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## Inclusion: What Came Before

*Judith Lesch*

When I grew up in the 1940s and '50s in southern Indiana, I never saw a child with a disability in my school or in my community. As far as I knew, there were no adults with disabilities anywhere either. The same was true for my husband, growing up in Queens in New York.

Where were all those children, all those people, who must have existed somewhere? In the early part of the 20th century, sadly, it was routine practice to send children with physical or intellectual disabilities away to institutions. Although there were notable exceptions to this pattern, many people in this era saw disability as a source of shame, and individuals with disabilities were often warehoused in institutions for their entire lives (Shonkoff & Meisels, 2000).

Fast-forward to an unseasonably warm day in February, 1993, in the playground of a New York suburban elementary school where first and second graders enjoy the freedom of running without coats and hats. I watch Rudy, an engaging eight-year-old with Down syndrome, join a group of boys who are playing with a football. I hear one of the boys say, "Let's see how you run, Rudy." And Rudy runs off with amazing speed for his solid frame.

Perhaps because I used to be Rudy's teacher in a self-contained special education classroom, I wonder, protectively, are they trying to get rid of him? But no, they all run to join Rudy at the other end of the field, saying, "Yeah, he can run." When I look again he has the ball in hand, ready to make a pass, motioning for the receivers to get in their places on the field. The enthusiasm and glee of active, intense physical play is present on each child's face.

To an outside observer, this playground scene might seem unremarkable, but it was the result of a long process that had led to Rudy's full inclusion in a general education first-grade classroom and in the life of his elementary school. It was also an example of the changing historical and cultural beliefs about disability, as we have moved away from the invisibility and stigmatization of disability toward a more humane and inclusive society.

The story of this progression can be told from different points of view: of the parents who labored for laws to protect and educate their children with disabilities; of the disability communities themselves, who advocated for their own self-determination; and of the policy makers and educators who worked to implement these ideals of social justice and equality for all children.

When I began work as a special education teacher in 1978, shortly after the enactment of PL 94-142 (the Education for All Handicapped Children Act of 1975), it was the beginning of a new educational era, one described in legislation but not yet established in practice. By writing about my experiences in the classroom during these early days, I hope to highlight some of the challenges and changing perspectives

of a previous era, and to consider the continuing promises, contradictions, and complexities of educating children with disabilities in what has come to be known as the “least restrictive environment.”

### **PL 94-142 and Its Consequences**

PL 94-142 established the right of all children, including those with disabilities, to a free and appropriate education in the least restrictive environment (LRE) (Education for All Handicapped Children Act, 1975). Children with severe disabilities who had been excluded from public schools— sometimes educated in church basements and other separate locations through private organizations—now had the right to be educated by their home school districts without cost to parents. Children (such as the newly identified population of children with learning disabilities) attending local schools but needing different kinds of instructional services to learn, would now receive those services in their local school settings.

A separate “special” educational system began to emerge to provide these services, with different teacher certifications, separate administrators, and a whole range of legally binding requirements, paperwork, and expectations. To meet the increasing demand for educational services, school districts all over the country established new self-contained special education classes to serve the children with disabilities within their jurisdiction. For the first time, under the law parents were given the right to appeal educational decisions regarding their children, and as a result, the intervening years have seen a huge expansion of due process litigation over the rights and responsibilities of all stakeholders.

While children with disabilities were for the first time guaranteed appropriate schooling and services, the need for these services had to be verified through formal testing and labeling of the child with a disability. The form of this eligibility requirement was distasteful and troubling for many parents and teachers.

The practice of separating out those who were different from the “norm” was for many an issue of social justice, an educational practice that reinforced the view that some children were seen as “better” and others as “deficient.” From the beginning, this practice set up an ongoing tension between what it meant to provide an appropriate education and the unintended consequences of labeling a child as having a disability.

For many children and families, labeling led to entrapment in a special education system that they could never leave, a system that could undermine self-esteem and lead to self-fulfilling negative prophecies. Many assessments and the labels themselves were later seen to be of questionable validity, yet they were often used to remove children who were “hard to teach” from general education classrooms, reducing general education teachers’ need to expand their own teaching repertoire (Skrtic, 1995).

