

A Brief History of the Parent Advocacy Movement

Like all historical grassroots movements, the advocacy movement in special education began as a result of parental dissatisfaction with the opportunities offered to their children with disabilities. Special education programs throughout the country resulted from a bottom up approach, that is, it initiated in the communities, to the states, and finally, resulted in national legislation to ensure that every child with a disability received access to educational services.

Parents have always led the fight for better services for their children. Parents have always been in the forefront of change, often nudging and encouraging the professionals along with them. Only a generation ago, children with disabilities were routinely excluded from participating in the educational programs offered by local communities. Options often ranged from institutionalization to sitting at home, with little in between.



Parents, who found this unacceptable, organized and started segregated, private programs. These were often located in inaccessible church basements or condemned school buildings. Parents began by teaching the children themselves. They raised money and hired staff. They showed the education officials that it could be done. When the professional educators took over, the programs eventually became absorbed by the local or state education agency or another state agency.

During this time, programs were based on the kindness of others for these unfortunate children? Conditions in the programs were often substandard, but they were the only thing available. Institutions and some public educational programs often offered little more than custodial care. That was best practice at the time. Parents were encouraged by professionals to place their children in institutions for the good of the family. That, too, was best practice at the time. Parents who chose another option (home care) were belittled, blamed, and often ostracized. There were no programs of support and assistance for them.

The first public schools for children with disabilities were established in the late 1800s and early 1900s. These were segregated programs, and often served children with specific disabilities. Children with disabilities did not go to their home schools; consequently, they were not known in their communities. They also did not have role models to show them acceptable behaviors. They all acted alike, because the behaviors of other children with disabilities were all they saw and knew.

In the late 1940s and early 1950s, several national disability organizations, such as United Cerebral Palsy, the Epilepsy Foundation and the Association for Retarded Citizens, were established to advocate for people with these specific disabilities. These

groups were composed of parents and professionals who provided services to children and adults with disabilities. Again, parents were in the forefront. Parents would start a program, and later turn it over to the professionals to run.

Parents across the country were making connections with one another. Local parent groups were springing up. Seeing power in numbers, parents joined together to form local, regional or statewide groups. These groups, which formed voting blocks, began to realize the power they had. Working together, they could force change through state and local government.

Other events were also occurring. The plight of children and adults with disabilities was becoming known, largely through the efforts of their families. During World War II, great strides were made in medicine and rehabilitation for adults. Parents began demanding the same kind of attention for young children with disabilities.

State governments were also beginning to respond to the need for change, but services were often fragmented and inequitable. State statutes did not always give exclusive authority for the education of students with disabilities to any one agency, so children were often lost between systems. Services were provided to children and adults with different disabilities by various state programs, with little or no coordination.

There were no specific guidelines from the Department of Education for school districts to use to make accurate diagnostic or placement decisions. Local school districts relied heavily on the skill and expertise of the private providers, who were the major source of knowledge concerning special programs for children with disabilities (Kennedy, 1980). This produced many problems. Local school districts did not know how many students with disabilities resided in their districts, and so had no knowledge of the costs of educating these children. School boards could not appropriate funds for special education programs without this data. As the private sector saw greater utilization, there was decreased demand on the public sector to create programs.

As states moved ahead to improve educational services for children with disabilities, many changes were occurring on the Federal level, which would have a profound effect on special education services across the country. Congress began to put money into training programs for special educators and into research regarding education. In 1967, Congress established the Bureau of Education for the Handicapped (BEH) to advance the education of students with disabilities. Still, Congress and BEH thought in terms of separate, specialized programs. BEH funded programs to create special techniques and programs. Children who had been denied any services now had the opportunity to attend specialized, largely segregated programs. There was little quality control of these programs. The students' families were expected to be grateful for whatever services were offered to their children. Families were often required to contribute towards the cost of maintaining special education programs and services. As a requirement for service, many agencies required the parent (usually the mother) to volunteer a certain amount of time to the program each month.

