## Am I Being Selfish for Asking for Services for my Child? Advice to Parents and Advocates © 2005

The individual advocacy, case by case, parent by parent approach does work, although it is a slow process. Parent must remember that when they achieve a new benefit, program, or related service for their own child, the "system" often justifies its actions by finding other children who can also benefit from what is being required to provide for your child. If your child needs a particular service, device, or assistance, he or she is likely not the only child in need. I call this the "domino effect". Schools call it "opening the floodgates".

In 1987, when we requested a due process hearing for our child, a key issue was whether she needed a laptop computer. (This was way before the words, "assistive technology" were in the laws). In settlement negotiations during the hearing, the school agreed to provide the computer. However, moral of this story is that the school did not purchase just one computer; it purchased three. Two other children ultimately benefited from what were able to obtain for our child. Many other children have since received laptop computers to assist them in their education.

A second key issue was whether my child required Adaptive Physical Education (APE). At the time of the hearing in 1987, no APE was provided to any child in the entire county. The hearing officer ruled that my child did require adaptive physical education and by the next school year, the school had hired a physical education teacher with a masters degree in adaptive physical education. Since 1988, APE has been provided to hundreds of children within the county.

A third key issue was whether my child required direct Physical Therapy (PT) and Occupational Therapy (OT). At the time of the hearing, the school contracted with a physical and occupational therapist for six hours each per week. My child was the only child in the entire county who was receiving direct physical and occupational therapy. Those who had physical or occupational therapy listed on their Individual education plans were served by a "consultation" model. A "gross motor aide" who was paid minimum wage and who was required to have at least a General Equivalency (GED) or High School diploma provided "exercises". The hearing officer ruled that my child required direct services. As a result, since 1988, hundreds of children in the county have received services from full time and part time, OT's. PT's, Physical Therapy Assistants (PTA) and Certified Occupational Therapy Assistants (COTA). The school has at least two full time physical and occupational therapists on staff throughout the entire year. Many, many children now receive PT and OT direct services. Some continue to receive "exercises" from a gross motor aide, but those parents most likely do not know what their children are receiving.

In the fall of 2000, approximately thirteen years following our hearing, I happened to meet a retired teacher who remembered our hearing. She actually thanked me, stating as a direct result of our hearing she was able to obtain services for her kids that she had never before been able to obtain.

Our hearing was well publicized. It was open to the public with television cameras and radio reporters in attendance. We invited parents to attend, so that they would be able to see what an actual hearing was all about. After our

hearing, six other parents requested hearings. Some were settled. Others went to hearing. Many other parents filed successful state and OCR complaints. Two superintendents eventually retired or resigned, we elected at least four new school board members, and the director of sped chose early retirement.

I am in no way advocating that all parents take public stances with their school disputes. That is an individual decision that each parent must make based on the issues and facts that relate to their own case. In 1987, my child was in the second grade. None of her friends read the paper or watched the news. The publicity had little impact on her. Had she been older, our decision to be so public in our dispute with the school would likely have been different to protect her privacy. However, for those who have strong family support and courage to publicize their sped issues, your bravado can provide quite a learning experience for other parents of children with special needs. You will make some enemies. You will make some new friends. You will learn quite clearly who your true friends are.

Individual advocacy does make a systemic impact. Sometimes the impact will be greater than you ever would believe. It is, however, a slow, slow process. It is one that has taught me more about patience than any other experience in my life. That's why I continue to go through life "Changing the World – One Child at a Time".

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