

Individualized Education Program Research Paper #2
Parent's Perspective

Angie K. Millgate
Salt Lake Community College
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Introduction

I've chosen to follow Marina in her process to qualify for her IEP... third year in a row they are attempting this process. On the 18th of September, her mother, Tree, told me, "Marina got qualified!" We were very excited. However, it is a heartbreaking triumph.

Tree told me this news as she leaned heavily on her cane, breathing shallowly and looking like she had risen from the grave. She does not have very long to live. Doctors say weeks. She's pushing for the end of this school year so she can see Marina graduate from 8th grade. That is still over seven months away and seems impossible, but Tree is a strong, obstinate, opinionated woman with a lot to say and still a lot left to do. If anyone can pull it off, it's her.

At any rate, their family is in a whirlwind of emotion as they stare down the tunnel toward the light that is coming for Tree. They got Marina through the ongoing, tumultuous and emotional process of qualifying for IEP and I believe that it was a small victory for Tree that will allow her to breathe easier as she faces the end of her life. It provides a clear cut, delineated path for everyone to follow in support of Marina when Tree is gone.

In the times that I talked with Tree last year, before her cancer had eaten away the bulk of her body, she had tearfully said, "I am so frustrated with the whole IEP process. There is so much paper work, so much busy work. And no one seems to care but *me* about getting support

for Marina so she can succeed in school!” I remember thinking how hopeless she sounded and my heart ached for her. She showed me the stacks of papers and the files and the hundreds of emails and the plethora of research she had done in support of Marina’s case. *I* felt overwhelmed.

In talking with Chris, the principal of the Open Classroom, the K-8 school Marina attends, I’ve discovered that everyone *does* care, but they are stretched really thin. “In a perfect world,” Chris said, “there would be enough funding and enough personnel to easefully support *all* of the children and their parents in the process.” But our world is far from perfect, as is pointed out on the cerebralpalsy.org website:

School funding varies from state to state. Each state also sets its own “standard” or level of disability that your child must demonstrate in order to qualify for educational assistance.

What this means: while your child’s mental impairment or physical handicap may in fact interfere with her learning, she may not qualify for special assistance in your state. But she may qualify in another state.

For example, if you live in New York, it is easier for your child to qualify for special education help than it would be if you lived in Utah. New York has a higher tax rate than Utah and allocates more money to helping children in need. With more funds available to help children, more children can qualify for help. (Cerebral Palsy Special Ed Info)

Chris told me last week that our school has over 40 children qualified on IEPs, more than 10% of our student body and many more that could probably qualify but they have to be

selective. We have one full time special ed teacher and three part time aides in the school. I asked him how they did everything required on each student's IEP. His response, "Not very well, honestly."

Because of the emotional turmoil Marina's family is currently facing, I'm choosing to continue supporting her, watching out for her and working with her, but my research will come through other sources from here on out unless a miracle occurs. In researching for this particular part of the project, I tripped upon a blog written by the mother of a young boy with cerebral palsy. I read through several of her entries and could feel in my gut the intensity of the experience of raising a child with special needs.

For me, it put into sharp focus my gratitude for my healthy baby. I remembered days when I thought I could not go on, being a single mother and raising this beautiful baby all by myself. I remember thinking how hard everything was and then, as I read this mother's words, tears ran down my cheeks. I've had no idea how "difficult" life could really be:

I put together the best team of experts I could find. I researched doctors and talked my way into appointments, shamelessly throwing myself at the mercy of secretaries. I made sure Max had experienced Early Intervention therapists. If someone wasn't working out, I'd go to bat to find a replacement. I fought the insurance company to pay for more therapies. And we tried alternate stuff, too, like craniosacral therapy and hyperbaric oxygen treatment. I was determined to give Max every possible chance at succeeding in life. Taking action was helpful for me, too; I felt like I had some control

over a situation that seemed wildly, and scarily, uncontrollable. (Love That Max, “How I Made Peace” 2010)

Child’s Strengths

Marina is a vivacious young woman who excels at all things creative. She has the ability to read stories out loud in a way that they come to life in an eloquent production. However, according to her father, she retains very little that she reads when she reads out loud. She dances, she acts and she sings. She has a heart of gold and loves freely, easily and trustingly. She is kind through and through with the most beautiful spirit of acceptance about her.

Last year, when I would speak with Tree, she would more frequently speak of her frustrations rather than her appreciations. To be fair, I got to know Tree *after* her breast cancer diagnosis and I’m imagining that the experience has drastically changed her. From what I understand, she has always been a dynamic, outspoken woman but the acid edge of bitterness and anger is new since her diagnosis. When she and I would talk, she would complain about how the teachers were ignoring her and Marina, not supporting Marina to succeed and being uncaring.

In all honesty, I observed only one of the five upper grade teachers who was willing to work with Marina and she bent over backwards to accommodate her even without an IEP. She wanted to see Marina succeed and what ended up happening was all the other teachers abdicated their duties and just shrugged Marina off onto Gaby because Gaby was willing to do whatever it took to help Marina.

Because Marina's excels in areas that are strongly creative and because her various conditions lead to severe learning disabilities, her talents and abilities rarely get acknowledged. She struggles with academics and excels in the arts – even for a child without disabilities that is not a road map to being teacher's pet. Add to that Marina's ongoing struggles to learn, her physical sensitivities and her health requirements and you have a recipe for frustration on everyone's part.

