i.e.: inquiry in education

Volume 4 | Issue 1 Article 5

6-25-2013

Full-inclusion as a Lived Experience: The School Career of Martin Schaeffer

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Full Inclusion as a Lived Experience

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Purpose of the Study

Rarely in American education do we examine the impact of federal and state education legislation and policy as it relates to a single individual's school career. The purpose of this paper is to do just that. The questions addressed in this study are: What was the inclusion experience like for the student, his parents, and educators? What was the actual outcome of the full-inclusion experience? Did the student benefit from full inclusion and make a successful transition into adult life? These questions are examined through the school career of Martin Schaeffer, an individual with severe and multiple disabilities, who was fully integrated into general education from first through twelfth grades. Martin is the subject of study because his story details the challenges of full inclusion, including the political and advocacy challenges for parents and educators. Further, Martin's story was chosen because the outcome of his experience was very positive. Rendering a positive portrait of full inclusion is important at a time when postsecondary outcomes for students with disabilities are poor. Now twenty-two years of age, Martin is successfully completing a baccalaureate program at a university. Martin's school career provides a window into the Individualized Education Program (IEP) and full inclusion as a lived experience.

Rendering a positive portrait of full inclusion is important at a time when postsecondary outcomes for students with disabilities are poor.

Method of Study

Inquiry into the school career of Martin Schaeffer requires a qualitative research approach. In this research model, Martin, his parents, administrators, teachers, and related service providers were interviewed about their experiences from first grade through high school. Interviews were recorded and verbatim transcripts provided a rich data base of experiences. Interviewees signed an informed consent prior to the interviews. Transcripts were analyzed for themes, patterns, and issues important to the interviewee. These data were triangulated with case study evaluation documents, and IEPs. Document artifacts contained within the comprehensive case study evaluation included pre-Kindergarten through high school educational reports, including: psychological reports, medical reports, social developmental studies, correspondence, grade reports, and other pertinent school records. Field notes constructed contemporaneously to interviews were also data for analysis and interpretation.

Confidentiality

Martin Schaeffer is a pseudonym to protect his actual identity. Similarly, characters in the story have had their names changed. The actual school districts and communities have also been changed.

The Literature of Mainstreaming, Regular Education Initiative, and Inclusion

In 1975, the United States Congress passed the Education for All Handicapped Children Act (EAHCA), often referred to as Public Law 94-142. Apart from the Elementary and Secondary Education Act (1965) and Title IX of the Civil Rights Act (1972), EAHCA was one of the most far-reaching pieces of federal education legislation to be enacted in American educational history. It was a dramatic legislative act that brought into the educational system approximately a million students who were barred from public education solely on the basis of their disability (Alexander & Alexander, 2005). Rothstein and Johnson (2010) contend that three million students with disabilities did not receive appropriate educations during this time. Building on a civil rights agenda that began with *Brown v. Board of Education* (1954), and based on *Pennsylvania Association of Retarded Citizens v. the Commonwealth of Pennsylvania* (1971), *Mills v. Board of Education of the District of Columbia (*1972), and the Vocational Rehabilitation Act of 1973, EAHCA imposed a strict set of federal rules and regulations regarding free appropriate public education (FAPE), least restrictive environment (LRE), nondiscriminatory evaluation, IEPs, due process, continuum of educational services, and zero reject on public schools across America. EAHCA was sweeping in its impact, particularly with the multitude of United States Supreme Court decisions that flowed from ambiguities in the language of the act that had to be clarified, interpreted, and ultimately enforced.[1] Further, an important Appeals Court decision, *Timothy W. v. Rochester School District* (1989), made it indelibly clear that all children with disabilities must be served under EAHCA regardless of the severity of disability. Since its passage in 1975, the federal special education act was renamed

[1] *Board of Education v. Rowley,* 1982; *Independent School District v. Tatro,* 1984; *School Committee of the Town of Burlington v. Department of Education of Massachusetts,* 1985*; Honig v. Doe,* 1988*; Florence County v. Carter,* 1993*; Sacramento School District v. Holland,* 1994*; Cedar Rapids Community School District v. Garret F.,* 1999*; Schaeffer v. Weast,* 2005*;* and *Forest Grove School District v. T.A.,* 2000.

the Individuals with Disabilities in Education Act (IDEA) in 1990, and reauthorized in 1997 and 2004.

With EAHCA came a debate and discourse about the mainstreaming of students with disabilities into general education classrooms. With the mainstreaming model (Dunn, 1968), students with disabilities were integrated into general education, but mainstreaming was only partly successful as a service delivery system. While many students with mild learning handicaps were educated alongside students without disabilities for most of the school day and benefitted from mainstreaming, many students, particularly students with moderate to severe disabilities, were served in special education instructional programs, self-contained classes, and alternative education settings, or institutions. With leadership from the Office of Special Education and Rehabilitation Services (OSERS) of the U.S. Department of Education, the Regular Education Initiative (REI) proposed making the boundaries between general and special education more flexible, and promoted the notion that all educators had a responsibility to serve students with disabilities (Will, 1985). Like mainstreaming, REI had limited success. Some progressive educators forged alliances between general and special educators to increase the number of students with disabilities in general education. However, the very same tensions that limited mainstreaming also limited REI. That limitation was the resistance of many general educators to serving students with disabilities in their classrooms, some parents of students with disabilities who feared an erosion of entitlement services, and lack of training and professional development for general educators in serving a more diverse student body. The limitation was also a reflection of the lack of training and professional development in collaboration and consultation skills for special educators to support their general education colleagues. The result was that REI became little more than an expanded mainstreaming model, largely serving students with mild disabilities.

