed to Diane Ryndak, University of Florida, Department of Special Education, 1403 Norman Hall, PO Box 117050, Gainesville, FL 32611-7050. E-mail: dryndak@ufl.edu

ies of graduates of special education consistently reveal dismal outcomes. For example, following graduation, students with significant disabilities typically: (a) are isolated socially, with little contact with persons who do not have disabilities; (b) experience long periods of inactivity; (c) experience a low level of employment and, even when employed, seldom work full time and earn very low wages; (d) live with a parent, guardian, or relative; and (e) rarely are involved in activities outside of the home (e.g., Edgar, 1987; Haring & Lovett, 1990; Johnson et al., 1995). These results are consistent with findings from a comprehensive longitudinal report issued by the National Center on Disability and Social Security Administration in 2000.

With an emphasis on access to general education settings and curricula, accountability, valued membership in peer groups, and facilitation of friendships that may lead to natural support networks, inclusive education has been considered a practice that not only is consistent with civil rights, but also is a way to alleviate the discouraging outcomes for adults with significant disabilities. Although existing research indicates that inclusive education can benefit students with significant disabilities on a short term basis (e.g., Fisher & Meyer, 2002; Ryndak et al., 1999), there have been no follow-up investigations of the lives of adults with significant disabilities who experienced inclusive education for lengthy periods of time. Given the lack of long-term follow-up investigations, it is difficult to determine whether or not persons lead more satisfying lives as a function of educational services in inclusive or segregated settings. This investigation addresses this question by studying how two brothers with similar early diagnoses of significant disabilities functioned through age 17, although they received educational services in different types of settings in the same rural one-building school district.

Method

Two brothers with significant disabilities participated in this qualitative study. These individuals and the methods used to describe their experiences, services, and outcomes across time are described below.

Participants

Prior to this study, the first author had an ongoing relationship with the brothers and their family for approximately 11 years through the parents' advocacy for the development and implementation of effective services for their sons in inclusive general education settings. Mark and Jim were part of a family of seven (i.e., five children and two parents) who resided in a small town in a rural area of a northeastern state. All five children attended the same one-building public school district in their home town. The brothers had a 10 year age difference and received special education services in different types of settings – the older brother received services in self-contained special education settings until age 17, while the younger brother received services in inclusive general education settings until age 17. Because of their family relationship, initial diagnoses, and residence in a rural one-building school district, these brothers presented a naturally-occurring opportunity to study the long-term outcomes of special education services provided in different types of settings within the same family, community, and district contexts.

The first brother, Mark, was the eldest of five siblings. At age 3 Mark was considered to be at-risk of having disabilities and began to receive preschool services. At age 4 he was diagnosed as having significant disabilities and received services in self-contained special education settings through age 16. Throughout this time Mark's records indicated minimal to no access to peers without disabilities. However, while in high school at age 17 his access to high school students without disabilities increased to part of the school day. This access continued until the age of 21 when he exited school. Throughout his educational career, Mark was labeled as having mild to moderate cognitive disabilities. At the end of this study, Mark was 28 years old, labeled as having significant disabilities, and receiving job-related and personal support through the Medicaid Waiver Program.

The younger brother, Jim, was the fourth of the five siblings. He was identified at birth as being at-risk of having disabilities and thus received early intervention and preschool services starting at four months of age. During

his years in preschool he spent part of the week in a self-contained special education class and part of the week in a regular preschool class. From kindergarten through age 17 he continuously was included in general education settings. Throughout his educational career Jim was labeled as having multiple disabilities or moderate cognitive disabilities.

Data Collection

When Jim was 17 and Mark was 28, four of the co-authors used three qualitative methods to collect information related to their educational experiences and Mark's current performance and support as an adult. First, the co-authors worked with the brothers and their parents to obtain archival data relevant to their educational and adult services, as well as descriptions of the brothers' performance levels over time (Hammersley & Atkinson, 1995; Mason, 1996). These data included records of observations of both brothers periodically conducted by the first author over eleven years, school records, health records, and anecdotal records of numerous school personnel and adult services providers. Second, the co-authors used semi-structured interview protocols to interview the brothers, their parents and, when possible, their current service providers (Kvale, 1996; Mason; Rubin & Rubin, 1995; Strauss & Corbin, 1998). The current service providers for Mark included a paid adult services caregiver, while for Jim this included members of his special education team at school. Third, the co-authors conducted observations of the brothers in their naturally-occurring contexts (Bogdan & Taylor, 1975; Mason; Patton, 1990; Strauss & Corbin). Observations were conducted of Mark with his adult services caregiver in the community, of Jim across school contexts, and of both brothers with their parents at home.