African Americans, English Language Learners, and children from other underserved groups were disproportionately identified as needing special education services, reflecting the cultural and historical

biases of many teachers and the educational establishment during this period (Artiles, Kozleski, Trent, Osher, & Ortiz, 2010).

The promise of the new law and the contradictions of the requirements made the new special education enterprise controversial and full of complexity. Who belonged in a general education classroom and who needed to be excluded—and under what circumstances? What did special education services look like and where should they be given—in a self-contained classroom, a resource room, or a therapy room?

My teaching experience in those first 20 years after the passage of PL 94-142 mirrors to some extent the changing progression of attitudes and beliefs as localities all over the country struggled to determine what constituted the least restrictive environment for children with disabilities.

### **A Separate Classroom**

My first job was to coteach a new self-contained special education preschool class in a suburban district near New York City. Because it was in a small district, this single special education class served preschoolers with different disabilities, needs, and levels of functioning. In our cross categorical classes, my coteacher and I had the benefit of working with children with very different learning profiles who all could participate in the same classroom community.

Although we were housed in a separate classroom in a reconfigured basement storage room, our class was in close proximity to an established prekindergarten program for low-income children and had daily contact with other young children without disabilities. Most important, the experienced and caring early childhood staff was genuinely welcoming to our special education team and to the children in our class. Our 10 years in the prekindergarten program were intensely collaborative, working with general education teachers, therapists, social workers, and families to figure out what an appropriate education would be for each child who came our way.

Tyler was born with spina bifida and arrived at two and a half with full leg braces and crutches, a shy manner, and no speech. His mother enrolled him in our program when she found that he had been left alone for long hours at the babysitter's home because it was difficult for the babysitter to move him from room to room. Our team figured out how to give him access to every preschool activity, how to get him up and down the basement stairs to our classroom, and how to make sure that he was fully integrated into our classroom and the program. As his language and social skills emerged we recognized that except for his physical disabilities, he was a typically developing preschooler.

Warren, at three, was withdrawn and did not relate to other people, did not respond to language, and wanted to spend most of his time rolling a car back and forth on the rug. He made screeching noises during transitions. Today he would be diagnosed as being on the autistic spectrum, but in those days he was said to have a language delay. His parents told us that he loved letters, and to our amazement he learned to read at four and used written language to help himself learn how to speak.

We taught many other children with different labels and behaviors during those years, some who blossomed in our small segregated classroom, and others—like the child who spent all day tapping surfaces with a wooden block—who we didn't have the skills to help. What I learned from this period was that for each child and each family—and for the specific experience of disability within that family—there was a huge range of different needs and expectations.

This was indeed what the special education law required, that each educational plan should be individualized for each unique situation. And so in the beginning we created elaborate individualized educational plans (IEPs) for each child, written in longhand on carbon paper (there were no computerized list of goals and objectives in those days), each one addressing what we thought were the most important learning steps for each child and family.

I realize now that most of the children placed in our self-contained classroom in those first years could easily have been included in a general education preschool. In fact, many of the children in our preschool classes, including both Tyler and Warren, went on to participate in general education classes throughout the rest of their schooling, often without having any special education label or services.

That self-contained pre-K class was a first attempt by the school district to define the least restrictive environment for children's special education schooling. It was a beginning step toward inclusive schooling at a time when acceptance of special education was far from universal, when most adults and children were uncomfortable around people with disabilities, and when some parents voiced concern that disabilities themselves might be contagious.

### **Mainstreaming**

In 1987 I began to teach a special education kindergarten, first-, and second-grade class in the same elementary school where I had taught preschool. This time my "cross categorical" self-contained classroom included children who "looked different"—such as children with cerebral palsy or Down syndrome—but also children who did not have noticeable disabilities.

