

RAISING A CHILD WITH FETAL ALCOHOL SYNDROME (FAS)

By: Kathryn Shea

I am a clinical social worker and parent of a 15 year old son with FAS. Little did I know when Seth came to us as a foster child at the age of four months, how our lives would change. I remember the phone call so well. The case worker said, "We have a small boy ready for discharge from Harlem Hospital. He has fetal alcohol syndrome and a cleft palate, which can be repaired." I had no idea of the long term effects of FAS. As a social worker, I believed nurture always won out over nature, and with love, a nurturing environment, and appropriate stimulation, he could overcome anything. Love is a wonderful healer, but it can not undo brain damage. By the time Seth was age two he was totally out of control. Our then seventeen year old daughter assisted us tremendously in caring for him, but on one very difficult evening she looked at me and said, "Mom the ratio here is three to one and we're losing." She was absolutely correct. If I were not experiencing it myself, I would have never believed a two year old could have taken such control of a family's life. I called the pediatrician the next day and asked for help. We saw a pediatric neurologist within two weeks and at the age of three he started on medications for behavioral control. The neurologist advised us not to adopt Seth. She told us the brain damage he suffered as a result of his mother's alcohol consumption during her pregnancy was so severe he would probably require institutionalization by the age of seven. But we had fallen in love with him and could not imagine what would happen to him if we did not adopt. He would become one of those statistics that I witness every day in my work. Another foster child moved from one home to another, possibly abused, multiple psychiatric hospitalizations, and then long term residential care or even worse, a detention facility. The mere thought of that possibility created sheer panic and we adopted Seth at the age of four.

That was eleven years ago. Since then he has been on more than 16 different medication trials and is currently on five psychotropic medications. He has had 24 ear tube placements, and cleft palate repair, and surgery to remove the mastoid bones from behind both ears due to infection. There is probably not a day that goes by that he is not in some kind of pain, either physically or emotionally. My husband and I have been his case manager, advocate, nurse, teacher, and parents. And when we were exhausted, we could not call a baby sitter or relative, because no one could manage him. And of course, there has never been respite. We were fortunate in New York to work with our school district to develop a very individualized educational program with a one-on-one aide and staff who were willing to listen to us and use strategies with him that were successful. Seth made great progress in an included classroom with typically developing peers for three years.

The move to Florida four years ago was very difficult. Change is extremely hard for these children. His school placement during the first year became a nightmare. The first teacher filed a petition to have Seth removed from her classroom and he had to be moved to another room. An additional support person was added to the classroom, one who had been a kitchen aide, with no experience or training in working with children with special

needs. He was in this room less than a month when, while being removed from the room he grabbed the aide and she filed assault charges against him. We did not know that in the state of Florida it is now a felony charge when a child hits a school board employee, even when that child has a disability. The nightmare went on for four months, while we tried to say Seth could not go to teen court to be tried by a jury of his peers. He had no peers. He would have no understanding of what was taking place or what was happening to him. With the assistance of the State Attorney's office, we were able to obtain a diversion plan, but the charge remains against him. I can not describe to you what it is like to be a parent and worry that your child will be sent to a juvenile detention facility for a crime he did not willfully commit and has no understanding of. And yet, we know there are hundreds, if not thousands, of children and adults across this country in detention facilities or jails with fetal alcohol syndrome and effects, with parent's hearts broken, unable to do anything.

Seth is now doing very well. He attends Oak Park, a very special school with very dedicated staff. We and he were blessed with a wonderful teacher the first two years who loved him and respected us. She listened to us when we told her what worked and what did not work. School environments and teachers are often the greatest source of stress for children with fetal alcohol spectrum disorder, as well as for their parents.

Seth has been on a wait list for respite and recreational services with Developmental Disability Services for three years now with no end in sight. He reminds us daily that he is now a teenager and wants to be with other kids his age on the weekends and during school vacations. So we do our best to create inclusive activities so he can be with his peers.

Our challenges are no different from other parents raising children with FASD. We all are asking for the same things: show us what works, give us respite, teach our teachers to educate our children in a way they can learn, help us learn how best to advocate for their needs. Listen to us and provide the resources we need to help our children grow to the best of their abilities. And while we must be concerned about prevention of FASD, far too many federal dollars are being spent for prevention and not nearly enough on intervention for the children we are taking care of now. His father and I do worry about him as he ages. What will happen to him when we are gone? Will people love him and respect him for the wonderful, caring, person he is or will they make demands on him he cannot possibly meet? My husband has one prayer at night and that is to live one day longer than Seth does, because we can not imagine leaving him behind in a world that does not understand him.

Seth has been both a challenge and a gift to our family. I am a better person because of him. The other night while out looking at the stars, Seth held my hand and said, "I am so glad I am alive mom, and that I have you and dad." So are we, Seth.