BEYOND SUFFERING
A Christian View on Disability Ministry

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Challenging the IEP for My Daughter with Down Syndrome

By Lori Lucore

One of the obstacles many parents of children with special needs face is the dreaded public school Individual Educational Program (IEP) meetings. But thanks to the knowledge I gained from the Joni and Friends *Beyond Suffering* program, I was equipped to overcome this challenge by standing up for better alternatives of integration for my daughter, Violet, who has Down syndrome.

In May of 2008, I met with the IEP committee at my 12-year-old's elementary school. Since her first day in kindergarten, I have always pressed for her full-inclusion and advocated for aid, speech therapy, and special education. As a result, Violet progressed in reading, writing, and connecting with her peers. Her helpful nature, self-sufficiency, and sense of humor abounded. I was proud that Violet not only consistently received awards for *Compassion and Perseverance*, but that she inspired her classmates. Her teachers said Violet eagerly anticipated every lesson, and that they wished all of their students showed such respect and joy.

Transitioning from Elementary to Middle School

Before Violet could progress to middle school, I had to face a team of six school authorities around the IEP table including the special education director, principal and school psychologist. As a result of their pre-collaboration, they informed me that my daughter would not be attending our neighborhood middle school, even though she had already toured the school with her 5th grade peers. They recommended that Violet attend a disability program located in a lower income area far from our home. Their secluded classroom was specifically developed to teach life skills to students with intellectual disabilities. Violet would not integrate with "normal students" for the next three years. I was shocked, but held back my tears and tried to resign myself to what seemed like a dismal prediction for Violet handed down by those in authority.

According to Violet's standardized test labels, she had the mental abilities of a 5-year-old. But it was obvious to those who knew her that Violet's maturity, experience, compassion, stylish dress, and "cell phone talk" more closely resembled her own age group. However, I agreed to take a tour of the disability program at the recommended school.

Touring the "Functional Academic Curriculum Track (FACT)" Class

I arrived at the far-off middle school in the company of my older son who had just returned from Yale. At our first sight of this "special program" room, it was noticeably dirty, old, and unkempt, and had very few of the interesting wall displays typical of schoolrooms. There was only one teacher among 20 or more students, although we were told that a couple of these were student aids. Among the students with "disabilities" was a recent immigrant whose sole impairment was that he spoke only Spanish. I wondered how much longer it would take him to learn English among speech-impaired students. In fact, how would any of these children with impairments learn best with only impairments to emulate? The teacher showed us the toy-like label-maker that each child was provided for learning to "type" (keyboard). I gathered that it was not expected for these students to ever use computers. The long-time teacher showed me the overhead that she used to teach the class collectively. Violet, who has won ribbons in horseback riding, been in numerous dance recitals, competitively dribbles and shoots baskets easily in full-sized hoops, has taken violin and piano, and won ribbons with her art, was now invited to color with several students—apparently a common activity.

When I asked if the students ever visited the rest of the campus, I was told they did not. Instead, a few "regular" students came into the room twice a year. In the discussion, I asked if Violet could elect a mainstream class, and I was informed that only a few students with higher potential had ever taken an art or music class. (This program had no art or music.) It seemed to me that the students were merely placated with time-consuming activities and not challenged. The environment was stagnating. I was even told that this class did not start until 10:00 or 11:00 am although the rest of the middle school began at 9:00 am—as if the effort to educate this group of children wasn't worth a full school day.

Leaving that classroom, my son and I were downcast by the thought of Violet's only option being such a dreary, isolated, and hopeless environment. I began remembering how excited my daughter had been to attend the well-lit middle school on the hill in our neighborhood with its state-of-the art technology and exciting theater just as her siblings had. I recalled how one of her best friends was a compassionate, intelligent girl she had met in a mainstream classroom. I could clearly see that the school system's premise was erroneous. After taking the class at the Joni and Friends International Disability Center, I was armed with the tools and my theology was strengthened. It was clearly God-ordained!

Based on the new information and with a heart to provide my child with the best possible education, I called the elementary special education director. I shared that I had recently completed the course and that I could clearly see that the recommended middle school was an unacceptable solution. I explained that I did not understand why Violet could not attend school in her own neighborhood with her own friends and siblings. I insisted on touring the Special Education classes at the progressive middle school in our area. The special education director agreed to a new tour of our neighborhood school, after hearing the incontestable facts regarding the questionable benefits of segregation.

Another Day, Another Tour

When I arrived at the neighborhood middle school I was introduced to the special education director. My first impression was that she seemed resistant to including persons with disabilities in her school. Nevertheless, I offered her the impactful pamphlet from the Christian Institute on Disability (CID) of Joni and Friends, with which I was proud to tell her I was affiliated. The director commented about seeing an article in the newspaper about the CID with a photo of Joni Eareckson Tada. As we began to discuss Violet's options, I addressed each of their misconceptions with an enlightened truthful argument. I pointed out that some of their assertions were not in compliance with the Americans with Disabilities Act and the school officials had no counter argument.