The professional discourse and debate of the 1980s included calls for unitary administration of general and special education (Lipsky & Gartner, 1987; Reynolds & Wang, 1987; Stainback & Stainback, 1984). As a new educational subsystem, special education was administered as a separate entity. A number of scholars and practitioners complained that special education was the repository for the hard-to-teach and that over-referral to special education was symptomatic of both educational and organizational challenges (Deno, 1970; Skrtic, 1991). This was especially apparent in the over-representation of students of color in special education, as African American and Hispanic students were often found in self-contained classes for students with behavior disorders, learning disabilities, or cognitive impairments. Advocates of a unitary administrative system argued that by bringing all compensatory education services under one roof, special education, Title One Reading and Math, and English as a Second Language Program could be more efficiently and effectively administered. There was by no means a consensus to implement such a model. Indeed, there was a significant backlash (Mcleskey, 2007). A number of scholars argued that the merger of general and special education was, at best, naïve, and, at worst, reckless (Kauffman, 1988; Lieberman, 1985; Messinger, 1985). However, it was within this context that full inclusion of students with disabilities was promoted by parents and educators of students with moderate to severe disabilities (Gartner & Lipsky, 1997; Skrtic, 1991; Stainback & Stainback, 1984; Villa & Thousand, 1995). The inclusion movement spanned the mid 1980s through the turn of the century. Proponents argued that all students, regardless of the severity of disability, should be educated in their neighborhood school with chronological-aged peers. A

radical proposition, the inclusion movement generated a passionate and often fierce debate among parents, educators, and policy analysts. Many school districts adopted this service delivery model, integrating some of the most severe and multiply disabled students in general education. Many schools also resisted the idea, arguing that the idea of full inclusion went too far. Opponents of full inclusion pointed out that the Least Restrictive Environment clause made specific provision for students who would require more support and structure than could be provided in a general education classroom (Kauffman & Hallahan, 1995). The debate over full inclusion continues to this day.

Elementary School and Full Inclusion

Dr. Joseph Reinhart was the Director of Special Education for Lakeview Elementary School District, a newly incorporated school district formed by plebiscite when one of the three predecessor elementary districts declared bankruptcy. On his first morning on the job, Reinhart found a stack of student records left by his predecessors. These were the records of students with complex needs the previous director decided to pass on to the new Lakeview director for decision making. After scanning the files, Dr. Reinhart selected the thickest file for review. It was the file of Martin Schaeffer.

An experienced administrator and state due process hearing officer, Reinhart had conducted hundreds of file reviews in his career. As he read through the records, Reinhart learned that Martin was a typically developing infant, until he contracted post encephalitis syndrome at two weeks of age. According to school records, the virus settled in the basal ganglia, which caused an infarction and resulted in brain injury. The report went on to say that Martin's symptoms were much like that of a child with cerebral palsy. The medical record indicated Martin's medical diagnosis was "spastic quadriparesis, secondary to neonatal encephalitis." As a result of injury to the cerebral motor cortex, Martin's overall motor functioning was severely compromised. He had extremely compromised muscle control due to tightened and stiffened muscles and muscle spasms. Additionally, the ability to swallow and vocalize was also compromised. As a result, Martin was completely dependent upon adults for his care. Speech and language development was severely limited. With the exception of yes and no responses, Martin was virtually nonverbal. School records further revealed that the task of caring for Martin was extremely challenging, as he needed to be repositioned multiple times during the day and night. Mr. and Mrs. Schaeffer were very proactive in obtaining early intervention services for Martin through a private clinic. Physical therapy, occupational therapy, and speech language therapy were essential. When Martin completed early intervention services, Mr. and Mrs. Schaeffer created their own therapy team, and therapists regularly came to the Schaeffer home to provide various therapies. When Martin was three years of age, a special education case study evaluation was conducted and he was found eligible for early childhood special education services, which were sponsored by the local school district but provided by the Regional Special Education Joint Agreement (RSEJA). As Martin matured, he matriculated to Kindergarten at Twin Rivers Elementary School (TRES).

While this school had considerable experience with students with physical disabilities and health impairments, and the principal was a former special educator, Mr. and Mrs. Schaeffer were dissatisfied with Martin's education at TRES. Within the case study record, Dr. Reinhart found a

series of letters written by Mr. and Mrs. Schaeffer to the superintendent of the RSEJA. Mr. Schaeffer, a personal injury attorney, carefully crafted critical letters posing questions to the superintendent about Martin's education and care. From bus transportation to consistency of care to augmentative communication and literacy, the Schaeffers believed that Martin was receiving a less than adequate and appropriate education. Responses from the RSEJA superintendent were either vague or not forthcoming. After reading the letters and the comprehensive case study, Reinhart saw a due process hearing was inevitable over FAPE and LRE.

Realizing the matter was conflict-ridden, Reinhart invited Mr. and Mrs. Schaeffer to meet with him at the Lakeview district office. Reinhart explained that he was interested in their perspective of their son's education, and for two hours Mr. and Mrs. Schaeffer related Martin's history and their concerns about the adequacy of his education at TRES. The parents felt it critically important to impress upon Reinhart that Martin was not mentally retarded. In their view, people who saw Martin in a wheelchair with an alternative augmentative communication device generally assumed he was mentally retarded. They were insistent that he was not, as evidenced by his capacity for humor.

