Since the early 1980s, public policy toward children with disabilities has undergone a remarkable and significant transformation. The reauthorization and subsequent revisions of the original PL 94-142, now known as the Individuals with Disabilities Education Act (IDEA), have greatly extended the reach of guaranteed services to disabled children from birth to age 21. There also have been added several new categories of disability, including Traumatic Brain Injury, Autism, and Attention Deficit–Hyperactivity Disorder (covered under several possible health- or behavior-related categories). The Americans with Disabilities Act (ADA) of 1990 addressed concerns for persons with disabilities of all ages regarding accommodations to disability in all walks of life and work. As a result, today the American public has a greater awareness of issues related to disability and how they affect the lives of children than it did even a generation ago.

Yet in many ways little has changed for children with disabilities since the mid-1800s, at least in terms of the way they perceive and are perceived by American society. In this book we have been exploring the lived experiences of children with disabilities who have been shaped by a world that has offered them a multitude of contradictory messages. The history of childhood disabilities is remarkably consistent: parents, teachers, and even students continue to express concerns and viewpoints that were stated either directly or indirectly
150 years ago. Consider the following recent quotes from parents and students involved in special education:

When kids with special needs were first given the opportunity to go to school, they were separated. That’s how it was done because that’s what we thought was best. Now we know that it’s better for kids with and without disabilities to grow up and learn alongside one another. We need to start out when they are young so that these kids, when they are our community leaders, will accept people who are different and give them the opportunities to succeed that everyone deserves. [Parent of a child with special needs, 1996]1

I do not want the “retarded corner” of the school. [special education student, 1994]2

I have experienced both, mainstream and deaf school. I’m not disabled, just deaf. Learning through an interpreter is very hard; it’s bad socially in the mainstream; you are always outnumbered; you don’t feel like it’s your school; you never know deaf adults; you don’t belong; you don’t feel comfortable as a deaf person. [Deaf student in a regular classroom, 1992]3

Embedded in these words are themes, concerns, and possibilities about the lives of children with disabilities that have existed since the beginning of special education in the United States. Those persons involved in the early years of formal education for disabled youngsters experienced much the same kind of hope, frustration, alienation, and uncertain identity expressed above. This chapter offers some reflections on the assumptions and beliefs about childhood and disability that reflect this continuity in the history of the lived experiences of children with disabilities in this country. Indeed, the questions and themes noted in the Introduction speak to these reflections in multiple ways.

THE PRACTICALITY OF SPECIAL EDUCATION: EFFICIENCY IN SCHOOL OPERATION Vs. THE NEEDS OF CHILDREN

In the decade immediately following the passage of PL 94-142 in 1975, participants and stakeholders in special education encountered a series of obstacles as well as pleasant surprises on the road to more thorough and
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authentic mainstreaming of children with disabilities in the public schools. Experiences and judgments varied drastically as to the value and efficacy of the mainstreaming movement. Witness these two summations of the impact of the law, published less than two years apart:

Initially, laws promising education for handicapped children appear as a human effort on the part of our government to embody in legislation the basic Constitutional guarantee of equal opportunity for all. In reality, PL 94-142 is an ill-conceived law embodying a “Pollyanna-Horatio-Alger-like euphoria contrary to fact perception of reality.” It threatens the education of an entire generation of handicapped youth and squanders the limited educational funds available in our country for both disabled and regular children. ... At a practical level, PL 94-142 jeopardizes realistic efforts at serving disabled children by legislating the impossible and by indiscriminately wasting fiscal resources. ...

If the road to hell is paved with good intentions, PL 94-142 certainly represents enough of a brick to cover half the distance. It is to education what Three Mile Island is to the use of nuclear energy. [1981]

Does mainstreaming work? It clearly does. ... Change is never easy, but in our travels we have seen remarkable progress. Parents who once took what they could beg now actively monitor the quality of the education their disabled children receive. Children once sentenced to the wards of huge institutions now sit side by side with high-achieving youngsters in high-prestige schools. Everywhere people are speaking a different language, becoming sensitive to the derogatory connotations of such words as “cripple” and “retard,” understanding disabled students as people endowed with human rights. We have seen teachers and principals flourish under the challenge of doing things differently for youngsters who are different. ...