The director had prepared to have me greeted by a model parent of a daughter with Down syndrome who had participated in the proposed "only" option of the FACT class at the downtown school. This mother was also employed by the school system. She repeated a theme I had heard much in previous IEPs, that her daughter was best suited to this program because she felt safer in a closed environment.

The first misconception was that an isolated environment makes a child feel safer or more confident and so the child is able to better function.

I countered that Violet would be living in an integrated society, and should be preparing to deal with the realities of the world if she were to succeed. I confidently argued that isolation limited her potential.

I also explained that from a Christian point of view, we are all parts of one body, the lesser being more valuable because God's power works best in our weakness. This principle serves as the basis of the Joni and Friends International Disability Center, which operates under the Luke 14 mandate: "Go out quickly… and bring in the poor, the crippled, the blind and the lame . . . so that my house will be full." Further, I expounded that you can often tell the compassion of a society by how it treats the least of its members. Still sensing pressure to put Violet in the institution-like program, I was able to back up my views with writings about "the indispensable nature of persons with mental retardation" by CID professor Dr. Jeff McNair, who heads the first graduate program on disability at California Baptist University.

Amidst their ongoing insistence that Violet did not fit into the accommodations at our neighborhood school, but only in the segregated program for all of the disabled, I asked, "What's all this about Violet *fitting into your program?* She has a right to attend school in her own neighborhood and that school needs to adapt an educational program to accommodate *her*." I challenged that if the FACT program was of such educational appropriateness and benefit, then why wasn't it offered at the larger progressive school, especially since 12 percent of the present population has disabilities? The ADA requires public schools to make available to all eligible children with disabilities an education in the "least restrictive environment" appropriate to their individual needs. I mentioned Violet's maturity, and that she was appropriately cooperative and adaptable, which had been confirmed by her elementary director. I added how she loved to go from class to class, dress in matching trendy clothes. There was no adequate "excuse" to exclude Violet from a middle school experience.

The second misconception was that a child with disabilities should have only disabled friends and will relate better with them. To this fallacy, I pointed out that much of Violet's previous success in school resulted from freely associating with siblings and friends who were typical, prompting her to adjust, excel, and learn from her environment, in contrast to leaving her no option but to emulate disability from others with disabilities. Violet's school report card from her mainstream 5th grade teacher reads, "She is more outgoing in class and initiates more interaction . . . Violet's self-confidence has grown and she is a loved member of our class." That happened when the bar was set high and she was not segregated.

The third misconception presented was that when our children are in kindergarten, there is little to no apparent difference, but as the children grow into higher grades, the intellectual differences widen and necessitate separation. My newly acquired knowledge prepared me to immediately counter by pointing out that the maturity level of children also grows to account for increasing differences, which fosters a beneficial tolerance, mutual collaboration, and compassionate ministry to each other. I pointed out how fond the teachers and students had grown of Violet in her elementary school, and how this accelerated an understanding and trust for diversity—something of increasing necessity in our global world. To know Violet's loving nature and to see her struggles had taught the students to lift others up instead of compete, thereby refining their character as societal contributors. These factors would likewise benefit all those in the neighborhood middle school.

I was finally allowed to tour the newer campus, and to our delight, the Special Education rooms averaged from only five to 10 students, had computers, bright centers and posters, and were spacious and well-lit. It was clear to me that the school did not lack resources, but only the motivation to include those with disabilities. All of the irrefutable facts and arguments I'd gleaned from the Christian Institute on Disability finally silenced the administrators' insistence that my daughter be enrolled in the FACT class. An appointment was later scheduled for an addendum to Violet's IEP.

Not What Was Expected

For this third meeting to resolve the IEP, I was asked to visit the district office instead of a school. It soon became apparent that we had been brought to the district office in another attempt to persuade me to consent to a three-year closed classroom for the impaired. My adult son and I were escorted into the office of the district director who offered us a seat in front of his large desk and closed the door. He proceeded to suggest how Violet would be best served in the one district FACT classroom especially made for the disabled. He consistently said he did not understand what we had claimed about the unkempt nature of the facility and flatly denied that students did not integrate with the rest of the campus, which was a direct contradiction of what the head teacher had told us.

A fourth misconception became apparent during this meeting: Those with mental impairments cannot assimilate or process grade-level material. I reiterated what I had learned in the CID class; that it didn't matter if she processed all data in the same way as others, but the mere fact that she would be exposed to real life meant that she uniquely assimilated part of it and was a distinctive part of it. I explained that Violet has matchless talents to offer (as each individual has, regardless of performance capability) in addition to her valuable character and perspective that could be beneficial to other students and faculty—not the least of which were love, joy, and consideration. The district director emphasized that they did not have a program available at our neighborhood school because there had not been any *need* for it, as if we were making an irregular, outrageous demand. I countered that such was the case merely because students with disabilities were all diverted (with similar pressure) to the one institution-like program.