In their conversation, the Schaeffers related four issues that were of significant concern to them. The first issue of concern was safety regarding special transportation. The parents related that bus personnel sometimes failed to secure Martin's wheelchair, and they thus feared a tragic accident might occur. They also described an incident in which a school bus driver, unable to calm Martin when he was crying, threatened not to take Martin home if he did not stop crying. As a result, Mrs. Schaeffer assumed responsibility for driving Martin to and from school each day. Although Martin remembers little from this time, the trauma of this event was etched in his and his parents' memories. For Martin, this was a terrifying experience that exposed his complete vulnerability to an insensitive district employee. For his parents, this raised the serious question of whether the school district could be trusted to safely transport and care for Martin.

The second issue was consistency of care and education. The Schaeffers noted that a family friend, who had a child in the Physically and Health Impaired Program at TRES, found Martin and other children left lying unattended on a filthy floor mat. Mrs. Schaeffer told of visiting the first grade classroom and meeting the teacher at TRES, and it was her impression that the teacher was very competent, but the size of the class and the special needs students enrolled in the class would not allow her to give Martin the attention he would need and therefore adequate services.

The third issue for the parents was literacy. Alternative augmentative communication (AAC) systems were just emerging, and they were upset with the RSEJA for failing to be proactive in hiring a speech language pathologist with strong AAC training. Since Martin was using a Light Talker, a device involving a light beam attached to a head band that could be focused on an icon on a laptop computer, Mr. and Mrs. Schaeffer complained that the staff was insufficiently trained in the use of the system. Mrs. Schaeffer described coming to school to pick up Martin to find staff indicating the Light Talker wasn't working. Mrs. Schaeffer quickly diagnosed the problem and made the Light Talker operational. Further, Mr. and Mrs. Schaeffer related that the RSEJA had finally hired someone with good AAC skills, but did not retain her. They speculated that this professional's training was a threat to TRES and RSEJA staff because her ideas about the effectiveness of the program differed from that of the administration. Overall, the Schaeffers

expressed concern that Martin had no incentive to use his AAC system, and, if he did not, he would have no way to express himself, much less develop literacy and numeracy skills.

The fourth concern they related was their ability to work in collaboration with TRES and RSEJA personnel. The Schaeffers chaffed at what they considered an unspoken RSEJA agenda to maintain the program's structure. Despite being well educated and knowledgeable about Martin's condition, the Schaeffers felt "bamboozled" in IEP meetings. Despite the fact that Mr. Schaeffer was an attorney, he was not educated in special education law and regulation, and thus was confused by the language employed by the special education professionals. At a time when the full inclusion debate was being operationalized at the local school level, it was the Schaeffers' view that Martin's inclusion in general education was more symbolic than real. The Schaeffers were looking for meaningful integration into a general education classroom. However, in their view, they did not think this was likely to happen at TRES.

To the Schaeffers' surprise, Reinhart agreed with them that Martin needed to be fully integrated into first grade. Reinhart observed the critical incentive for Martin to use his AAC system with peers, which could only be found in a general education first grade classroom. Reinhart further expressed his view that the relationship between the Schaeffers and the RSEJA staff was so contentious that Martin's best interests would be served by getting a fresh start in the Lakeview Elementary District. Reinhart and the Schaeffers concluded their meeting with the understanding that Reinhart would initiate an IEP meeting with TRES and RSEJA with a plan to transfer Martin from TRES to first grade in the Lakeview School District.

With that, Reinhart convened an IEP meeting with all of the stakeholders involved with Martin and facilitated a consensus decision to enroll Martin in a Lakeview general education first grade class. While the ideal situation was to enroll Martin in his neighborhood school, the reality was that this school was built in 1910 and Martin, a wheelchair user, could not access the building. Lakeview had only two elementary schools that were single story with easy access for wheelchair users. One school, Lakewood Elementary School, had successfully embraced a program for children with hearing impairments and prided itself on the faculty's creative ways of including students with disabilities in general education classes. As fortune would have it, Reinhart had a relationship with the principal, who had been a colleague in doctoral study. As a result, he figured the best place for successful inclusion of Martin in first grade was at Lakewood Elementary. He therefore initiated a meeting between the Schaeffers and Lakewood Elementary School principal, Peter Morino.

While the decision to implement full inclusion had been made by the IEP team, the details of the process were complicated for several reasons. First, there were significant trust issues between the Schaeffers and school personnel in general. They had been soured by their experience with the RSEJA and feared that a similar circumstance could arise in Lakeview if they did not have significant input and control over certain processes. In particular, the Schaeffers wanted nothing to do with RSEJA personnel. They were clear that they could not work with the cooperative's speech language therapist, occupational therapist, physical therapist, or social worker. Further, in their view, the decision to hire a one-to-one teacher assistant was critical, and they expressed a desire to be part of the interview and hiring process. As this was something that had not been done by the predecessor school districts or by the RSEJA, parental involvement in the hiring

process was a departure from the past. Given the uniqueness and complexity of Martin's needs and the Schaeffers' special knowledge of their child's disability, the inclusion of parents in this decision making presented a unique challenge and opportunity.

[Morino] would comment in an interview some years later, "If we could educate Martin, we could educate anybody."

Second, although Lakewood Elementary had a long tradition of including students with hearing impairments in general education classes, these students were not fully included, as Lakewood operated a mainstreaming model of special education. The principal, Peter Morino, nonetheless worked hard to integrate the hearing impaired program into the school culture. Sign language classes were offered as professional development for general education staff, and students with hearing impairments were regularly involved in assemblies and holiday events. While Morino was not satisfied with the level of integration, he was clearly committed to community building. As partially included students, the hearing impaired program within the building was home base for these students and their teachers. Martin Schaeffer represented a different challenge, one of full inclusion. Indeed, Morino saw Martin Schaeffer's enrollment as a unique challenge. He would comment in an interview some years later, "If we could educate Martin, we could educate anybody."