Within our classroom, in spite of the range of ages (five- to eight-year-olds), the children developed a strong social and learning community, accepting each other's skills and struggles in surprising and supportive ways. It was clear to me, however, that it was also stigmatizing for the children to be separated from their age-level peers—to belong to a "special" classroom, sit together as a class at lunch time, and play separately during recess. We were nearby but distinctly different, with all the subtle meanings that can have for children in a school community.

I also felt isolated from the elementary school teachers, who were either uninterested in or actively hostile toward special education practice. The special education law now required children from my self-contained special education class to be "mainstreamed" (as it was then called) into general education classrooms during specific times each week.

But children had to be “ready” for mainstreaming—that is, at the same academic level in a particular subject as children in the general education classrooms. Since few children in my self-contained classroom could participate in the general education academic instruction, they would be routinely scheduled for mainstreaming during physical education, music, or art, or a “choice” or “play” period. Ramon, a shy child, went reluctantly every Tuesday for a half hour to Ms. D’s class, but Ms. D. said he only played with the Legos and never spoke to anyone. Denise, a vibrant kindergartner, played in the dress-up area mostly by herself. And Tony dumped the toys on the floor and was not asked back.

Everyone in my school, including me, saw that this was a misguided approach to fostering educational equity. Asking a child from an established social group—my classroom—to enter another fully functioning social group—the general education classroom—was sort of like inviting someone to a cocktail party full of strangers where everyone else knows each other. How could we ask that of a child who was already struggling with language and social interactions?

### **Toward Inclusion**

During the late 1980s a new movement for educational change swept the country: the regular education initiative (REI) proposed the unification and redesign of general and special education systems so that all children would be served in general education settings (Wang, Reynolds, & Walberg, 1986). It was during this period that the term “inclusion” came into use, meaning that all children, regardless of disability, would be taught in general education classrooms and would receive all their special services there.

In 1992 a court case affirmed that inclusion in general education classes is a right, not a privilege, and that children could no longer be excluded because of their cognitive or physical disabilities (*Oberti v. Clementon, CA*). But again, as with every legal step forward, the complexities of the issue became more apparent. Should or could all children with disabilities really be included in general education classrooms?

In 1989 I moved with my self-contained special education K–2 class to a different elementary school in the same school district. Again the class was cross categorical and multiage, and the children had many different kinds of disabilities. Although the children in this class were significantly more disabled than in my previous classes, the atmosphere in this new school was more welcoming, with strong parental support and a school administration and teaching staff ready to take on the challenge of the REI initiative and inclusion.

At this point in my career I fully supported the inclusion movement, feeling that there was no other way for children with disabilities to be completely integrated into their school communities. With grants from New York State and collaborative planning with several committed general education teachers, we moved toward the goal of full inclusion for my students.

Over a three-year period, the students in my self-contained classroom, with all of their unique personalities and various disabilities, became a real part of the school community; there were visits back and forth between both general and special education settings, and half-day placements in general education classrooms for some children, including Rudy, the boy with Down syndrome whom I'd watched playing football. By the third year, some of the most disabled children in my class were fully included in general education classes, with minimal support from me or other special education personnel.

### **The Benefits and Challenges of Inclusion**

There were many positive results to this experiment. The children with disabilities now truly “belonged” to the general education classrooms, starting the day there and taking part in all class activities; they were identified as members of the class, not visitors from a separate and specialized setting. There were positive outcomes for the included children, in spite of their very complex needs.

Serena, a child with a range of neurological disorders, learned to keep her lips together to control her saliva because she realized that the other girls didn't want to sit next to her if she couldn't manage this task. While such a skill is not always under a child's control, Serena was able to accomplish one of her longstanding goals in this general education setting and to establish friendships with other children.

There were positive effects on the children in general education as well. Many of these children, with the help of thoughtful guidelines, honest discussions, and the model of caring teachers, came to understand the special qualities and strengths of the children with disabilities, defending them against bullying in the playground and finding ways to include them in class programs and everyday activities.

The inclusion of children with such a wide range of abilities in the classroom—children who worked hard to accomplish the most basic academic tasks—also helped make some of the most competitive and capable children more aware of the range of human development and of the power of hard work.