...[Any] supposed failures of mainstreaming are problems of organizational arrangements, internecine politics, and a lack of will and skill of school personnel. [1983]4

These viewpoints represent not only differences of opinion but also of perspective and priorities. Disagreements regarding the structure, operation, and value systems of education for students with disabilities have existed since
such programs began. On the one hand are arguments that focus on the impact of special education on the structures, budgets, and operation of schools and school systems. On the other hand are those that claim the only concern should be the effective education and socialization of the children assigned to special education and, additionally, its impact on all children. Such arguments exist in varying degrees along a continuum, of course, and by no means fall into an either–or positioning. Yet the differences are real and significant. As special education has entered the current era, stakeholders in special education have become more vocal about these issues, with their views reaching a much wider—and perhaps more attentive—audience than ever before.

Originally, special education in the public schools addressed the perceived needs of the teachers and the schools more than those of students considered eligible for it. Teachers in the 1800s faced enormous class sizes by today’s standards—often as many as seventy or eighty in some of the large urban systems. Teachers worried the most about pupils whose academic struggles and behavioral problems created numerous distractions. As early as the 1850s, teachers in Boston called attention to such children, pleading for their removal from the classroom in order to make their workload more manageable and their teaching more efficient. Moreover, the rapidly growing urban school systems grew increasingly concerned over students whose struggles led to their “lagging” in the regular classroom. Such students seemed to interfere with the efficient operation of schooling by failing to keep pace in moving up the educational ladder. Their removal to a specialized setting where they could be isolated from the proper flow of students pleased frustrated teachers as well as efficiency-minded administrators. Even settings such as the Horace Mann School for the Deaf in Boston, which clearly targeted a specific population for instructional purposes, was founded largely to save money: it was cheaper for the city to operate a day school for resident deaf children than to help fund their education and residency at a distant state institution.

In some respects, children in public school special education were viewed the same as were all students: as units to be managed effectively and prepared to be functioning members of society. At least for most school administrators, the pressures of rapidly growing urban school systems filled with children from a wide range of ethnic and linguistic backgrounds left little time and few resources for caring too much about any individual child. In small-town and rural districts, children with disabilities—typically not formally identified, at least until the 1940s—attended and participated in normal school activities.
to the extent they could. Teachers adjusted instruction accordingly. Disabled children neither demanded nor obtained more special treatment than any other child, at least until such districts developed special education programs. To public school officials, children with disabilities were by and large students first and exceptional students second, at least until the mid-twentieth century.

Nevertheless, there also have always been teachers and administrators who focused their attention on disabled students and sought to bring a truly special education to them. While certainly a distinct (almost invisible) minority in the early period of special education, their ranks increased steadily as special education programs expanded, specialized teacher training for students with disabilities became entrenched, and special educators found that their time with the children themselves enriched their professional lives. Even among the earliest special education teachers—for example, Harriet Lyman and the staff at the Horace Mann School in Boston and Elizabeth Farrell in the special classes of New York City—one could see in their writings an intimate connection with their students. These educators, assisted by small class size, recognized the uniqueness of their pupils and established a personal relationship with them. Among these educators there was a commitment to giving each child a chance to succeed on her or his own terms.

These distinctions between the needs of the schools and the needs of disabled pupils exist even today. Many of the debates circulating around the concept of inclusion focus less on the children and more on the ideology, legal issues, or practical ramifications involved. At the heart of much of this discussion lies the issue of money: to what extent is special education defined, or even driven, by financial considerations? To what extent are these children “worth it”? How much is too much for a district in making “reasonable accommodations” for a disabled child, according to law? McCay Vernon, a strong early critic of PL 94-142, openly challenged spending $60,000 a year on “Judy,” a “psychotic child three years old ... who is severely mentally retarded and has multiple other physical and psychological problems.” Using Judy as an example, Vernon asks bluntly whether “we as a country [should] be making by far our heaviest per capita educational financial investments in those youths least able to contribute to society.” Furthermore, the debate over the funding of special education and the practice of making decisions based on either cost to, or in many instances potential income for, the school clearly shows that the children involved are by no means the top priority. Others suggest that cost should never be an issue, that a child is a child and worth whatever the price to accommodate them successfully in the public schools. Multiple court
cases involving children with disabilities have considered this very question. Efficiency and cost have been fundamental issues in special education since its inception; in many such instances the central concerns of children themselves have taken a back seat.7