Data Analysis

The records for each brother were organized chronologically. The set of records for each brother then was read several times by two of the co-authors, and codes were developed related to the content of the records (Kvale, 1996; Rubin & Rubin, 1995; Strauss & Corbin,

1998). These two co-authors independently coded the content of the records, and then met to compare their codes. When differences were found in the manner in which specific content was coded, the two co-authors discussed the differences and agreed upon how the content would be coded (Kvale; Rubin & Rubin; Strauss & Corbin). This sometimes resulted in the addition of a new code, or in clarification of the meaning of an existing code. Once these two co-authors agreed on how the content was coded, the content and codes were shared with two of the other co-authors. If questions arose about any of the codes, these four co-authors met to discuss the issue and reach consensus on the relevant codes for the content. When all of the records were coded, sections with similar codes were grouped and analyzed for meaning (Kvale; Rubin & Rubin; Strauss & Corbin).

Interviews were conducted and audiotaped by four of the researchers. While some interviews were conducted with one individual (e.g., a brother or a service provider), other interviews were conducted with more than one person present. For instance, the brothers' parents participated in a joint interview. Some interviews took two to five hours to complete and were conducted over two to three days. Other interviews (e.g., interviews with the brothers) took one to two hours to complete. Interviews were conducted using guiding questions established in an initial protocol (Creswell, 2003; Kvale, 1996; Rubin & Rubin, 1995; Strauss & Corbin, 1998), but with several probing points per question to encourage the interviewees to give complete answers with meanings that were delineated clearly. Whenever possible, the interviewees were encouraged to expand their answers, give examples that illustrated a point, and reiterate answers in another way in order to clarify their points (Kvale; Rubin & Rubin; Silverman, 1993). The audiotapes then were transcribed and submitted to the interviewees for verification and edits of the content. Changes then were made to the initial transcripts, reflecting the interviewees' feedback. The content of the final transcripts then was coded (Kvale; Rubin & Rubin; Strauss & Corbin) for analysis, using the same coding procedure used with the records.

Field notes were taken during and after

observations of the brothers by one to three of the co-authors (Hammersley & Atkinson, 1995). When observations were conducted with multiple observers present, each independently took notes. Current observations were conducted on multiple days, across multiple contexts, across two weeks. After these observations, the observers finished their independent notes and then discussed what they had observed. The observers then returned to their independent notes and made additional comments when appropriate (Hammersley & Atkinson). The same two co-authors who coded the records and interviews also coded the field notes using the same coding procedure used with the records and interviews (Hammersley & Atkinson; Kvale, 1996; Silverman, 1993).

Once the coding procedures and analyses were completed for the content of each set of data (i.e., records, interviews, field notes of observations), the co-authors used triangulation strategies across the data sets to increase the trustworthiness of the data analysis methods (Hammersley & Atkinson, 1995; Kvale, 1996; Mason, 1996; Silverman, 1993) and overall findings were articulated. These findings were sent to the brothers' parents for review (Mertens, 2005) and the parents were provided the option of reviewing the findings with the brothers. In either case, the parents were encouraged to make suggestions about edits, additions, and deletions that would either ensure that the findings were accurate or clarify any confusing points. This feedback was used to modify the findings.

Findings

School and district personnel in the brothers' one-building school district were stable over the years, resulting in many of the same professionals working in the school during the educational careers of both young men. In fact, some of the general and special education teachers in the high school had taught both brothers and the director of special education had held that position throughout each brother's attendance. In addition, the parents were very active in the education programs for all of their children and, therefore, had ongoing interactions with many of the school and district personnel.

In the following sections Mark's and Jim's educational experiences and progress are described in age-related categories, including the early years, the kindergarten and elementary years, the middle school years, and the high school and transition years. Tables 1 and 2 provide descriptors of the brothers across these age-related categories. Note that since Mark, the older brother, progressed through school 10 years ahead of his brother, Jim, occasionally his chronological age does not match the typical age at which most students have experiences in elementary, middle or high school. Where this occurs, clarifications have been provided in the sections below.

The Early Years: Birth Through Five Years of Age

Mark birth through five years of age. Mark was the eldest child in the family and was born after a normal nine month pregnancy and with no noted birth abnormalities. Although his mother stated that she was not aware of all aspects of child development when Mark was born, she did not notice a problem with Mark's overall development until he was three years old. She described Mark as an easy baby with some minor medical issues (e.g., ear infections) during his first year. Mark often was described as a tense toddler who cried frequently. In retrospect, after raising five children and having the knowledge learned from that, his mother stated that she should have noticed that Mark developed skills later than his peer group. For example, he started walking when he was 15 months old, and began toilet training after the age of three years. Given her later understanding of child development, his mother indicated that if Mark had not been her first born child she may have requested that her pediatrician test him earlier for developmental delay. However, since Mark showed no serious medical signs of disability, she believed he was a normally developing child. At the age of three years, Mark was labeled as being at-risk for developmental delays and was enrolled in a private preschool program that included children with disabilities. Though records during this time were incomplete, Mark's mother stated that he received occupational, physical, and speech therapy in a daycare setting. As Mark prepared

