

Parenting by Principle

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It was early November 1997. Our baby was due any day and we were so excited. The nursery was perfect, the house was spotless, and I had Preparation for Parenting almost memorized! I had many sonograms during my pregnancy and from those reports Jeff and I were expecting a healthy, baby boy. The day finally came. We would never be the same. Our first-born son, Stephen, was diagnosed with Goldenhar Syndrome. Over the next few days we would learn about several medical problems, the most severe being a heart defect requiring open heart surgery. As the months passed, we learned even more about how this syndrome was affecting our child. As Stephen grew we realized he was not responding to sound. A hearing test revealed that he was profoundly deaf. Further testing confirmed damage to the inner ear giving no hope for medical intervention. Stephen struggles to keep up developmentally because of scoliosis, restricted neck movement, limited eye movement, an abnormality with his left hand, and a hypersensitivity problem. He receives physical therapy, occupational therapy and deaf education weekly.

My husband and I are easily overwhelmed with caring for our son. It may seem that the last thing on our minds would be Preparation for Parenting and the Toddler Years. However, we have found that the principles in Prep still apply to our special-needs child. It would be easy to use Stephen's disabilities as an excuse to exempt him from the training process. Stephen's sinful nature needs to be tamed just as much as any other child's. The principles and ideas in Prep are working for us; they just take longer and require a bit of creativity.

We refuse to lower the behavioral expectations for our son. The standards remain high, but we give him longer to achieve them. We also find alternative ways to reinforce training. For example, Stephen cannot speak or sign yet at sixteen months, however, we still require that he greet people and say "thank you." We move his Hands for him motioning the correct sign as he makes eye contact. Although Stephen is deaf, we still use correction for arching the back, kicking, and rebellious behaviors because these have nothing to do with his physical disabilities. On the other hand, there are certain behaviors we allow because of his challenges. Stephen is allowed freedom with his hands in the high chair. Because of his over-sensitivity problem he will not touch a vast array of textures. We encourage him to touch as many different types of textures and foods as possible. When he touched the Christmas tree for the first time, we were thrilled! Stephen loves to lie on his back and playfully kick the wall, couch, bed, etc. Due to his hearing loss he needs various types of input and this is a great way for him to receive a different type of stimulation. If he wants to kick at someone else's house, I simply redirect him to another activity. The key to allowing these types of behaviors is knowing why you are allowing it and expecting that you will have to re-train later.

It has been important for me to remember that I should be concerned about my child's heart and not overly consumed with his outward behavior. I cannot expect my son to match up with another sixteen month old Prep baby. I struggle with pride around other moms at times and fear they may judge me for allowing certain behaviors that they may not understand. I know, however, that God is leading us in His wisdom. We are parenting by principle, not by rule, remembering that our goal is training the heart.

It is a gift to have a child as special as Stephen. Because of the many obstacles and challenges, we are forced to lean on God and be led by His Spirit. We have learned that there is no formula for parenting. If there were, then we would not need God. Preparation for Parenting, Preparation for the Toddler Years, and Growing Kids God's Way have been a tremendous help to guide us in the right direction with our special-needs son.