The district director asked if I wanted a copy of my rights under law and I answered that I was well aware of disability law, also taught by the CID. I was able to profess that I believed the biblical promise that the meek would inherit the earth, and also gave him a pamphlet and informative DVD from the CID. I immediately saw a change in the district director, who realized I had the legitimate backing of a powerful organization. I began to sense that we had the means to remove the barriers of a hard-hearted school system, and dispute the routinely circulated misconceptions that suppress the families of children with disabilities.

Though the administrators had insisted that Violet would be enrolled in the FACT program, it was not legal and they finally saw that we would not give in to the status quo that had been forced on so many others. The district director realized he had no choice but to begin reluctantly writing out an Addendum to the IEP for "Specialized Academic Instruction daily, separate classes, and support services" for Violet at our neighborhood school. I knew God was using us to pave the way for others with disabilities. Violet's presence at the middle school would be an opportunity to enlighten and soften the hearts of many.

My son noted the irony that the district director who was so intent on segregated programs and intensely against Violet's rights to be an inclusive student in her own neighborhood school, had a physical disability himself. As I prayed that his life was impacted, I recalled that we are all made in God's image and fallen from perfection. We *all* have disabilities that God allows to accomplish his glory. In Genesis 32:22–32 we see that to wrestle with God as Jacob did, resulting in a "*wrenched*" hip, was to be "*blessed*," and to "*see God face to face*." Exodus 4:11 demands, "*Who gave human beings . . . sight or makes them blind? Is it not I, the Lord?*" The psalmist in chapter 139 writes that our "*frames were not hidden*" from God, but that we were "*knit together . . . fearfully and wonderfully*." A consistent theme of the Bible is that the **meek** and the **weak** are blessed, while the strong are conquered and the wise in the world are deemed foolish. Jesus himself often reached out to the disabled, declaring in John 9:3, "*but this happened* ***so that the works of God might be displayed*** *in him*." Our disability makes God's ability evident as in 2 Corinthians 12:9, "*for my strength is made perfect in* ***weakness***" (emphasis added.) I am so grateful to the CID for enlightening me and multiplying the blessing of God's powerful theology on disability.

Time Marches On

Violet's three middle school years were coming to an end. Surprisingly, her grades had been straight As in her modified curriculum with special notations of "Positive Attitude/Influence in class" and "Puts forth a high degree of effort into her work. She is an absolute joy!" Violet's homeroom teacher invited us on a tour, including appointments at the high school with various teachers and the director of special education. I was impressed with the class for students with disabilities—a spacious open room, one-on-one individualized study with high school students who elected semester credit to assist a single student, and ample sophisticated computer areas. Caring teachers presented various options for accommodating mainstream electives. I profusely thanked my daughter's middle school teacher for arranging the appointments and personal tour of the high school. He replied, "I set this up because I want to secure the best for Violet—I genuinely care for her and her welfare!" He had learned to know her as a person, not as a disability.

A few weeks later at Violet's last IEP meeting at the middle school, I was surprised to see all of the attendees whose presence was not mandatory, nor even indicated. The science lab teacher came specifically to offer gratitude for Violet's contributions to his mainstream Science Lab class. He enthusiastically described her complete participation, adding that he and all of the students "loved" her. Violet's regular education English teacher announced that with minor adaptation, Violet contributed in all class activities, adding that she wished all of her students had such a positive and helpful attitude. The physical education teacher was also present to share that Violet's perseverance had allowed her to keep up with the regular education kids, and he was now eager to visit and encourage her in sports at the high school. This team of teachers—in a middle school that had initially rejected her—now appreciated the differently-enabled! This pattern of accommodation had developed an enthusiasm that would continue for years to come.

Most surprising was that the district director of special education showed up for Violet's IEP. He, too, was smiling, and no longer limping with a physical disability. Listening through our entire IEP meeting of department heads and administrators, he was particularly attentive to the volunteered testimony of the other teachers. Suddenly, he turned to me and emphatically asked with pride, "So, how did you like the new special ed program at the high school?" It was then that I realized the impact made by our previous challenge to the district. All of those arguments for integration and equal accommodations, learned from the CID, were not futile! The improved high school accommodations were, at least in part, directly inspired by our confrontation with the district director three years earlier. This IEP meeting was a celebration of understanding, and synergy created by a diverse group in active collaboration! The way had been paved for many others to benefit from an excellent school program of individualized accommodation.

About the Author

Lori Lucore formerly served in correspondence with Joni and Friends, overseeing resources at Joni and Friends. She studied International Relations and earned her B.A. in Business Administration. Above all, she enjoys being a mom—to Violet and her brothers and sisters.