TABLE 1

Summary Descriptors of Mark Across Years

<i>Early Years: Birth to 5 Years</i>	<i>Kind & El Yrs: 5–11 Years</i>	<i>Middle School Years: 11–14 Years</i>	<i>High School and Transition Years: 15–21 Years</i>	<i>Adult Life: 28 Years</i>
Normal pregnancy; no birth abnormalities	Anxiety documented annually; 1:1 counseling annually for coping skills	Self-contained special education classes outside of school district annually	Self-contained special ed classes outside of school district for 2 years	Lived with parents and siblings
Described as a “tense toddler”	Easily frustrated with tasks; cried easily; difficulty changing routine	Counseling for developing relationships, coping with frustration, adjusting to changes in routines, decreasing self-injurious behaviors	At 17 accessed peers without disabilities in homeroom, lunch, and physical education; remaining time in self-contained class	Worked less than 15 hours per week
Walked at 15 months; toilet training begun after age 3	Slow academic progress; some IEP objectives repeated 5 consecutive years	OT, PT, Speech services provided primarily in segregated isolated settings	At 18 began attending general education classes; remaining time in community-based instruction	Relationships with family and paid caregivers – female only
Began OT, PT, Speech at age 3		Academic skills remain at K to 1st grade level	Counseling and SLP to develop relationships (esp. with males) and decrease anxiety	Remained anxious, wary of others, protective of belongings
Age 3 labeled at-risk of developmental delays				
Initial IQ score of 46; labeled with cognitive disability		Vocational assessment at age 13 with IEP shift to pre-vocational skills; projection of congregate care “community residence” as adult	2 nd grade reading level; IQ score of 61; 8 years 1 month on PPVT	Needed calendar to structure daily activities; completion of tasks <i>only</i> if on calendar
			Described vocationally as “not able to work independently;” “requires constant supervision to complete tasks”	Stated willingness to engage in social activities but was “too busy”
			IEP shifted toward acquiring skills in general education contexts after inclusion began; continued focus on job skills	

TABLE 2

Summary Descriptors of Jim Across Years

<i>Early Years: Birth to 5 Years</i>	<i>Kind & El Yrs: 5–11 Years</i>	<i>Middle School Years: 11–14 Years</i>	<i>High School & Transition Years: 15–21 Years</i>
Normal pregnancy with numerous birth abnormalities – cleft palate, microcephaly, possible cortical blindness, gastro-intestinal tube feeding	1 st year in Kindergarten – no special ed support; 7 months growth in receptive language (most growth to date)	Described as flexible; exhibited few anxiety-related behaviors	Navigated school independently; attended to tasks in classes; demonstrated curiosity of new tasks and content
Labeled as multiply impaired; Early intervention at 4 months with OT, PT, Speech intervention	2 nd year in Kindergarten – coordinated OT, PT, Speech, special educator support; a 1.9 year increase in receptive and 1.1 years in expressive language; reduced anxiety	Tolerated mild changes in routine without disruption; preferred set routines	“Hung-out” with classmates before, after, and during school; mirrored social cues; demonstrated flexible demeanor; comfortable interactions with numerous peers and adults
Self-contained pre-K in AM; day care with nondisabled peers in PM	Labeled with cognitive disability	OT, PT, Speech in both general education and pull-out settings	IEP focused on functional academics and communication with peers
A few months growth per year	2 nd grade – stopped services for anxiety	IEP goals focused on functional academics and keyboarding	Played drums in school band; participated on track & field team; played bells in church bell choir
Age 3 and 5 IQ scores of 40			
Significant delay at age 4 assessment of coping skills (2.6 year level)	IEP goals focused on participation in general education science, social studies, reading, and math	Participated in extra-curricular activities, with support when needed	9 th grade – dismissed from OT and PT Academic skills remained at K–2 nd grade level; IQ score of 46

to leave preschool services he was evaluated for disabilities and records indicate Mark had an intelligent quotient (IQ) score of 46. No specific reference, however, was made to the tests used to determine this score. Subsequently he was labeled as having a cognitive disability. The school district recommended a self-contained special education Kindergarten class that was directed by a regional special education cooperative and was located in a classroom rented in one of the surrounding school districts. His mother questioned the appropriateness of a self-contained class that was located 90 minutes away from his home.

Alternatively she requested that Mark attend Kindergarten in his one-building home school district, believing it would be more appropriate. Her request was denied by Mark’s school district and he was placed in the self-contained special education Kindergarten originally recommended.

Jim birth through 5 years of age. Ten years later Jim was born after a normal and uneventful nine month pregnancy and was the fourth of five children. He was diagnosed with a cleft palate, failure to thrive, microcephaly, and possible cortical blindness. In addition, his records indicated early concerns regarding

possible signs of Pierre Robin syndrome. Medical appointments and therapy sessions became part of Jim's daily life. He was labeled as having multiple impairments and began to receive early intervention services at home at four months of age, focusing on language and physical development. In addition, Jim was fed through a gastrointestinal tube prior to the repair of his cleft palate when he was two years old.