Third, a process had to be developed to ensure clear, open, and transparent communication. This required that the parents, Reinhart, Morino, and the Lakewood staff work closely together on virtually everything that needed to be communicated about Martin's needs. The devil, they all knew, was in the details.

Fourth, Martin's full inclusion represented a leadership and management challenge for Reinhart. As a central office administrator, he did not want to be seen as micromanaging this process or for this process to be seen as imposed by central office administration. In a new district and in a new leadership role, Reinhart was cognizant of how tensions between the central office and the school could sabotage even the best laid plan.

To address these challenges, Morino and Reinhart made several decisions together. The first was assigning Martin to a classroom with a teacher that would be open to full inclusion. In Morino's view, a new first-year hire, Karen Ward, was the appropriate teacher, given her personality and her background in previously working with students with disabilities. The second decision involved making the parents full members of the interview team in the hiring of the one-to-one teacher assistant. A third decision involved related services personnel—speech language therapy, physical therapy, and occupational therapy. Reinhart took it upon himself to hire the Schaeffers' private therapy team, reasoning that the process would go much smoother if an already intact team was available to help Martin, his first grade classmates, and Karen Ward. Additionally, Morino and Reinhart reasoned that the Lakewood Elementary School social worker was fully capable of working with Martin, his family, and his teachers. This left a final decision that had to be made, and that involved a communication process between all the personnel working with Martin. It was agreed that the team would meet once a week to discuss Martin's progress, and that Morino would lead the team meetings. Importantly, Morino did not think it was important or even prudent to make a prior announcement of Martin's enrollment in Ms. Ward's class. Martin

was simply another first grade student. Over the course of the first grade year, team meetings occurred on a weekly basis. These meetings, unusual for most elementary school special services teams, were necessary to build a cohesive team, facilitate trust with the Schaeffers, and ensure open and clear communications. Morino was a critical factor in ensuring that open and transparent communication occurred between team meetings, as well as making sure that team decisions were implemented and evaluated.

Building a cohesive IEP team on behalf of Martin was no easy task. The team was essentially an intergroup experience. Mr. and Mrs. Schaeffer were one group. While on board with the overall plan, they did not trust the Lakeview educators. The only experience they knew was their experience with was the TRES and RSEJA. They still did not know Reinhart or Morino or other team members. Reinhart and Morino constituted another group. Some school personnel were wary of the plan and wondered what the administrators had up their sleeves. Was Reinhart about to dismantle a traditional special education model and institute full inclusion for all students with disabilities across the district? A third group consisted of teacher Karen Ward, the school social worker, school psychologist, and special education supervisor. The full integration of a student with Martin's needs was a completely new experience for them. A fourth group was comprised of Martin's private therapists. The idea of employing the Schaeffers' private therapists made Reinhart suspect in the eyes of some Lakewood Elementary School staff, as this was a significant departure from using school-based related services personnel. As one of the private therapists remarked in an interview, "It was an 'us' and 'them' situation. The parents and the therapists were the 'us,' and the school staff was the 'them.'" Despite the tensions and splits, the focus was always Martin.

With a lot of moving parts to the team, it met weekly to ensure consistency of communication, proper programming of Martin's laptop computer, working out such things as the disruption of therapists coming in and out of the classroom, and encouraging peer support for Martin. Indeed, the most time-consuming issues were concrete issues, such as making bathroom facilities accessible, deciding who would take Martin to the bathroom, and programming the AAC system. An early issue was how to engage the first grade students in supporting Martin's use of the Light Talker. Various words, phrases, and sentences were programmed into the laptop, which allowed peers to ask Martin questions and get responses. Despite the positive student interaction, some first graders tended to treat Martin as a mascot, patting him on the head or speaking to him in a juvenile manner. To address this situation, the team agreed that the teacher and the social worker would have a discussion about Martin with the class when he was not present. A meeting was arranged and the teacher and social worker explained Martin's physical and communication challenges. It was also an opportunity for students to ask questions and explore how to build relationships with Martin.

To be sure, joining as a team was challenging. Crucial to Martin's learning and the team's function was the hiring of an excellent teacher assistant. As the person who was with Martin the most, the teacher assistant had the best firsthand knowledge about Martin's day-to-day functioning and was thus a critical communication link to Mrs. Schaeffer, who interacted with the Lakewood Elementary School staff on a daily basis. While Mr. Schaeffer generally did not participate in weekly team meetings, he did participate in IEP meetings. Mr. Schaeffer had the ability to raise the anxiety level of these meetings, as he, on occasion, became loud and critical.

The team's anxiety level was particularly high with Martin's triennial case study evaluation. Lakeview's school psychologist had no experience evaluating a first grade student like Martin, and employing an RSEJA psychologist was sure to meet opposition from Mr. and Mrs. Schaeffer. Reinhart called upon a colleague, Dr. Mark Miller, a clinical psychologist in private practice who specialized in complex children, including children challenged with cerebral palsy. Mr. and Mrs. Schaeffer were agreeable to the arrangement, but Mr. Schaeffer was clear that whatever data was collected and interpreted was not likely to be valid given Martin's unique circumstances. Nonetheless, he understood that the district was required to conduct a triennial evaluation. Dr. Miller's report was relatively benign. Importantly, Dr. Miller concluded that his findings were "probably not fully reflective of his potential." According to his report:

> Overall the results are consistent with the reports of his therapist and teachers. It was noted by his teacher that he has clear conceptual and visual knowledge of numbers one to six. He is able to count pennies adequately. He has been improving sign vocabulary, with current progress in letter–sound formations. He is able to remember grammatical sequence of icons for verbal expression on his Light Talker.