The sixties and seventies were exciting times for parents who had begun to see that their children could do more and better, if given the opportunity and training. Parents organized all across the country. They found support, understanding, affirmation and strength from one another. They found that they were not alone. They found that what they wanted for their children was the same thing that other parents wanted. The 1964 Civil Rights legislation made parents think about the need for civil rights protection for people with disabilities. They began to form alliances or coalitions with organizations of and for adults with disabilities.

Parents began to be politically active in their states and in Washington, DC. Congress became more aware of the needs of children with disabilities and their parents, and began to respond. Several legislators, who had children or family members with disabilities, pushed Congress for new programs and greater funding. They asked the professionals to come up with new and better models for educating children with disabilities. One of the strongest advocates was Senator Lowell Wiecker of Connecticut, who was the parent of a child with a disability.

Several lawsuits became the catalyst for change. The Pennsylvania Association for Retarded Citizens (PARC) v. Pennsylvania and Mills v. District of Columbia Board of Education won decisions affirming that exclusion of children with disabilities from public education may be a violation of their due process and equal protection rights. These decisions, taken with the 1954 Brown v. Topeka ruling that segregated schools violated the 14th amendment, gave parents the legal avenue they needed to call for inclusion of children with disabilities in the public schools.

Imagine the courage it must have required of these parents to take on the whole educational establishment. They risked being ostracized by the community. They risked ridicule from friends and neighbors. They risked their money. But they knew that they were right, and that they had the support of other families like themselves. These individuals were the pioneers of the parent advocacy movement.

Building on the Architectural Barriers Act of 1968, Sections 503 and 504 of the Rehabilitation Act became law in 1973. This law extended basic civil rights protections to qualified individuals with disabilities in Federally assisted (public) programs. In 1990, the Americans with Disabilities Act expanded this coverage to the private sector.

In the mid-1970s, parents' efforts really paid off. Public law 94-142, the Education for All Handicapped Children Act (now the Individuals with Disabilities Education Act) was passed. This landmark legislation, which was developed with input from parents and professionals, opened the doors of the public school system to all children with disabilities. Like other minorities, it was the first time that children with disabilities, as a class of individuals, were allowed into the mainstream of education. P.L. 94-142 invited parents into the special education process for the first time. It acknowledged the need for parental involvement in order to maximize the benefits of education. It gave parents, and their children, rights and responsibilities they had not had before.

It is important to remember that this was, and is, not just an issue of education. It is also about human rights. Equality. Dignity. Equal access and treatment. The right to succeed or fail on your own. The right to set high standards. The right to attend school with everyone else. The right to attend your neighborhood school. The right to participate in extracurricular activities.

Besides active parents and parent groups, we were fortunate at the time to have exceptional leadership in Washington at the Bureau of Education of the Handicapped. Edwin Martin, the director of BEH, was incredibly supportive of family involvement. He recognized the strength and power of parent organizations and parent coalitions.

During this time, many parent organizations were founded that led the way for parental involvement in special education. Five Parent Information Centers (PICs) were funded by BEH in 1976 as an experiment; utilizing parent run organizations and staff who were parents of children with disabilities to train and inform other parents. In addition to the New Hampshire Coalition for Citizens with Disabilities\Parent Information Center in Concord, New Hampshire, the four other parent coalitions funded were: the Federation for Children with Special Needs in Boston, Massachusetts; Coordinating Council for Handicapped Children (now the Family Resource Center) in Chicago, Illinois; Southwestern Ohio Coalition (now Child Advocacy Center) in Cincinnati, Ohio; and the Task Force for Handicapped Children (now IN*SOURCE) in South Bend, Indiana.

Other parent centers were established and joined with the PICs. These included PACER Center in Minneapolis, Minnesota; APNI in San Juan, Puerto Rico; Parent Educational Advocacy Training Center in Alexandria, Virginia; and the arc/Georgia in College Park, Georgia. The Parent Centers were included as a discretionary program in the first reauthorization of IDEA, and funding for the system of Parent Centers, as well as a technical assistance program, was appropriated. The technical assistance system, originally known as the Technical Assistance to Parent Programs (TAPP) Project, worked with parent coalitions and community organizations around the country to expand the number of Parent Training and Information Centers (PTIs). This system has expanded so that now every state has at least one such center (large urban areas may have several PTIs).