When he was 3 years old, Jim was labeled as having multiple disabilities and placed in a self-contained preschool program run by the regional special education cooperative. During his second year of preschool services Jim attended two programs — mornings he attended a self-contained language-based preschool program through the special education cooperative; afternoons he attended a general education preschool in his home town. When he was three and five years old Jim was formally evaluated for disabilities, resulting in a reported overall IQ score of 40 for both evaluations. Similar to his brother Mark, no specific tests were referenced in the records to indicate the original source for this intellectual score. In addition, Jim was assessed for anxiety with his coping skills evaluated to be at a 2 year 6 month level.

When he was exiting preschool services, Jim's mother again requested that her son be placed in a general education Kindergarten in his one-building home school district. As 10 years earlier with Mark, this request was denied by the school district. At this time the district stated that (a) Jim's intellectual abilities and coping skills were too low for him to demonstrate any benefit from being in an inclusive general education Kindergarten, and (b) his need for total communication strategies could not be met in a general education Kindergarten. Jim's parents invoked their due process rights, and refused to sign the IEP developed by the district, ensuring that he would be placed in general education classes until the disagreement was settled through a due process hearing.

The Kindergarten and Elementary Years

Mark 5–11 years of age. Throughout his Kindergarten and elementary school years Mark received special education services in

self-contained special education classes administered by the regional special education cooperative. His psychologists, therapists, and special educators reported that Mark was an anxious child, especially in new situations. Because of this he performed best during set routines. Mark was known to cry easily, seek adult reinforcement continuously, and become frustrated easily during demanding tasks. Records also indicated that Mark needed an adjustment period at the beginning of each school year before he spoke at school. By 7 years of age (i.e., 2nd grade) he was evaluated in relation to his anxiety and each year he received either one-to-one or small group counseling to facilitate the development of coping skills.

In addition to addressing anxiety and coping skills, Mark's early IEPs focused on the development of academic and social interaction skills within his special education classes. Although some IEP objectives were repeated over 5 consecutive years, the most consistent concern over time appeared to be Mark's level of anxiety, especially with males. He also remained nervous, cried frequently, and obsessed about changes in his routine. Most of his service providers, however, reported they were pleased with his incremental progress and repeatedly recommended that he continue in self-contained classes.

Jim 5–11 years of age. Ten years later, when Jim was in Kindergarten and Mark was in middle school, Jim's parents filed two due process complaints against the school district requesting that both Mark and Jim receive services in their one-building home school district alongside their neighborhood peers who did not have disabilities. While the impartial hearing for Jim was underway, the school district moved him from preschool to a general education half-day Kindergarten. His time in the Kindergarten was limited, however, because he was removed from the class for occupational, physical, and speech/language therapy, as well as resource room support. Records and interview transcripts verified an overall lack of coordinated support for Jim and no integration of related services in the Kindergarten class or activities. Jim's parents won their impartial hearing and he attended general education Kindergarten for a second year, but for both the morning and afternoon

sessions. During this second year his services were slightly more coordinated and professional development activities were provided for his educational team by an outside consultant. This was the only time in his educational experience that Jim spent more than 1 year at a grade level.

During his second year in Kindergarten, Jim's IEP focused on independent functioning and success in the general education environment, as well as on reducing his anxiety. In addition to support from a special educator, therapists, and a paraprofessional, Jim received one-to-one counseling weekly to address his anxiety. Although he was identified as having higher than normal levels of anxiety, Jim's education team believed the anxiety was due partially to his learning style. Interviews and reports indicated that Jim often would watch his classmates participating in a new activity before he began to participate, especially when the activities required motor involvement. Progress reports from his early intervention and preschool programs indicated that Jim consistently demonstrated growth of only a few months per year. Despite the lack of coordinated special education services during his first year of Kindergarten, records revealed that Jim made 9 months of progress in receptive language as measured by the Preschool Language Scale Profile (Zimmerman, Steiner, & Pond, 1969), while his expressive language level remained relatively unchanged. It was during his second year in Kindergarten that Jim made his greatest growth. Specifically, his receptive language level increased by 1.9 years and his expressive language level increased by 1.1 years. His end-of-year speech-language report stated that Jim no longer required the use of total communication strategies, as he was communicating effectively without those accommodations. Additionally, the end-of-year counseling report indicated that his level of anxiety had reduced significantly across all situations.

Following his second year in Kindergarten, Jim continued his elementary education in general education classes with 1 year per grade. His disability label changed from multiple disabilities to cognitive disability. Beginning in third grade, his IEPs focused on acquisition of academic content across all areas of the general education curriculum. Al-

though all curriculum areas were modified for him, the focus of his program became one of participation to the greatest extent possible in general education science, social studies, math, and reading. Similar to his older brother Mark, Jim continued to receive speech and language services, occupational and physical therapy, and counseling. Many of these services, however, were delivered in Jim's general education classroom, and counseling was removed from his IEP by second grade.