In short, Dr. Miller did his best to further the IEP team's joining and work by simply addressing Martin's history, conducting a brief assessment, and making recommendations aligned with what the IEP team was already implementing on behalf of Martin.

Over time, the team joined. Reinhart became progressively less visible at team meetings, but he continued to be involved. Peter Morino was appreciative of Reinhart's stance. In his words, "I always knew he had my back, and if there was something going on, I could say to him I need you to do this or to do that." The team was working so well that when it came to the annual IEP review at the end of first grade, Reinhart completely forgot to attend. The IEP team, in fact, didn't need him. Although it took several years to build a cohesive and trusting team, Martin's speech language therapist noted that trust occurred over time because Mr. and Mrs. Schaeffer knew that when something didn't go according to plan, they would be listened to by Morino and their issues addressed. Evidence of trust emerged in Martin's second grade year. With the best of intentions, Martin's second grade teacher showed a video of the class at an open house for parents. Unfortunately, she videotaped Martin while he was sleeping, and, to make matters worse, did not get written permission from Mr. and Mrs. Schaeffer to release a video image of Martin. Notwithstanding this breach of confidentiality, Mr. and Mrs. Schaeffer took the matter in stride, having the confidence that Morino would address their concern with the teacher.

Morino was careful to hand pick Martin's teachers from year to year, and, in collaboration with the parents, hired excellent teacher assistants. With keen insight into his staff's strengths and weaknesses, Morino laid a lot of groundwork before he made a teacher assignment. As months and years progressed, the private therapists became increasingly part of the school routine. IEP meetings became increasingly less anxiety-provoking for the staff. And over time, the Lakewood Elementary School speech language pathologist was integrated into the team to compliment the work of the private speech language pathologist. So too was an RSEJA adaptive physical education teacher. For Mr. Schaeffer, Martin's full membership of the school community was

evident when Peter Morino disciplined Martin for failing to turn in a library book. In Mr. Schaeffer's view, Martin was being treated like any other Lakewood student.

Throughout his experience at Lakewood Elementary School, Martin excelled. IEP goal evaluations from first through fifth grade indicated Martin was an attentive and motivated student. IEP goals during these years addressed improvement of receptive and expressive language; acquisition and execution of reading decoding, comprehension, and vocabulary skills; written expression skills; math skills; muscle tone; and wheelchair mobility skills. A particularly important goal was to increase use of and improve accuracy of the Light Talker and Power Book. His ability to use eye gaze, facial expression, vocalization, and single words along with his augmentative communication indicated that Martin was indeed making consistent progress in communicating with others. Partnering Martin with reading buddies was the peer pressure he needed to communicate with peers. Martin's IEPs for third, fourth, and fifth grades reveal similar goals with progressive changes in instructional objectives.

IEP accommodations and adaptations included extended time; shortened assignments; oral reading of tests and quizzes; personal assistance for eating, toileting, and managing books; as well as the use of specialized equipment (e.g., a stander for repositioning). Reflecting as an adult on his progress during fourth grade, Martin recalled that he was "proudest of the friendships I have developed." He further stated that his best skill was writing and that he was "trying hard to become a better writer." His fourth grade teacher noted, "Martin has an excellent attitude toward school…He enjoys working in group situations…and he becomes involved in the give and take of group process, readily offering his opinions." His fifth grade teacher noted that Martin was "becoming more independent socially," and, with the use of his Light Talker and Power Book, "enjoys participating in the daily Speak Out." What Martin now remembers about his Lakewood experience was the students and staff and being a fully fledged member of the school community. When asked about his memories of Lakewood, Martin stated: "What I remember more than anything else was the people—more than anything else. Mr. Morino, my teachers, aid, and my therapists. I remember being included in the annual plays and birthday parties."

Middle School and Full Inclusion

With Lakewood School being a K-5 building, the IEP team was forced to consider where to transition Martin for sixth grade. As a result of the changes in the middle school attendance areas, Lakewood students for the first time were to transition to Lakeside Middle School (LMS). Unfortunately, LMS was a four-story school built in the early twentieth century and contained no elevator. Given this reality, Martin had two middle school options available to him. One building was a single-story school, and the other was a three-story school with an elevator. A concern for the parents, staff, and Martin was the fact that Martin would lose the friends he had acquired at Lakewood. Martin was fearful of the transition to a new school. In his words: "I was afraid that my classmates would go to another school, and I wouldn't know anybody." In a letter to Dr. Reinhart, Mr. and Mrs. Schaeffer advocated for Martin's inclusion with his class as it transitioned to LMS:

> To subject Martin, suddenly, to a completely new environment along with his classmates will be something that requires attention and planning as the

> development and execution of his program thus far. This is an extremely important time for Martin and other children. To subject him to this transition alone, with absolutely no support system for his social integration into the system, would be devastating.

The Schaeffers' letter was timely because the Lakeview superintendent and board of education were considering including an elevator in the renovation of LMS. The superintendent, board, and business manager were sympathetic to Martin's situation and were firmly in support of making all of the district's buildings accessible to persons with disabilities.