I know that in the first year of our time at the OC, I watched Marina a lot. Kaitlyn, my daughter, was curious about her. There was another girl their age, Lilly, who was an extremely sensitive child diagnosed with highly functioning autism. Because Lilly and Marina were “different” they bonded together, but it was a harsh relationship because Lilly was so volatile and Marina was so tender. The students made fun of both girls and my daughter felt sad, but could not figure out a way to get into either of their worlds.

The taunting from the students was horrible and I later learned that it was more horrible than I realized. Horrible enough that Marina did not want to go to school and Lilly demanded to be home schooled at year's end. My heart ached with the meanness of the kids and I resonated with it as I read Max's mother's words, “Sometimes, when I'm with Max and we're around other kids who don't know him, I watch them watching him. They tend to blatantly stare, as kids do, and look perplexed.” (Love That Max, “Things Kids Say...” 2010)

These children with disabilities – *all children* – need to know how important their existence is in this world. They need to be loved, *feel* loved. They need to *feel* respected and supported. To play to their strengths and work *with* their skills is the greatest gift that I can give

any student in my classroom. It builds confidence and an “I CAN DO IT” attitude that each person on earth so desperately needs.

Family Impact

As I’ve worked on this project, Marina’s father, Jim, has found time and energy to respond to some of my questions through email. I read through his words and could feel the exhaustion that has resulted from their IEP battle. I was shocked to learn how much they have been misled and, literally, lied to. Our school has been in transition for the last four years; there have been three different principals and their experience has been that they literally had to start from scratch with each new principal. Jim said, “There are many people who have the capacity to mess up the whole process. Principal Jeff told us flat-out lies about procedures, keeping us in the dark about our rights regarding testing, appeals, etc. Dellis wasn't a liar, but not much better. Chris really cares, but even so, is learning the process himself.”

Their family has endured a time-consuming process with helping Marina succeed in her school, going as far as homeschooling her through the end of fourth grade in the hope of supporting her enough to get what she needed. Once she hit public school at the OC, her parents and her sister worked extensive hours weekly to reconstruct her homework so she could understand what was being asked of her and what she needed to learn.

Now that she is qualified for her IEP, finally, it is a game for them to find what is *really* going to work for her. She has a hard time reading and retaining information for longer than a few hours, but because the reading comprehension test was done immediately, she skyrocketed

on her reading comprehension scores. She “tested” low on math, but *loves* it, apparently – although that is when I witnessed the most frequent bouts with her cyclic vomiting last year. They dropped her a grade level in math in an effort to ease her struggle, but she pitched a fit, so they moved her back up. According to Jim, “Math is the subject that the testing showed she needed the most help in--it was the subject that flagged her as IEP material--and in previous years, I tutored her constantly. She just didn't retain things she learned from day to day. We'd get a concept down on Saturday, then on Sunday, she wouldn't need to be reminded so much as she needed to completely relearn it.” That is an example of the great lengths this family goes to in order to support her.

They've relied heavily on friends, family and their church for support, especially over the last two years as Tree's health has declined. In her words, “They say that cancer is a family disease. This is partly true. It's also a friends, neighbors, school, workplace, church, and playgroup disease. I'm so sorry to drag everyone through it, and yet am always so grateful for all of your help, love, and prayers that is getting us through it.”

In short, I've re-learned that everything is not as it appears on the surface. Taking this knowledge into my classroom will help support me in being the best teacher possible. Keeping my eyes open, as well as my mind, for the truth that may be simmering below the surface will help me to *truly* see my students.

Relationship with Educators

Traveling this path, in a small part, with Marina's family has been heartrending. I spoke with Jim today and he literally vibrated with frustration of the process. He said to me, "We just want someone to *help* our daughter, to provide what is her legal right. It seems that no one gives a damn about it and has put in very little effort to make this happen."

As a mother, myself, I know that what I want for my daughter is for her to feel safe and comfortable at school. I want her to be able to learn – and, hopefully, enjoy it. Marina's parents want the same for her. They want her to get in a groove of support so that as she graduates into high school, she does not feel lost in a sea of faces and they lose her all together.

For me, I know that through my experience with them and with other students of whom I'm becoming aware are covered with IEPs, I'm beginning to understand how much of an impact *I*, as their teacher, can have on the whole process. Marina's family have not felt like they have had an advocate that has worked for them because the teachers, according to them, have appeared disinterested and disbelieving throughout the process. I know Gaby very well and she is the one teacher who has been involved and I know she cares. She has gone above and beyond the call of duty to support Marina. However, Marina is the baby of Tree and Jim and, unfortunately – or fortunately, depending on how you look at it – generally no one cares as much for a child as does her own parents.

Conclusion

I have developed a wealth of empathy in this process. This empathy will only enhance my ability to be a better support to the parents of my students. I also believe that my

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IEP Project #2

understanding of healing and energy work will also benefit myself, my colleagues, my students and their families. I think that the greatest form of support to my parents – to anyone, really – is to *listen to understand* first. Providing that for my students and their parents will lay a foundation of trust upon which I can support them in their endeavors.

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