Building on the success of the PTIs, Congress appropriated additional funds to provide for the establishment of Community Parent Resource Centers to work with specific populations or within specific geographic areas. PTIs and CPRCs were expected to work collaboratively to serve families of children with disabilities in those states where multiple Parent Centers exist. The current technical assistance program is known as the Technical Assistance Alliance for Parent Centers.

In the past, parent training had almost always been conducted by the universities. The experts told parents what they needed to know and do. BEH decided to let the parents become the experts (which they already were). These parent coalitions, which were funded by BEH, would work with the National Information Center for Handicapped

Children and Youth (Closer Look) and Grey North, a public relations company, to provide information and public awareness about P.L. 94-142.

In the early 1970s, the parent-to-parent movement was born. Parents, encouraged by Wolf Wolfensberger, realized the benefits of providing a supportive parent as soon after the birth of a child with a disability as possible. They went to pediatricians and hospitals and convinced them of the need for this type of support, as well as the benefits to the parents and child (Raskin, 1993).

P.L. 94-142, the Education of All Handicapped Children Act, was one of the best written laws ever passed. Testimony by parents, educators, administrators and individuals with disabilities before the IDEA Work Group led by Senator Trent Lott ^월 Chief of Staff, David Hoppe, during hearings on the reauthorization of IDEA, pointed out that many of the problems with the law occurred because of poor implementation, inadequate funding, or lack of enforcement, not from flaws in the way the law was written. Rather than throw out the law and start from scratch, the Work Group tried to build upon the successful practices that had developed over the past 20+ years of implementation, while updating the law to incorporate current best practices in education.

Working together and with educators, adults with disabilities, and other social activists over the years, parents have created a quiet revolution. Changes have occurred in many areas which have improved the lives of children and adults with disabilities and their families. In addition to the Individuals with Disabilities Education Act (IDEA) and its most recent amendments, some notable national accomplishments include the Family Education Rights and Privacy Act, Attorney ^월 Fee Bill, Part C (early childhood amendments to IDEA), Assistive Technology Act, Katie Beckett Waiver, Carl Perkins Act, and the Americans with Disabilities Act.

Many states continue to grapple with the question of how to best pay for education, as well as what constitutes an ^만adequate education? Several states are under court decree to revise the way they raise or apportion funds to pay for education. Parents must continue to advocate for adequate, equitable funding for all students, including those with disabilities.

The extraordinary changes which have occurred in education over the past twenty years must be safeguarded. In 1996-97, the IDEA went through an extremely difficult and caustic reauthorization process. The amended law, which was signed by President Clinton in 1997, and the accompanying regulations promulgated in 1999, reaffirm the right of ALL children with disabilities to an appropriate public education. The law is once again being reauthorized, and sweeping changes are being contemplated.

Problems remain to be overcome. Congress has not lived up to its obligation to fully fund their portion of IDEA. Some legislators continue to consider IDEA and the ADA to be ^발 unfunded mandates? Hysteria over the recent violence in a few schools has prompted a backlash against students with disabilities, particularly those with emotional and behavioral disabilities. Funding for educational programs in the states is often

inadequate. Good, well trained teachers are becoming difficult to attract and retain, and large numbers of experienced teachers will be retiring over the next decade. Voucher systems and charter schools continue to exert additional pressure on the public school system. Parents across the country need to continue to be actively involved in all aspects of the legislative process, expressing their concerns to community, state, and federal lawmakers. It is important to always maintain an historical perspective. We need to remember where we have come from, in order to keep moving ahead. Parents of young children and young adults with disabilities believe they have a right to services which will be protected. They believe that people will do the right thing. They don't believe that these rights can be taken away from them. **They are wrong.** History continues to repeat itself. The first generation of parent advocates understand how bad things were, and how bad they could be again. Young parents need to work together with these early pioneers to ensure that the gains that were won during the last two decades are maintained for future generations (Raskin, 1993).

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