**ISOLATION, REJECTION, AND ACCEPTANCE: THE LIVES OF CHILDREN IN SCHOOLS AND INSTITUTIONS**

Such monetary considerations were of little direct concern to the students in special education. For them, the realities of the classroom and of their place in school took center stage in their lives. For most of these children, the typical school day resembled that of all other students: routine, predictable activities planned by teachers. The nature of these activities depended on the particular setting, which in turn usually depended on the nature of the disability being addressed and the age of the children involved. There exists no evidence that special education classes lasted shorter or longer than the standard school day. The quality of teaching in special education classrooms likely varied as much as it did in regular classrooms (although in its early stages—especially before formal training programs for special educators took hold—teachers who were struggling in a regular classroom might well have been reassigned to a “special” classroom). As special education teachers developed better skills and a stronger sense of collegiality and purpose, the quality of instruction probably improved. For the students, a standard fare mixing academic, practical, and vocational content in varying degrees was the norm.8

What was different for these children was their segregation from their “normal” peers. Many thousands of students with speech disorders or other noncognitive or nonbehavioral conditions received a few hours each week in special training but then spent the rest of their time in a regular classroom. However, most children formally identified as disabled experienced complete and permanent separation from their nondisabled schoolmates from the 1850s until well into the 1970s. Disabled children attended separate classes in isolated classrooms or even special schools—for example, those for “crippled” children. Segregation presumably promoted school efficiency, protected the disabled and nondisabled from each other, and enabled greater personal attention and more appropriate and effective instruction for all students regardless of label. It also created chasms between children, generating mutual suspicion, ridicule, and a serious lack of compassion and understanding. The debate over the
merits and drawbacks of segregated special education, which began in earnest as early as the 1940s, continues in full force to this day.

For children living in residential institutions, life truly existed outside the mainstream of society. As noted in an earlier chapter, the nature of life inside the institutions for the mentally disabled remained a mystery to the public for generations. Annual reports of superintendents, members of boards of oversight, or government officials revealed only a sanitized view of institutional life. Even as the public perception of the capabilities of institutionalized mentally disabled children grew increasingly pessimistic in the late 1800s, official reports from these institutions proclaimed them to be efficient, humane, and effective vehicles for social control. However, the photographic and narrative exposés of the mid-1900s as well as recent scholarship has opened up a world that was at once disturbing and heartbreaking. Children engaged in aimless activity, or did nothing at all. They lived in hellish conditions. Attendants appeared incompetent and uncaring. Images of seriously disabled children living in various states of environmental and psychological despair startled the public and helped catalyze the deinstitutionalization and normalization movements of the early 1970s.

Children in residential institutions for the deaf and for the blind apparently fared much better. These institutions avoided becoming warehouses for children abandoned by society. They sustained their strong educational purpose and function for a small but capable student population. The relative clarity of the disabilities and the specific nature of instructional techniques for the blind and for the deaf further solidified the reputations of these institutions. Even the intense debate within the deaf community regarding the merits of oralism versus manualism did not destroy institutions for the deaf. Dedicated teachers and staff, most of whom had considerable training in the treatment of deafness or blindness and in the effective education of children with these conditions, contributed to the reputation of these institutions. Consequently, conditions within these institutions were significantly better than those in institutions for the mentally disabled. The children within benefited accordingly.

THE LIVES OF DISABLED CHILDREN: THROUGH THE EYES OF PARENTS

Parental involvement in the lives of children with disabilities has always been hugely important. Given the limited body of historical evidence produced by children with disabilities themselves regarding their lives, much of
what is known about those lives comes from the words and actions of parents. Unfortunately, their voices have not revealed much at least until recently. During the nineteenth century, civic and educational leaders did not see parents as partners or allies in efforts to address disability. Most parents of children with obvious and/or serious disabilities kept their child at home, sequestered from the skeptical eyes of neighbors and strangers. Those whose children did attend schools or reside in institutions usually were quietly deferential to the advice and directives of professionals or doctors. State agencies were often hostile to parents of disabled children, who were labeled unreliable and became the targets of legislation and policies that attempted to compensate for parents’ alleged lack of concern or cooperation regarding the child’s activities and behavior. As belief in the hereditary nature of mental disability gained credence between the late nineteenth century and the early twentieth century, parents were widely believed to be responsible for perpetuating disability through procreation and thus became highly suspect, if not contemptible, in the eyes of the public.

