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ROAD WARRIORS: TWO PARENTS' PERSPECTIVE ON GETTING SERVICES FOR CHILDREN WITH SPECIAL NEEDS

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The "intersection" of law, education and health care for children with special needs is a bad traffic roundabout, like those common to the East Coast. In these marvels of transportation engineering, cars enter at top speed, from all directions and with little warning onto a street circling around a grassy hub. The cars change lanes suddenly and peel off unexpectedly as their drivers catch a glimpse of the street sign for their exit. Would that there were an intersection of law, education, and health care, with clearly defined marked street signs, traffic lights and left turn lanes; what a wonderful thing that would be. For parents of children with disabilities trying to negotiate the traffic roundabout, competing professional competencies, functions, and standards often collide in a hurly-burly of jargon and bureaucracy.

The purpose of this essay is to identify, from two parents' perspectives, where on the roundabout these collisions and other near misses are most likely to occur. Our hope is that, spurred on by the ruminations of this volume of the *Journal of Health Care Law and Policy*, legislators, advocates, parents and policy-makers can work collaboratively to simplify the road traveled by children with disabilities and their parents.

I. BACKGROUND

We are but two parents and one child. The stories of our effort to get educational and therapeutic services for our daughter, Helen, are anecdotal and idiosyncratic. But, countless hours of talking with numerous other parents about their many more children suggest common themes. By way of disclosing the biases that inform our thinking,

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we digress for a bit of description of the experience that brought us to these words.

Helen's caregivers at the Catonsville Community College Child Care Center, not her pediatrician, first suggested that she be formally evaluated for developmental delay when she was ten months old. Although she had spent nearly ten days in neonatal intensive care at birth for apnea and had come home on a heart and breathing monitor, most of those problems appeared to resolve themselves by four months. Most apparent at ten months, and really the only aspect of her development that caused us any concern, were her gross motor delays. We were told repeatedly by friends, family and co-workers not to be concerned, that we were over-reacting, and that kids develop at different rates. In fact, Helen's pediatrician monitored her progress closely, but expressed no serious concern over her development. When we told him that the day care providers had suggested we have her evaluated, he agreed and referred us to the Baltimore Infant & Toddlers program. He did not suggest that any kind of developmental evaluation by a pediatric specialist in our health plan was necessary.

A team of four specialists, including speech, occupational and physical therapists and a developmental pediatrician, evaluated Helen. We were stunned when, after an hour of playing with our daughter, we were told that while her gross motor issues would resolve themselves by age six or so, there were other "grave concerns." Someone muttered something about this would be the hardest day. The doctor rambled on about how her cognitive, speech and social interaction delays would probably be with her for life. He offered as encouragement that her prognosis was unpredictable, but for a child like Helen, "living independently is a good goal." They filled out a blur of paperwork, asked us to sign if we agreed with their recommendations, put us in our car, and sent us home. We never spoke to any of these people again.

The questions that arose on that most disorienting of days are, in many ways, the ones we live with still. Our experience is that there are no ready answers, nor is it even very clear at times how or to whom we are to ask them. There is no map, and the street signs are hard to read when you are driving in a circle. The questions range over a variety of topics:

- *Medical:* Why is she like this? Is she healthy? Who can tell us? What kind of specialists should she see? How do we find that specialist? How do we know if they are any good? What kinds of tests should that specialist do? Are there treatments for this?

- *Insurance:* Will insurance pay for the specialists she needs? Will it pay for the tests she needs? Will it pay for the therapeutic services she needs? If it refuses, how do we appeal the company's decision?
- *Legal:* To what is she entitled by law? Who should answer that question? How do we ensure she gets everything she is entitled to? What do we do if we disagree?
- *Childcare:* Will the day care center continue to take her given her special needs? Is that still the best place for her? Should she be at home? How do we decide what "best" means now?
- *Education:* What should be her academic goals? How do we know? What is the best setting to achieve those goals? How will we measure her progress? How do we know those measures are good ones?
- *Supplemental services:* What does she need? Who are the therapists? Are they any good at what they do? How do you know? Are we doing too much? Are we doing too little? How do you know?
- *Financial:* If independence is a "goal," then dependence is a possibility. How would we pay to support her for her entire life, and after ours if necessary?
- *Employment:* Will our employers allow flexibility in our work schedules to participate in her therapies? Should one of us not work?
- *Emotional:* Will she be happy? Will we be happy? What will we say to family and friends? Will she have friends?
- *Spiritual:* Why did this happen? What does it mean?

Since those early days, Helen has benefited from a wide range of services and programs including the Maryland Infant & Toddlers Program, the Baltimore City Public Schools, the Baltimore County Public Schools and private therapies. Her doctors and therapists have all been professionally competent and some have been outstanding. She appears to be getting what she needs in appropriate amounts, but we cannot be sure because this is an ongoing experiment with a sample of one.

