

Foreword: "Children with Special Needs: The Intersection of Health Care, Education & the Law"

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FOREWORD

SUSAN P. LEVITON

A mom takes her first grader to school one day to meet with his teacher. As they are entering the school, the mom sees a youngster with crutches having a very hard time walking up the steps. She turns to her own son and says, "What's wrong with that kid?" Her first grader turns to her and replies, "Nothing mom. He looks like this every day."

We have witnessed a tremendous revolution in regard to the rights of children with disabilities over the last 30 years. Children whom we never thought would be able to live at home, go to school and find a job are now productive members of our society. Our accomplishments of the past 30 years demonstrate that through effective organizing and advocating for the rights of children with disabilities, we can change attitudes and open the doors of opportunity to all people. During these years, parents advocated, organized and developed programs to prove that children with disabilities were capable and with proper instructional techniques and accommodations they could succeed. Many of these children have been able to complete school and successfully enter the workforce through the efforts of educators, health care professionals and community workers. Yet every day parents are forced to navigate difficult bureaucracies with complex and conflicting rules and regulations to try to get the services their children so desperately need.

For children with disabilities, we erroneously believed that once the court had spoken, disabled children would be able to enter all classrooms and be successful, just as we believed that black children in 1954, would immediately be placed in integrated schools. We now know that, although litigation is an excellent means of declaring the rights and responsibilities of our society, it is not at all self-enforcing. So even if we have excellent laws, without aggressive advocacy, sufficient funding and trained professionals, children do not get the services they need.

As we enter the twenty-first century, our challenge will be to answer the following questions. First, if we do know what effective practices are, why aren't they implemented? Second, why do we continue to miss opportunities for prevention and early intervention as opposed to only serving children after the problems are severe and chronic and much more difficult to ameliorate? Finally, why does our

knowledge to identify and treat children with disabilities outpace the capacity of our service system to deliver services to all who could benefit?

In May, 2001 the Law and Health Care Program at the University of Maryland held a symposium to explore these issues . Because children with special needs are impacted by the delivery of services in multiple systems, representatives from numerous disciplines listened to lectures, questioned government policy makers and met in small groups to develop proposed solutions that cross disciplines. Parents, lawyers, educators, psychologists and social workers discussed new perspectives in educating children with very challenging behaviors. Others tackled the role of Medicaid and managed care in financing health care for children with chronic health problems.

We were able to learn from each other how difficult it is to implement laws and change systems and institutions. We were also encouraged by many of the successes brought about by parents and professionals who refused to give up. For example, in Baltimore County, parents organized and met with the school boards, county leaders to ensure that adequate funds were budgeted and additional staff hired so that more children could be successful in school. We heard of numerous efforts to ensure that children would be able to successfully live in the community. For example, through the extraordinary efforts of Cathy Surace and the Maryland Disability Law Center, the state was persuaded to provide in-home behavioral aides. Now children who would otherwise be institutionalized are able to successfully go to school and live at home. We also heard about the successful campaign that parents and providers implemented to persuade the legislature and the governor to adequately reimburse community providers so that children with disabilities will be able to live in individual and group settings in the community. Finally, we learned more about the autism waiver, which enables families with children with autism to receive in-home supports such as respite care, family training and intensive case management so that their children will be able to successfully live at home.

Looking towards the future, the participants discussed various proposals, including funding mechanisms that will enable children to receive the services that they need without their parents having to relinquish custody to the state. They also discussed how to eliminate many of the turf battles between the various child-servicing agencies and to begin to focus on seeing children with special needs as the responsibility of the entire state so that all agencies can collaborate to provide the best services possible. Finally, they noted the necessity to

create a system that links data, services and budget together so that we can improve the outcomes for children. Encouraged by the successes of the last 30 years, participants at the symposium realized the long road we still have to travel before children with special needs will be able to have the basics: a decent education, medical care and a place in the community to call home.