There were also ways in which the whole school community benefited. I remember one teacher especially, a veteran of many years, whose style and methods were firmly established for the range of typically developing children he had taught. At the end of the year he told me that he would never teach the same way again and that having Bobby in his class had been the most profound learning experience of his career.

Of course there were problems. For all the good will that most of the children expressed, there were still incidents of cruelty, teasing, and taking advantage of a child's naïveté, as when a boy was induced to take down his pants because someone else said it was the right thing to do. I worried that Serena had stopped making progress in math because her level of understanding was so different from that of her classmates. And there was the nagging thought that the newly included children had left behind the

deep social connections—the friendships that had emerged, the shared play dates and birthday parties—that they had formed over two years in our multiage, multiskilled classroom.

Parents themselves had different points of view about inclusion. For every parent who insisted on full inclusion for her or his child—like the mother who said to me that she “didn’t want her daughter to audit life”—there were others who wanted their children to have the individualized instruction provided in self-contained classrooms.

The goal of the inclusion movement at this time was aimed toward social integration, and there were few real attempts to adapt curricula for the included children’s individual needs. The major accommodation in most classes was the addition of a one-on-one classroom aide to support the included child. My own role as a special educator was unclear. It was much more difficult to collaborate in another teacher’s classroom, no matter how welcoming he or she was, than to teach in my own.

Although the inclusion experience had profoundly changed the beliefs and attitudes of this school community toward disability, I was also aware of the complexities and imperfections of our progress, perhaps especially for the children with disabilities themselves. They were no longer separated and apart, but were they also getting a truly individualized education that would appropriately develop their unique capacities and lead to outcomes that were meaningful for them?

### **Enduring Struggles**

Ironically, my last teaching assignment demonstrated the persistence of the troubling patterns that had emerged as unintended consequences of the special education law enacted 20 years before. Back at my original elementary school, I taught a newly formed self-contained special education class for children who were not “making it” in their general education classroom.

The group, mostly boys, was again made up of children identified as having various kinds of disabilities, and included several children who were labeled “emotionally disturbed.” None of these children had the degree of physical or cognitive disability of the children who had been successfully “included” in my last school setting; yet in this school in the same district it was determined that these children needed a separate special education classroom placement in order to learn.

Following national patterns of disproportionate representation, African Americans and Latinos made up the majority of the class. The older boys in this new class were resentful and clearly ashamed of being placed in this “special” classroom—this time housed in an unused storage room on the third floor of the school, far away from their general education peers. My job, it seemed to me, was to keep them quiet and allow the general education staff to get back to teaching.

My students were unique and endearing children, but it was also exceedingly challenging to form them into a viable classroom community and to help them grow academically. The renewed focus on educational accountability was just beginning, and IEP goals for the first time had to be written as

grade-level curriculum outcomes. It was a year of frustration as I tried to keep up with different grade-level curricula in each area and to provide three different levels of homework each day.

I remember Frederico especially, a Latino fourth grader who had missed a lot of school in previous years in order to accompany his father back to Guadalajara for the winter migrant farming season. This year he was staying home, taking care of his mother and little brothers during their father's absence. I could see that Frederico was capable and very proud; it was hard for him to acknowledge his problems with learning to read.

But he did learn to read that year, in spite of the many challenges in our classroom. I was shocked to see him two years later, still in a separate special education class in another school; special education had become a long-term placement for him—which, in my opinion, did not provide him an appropriate education. If my earlier teaching assignment had shown me some of the promises of inclusion, this class clearly demonstrated the inequalities of a self-contained classroom. I understood even more clearly how a special education placement could be used to marginalize and stigmatize children and undermine their expectations of themselves.

In this teaching assignment I also had to question my beliefs about the feasibility of developing a strong learning community in a class that included children with serious emotional and behavioral problems. For two of these children, whose anxiety, anger, and aggression resulted in continuous classroom disruption, it seemed that something radically different from my classroom might be necessary.