Unfortunately, serendipity has played too big a role in all she has received. The meshing of medical and education systems has not occurred smoothly, but rather has more often worked as shouts across a chasm. Especially in the cases of complex evaluation and testing, and intensive speech and physical therapies, the medical and educational establishments have looked to each other to provide and pay for the service. On the one hand, the school system claims speech therapy is

“medical” while, on the other the medical system claims assessments are “educational.”

It is when these systems interact, or fail to, that parents seeking answers to these questions are left confused and unable to help their children get what they need. Four key areas are outlined below.

II. HAZARDS IN THE INTERSECTION OF LAW, EDUCATION AND HEALTH CARE

A. *Diagnosis*

Although some children with special needs are easily diagnosed at birth, for many more children diagnosis is subtle, complex and unclear. Yet, an accurate diagnosis is vital to parents because it can guide intervention. Diagnosis is the main marker that links a set of parents to other parents with similar children and can be the key identifier that puts parents in touch with a wealth of information and support in the community, in books and periodicals, and on the Internet.

Responsibility for diagnosis can fall between the educational and medical establishments, especially in the case of disabilities of a psycho-neurological nature. Parents may be confused thinking that the educational assessments or the assignment of a child to a disability category in the context of a child’s Individual Education Plan (IEP) is a diagnosis. The school process of identification and assessment of a child does not necessarily refer parents to the medical establishment to seek medical diagnosis or treatment of a child’s newly identified disability. Moreover, the medical and insurance establishment may balk at a parent’s request for further psychological testing, claiming that such assessments are “educational” and within the purview of the schools.

Diagnosis is a medical function. The educational establishment should direct parents to medical resources to help them in understanding and getting medical services for their disabled children. Likewise, appropriate testing should be covered by insurance carriers. While interventions may, in many cases, be primarily educational, determining as accurately as possible how a child’s brain is working is not an educational function and should not be treated as such.

B. *Development of the IEP*

The annual development and revision of a student’s Individualized Education Plan¹ is, for most parents, an incredibly challenging

1. See 20 U.S.C. § 1414(d) (Supp. V 1999).

experience. Its context is fraught with emotional realities. The process forces parents to take an unblinking look at their child's strengths and weaknesses as well as their child's progress and the lack of it. Invariably it involves a comparison of one's disabled child with her typically developing peers. In simple fact, the IEP requires parents to remember that their child is disabled.

The political context of the IEP further complicates the process. Parents are usually out-numbered. IEP meetings regularly include eight or ten school system personnel,² each claiming some kind of specialized professional expertise. Some participants contribute extensively to the discussion while others remain strangely silent. The limited financial resources of the school system are the proverbial large white elephant in the room that everyone pretends not to notice, but that everyone realizes constrains how the school system defines what a child "needs."

Given this political and emotional context, parents need a double-check on the IEP process. Medical professionals can serve an important role by providing an independent analysis of the needs of a child and the level and nature of services provided in the student's IEP. The review of the IEP by medical professionals, including developmental pediatricians and clinical psychologists, provides parents with guidance and reassurance that the needs and resources identified by the school system reflect the best program for their disabled child.

C. The Language Barrier

The jargon of both the medical and educational establishments creates further confusion for parents trying to access services for their children. Part of the confusion stems from the fact that certain key terms of art refer to similar, but not identical, concepts. Compare, for example, the following concepts:

MEDICAL CONCEPT	EDUCATION CONCEPT
Diagnosis	Assessment
Medically Necessary	Educational Benefit
Maximum Medical Recovery	Free and Appropriate Education

2. See 20 U.S.C. § 1414(d)(1)(B) (Supp. V 1999).

Where the medical establishment speaks of diagnosis, medical necessity and maximum medical recovery, the education system speaks of assessments, educational benefit and free and appropriate education. Between these terms of art lies a kind of no man's land where both systems deny responsibility for meeting the needs of kids.

A case in point experienced by many parents is the need for supplemental therapies like speech therapy. Take, for example, a case of a child with a significant and pervasive language-based disorder. A school system pressed financially to serve more children than it can afford may limit the amount of speech therapy a student receives claiming that it is all a particular child needs. Skeptical parents who believe their children will benefit from additional therapy press the school system to provide more. The school system's rejoinder is typically that it is not required to provide the "best" education for the child, but only an "appropriate" one;³ it is only required to provide the therapies that permit a child to benefit from his or her educational program. It encourages the parent to seek private therapy and reimbursement from private insurance.

Conversely, the medical and insurance establishment may not provide or reimburse for supplemental therapy because it is not "medically necessary." Because the child's disability is pervasive and permanent, the therapy is habilitative, not rehabilitative, and is excluded from coverage.

Collaboration between medical and educational establishments is needed to find ways to bridge the gaps at the outer edges of their respective responsibilities. A shared language that captures the intersecting medical and educational needs of children is needed.