With the bricks-and-mortar issue of the elevator taken care of through board of education action, there were still significant challenges in transitioning Martin to LMS. The LMS principal, Michael Roth, was skeptical about full inclusion. For Reinhart and Morino, Roth's skepticism about full inclusion was really about his fear of educating Martin and his fear that he and the LMS staff might not be adequate for the task. Although LMS was widely regarded as a child-centered middle school, it had never had a student with Martin's complex needs. Recognizing Roth's fears, Morino met with him on several occasions to talk about the success Martin had experienced at Lakewood Elementary School. Reinhart had similar conversations with Roth, as well. With the issue of access resolved with the construction of an elevator, Roth was resigned to welcoming Martin to LMS. Morino and Roth orchestrated a series of meetings between the Lakewood and LMS IEP teams. Reflecting on these meetings, Morino expressed frustration with Roth, who held to the notion that Lakewood had pampered Martin and his parents, and that middle school was much more of the "real world." Morino and the Lakewood team deftly educated Roth and the LMS team about the importance of building a trusting relationship with the Schaeffers. Reinhart and Morino stressed to Roth that, while the Schaeffers had a positive experience at Lakewood, their prior experiences with institutions (Metropolitan Hospital, TRES, and RSEJA) would invariably make them somewhat untrusting of the LMS administration and team until they felt confident that LMS had Martin's best interest as an uppermost consideration. Fearing years of good work could be compromised, Morino and his team walked the LMS team through its first through fifth grade experience and the importance of keeping the related services group intact. Roth was quick to recognize that his team did not have the technical related services expertise and began to formulate a plan to integrate the private providers into the LMS IEP team. Morino was clear with Roth that one of his major tasks was to hire an excellent teacher assistant. He also stressed the importance of making Mr. and Mrs. Schaeffer partners in the hiring process.

During the summer, Roth beat the bushes to hire a teacher assistant but found the talent pool limited. In particular, Roth wanted to hire a male teacher assistant, since Martin was growing and was becoming difficult to transfer from the wheelchair to the stander or to the commode. When he engaged the parents about two of the candidates, Mr. and Mrs. Schaeffer felt neither were suitable. With a week to go before the opening of the school year, Roth was at his wits' end without a teacher assistant, until Marcia Levine appeared in an interview. Looking to become and occupational therapist, Marcia was a perfect match for Martin and the Schaeffers.

In retrospect, the Schaeffers regarded middle school as something to be lived through. Mrs. Schaeffer was especially challenged during this time because the Schaeffers were renovating

their home to make it more accessible and accommodate Martin's needs. In addition to helping Martin with his homework and being the communication link with LMS, Mrs. Schaeffer was supervising the renovation. As Morino and Reinhart had predicted, building trust with the Schaeffers was the most difficult task for the LMS IEP team. Team meetings were frequent, and communication between Marcia Levine and Mrs. Schaeffer went well. When it came to IEP meetings, however, tensions arose, as Mr. Schaeffer tended to cross-examine LMS staff. To be sure, the LMS team was intimidated, but, despite their fears, they were squarely focused on Martin's full integration into the school community. At the end of the sixth grade year, Mrs. Schaeffer expressed her gratitude for the work of the LMS team, noting that the principal and his assistant were "always available to troubleshoot when problems arose." For Mrs. Schaeffer, Martin's successful sixth grade year involved a coordinated effort by the district's central office, LMS administration, and the instructional team. General education teachers supported Martin with his participation in book club, writing movie reviews for the school newspaper, participating in a friendship group, and interviewing the superintendent. Important in making the middle school years work well was the consistency of related services personnel. The glue to coordinated team functioning was the work of Marcia Levine, who developed a strong relationship with Martin, his parents, and LMS teachers. Martin's special education resource teacher was also an asset. She was a technophile, who was fascinated by Martin's AAC system. Between the resource teacher, teacher assistant, and the speech language pathologist, Martin's technology needs were well covered. Rarely did he lose instructional time due to technology problems.

Martin's IEPs during the middle school years reflected the earlier efforts of the Lakewood IEP team. Martin's middle school IEP reading goal objectives focused on improving reading skills through decoding words containing diagraphs, diphthongs, r-controlled vowels, and ending blends. Reading comprehension goal objectives related to correctly answering "wh" questions regarding fictional passages. Mathematics goal objectives included recognizing numerals to 99,999, identify value for numbers to 99,999, and being able to write from dictation numerals to 99,999. Additionally, counting by tens, hundreds, and thousands; answering word problems; rounding to the nearest ten; fractions; and telling time using a digital clock were part of his mathematics objectives. Goals also continued for self-feeding, mobility, improving range of motion, and effective use of his Light Talker and Power Book in communicating with teachers and peers. Martin consistently earned "A"s in all of his classes. Teachers consistently commented that "Martin is conscientious in completing his work," "works cooperatively with lab partners," and "shows enthusiasm for work." Although excelling academically, what Martin remembers of his LMS experience was "going to Bar/Bat Mitzvahs and feeling sad about leaving LMS to go to high school."

On the whole, Martin's experience at Lakeside Middle School was relatively uneventful and nonconflictual. With the exception of a conflict over emergency evacuation procedures, parents, teachers, and administrators collaborated well. A measure of increasing trust between parents and school personnel involved Martin's triennial evaluation. There was little anxiety regarding it, as it was conducted as a routine procedure. A measure of the progress that had occurred over the years was the fact that the psychologist conducting the triennial evaluation was an RSEJA psychologist, who with the permission of the Schaeffers conducted a home visit. Anticipating a

transition to Lakeside High School, the RSEJA psychologist included a detailed history of Martin's educational experience in her report.