But what would that look like? In order to provide them with the intensive support necessary to realign their relationship with school, their families, and themselves, should they be sent away to an even more restrictive environment, without the models of other more typically developing children? At this time there were few alternatives in place and only a dim recognition of the need for different systemic approaches designed for our most troubled children.

At the end of my classroom teaching career, we had come closer to an understanding of the least restrictive environment, but still had much to learn about accommodating children's learning needs in order to give those children access to an appropriate education within that environment. In the following decade, accountability and a focus on educational outcomes would continue to shape the progression of educational policy.

### **Toward the Future**

After I left teaching to become an advisor at Bank Street (1995–2008), I observed a new wave of educational reform, embodied most recently by the accountability movement of the No Child Left Behind Act of 2001. The reauthorization in 2004 of the [Individuals with Disabilities Education Act](#) (IDEA) furthered the notion of outcome-based education for children with disabilities as well.

Many more children with disabilities are now included in general education classes, and general and special education teachers are collaborating in a variety of ways to provide differentiated instruction. Many special education instructional methods, especially in early literacy, are now part of the standard teaching repertoire of general education teachers (National Reading Panel, 2000). Identification of children's learning needs can be accomplished through the classroom-based [Response to Intervention](#) (RTI) method instead of through individualized testing, and special education services can be provided based on documented learning needs instead of labels (Kavale, Kauffman, Bachmeir, & LeFever, 2008).

In response to many critiques of special education practice (Skrtic, 1995; McLaughlin, 2010) special education approaches have shifted from focusing on an individual child's deficits to providing both accommodations in the learning environment and specific learning interventions. As most children with disabilities are held to the same curricular standards and participate in the same assessments as other children their age, the school establishment is necessarily being drawn into a reorganization of the roles of special education and general education teachers in the name of accountability and educational equity. With increasingly limited funds, and growing demands for educational improvement, the expertise of all teachers is under attack, even as new research helps us develop a deeper understanding of differentiated instruction for different ages, curriculum areas, and processing patterns (Brownell, Sindelar, Kiely, & Danielson, 2010; Lee, Wehmayer, Soukup, & Palmer, 2010).

After 35 years as an educator, as I look into the future, it seems to me that effective collaboration remains the most essential component in our society's journey toward a more inclusive educational system. Certainly my best educational experiences occurred as a result of honest collaboration with parents and with general and special education colleagues over ways to help all children achieve their full potential, whatever their developmental pathways.

I think with awe about the collaboration and instructional analysis we now expect from general and special educators in today's complex educational environment, with so many more children with disabilities placed in general education classrooms. How can we promote effective collaboration among all stakeholders in a way that is meaningful, systematic, and as valued by society as other accountability measures are today?

One promising approach, RTI, emerged from the 2004 reauthorization of IDEA. This systematic way of ascertaining children's needs for more extensive educational support is based on a child's response to a particular kind of teaching; in its best form, RTI can be a strong tool to promote collaboration among a school-wide educational staff, overriding the need for disability labeling and providing increasingly targeted instruction within the structure of general education.

As discussed by Fuchs, Fuchs & Stecher (2010), special educators and general educators must collaborate on the successive tiers of RTI, and highly trained special educators can take over the most intensive interventions, especially for the most disabled students. All teachers should begin their

careers with a background in general education curriculum and instruction as well as a thorough understanding of difference and differentiation. Special education preparation could then become an extension for only the most experienced and effective classroom teachers (Brownell et al., 2010).

### **An Unresolved Problem**

The education of children with emotional and behavioral disabilities continues to be an unresolved problem for our society, and those children from my self-contained classroom continue to haunt me. In the intervening years schools have become more effective at dealing with children's behavioral issues, especially in elementary school, through mandated system-wide behavioral plans (Lane et al., 2007).

But our understanding of mental illness has also grown. Experts in the field have developed a range of approaches based on differing physiological/psychological profiles and understand the critical importance of starting effective treatment at an early age (Insel, 2010).