D. Evaluation

The effectiveness of service systems for children with special needs is hard to measure. The "health" of children who are medically complex is difficult to define. The "educational achievement" of children engaged in an individualized educational program is difficult to describe. What passes as "analysis" is an accretion of anecdotes rather than a systematic assessment. The comparison of the health and educational achievement of these children with their typically developing peers may in fact be like comparing apples and oranges. Because of these complexities, assessing the effectiveness of the medical and educational systems serving children with special needs has focused on compliance with legal mandates rather than on the achievement of

3. See 20 U.S.C. § 1412(a)(1)(A) (Supp. V 1999).

goals. Assessment has focused on inputs rather than outputs, on whether parents get their ten-day IEP meeting notification⁴ rather than on whether their child can read.

As thorny as definitions of “achievement” and “health” might be for kids with disabilities, educational and medical systems need to work to develop assessment models that focus square on these outcomes. The effort can bear fruit. In fact, the Maryland State Department of Education, a national leader in educational accountability, is a frontrunner in trying to parse the achievement of students with disabilities. For example, it publicly reports the performance of children with disabilities compared to typically developing children on the Maryland School Performance Assessment.

FIGURE 1: DATA FROM MARYLAND SCHOOL PERFORMANCE REPORT 2000⁵

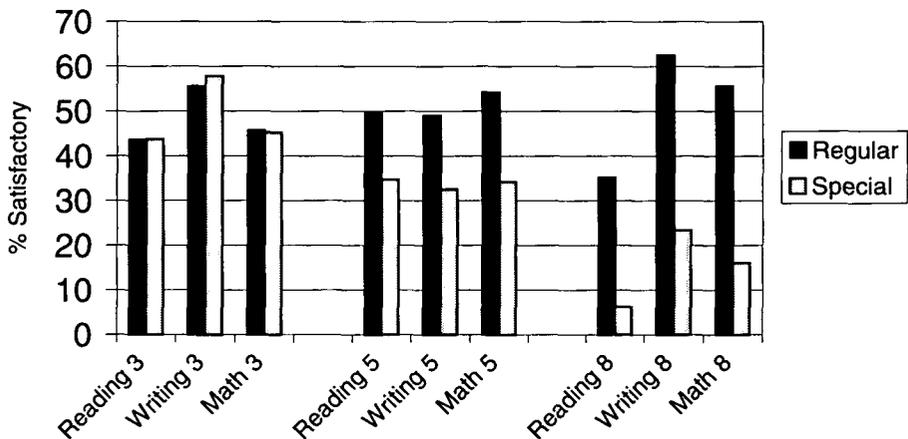


Figure 1 compares test scores for special and regular education Baltimore County children in grades three, five and eight on three key components of the Maryland School Performance Assessment. This data raises many important questions: Why are disabled and typically developing children performing similarly in the early grades? Why is there a precipitous drop in the achievement of disabled children as the children get older? Are we directing resources and developing programs to intervene in this drop in performance? How are individual schools being held accountable for achievement of disabled

4. See 20 U.S.C. §§ 1414(b)(1), 1415(b)(3) (Supp. V 1999).

5. See Maryland School Performance Report for Baltimore County, at <http://msp.msde.state.md.us> (last visited Nov. 27, 2001) (on file with the Journal of Health Care Law & Policy).

students on state assessments? These questions are valuable ones that go to the core aims of the medical and education systems, namely the flourishing of children with disabilities as learners and as participants in our communities.

III. FOUR ISSUES FOR CONSIDERATION

The four hazards in the intersection of law, education and health care, diagnosis, IEP development, language barriers, and evaluation, create important areas for further study and analysis. As parents navigating this road, we suggest four sets of particularly urgent questions raised by these concerns:

1. How can the health care and education systems work together so that students who are identified as needing services get a medical diagnosis and access to medical resources as quickly and simply as possible?

2. Given the emotional and political context of the IEP process, to whom should a parent turn for a second opinion on a child's IEP? Who should pay for that second opinion? How can the educational system build parent confidence in IEPs?

3. Can the medical, educational and legal systems develop similar terms of art to talk about similar things? Can the medical and educational systems bridge the "no man's land" between their concepts, or is legislative or legal intervention needed to force these systems to deal with the range of children's needs that seem to fall in this gap?

4. What measures are there to determine the effectiveness of the programs and services to children with disabilities provided by the medical and educational systems? In what instances is it useful to look comparatively at the achievement and health of typically developing children? How can reports of these outcomes be communicated most effectively to parents so they can make informed decisions about how well systems are serving their children?

IV. CONCLUSION

The parents we meet share a common belief: we have the most amazing children. The medical and educational systems, and we ourselves, regularly underestimate all the things our children can do. Our kids surpass our expectations with enough regularity that you think we would know better. They are a joy and a privilege to raise. Whenever we are caught in the traffic roundabout of law, education and health care, we are profoundly grateful they are along for the ride.