As public schools became more involved in the lives of disabled children, parents gradually came to be seen as allies and partners in addressing issues and conditions of disability. Social workers sought to enlist the entire family to assist in correcting social pathologies associated with disability. Parents often resisted placement of their child in special education; they believed that it was either too stigmatizing or that their child did not need it. However, most parents complied eventually. Parents did not understand disability as did school personnel and social workers. But parents also spent a great deal of time with their disabled children, and professionals sought to enlist them as allies in their attempts to keep disability manageable and under control in the community.

Parents of mentally disabled children struggled to understand the nature, extent, and impact of their child’s condition. The severity of the disability significantly affected the family’s home and school life, as caring for a significantly disabled child typically required an unusual amount of energy and patience. Parents of any obviously disabled child had to cope with social assumptions and prejudices concerning the origins and manifestations of the disabling condition. Life in homes affected by significant disability thus presented serious challenges regardless of the socioeconomic status of the family. Even for children with mild disabilities, segregation in school often generated an acute awareness of being different on the part of the child, which may well have carried over into the child’s home and social life.
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After World War II, however, the voices of parents grew much stronger. Parent groups had formed locally and informally as early as the late 1930s in an effort to help parents find solace and solutions regarding their multiple struggles with their disabled children. In response to parents’ expressed interest, this advice often appeared in the popular press instead of the professional literature and addressed practical as well as general concerns about their child’s welfare. Parents became more knowledgeable about disability and more activist in their approach to addressing it. Their conflicts with professionals reflect these shifts in power and authority. Nevertheless, parents in the 1960s and 1970s still took second billing to medical, psychological, and educational professionals in terms of determining what was “best” for their child. The angst and frustration expressed by so many parents who were advised “put him away” or “don’t become attached” or “let’s just see if it goes away” reflected their still secondary position vis-à-vis professionals in the field. Theirs was often a painful yet instructive learning process. As one parent noted, “It seems as if our son is constantly being tested. I know they have to know where he stands so they will know what to work on, but sometimes it seems as if they do more testing than teaching.” Another parent spoke to the inconsistent effort of professionals who worked with her child (a problem special needs children of course shared with all students): “I’ve discovered that how much our daughter learns is directly related to the quality of the professionals who are teaching her. Some of them are so much more knowledgeable and skilled at getting and keeping our daughter’s interest in the task at hand. Others of them seem kind of burnt out or apathetic.” Meanwhile, more and more parents spoke about their trials, sorrows, and joys at home with a disabled child—at first to each other, then to the doctors and teachers, and eventually to the public at large.9

As parents spoke out more, the lives of children with disabilities became more readily discernible. The first few years after the passage of PL 94-142 represented a new and challenging era of parental involvement in disability and the ways in which it affected children. After the law’s enactment, many parents learned that they needed to advocate strongly and persistently for the rights of their disabled children in order to get schools, government, the judiciary, and the public truly engaged in ensuring those rights and implementing the provisions of the law. Such activism occurred on several fronts. At the school level, parents slowly assumed more of a role in developing the Individualized Education Plans mandated by PL 94-142. Parents who believed they had failed in securing their child’s rights resorted to legal
action more often than in the pre-1975 era. These lawsuits in turn contributed to a growing corpus of legal decisions addressing the question of the extent to which school districts were expected to adapt facilities and instruction to accommodate children with disabilities. Parents also became more involved in advocacy and professional groups such as The Arc, The Association for Students with Severe Handicaps (TASH), the Council for Exceptional Children (CEC), Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD), and the Learning Disabilities Association of America (LDA). One highly visible example of how parents became much more actively involved in the political and legal processes of fighting for the rights of their children with disabilities occurred in Richmond, California, in the early 1980s. In this case, parents took active leadership roles in challenging school regulations and lobbying the government, in order to secure what they felt was a more appropriate and effective public education for their children.  