High School and Full Inclusion

Notwithstanding the success at LMS, there was considerable anxiety regarding Martin's matriculation to Lakeside High School (LHS). Lakeview Elementary and Lakeside High School districts were separate districts. This meant Martin and his parents would have to develop relationships with a new set of administrators, teachers, and teacher assistant. While the Schaeffers had other children at LHS, they were crossing the boundary into a new system in which there were many unknowns for them. Would Martin be fully included in general education as he had been in the Lakeview Elementary District? Would LHS continue Martin's related services team? Would LHS hire Marcia Levine as Martin's teacher assistant, or, if not, would the Schaeffers have a role to play in the hiring of the teacher assistant? Could the Schaeffers trust that administrators and teachers would do what they pledged to do? To allay some of the anxiety, Reinhart worked with the LHS administration regarding Martin's transition. With permission to share information with LHS administration, Reinhart reviewed in detail Martin's school history, conflicts that occurred over the years, effective strategies for including parents in the IEP process, and, perhaps most importantly, recommending that LHS hire Marcia Levine and the related services team.

As was the practice between the elementary and high school districts, an eighth to ninth grade IEP articulation conference was held at LHS. This involved a joint meeting of the sending and receiving IEP teams, parents, student, and interested parties. When the meeting convened, sixteen people assembled around the conference table to discuss Martin's history and case study, evaluate IEP goals, draft IEP goals for the ninth grade, and select ninth-grade courses. Although a meeting with some tension, the outcome was positive, as LHS concurred with the full inclusion of Martin in general education and agreed to hire the related services team that had been with Martin since preschool. Unfortunately, Marcia Levine decided to pursue teacher training and thus was not available for employment by LHS.

Despite the positive outcome of the meeting, Mr. and Mrs. Schaeffer felt the LHS special education director had her own agenda. Skeptical of her, their skepticism increased when LHS took the position that it would hire Martin's teacher assistant without parent input. In the LHS view, it was inappropriate for parents to be involved in personnel decisions. This decision served to backfire, as LHS hired a teacher assistant who was insufficiently trained and not invested in Martin. Early in the ninth grade year, Mrs. Schaeffer repeatedly asked the teacher assistant about homework and was assured that there was none. Martin, however, told a different story at home and was worried about the fact that he had not completed assignments that were being given by his teachers. This prompted Mrs. Schaeffer to make a series of inquiries of Martin's teachers, which revealed that indeed homework was being assigned. As a result, Mr. and Mrs. Schaeffer wrote a stinging eight-page letter to the LHS special education director and special education department chair. In a well-crafted letter, Mr. and Mrs. Schaeffer complained that the teacher assistant not only failed to communicate homework assignments, but was insufficiently trained in how to operate Martin's AAC device or his wheelchair. Additionally, they complained about a safety issue, as Martin was placed on a mat on a filthy area. The fact that Martin had received,

for the first time in his school career, "C" grades was directly attributable to the lack of communication. In the Schaeffers' view, "Martin doesn't need a babysitter. He needs an educator, an advocate, and an effective liaison between his teachers." Recalling this situation, Martin stated this was one of the first times he felt incompetent because his aide "did things to sabotage my learning and inclusion in the classroom."

The Schaeffers' letter had a significant impact. Indeed, after that point things went much more smoothly, as a new teacher assistant was hired. However, Martin's parents became concerned a second time when the LHS staff began discussing Martin's transition to postsecondary life. What was disturbing to the Schaeffers was that LHS staff was considering a vocational track for Martin. Mrs. Schaeffer made it indelibly clear that she, her husband, and Martin had college as a goal. According to Mrs. Schaeffer, "They had to change their whole dynamic with their educational expectations between him, me, and them. And then the ball started rolling."

While the ninth grade year was challenging, Martin excelled. He was enrolled in all general education classes and a special education resource class. The LHS special education department chair, Dr. Amanda Barrett, was an important asset in Martin's success. A solid advocate for students with disabilities, Dr. Barrett was a former speech language pathologist with expertise in augmentative communication. In particular, she understood how vitally important it was for Martin to be able to effectively and efficiently communicate with his AAC device. Not surprisingly, she paired particularly well with Martin's speech language pathologist. Barrett was also instrumental in arranging teachers for Martin, who could both relate well to him and teach higher level content. Among the assignments she made was pairing Martin with a part-time art teacher, Tim Collins, who developed a close relationship with Martin, attended classes with Martin, and tutored him in courses like chemistry and algebra. Martin's experience was also enhanced by Barrett's assignment of Mark Shear as Martin's special education resource teacher. As one observer noted, "Shear didn't know much about Martin or teaching Martin, but he dove right in." Shear recognized Martin's intelligence and formed a solid working relationship with him.

But for Martin, the biggest challenge of going to school with able-bodied kids was "wanting to be like them in an educational setting."

Reflecting back on his experience at LHS, Martin recalls that, while it took him four years until he made some friends in regular classes, he had "an awesome time at prom with a date and friends stayed overnight." According to Martin, "I remember the terrific aides I had, especially Tim Collins, who was able to figure out how to teach me chemistry with a special calculator." Martin noted that acceptance was a critical concern. As he put it, "The teachers had to accept me in the classroom, and that wasn't always easy." Martin was grateful that the special education department intervened "at times to support my educational needs," and he credits his parents as "a big part of my overall educational plan for college." But for Martin, the biggest challenge of going to school with able-bodied kids was "wanting to be like them in an educational setting." He appreciated all of the assistance of his teachers and parents, but, above all, he stated, "I wanted friends."

Transition to College and Full Inclusion

Like other LHS students, Martin and his parents began interacting with college guidance counselors about attending a four-year college. Dr. Barrett was insistent that college representatives come and meet Martin, whose record, while stellar, didn't reveal his unique needs. Ultimately, Martin and his parents settled on Metropolitan University, a college not far from his home, easily accessible, and open to making whatever accommodations were necessary for Martin. With the exception of one course in which he earned a "B," Martin earned "A"s at LHS. Indeed, Martin's academic success won him membership in the National Honor Society, and he was awarded the "You Make a Difference" Award and nominated for a scholarship. Given his high grade point average, Martin Schaeffer graduated from LHS with high honors.