The Middle School Years

Mark 11–14 years of age. Mark continued to receive special education and related services in self-contained classes outside of his home district through the regional special education cooperative. Anxiety continued to be a concern for Mark and he continued to receive counseling in one-to-one and small group sessions throughout his late elementary and middle school years. His annual IEP goals related to counseling focused on increasing meaningful interactions with peers (i.e., both male and female peers, although interactions with males were of more concern), sharing experiences with peers, improving communication skills when faced with frustrating tasks, accepting changes in routine, and identifying and coping with social situations that caused him discomfort. Though IEP updates indicated that Mark made progress in these areas, subsequent IEPs continued to focus on them. In addition, Mark's IEPs included goals for decreasing unspecified self-injurious behavior, although records never indicated that he demonstrated such behaviors.

At the age of 13, when he was chronologically a 7th or 8th grader, Mark's reading and math scores remained at the Kindergarten to 1st grade level. Though his previous IEPs had focused primarily on acquiring basic math, literacy, social/behavioral, and language skills, Mark's IEP for this year demonstrated a significant change in the focus of his overall education program. Although functional reading and math were still part of Mark's educational program, his IEPs now had a very strong emphasis on the development of specific work skills, communication skills within vocational environments, and independent

living skills. When evaluated for vocational potential Mark was determined to be unemployable at an independent level and to have numerous deficits, including fine motor skills (e.g., pulling tabs off cans), sorting, matching, and collating. The vocational evaluation indicated that Mark would require extensive practice to acquire new vocational skills. Other concurrent reports predicted that Mark would require supported living services as an adult. His IEPs incorporated content such as: (a) mixing soil for plants in a greenhouse, (b) developing knowledge of floral designs, (c) using a phone in a vocational setting, (d) developing work-related behaviors, (e) reading help wanted advertisements in a newspaper, (f) counting 10 objects, (g) making simple sandwiches, and (h) cutting vegetables. It was also during this year that Mark began to attend a highly supervised segregated special education vocational setting, where he remained for 3 years.

Throughout his middle school years Mark continued to receive speech, occupational and physical therapy, and counseling. Over several years his speech and occupational therapy services increasingly were delivered in the segregated vocational setting, while his physical therapy continued on a pull-out basis, focusing on isolated activities to develop strength and coordination.

Jim 11–14 years of age. Throughout his middle school experiences ten years later, Jim continued to receive related services in general education contexts. Overall, his IEPs focused on functional academic skills, including the use of keyboarding skills and the development of 1st grade skills in reading, writing, and math. In addition, his IEPs addressed participation across school contexts, speech articulation, and overall length of meaningful communication with peers without disabilities. Jim also continued to receive occupational and physical therapy. Though some therapy sessions were held in pull-out situations, all of his services were designed to assist Jim in being successful in the general education curriculum and contexts. For example, his work on the development of keyboarding skills was related to Jim's meaningful writing in classes, and his work on fine motor skills related to his completion of class projects that required manipulation of materials, including writing im-

plements. Jim was described as a flexible young man who exhibited few, if any, anxious behaviors. He tolerated mild changes in his routine, although he worked best under, and preferred, a set routine. Essentially Jim demonstrated steady progress through his middle school years and no specific academic or behavioral concerns were identified by his educational teams.

When Jim was in 5th grade his parents requested and were provided information regarding school-sponsored extra-curricular activities. Jim began to participate consistently in those activities. All classes and extra-curricular activities in which Jim participated were regularly scheduled for his same-age classmates who did not have disabilities; supports, however, were provided for him during those activities. Throughout middle school Jim developed many positive relationships with his classmates and other peers who did not have disabilities. He did not, however, develop any close personal friendships that extended beyond school contexts.

The High School and Transition Years

Mark 15–21 years of age. After four years with a strong IEP emphasis on vocational training in the segregated setting, Mark turned 17 years of age. At that point his parents were dissatisfied with his level of educational progress and with the lack of connection between the content of his educational program and the life they envisioned for him after school. At that point they requested that Mark attend general education high school classes for part of the school day in his one-building home school district. Mark began to have access to high school students who did not have disabilities on the bus, during lunch, in 10th grade homeroom, and in 10th grade physical education. For the remainder of the school day Mark received 1:1 support either in a self-contained special education class in the same school or during community-based instruction. The following year his parents then requested that Mark attend only general education classes and community-based instruction and the district agreed. When he was 18 years of age Mark attended 11th grade general education classes, including biology, com-

puter applications, health, study hall, and physical education.

During this time there appeared to be confusion about the outcomes desired for Mark and, therefore, about his learning priorities. For instance, consistent with his placement in general education classes the content of his IEPs shifted dramatically toward the acquisition of general education curriculum content. Unfortunately, however, his special education support in general education classes was inconsistent in its effectiveness to facilitate meaningful access to the general education curriculum and instructional activities. In addition anecdotal records and reports from outside providers still focused on preparing Mark for noncompetitive employment in a sheltered workshop and group home services upon exiting school services. Consistent with this, Mark continued to receive community-based vocational training for two hours per day. His speech and language therapy and counseling services continued to focus on developing positive social relationships with both male and female classmates who did not have disabilities. While a counseling report emphasized Mark's increased ability to interact with female classmates, it reiterated concern about his continued nervousness around, and reluctance to interact with, all males.