Based on compelling research about the negative outcomes for children who show learning and behavioral problems in their early formative years (Stacks, 2005) and the paucity of research demonstrating effective interventions for middle school and older children (Lane, Kalberg, & Shepcaro, 2009), it seems imperative to address emotional and behavioral issues as early as possible through a fully funded early intervention system.

The goal of educational equity should begin at birth, combining the many different service systems for families and young children, so that truly universal early childhood education can be used as the inclusive entry point for all children in our society (Bruder, 2010). Just as we have used the information about effective early literacy instruction to improve reading performance for all children in the early grades, so must we continue to develop evidence-based early intervention programs to help young children and their families develop positive emotional and learning health, thereby making the overall educational system more functional and cost effective (Reynolds, Temple, White, Ou, & Robertson, 2011).

### **Learning from the Past**

During my lifetime, children with disabilities moved from "hidden" to "visible but apart" to "included" in schools and communities. As the educational focus has shifted in the intervening years to accountability and outcomes, it may be informative to look at the adult lives of that first generation of included children whom I taught during my career as an educator.

Tyler, the child with spina bifida, went to general education classes in the elementary school across from his home that his siblings attended and for six years got himself up and down three flights of stairs because the building was not accessible for wheelchairs. He was the only child attending general education classes using a wheelchair for most of his 12 years of schooling. In our school district, he was the face of inclusion. But I sometimes ask myself if Tyler also needed to identify with other children who

used wheelchairs—if he was included in his academic schooling but isolated in his everyday physical experience.

Warren, the preschooler who appeared to be on the autistic spectrum, was also a full participant in general education classes throughout his schooling, mostly without a label and without special services. When he was an adolescent, he told me that other kids thought he was “strange.” However, in middle and high school he became an outstanding actor and singer and appeared with great success in many school productions. He went on to major in math and physics in college and is now a faculty researcher at a well-known institution.

If he had actually been diagnosed as being on the autistic spectrum, and that early label had followed him through school, would it have limited his choices and defined him in a different way? Very possibly. And yet, without the subsequent use of this label for other children and the research and programming that it has promoted, society’s deeper understanding of autism spectrum disorders would never have become as widespread as it is today.

And for the other children with more severe disabilities who had been included in 1993? Rudy and his classmates were part of general education classes for some of their schooling, but also went in and out of self-contained classes during their middle and high school years. Most did not graduate with a diploma. Now Rudy lives independently in his community and has a job at the supermarket and a wide range of acquaintances. His closest and most authentic relationships are those with his family and with his peers from the early general education classrooms that included him. His mother says that he seems to avoid other people with disabilities.

Serena’s disability progressed as she grew older. As with other young people who leave home after high school or college, when Serena’s schooling ended she went to live in an adult group home—at this point a normalizing experience for her. Serena’s family worked hard to find an excellent facility that gave her independence and expanded her world after she left home. However, there are very few placements (private or otherwise) appropriate for young people with multiple disabilities. For many of these young adults, life after 21 can be a hazardous experience, without the rights and oversight provided by the special education laws.

If there is a lesson to be learned from these children’s experience, it is, unsurprisingly, that each child and family has their individual pathway, and that each point of view has its opposite reality. The least restrictive environment can only be defined in terms of the individuality of a child’s overall needs at different points in time, not as a place but as a continuum of services that supports the child’s educational and adaptive needs as well.

We are still learning how to provide appropriate accommodations and instructional interventions for the entire range of children who are now included learners in our schools, and our ability to truly

differentiate instruction in different curricular areas is still far from developed (Fuchs, Fuchs, & Stecker, 2010).

Although many problems remain, it is also true that in the past 50 years US society has become a more inclusive place, with a general acceptance of people with disabilities that would have been unheard of in the 1950s. I look back on my early years of teaching as a time that captured the hearts and minds of the educational and social community in terms of beliefs about disability.

From the edges of society, from separated classes, toward a more situated presence informed by the members of the disability community itself, children with disabilities are now part of the educational fabric of our society. Their presence has indeed extended the scope of educational practice and human resourcefulness to address their needs, and we as a society have benefited from their gifts.

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