Reflecting on his overall experience, Martin states: "I am most proud of my determination to meet friends and not quit even though it's hard." For Martin, social interaction with others is vital to his social and academic life. In his words, "My communication disability puts me at an extreme disadvantage in this world. Sometimes I feel very lonely and wish I was like other people." Martin also expressed, "I am also proud to have been able to get into college and do well." His advice to others is to "keep trying, develop a good image of yourself, know your strengths, know your weakness, communicate your feelings, but above all, communicate."

At twenty-two years of age, Martin is a history major at Metropolitan University. He takes one class per quarter and attends class with a personal assistant. Metropolitan University staff and faculty have been very cooperative in accommodating Martin's needs. He is a straight-"A" student.

Conclusions

In looking back on his school career, it is important to assess why Martin's full-inclusion experience was successful. Seven things explain his success.

First, Martin's full-inclusion experience would not have been possible without the passage of the Individuals with Disabilities in Education Act (formerly the Education of All Handicapped Children Act, 1975), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act of 1990. These federal statutes along with state statutes guaranteed Martin a free appropriate education in the least restrictive environment. Moreover, Martin's full-inclusion experience would not have been possible without the parent and professional advocacy that occurred on the national level from the mid-1980s and continues through the present.

Second, Martin's parents were completely committed to Martin's full integration into the family and the community. Without question, one of the reasons for Martin's success was Mrs. Schaeffer's heroic efforts to care for him. This meant getting up at all hours of the night to reposition him, providing transportation to and from school, having daily communication with teachers and teacher assistants, and working with Martin day in and day out on homework assignments. Further, the Schaeffers were fortunate to have the personal resources to provide for the wide range of Martin's medical and educational needs.

Third, Martin's successes would not have been possible without the evolution of microelectronic computer technology. Alternative augmentative communication was greatly enhanced during this time by the invention and availability of the laptop computer. Martin's initial AAC device, the Light Talker, was eventually replaced with an eye-gaze system, which allowed him to use his eye movements to type, word process, email, and utilize images in ways that could not have been contemplated in previous decades.

Fourth, there was advocacy on multiple levels. Martin's parents were staunch advocates for their son. They sought out early intervention services and worked with a team of therapists that were completely committed to Martin. The Schaeffers' advocacy included a clear vision of what they wanted for Martin. The administrators and educators at Lakeview Elementary School District and Lakeview High School were also strong advocates for Martin. There was a dynamic of external and internal pressure to make the full-inclusion experience work. Further, Martin's teachers and teacher assistants, who truly cared and liked him, were powerful advocates for him.

Fifth, the Lakeview Elementary School District board of education and superintendent were committed to having all of its schools accessible to persons with disabilities, as evidenced by building and elevator at LMS. More specifically, they were fully supportive of Martin's full inclusion. At no time did the Lakeview superintendent or board question Reinhart's leadership on behalf of Martin, including the hiring of a private therapy team to serve Martin within the school setting. To be certain, educating Martin was expensive, but the board of education and administration took the IDEA mandate regarding free appropriate public education and least restrictive environment seriously. Thus, student needs rather than fiscal considerations drove the IEP from first through twelve grades. That the district received extraordinary care funding through IDEA helped to defray the expenses associated with highly individualized instruction, educationally related services, and paraprofessional support. In a community with lesser resources, fiscal issues might well have been a dominant concern. However, given the strong and powerful parental advocacy on behalf of Martin, this would invariably have resulted in a legal contest which would not have been in the best interest of Martin or the school districts.

Sixth, principal leadership skills and central office support of them were critical to Martin's success. Peter Morino was an exceptional principal, who established a collaborative school culture that encouraged risk taking. In his view, educating Martin was a challenge he wanted for his faculty. Truly committed to community building, Morino saw diversity as a clear asset for Lakewood Elementary School. Additionally, he was always approachable and available to Martin, Mr. and Mrs. Schaeffer, and his staff. Moreover, his excellent group facilitation skills were vital in helping Martin's IEP team join and work. Further, Marino was always approachable. Although Michael Roth was initially fearful of Martin's full inclusion at LMS, he overcame his fears and embraced Martin's program. Most importantly, Roth allowed his professionals to have full reign in doing what was in Martin's best interest. He simply stayed out of the team's way and allowed them to do what they did best. Administrative leadership at the high school level was also critical. LHS's decision to hire the private therapy team was a critical administrative decision. Moreover, LHS leadership was open to admitting its initial errors of judgment and provided full support to Martin and his college aspirations. Further, administrative coordination of a complicated school schedule and arrangement of effective teachers was vital to Martin's academic and social success. Throughout Martin's school career, the educational teams

that served him were committed to continuous learning about his disability and developing and refining effective instructional practices to facilitate his learning.

Seventh, Martin was a major contributor to his own success. As Martin matured, he progressively integrated a solid work ethic and self-determination. Attentive, motivated, and hardworking, Martin excelled because he was determined to do so.

There is no question that Martin Schaeffer benefitted from full inclusion from first grade to the present. Without the peer pressure, it's possible that Martin would not have made his AAC an extension of himself. Given the nature of his disabilities, Martin was at great risk of being isolated, and with isolation comes the potential for depression and surrender to dependency. What is apparent about Martin Schaeffer at this point is that he has every intention of being as independent and productive as he can. At this point it is unclear about what Martin will do with his B.A. degree when he earns it. However, it is safe to say that Martin and his family will find a productive outlet for his intelligence. His story represents what is possible for persons with disabilities who are similarly situated.

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