Two years later, when Mark was 19 years of age, his IEP focused on developing language, social, and academic skills within general education courses, including English 12, social studies 12, consumer math, physical education, and driver's education. While in driver's education Mark did not actually learn to drive, but participated in all other aspects of the course. An IEP was developed for each general education subject area, delineating the level of participation and content acquisition expected of Mark in each unit per subject area. Mark also continued to receive vocational training from a job coach in community-based work sites (i.e., a local grocery store, video store). In spite of this support records continued to indicate that Mark was unable to work independently, and that he required constant supervision from the job coach or another employee. Mark's vocational goals and objectives also focused on his social interactions in the workplace and his ability to work with a variety of supervisors. In addition,

anxiety continued to be addressed throughout Mark's educational experience and he continued to receive one-to-one counseling for his anxiety through his high school years.

It is noteworthy that the content of the quarterly comments and yearly updates during Mark's high school years reflected a second major shift. For the first time school personnel focused on Mark's participation in general education courses and contexts, curriculum modifications, and level of engagement throughout school contexts with peers who did not have disabilities. Prior to that time no comments related to these variables were evident in Mark's records.

As Mark exited the education system, his formal evaluations indicated that he demonstrated an overall IQ of 61, an age equivalent score of 8 years 1 month on the Peabody Picture Vocabulary Test, and a 2nd grade reading level. His transition from school to adult life consisted of continuing to live with his parents and four younger siblings, and continuing to be unemployed. With the assistance of a job coach, he eventually was employed at a grocery store chain but was released from the position after two years, without indication as to cause.

Jim 15–21 years of age. Ten years later, when Jim was 15 years old and Mark had transitioned to adult services, Jim spent his first three years of high school included in general education courses with special education support for modifications in curriculum content, materials, instruction, and assessment. His IEPs continued to focus on functional academics and communicating effectively with peers. Of particular interest to him were classes and experiences related to music and chorus. This interest extended to after school hours when he played the drums in the high school band and participated in a bell choir at his church. Outside observers who conducted ecological assessments remarked on Jim's ability to navigate the school, freely interact with peers, focus on class assignments, and act upon his curiosity about new experiences. By the end of his 9th grade year he no longer received either occupational or physical therapy.

The IEP for his junior year reflected approximately 1.5 hours a day of special education support in his general education classes.

There was, however, a clear contradiction between on-site observations and the IEP. Although Jim had been served in general education in past years and the current IEP stated that special education services were to be provided within general education classes, his special education teacher stated that she was not in favor of inclusive education and had decided to provide instruction for Jim in the special education classroom during the 1.5 hours per day he was to receive support. During an interview with one of the co-authors the special education teacher stated that while she had limited knowledge of Jim's brother and his outcomes upon exiting school, she believed that Jim should receive services in a segregated classroom, just like his older brother.

In spite of this discrepancy, Jim participated in school-sponsored extra-curricular activities, including marching band, track and field, and student clubs (e.g., Students Against Driving Drunk). Except for the undocumented time that the special education teacher removed Jim from his general education classes during his junior year, Jim's high school experience had focused on participating in meaningful ways with chronological age peers who did not have disabilities in general education contexts. He received no separate instruction related to vocational preparation or transitioning to adult life in the community. Data collection for Jim stopped with his junior year in high school, when he was 17 years old. No data, therefore, is provided for Jim from the ages of 18–21 years.

Final Observations

Mark in adult life. At the age of 28, Mark continued to live with his parents and 4 siblings. He later was employed less than 15 hours per week in the kitchen of a pizzeria. His mother had found this position for Mark, as well as procured support from a job coach. He was described as anxious in most situations, and demonstrated this anxiety during observations by three of the co-authors in naturally-occurring settings, even with family members present. For instance, Mark: (a) shifted his focus between people and objects quickly; (b) watched others in the setting in a surreptitious manner, as if wary of what they

were going to do; (c) removed and hid his possessions that initially were evident in the environment; and (d) frequently questioned what people in the environment were doing, especially in relation to him and his possessions. Mark engaged in conversations only when they were initiated by others, and he limited his responses to a sentence or two. At numerous times Mark commented that he did not enjoy working or interacting with men. While Mark had received counseling for this throughout his educational experiences, it continued to be of concern both to him and to those with whom he interacted. When at home, Mark preferred either to (a) be alone in his room where he listened to music or watched his own videos, or (b) work alone outside with his family's chickens and ducks.

Although Mark had a part time job, he had very few other activities in which he participated outside of the home. Support from adult services provided him with a paid female caregiver for six hours a week. She facilitated Mark's participation in activities both in the home and in the community. With her support Mark shopped for groceries, cooked meals, and went bowling weekly. The fact that the paid caregiver was female was an important factor, since Mark continued to be more wary of, and less responsive to, males. When asked if he would enjoy more social activities, Mark stated that he was very busy and could never find the time to do things, in spite of needing only 2 hours per week for his job and time with his paid female caregiver. Mark completed only tasks written on a calendar of daily tasks.