IDEOLOGY, ETHICS, AND THE DIGNITY OF PERSONS WITH DISABILITIES: AN EYE TO THE FUTURE

The signal feature of the lives of children considered disabled has been their marginalization from other children and the rest of society. Ironically, children who today might well be identified as mildly disabled—whether cognitively, physically, or behaviorally—often escaped such labels at least until the early twentieth century. Indeed, the absence of “sophisticated” mechanisms for “finding” disability, and the fact that children found their “subnormal” abilities had little bearing on their ability to function as a member of their family and small community, rendered such mild forms of disability either invisible or insignificant. However, until the early twentieth century, those children whose disabilities were obvious and/or debilitating were typically hidden away in homes, residential institutions for the disabled, or public facilities for the impoverished. Once public schools began to enroll more and more children with identifiable disabilities, severely disabled children found themselves in separate settings where they had little if any interaction with “normal” students. Even as segregation of disabled children began to crumble in the 1970s, they still had to struggle to gain authentic participation in school and community life. The stigma of disability and the continued limited access to standard
public facilities and activities keep a large number of children with disabilities on the outside looking in. As one student expressed it,

Summing it up, the only contact we had with the “normal” children was visual. We stared at each other. On those occasions, I can report my own feelings: embarrassment. Given the loud, clear message that was daily being delivered to them, I feel quite confident that I can also report their feelings: YECH! ... We were in school because children go to school but we were outcasts, with no future and no expectations of one.11

Advocates for disabled youngsters identified this marginalization as a key societal flaw and attacked it accordingly. Deliberate integration in schools and communities constituted their primary weapon. With the full force of the law behind them, advocates—as well as many persons with disabilities themselves—challenged society to reconsider traditions of segregation, marginalization, and degradation of the disabled. Deinstitutionalization, mainstreaming, access, accommodation, and equity became rallying cries for those committed to improving the quality of life for disabled children and their families. “[The] democratic ideals of American society can best be served and protected when diversity is highly valued and seen as the norm in all schools,” voiced The Association for Persons with Severe Handicaps. “[TASH] reaffirms that students with disabilities belong in general education classrooms and that they receive the supports and services necessary to benefit from their education in the general education setting.”12

Regrettably, such efforts have met considerable resistance on a number of fronts. Children with disabilities have been subjects of scorn, rumor, paternalism, condescension, and even of sympathy and compassion. They have been the subjects of experimental social policies toward disability. Over time their lives have raised more questions about what they are than who they are. Those with mild or less obvious disabilities still were often avoided in the community; typically segregated from their nondisabled peers at school; frequently subjected to a range of tests, school programs, or other interventions designed to render them more functional in school or the workplace and hence more useful to society; and at times singled out as incompetent, annoying, or even dangerous. In 1993, the American Federation of Teachers expressed grave concern about the placement of disabled children in regular classrooms “regardless of the nature or severity of their disabilities, their ability to behave or
function appropriately in the classroom, or the educational benefits they and their peers can derive.” For children with more severe cases of cognitive or behavioral disability, life could take an unmistakably dark turn: institutionalized, isolated, abused, and denied of their basic rights, rejected by families and neighbors, treated as little more than animal-like subjects by researchers, doctors, or other professionals. Although those in the latter category constituted only a small minority of children who have been identified as disabled, the lives they have led have represented a much more shameful and indefensible aspect of the treatment of disability in American society.

Yet during the past thirty years, a remarkable series of individualized and collective, limited and comprehensive, as well as practice- and ethics-based efforts to improve the lives of all children with disabilities have occurred. These have focused on a wide range of social institutions. Schools, community service agencies, families, employers, health care facilities, and faith-based organizations have all been called upon to support children identified as disabled and enhance the quality of services provided to them. Such efforts have addressed broad concerns such as access, financial resources, equitable treatment, and validation through dignity and respect. As John Dewey might have phrased it, the ultimate goal of this movement may well be said to render the immediate world of the child—the only world the child knows, whether or not she or he is aware of how that world is seen by others—more agreeable, more worthwhile, and more valued. Certainly, these efforts must confront and wrestle with a centuries-long legacy of ambivalence, neglect, misconceptions, and intentional attacks on the nature and character of persons identified as disabled. Furthermore there still exists significant disagreement as to what constitutes the best paths of action for enriching and validating their lives. Indeed, this complex, often contradictory legacy may well complicate or slow the success of efforts to improve the quality of life for children with disabilities. However, recent trends and initiatives—far more sizable in terms of number, strength, and commitment than similar efforts in the past—strongly suggest that an important corner has been turned. Let us hope that we continue to move toward an era of dignity and equity, and that there will be no turning back.

NOTES

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8. Osgood, *For “Children Who Vary from the Normal Type,”* 85–89.


