

An Inspiring Story from the ASDC Conference

By *Tami Hossler*

Denise Stoner is a single mother of four children. Her youngest daughter, Shakira, is Deaf from complications due to a hospital's misdiagnosis and treatment of an ailment, which led to meningitis and a coma at five months old.

After Shakira came out of her coma, the diagnosis was DiGeorge Syndrome, which for her included heart problems, a cleft palate, mobility problems, and learning disabilities. The doctor asked Denise whether she wanted to keep her daughter or place Shakira in an institution. Denise stated to the doctor with all the conviction of a mother, "I have prayed for three months for my daughter and am not going to give up on her now or anytime in the future."

Immediately Denise and her family started with early intervention services and then transferred to services provided by the early intervention program at Pennsylvania School for the Deaf (PSD) when Shakira was one year old.

As Denise went through her own battle with addiction, she was also battling with the stigma she felt surrounding sign language. She eventually began to learn sign language through a sign language tutor and Deaf mentor when her daughter was four years old. This began an awakening into her daughter's world. Through this, her own personal stigmas about sign language began to change to the point where she could fully embrace her daughter's first language. During this time, she met a grandmother, Denise Tucker from PSD, who opened her heart and provided Denise S. with a support system so that she was empowered to actively involve herself into Shakira's life.

Because of Denise's experiences and the support she received from Denise Tucker and PSD, she is now motivated to help others by speaking about her journey as a parent who deals with her own personal challenges along with parenting a child with multiple special needs.

This year was Denise's first ASDC conference, and it is obvious, through her love for her daughter and her newfound connections, that this is only the beginning of her involvement as a parent of ASDC. One key reason for Denise's participation in this year's conference was the simple act of a grandmother, Denise Tucker, reaching out to her and sharing her passion for ASDC and its biennial conference.



Denise Stoner and Shakira



Denise Tucker and Denise Stoner

Denise Tucker is the grandmother of Danisha, who was born in 1989. Denise T. and her family have attended many ASDC conferences over the years, the first one being at Gallaudet University. It was there that Denise T.'s family began to love ASDC, which brought them together with other families who experience so many of the same things in their everyday lives.

Denise T. has always been an involved mother and grandmother. When her granddaughter, Danisha, was three months old, Denise felt that something was not quite right. Danisha was not reacting appropriately to certain sounds. When Danisha was old enough to crawl, she would crawl up to the television and look up at it intently. Denise's daughter took Danisha to a doctor at a well-known hospital in Philadelphia and the doctor said, "Oh don't worry, some kids don't talk till age two," and that was that. The family contacted Saint Christopher's Hospital where they finally got answers from a doctor who basically diagnosed Danisha over the phone. Immediately they took Danisha in for more testing and learned that Danisha had the genetic Waardenburg syndrome. The characteristics of this syndrome include eyes of different colors, a patch of gray hair with non-pigmented skin, and deafness. Later Danisha's sister Damiya was also diagnosed with Waardenburg syndrome; Damiya, however, is deaf in only one ear.

As many hearing families do, they grieved because they were not familiar with this experience. They had never met a Deaf person. All they knew was that they must communicate with Danisha.

Danisha started out in a local Catholic preschool that served Deaf and Hard of Hearing students utilizing an oral approach. This only lasted a short time once Denise real-

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