At the time of this study, the state agencies were erecting an apartment building for a supported living program for approximately 10 adults with disabilities. The advocacy for this program had been initiated by Mark's parents when he was of middle school age. Their advocacy resulted in Mark being on the waiting list for this program and it was expected that he would move into this program as soon as the building was completed. In addition, Mark's parents anticipated that he would continue to work part-time in the community throughout his adult life.

Jim in 11th grade. As indicated in the previous section, during 11th grade Jim officially was included in general education courses

with special education support for modifications, although his special education teacher provided that support in a segregated special education class for 1.5 hours per day. In addition Jim participated in numerous school-sponsored extra-curricular activities. Speech-language therapy services had been decreased to twice a week for 30 minutes. His last reported IQ score was 46 on the WISC III (Wechsler, 1991) and he performed academically at a K-2nd grade level. His Medicaid Waiver evaluation during 11th grade described his involvement with numerous clubs at school and in the community, and the level of ease he demonstrated when interacting with peers and adults throughout the school. When observed Jim spent unstructured time with his peers who did not have disabilities, joined groups of students outside the school building and, just like his peers, “hung out” until the school bell rang for students to enter the school and prepare for homeroom. During this time he joined a group of students from the school’s marching band. Although his interaction with each peer was short, he exchanged “high-fives,” smiles, and verbal greetings with several students. When the other students were engaged in informal conversation, Jim laughed at appropriate times and mirrored the body movements of his peers. Essentially, Jim blended into the social milieu of his peers, so that an observer would not have identified him as having disabilities without prior information. Jim joined his peers in independently entering the school, finding and using his locker appropriately, and proceeding to homeroom. Throughout these activities Jim appropriately greeted both school personnel and other students in the hallways, blending into the social context.

Upon entering classrooms, Jim continued to demonstrate an awareness of and appropriate response to the expectations within each context. He prepared for and participated in class activities in ways that matched his peers who did not have disabilities (e.g., gathering materials, copying information from the blackboard, following verbal instructions), although his instructional goals and materials were modified.

General Findings

For the findings discussed above to be meaningful, the educational experiences and performance of Mark and Jim need to be reviewed and analyzed over time. These reviews and analyses are briefly discussed for each brother in the following sections.

Mark’s experiences and performance over time. Unfortunately, Mark’s overall performance on academic, social, and vocational skills did not appear to change significantly over time. Initially, he was described as an irritable baby who cried often. While the crying behavior diminished with age, other related behaviors (i.e., anxiety; nervousness) were manifested during his middle school, high school, and adult years. Though counseling to address his anxiety occurred throughout his educational career, Mark continued to display uneasiness in social situations into his adult life. He continued to live with his family, though he was making plans to live in an apartment of a supported living program in his home community. Beyond his activities with family members, his social or networking activities were with one female caregiver who was paid through the Medicaid Waiver.

Although his early standardized testing indicated a moderate level of cognitive disability with an overall IQ of 46 (i.e., six points higher than that of his brother), Mark’s last set of tests reported an overall IQ of 61, which was 15 points higher than that of his brother. While his reported IQ score increased over time, Mark’s assessed reading and math levels continued at or below a 2nd grade equivalency level.

Although his IEPs began to address vocational and work-related behaviors at the age of 13, vocational evaluations reflected a clear expectation that Mark would not develop skills that would make him competitively employable. At 28 years of age Mark was employed for less than 15 hours a week at a local pizzeria with the support of a job coach twice a month.

Jim’s experiences and performance over time. Jim’s performance changed significantly over time. He demonstrated an increase in independence and participation in daily life at his school, in his community, and at home. Although when compared with his older brother, Mark, more physical complications

were evident at Jim's birth (i.e., a cleft palate, a gastrointestinal tube for feeding, demonstration of failure to thrive, microcephaly, possible cortical blindness), these challenges were overcome and did not appear to have long-term impact on his involvement in the general education curriculum and extra-curricular activities at school. Though his overall standardized academic scores remained far lower than those of his older brother, Jim was more able to follow large group routines, use environmental supports and peers to seek answers to questions, and engage in a meaningful way in instructional activities related to the general education curriculum.

Although both Jim and his older brother were identified early in life as having high levels of anxiety, Jim's services and goals related to anxiety completely faded from his IEPs and records by 3rd grade. Though when in 11th grade Jim still preferred consistent routines, he was able to tolerate schedule changes. In addition, he attended to the cues of others regarding social behavior, and demonstrated social competence when moving about his school, community, and home. This was a marked contrast from his older brother's behavior across environments and situations.

Jim's educational files did not reflect any specific vocational goals or objectives. Nor were there any predictions as to Jim's ability or inability to be competitively employed in the future. Though it is too early to study Jim's educational outcomes related to vocational skills, employability, independent living skills, or social networks in the community as an adult, the progress he demonstrated by the age of 17 was significantly more substantial than his brother's progress.

