



Complex Child E-Magazine

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Trying to See Clearly by Colleen M. Proctor

A child with complex medical needs? I've got one of those. His name is Zachary and he just turned three. He suffered non-accidental trauma when he was only one month old and spend almost a month at UCSF before discharging home to foster care. A year later, I learned about him, and after a few get-to-know-you visits, he came to live at my house and was subsequently adopted.



When he came to our home, he was 17 months old and very stiff. He could hardly move his arms and legs, couldn't roll over or hold his own bottle, and could not eat solid foods. He had a diagnosis of Quadriparetic Cerebral Palsy, Strabismus, Cortical Vision Impairment, Dysphagia and the ever-present "Developmental Delay."

Because of my background working a Nurse Consultant for California Childrens' Services (CCS), I was well able to advocate for Zachary and make sure he had access to the specialists, therapies and services to help him reach whatever potential his abusers

had left him. Although I am very grateful to have this child in my life, as is my extended family, I certainly do hold our court system responsible for the fact that no one was ever charged with the injuries he sustained.

Since this issue is about Vision and Hearing, I thought I'd write about a dilemma I recently faced regarding my son's glasses. It's one of those hopeless dilemmas parents face when they get conflicting advice from the specialists hired to help direct the medical care of their child.

From an early age, Zachary had been prescribed patching for his strabismus, also known as lazy eye, in which the eyes don't coordinate well with each other. As he became better able to control his body, he let us know how much he hated them and would rip them off. The same thing happened with the eyeglasses prescribed at age two. We tried many options for keeping them on without much success.

After a yearly visit from the Blind Babies foundation staff due to his Cortical Vision Impairment, we were also recommended to attend a Low Vision Optometric Clinic in the Bay Area. This was primarily for an assessment of how best to offer materials to him, especially as he neared the age to enter formal school system services. Boy did they have a different opinion about the glasses! I felt their assessment was fairly comprehensive, and they indicated that the reason Zach hated the glasses was because they "over-corrected" his normal toddler farsightedness and made things blurry for him. They recommended that we should be encouraging him to use the vision he has, and not frustrating him at every turn.

We happened to have a visit with the traveling Ophthalmologist the next day, and from the moment we mentioned Zachary had been to an Optometrist, the doctor just went off. It was made clear to me that if I *ever* wanted surgery to correct the strabismus, Dr. T would NOT perform it unless Zach wore the glasses at least one hour per day. Despite my extensive background, I left that visit feeling very rattled.

How did I decide which path to take?

Zach lost the glasses the next week, and after much soul-searching, we decided not to replace them. He really did hate wearing the glasses. I have six grown children, and two of them had strabismus. They loved their glasses because it opened up the world to them. Zach, on the other hand, has had enough done to him, and the glasses were just not working. I am his Mom now, and I've taken on the responsibility for listening both to him *and* the acknowledged experts.

And I'm willing to let the buck stop here when a decision to buck one or more of the experts is needed.