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By: Cathy Healy

Several weeks ago I attended a meeting with parent advocates and agency representatives to discuss disability services in my community. One of the other parent advocates began telling us about a recent IEP meeting she had attended with a parent. The parent, a mother, had come to the meeting if not more than, at least as prepared as the professionals at the table. She had organized a binder notebook complete with color dividers for assessments, progress reports, IEP's, samples of the child's work, home observations, and additional information. The binder even proudly showcased an 8x10 glossy photograph of the child inserted in the front cover. My friend, the parent advocate, was exclaiming what a wonderful job this mom was doing in an effort to be an advocate for her child. All the service providers sitting at the table nodded in agreement.

I saw myself in that mother when my children were younger. I wanted to do everything just right for them. When my fourth baby was born with Down Syndrome, I knew I could tackle the job of being his advocate and first teacher. I researched the syndrome, connected with organizations, began to learn about service systems, and developed language to communicate with service providers. I kept all of his records in a huge binder and referred to assessments as I devised activities that would be beneficial in advancing him to meet developmental milestones. It all seemed so appropriate until one day I looked around and observed stacks of games and books and markers and manipulatives cluttering up the house, gathering dust. I just *bought* the materials, I never had the time to actually open the packaging and use them with him, because I was so busy keeping his records neat and orderly and searching out new tools and new methods for "teaching" my child to be "normal". Somehow I

Fixations #1: Take Back Your Life!

had gotten the message that if I just provided him with the right toys and if I just gave him opportunities to develop typically, he would.

When we hit elementary school, learning about special education didn't help. The IDEA amendments require parents to be involved in their children's education. Thirty years of research strongly substantiate that the more involved a parent is in a child's education, the more likely a child is to succeed. Moreover it is assumed that parents will not only be involved but will "steer the IEP ship." A recent Framing Paper on

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Family Involvement published from the US Dept. of Education and the IDEA Partnerships for the National Summit on Shared Implementation of IDEA explores the role of parents in the IEP process and the importance of parent involvement. "Given this connection between the IEP and the general curriculum, the parent becomes even more important as a partner

in setting high expectations for their child [and] making certain that services in the IEP are provided." Understanding this responsibility I was glad to meet the challenge. I was happy and pleased to partner with the school and ensure that services were being delivered. After all, my dream for my son was that eventually he would graduate high school with a regular diploma.

Upon entering middle school, I became disillusioned. It never occurred to me that in order for him to accomplish my dream, I would have to spend hours and hours drilling and working with him, enforcing reading and writing, reinforcing the things he had just learned while

also introducing new skills. I would have to walk the halls of the schools meeting with all the different teachers every week to ensure that services were being delivered. Don't get me wrong, I think parents need to have high expectations for their children but somehow I was lulled into thinking that high expectations alone will make the difference. I have come to learn that service providers sometimes are not so anxious to have the 'realistic' talk with parents; especially when we seem to be so organized and so well prepared to meet the challenges of raising children with disabilities.

Having high expectations is one thing; having realistic expectations is quite another. I'm not exactly sure of the date or time when I woke up and understood that his disability really did make him a *different* child. His disability *was* going to prevent him from reading proficiently and it *was* going to prevent him from living life completely independently. But his disability didn't make him any less valuable as a human being nor any less loveable. His disability didn't make him any less worthy of finding his own place in the community.

Now that my son is a little older and the dream of a regular diploma begins to grow dim, I am a little wiser. I say to the parents of America "Take back your lives!"

Be organized. Be effective advocates. Be good first teachers. But do not put on a badge and become a law enforcement agent. Do not become a therapist, or a case manager. Do not think that you must be the *professional* in your child's life. Do not spend every waking and sleeping minute *fixating* over how you can help your child overcome his deficiencies. Recognize and celebrate what you are to your child. Of all the roles we play, the most important one is the child's parent. I really need to be my son's mother. I need to nurture him, play with him, laugh with him, protect him, discipline him, and instill our family's values in him. I need to have time with his siblings and time for myself. I need to nurture my spirit and keep our lives in balance. The day I realized this was the day I took back my life and began to give my son one of his own.

Fixations was a three-part series by authors with personal experience with disability. The mother of a middle-school aged son (Fixations #1), a young adult with a physical disability (Fixations #2), and the mother of several young children, one of whom has a disability (Fixations #3).

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