Discussion

One argument that has been provided for developing inclusive education practices for students with significant disabilities has been that inclusive education practices are consistent with the students' civil rights, focusing on equal opportunity for access to general education curriculum, instruction, materials, and activities. This access has led to the inclusion of students with significant disabilities in state and district assessments and accountability sys-

tems, and has facilitated development of friendships with same-aged peers who do not have disabilities, leading to equal membership in peer groups and more extensive natural support networks. Finally, it has been hoped that through access to general education, accountability systems, and membership with peers in natural support networks the long-term outcomes for students with significant disabilities would be more positive than has been indicated in past follow-up studies.

The purpose of this study was to compare the long-term outcomes of services for two siblings with significant disabilities who had similar early diagnoses. While the brother who had attended inclusive school settings seemed poised for more positive post-school outcomes, the results must be viewed in light of the following limitations. First, descriptive data were collected and analyzed on only two individuals using case-study methodology. This small set of participants and methodology do not allow for generalization of findings to other individuals with significant disabilities. Second, while the authors collected data over time from multiple sources, no causal relationships between school placements and long-term outcomes are implied. We are aware that there are a myriad of individual student characteristics, setting characteristics, attitudes, and expectations of family members that surround any individual that may interact to influence post-school outcomes. The comparisons of outcomes addressed in this study occurred naturally in the lives of the two brothers. No effort was made to control for other variables that might account for the differences found. For instance, limited information was gathered in relation to the services provided in either the self-contained special education classes or the inclusive settings. No attempts were made during this study to influence the quality, type, or amount of those services, nor the availability or quality of the adult services.

In spite of these limitations, the brother who received inclusive services in general education contexts demonstrated more skills that were critical both to interacting with peers and adults who did not have disabilities, and to functioning independently across contexts, including at school, at home, and in the community. In addition, this brother acquired

and used knowledge and skills in meaningful naturally-occurring contexts. As he became a young adult, he developed and maintained a life that more closely approximated that of his same-age general education classmates, even though his IQ and achievement test scores were lower than those of his older brother who received special education services in self-contained classes until he was 17 years of age.

It could be argued that the presence of a deeply involved parent advocate who over time had learned about child development, inclusive education, and the rights of students with disabilities could have accounted for differences between the educational experiences and progress made by her two sons. In his classic studies of adults with disabilities who had moved from institutional to community living environments, Edgerton (1967, 1978, 1984) discussed the influence of a "benefactor" on the lives of those individuals. This study seems to support that concept. Undoubtedly, the fact that the brothers' parents increasingly called for inclusive educational services over the years and exercised their due process rights when not satisfied with their sons' educational services impacted the nature and quality of services received by their younger son. Their role as advocates argues for the ongoing involvement of parents and others as benefactors who ensure that special education and related services, as well as adult services, provided for individuals with significant disabilities reflect each individual's needs and assist each individual in acquiring and maintaining a high quality of life. While most often advocates are students' parents, other family members, or guardians, any interested individual (e.g., teacher, paraprofessional, counselor, family friend) might serve in this role (see, for example, Alper, Schloss, & Schloss, 1995). In addition, the expectations of adult service providers, including vocational and home living personnel, appear to have become more positive. At one time expectations for adults with significant disabilities remained restricted to congregate care residential placement, adult day care, and sheltered, if any, employment. Today, it is more the norm for adult service providers to strive for the goals of independent or semi-independent living in the community and supported employment that leads to competitive

employment, as we have learned about the capabilities of persons with significant disabilities when appropriate training and supports are provided (Rizzo, 2002; Wehman 2006; Wehman, Brooke, Green, Hewett, & Tipton, 2008; White, 2004). Additional research is required, however, to understand the influence of the presence or absence of a "benefactor" in the lives of individuals with significant disabilities.

Another variable that might have influenced the outcomes achieved by the younger brother in this study was access to and participation in activities that fostered the development of self-advocacy and self-determination. While not specifically considered in this study, Jim, who was included in general education contexts, had access to role models without disabilities who were developing and using self-advocacy and self-determination skills in their daily lives. The mere access to these role models may have facilitated development of these skills. Additional research, however, is needed to assist in our understanding of the influence of such models in inclusive settings.

It would be simplistic to argue that placement in inclusive settings in and of itself leads to more positive outcomes. Post-school adjustment is undoubtedly determined by a complex set of interrelated factors. It seems likely that best practices in inclusive education, the presence of on-going benefactors/advocates who hold high expectations, and instruction in self-advocacy and self-determination skills all work in harmony to yield positive outcomes.

While the findings of this case study suggest that, when compared with services in self-contained special education settings, providing special education and related services in inclusive general education settings may lead to better outcomes for students with significant disabilities, these results must be viewed with caution. Considerably more research that involves many more individuals with significant disabilities over multiple years is needed before widespread conclusions can be derived about the efficacy of services in these settings. Until such research is conducted, however, this study offers encouragement that the current trend to include students with significant disabilities in general education contexts can lead to positive long-term outcomes.

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Received: 3 September 2008

Initial Acceptance: 8 November 2008

Final Acceptance: 5 February 2009