

SCREAMS – The Sweet Sound of Success

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I'll never forget the day that I first realized the success I had achieved as a mother of a young adult with FAS. When the light of awareness went on in my mind, it was bright in contrast to the darkness I had been carrying for years. I had been somewhat depressed over the hopelessness of the idea that FAS is permanent brain damage for which there is no cure. What made this concept so devastating is that it is 100% preventable - theoretically speaking anyway.

My son John had just turned 18, that magical age when a person legally becomes an adult. But I knew that he really was and always would be a boy in a man's body, never able to function independently in the true sense of the word. He would always need supervision and support services. I had tried so hard all his life, worked so diligently, to help him achieve his potential, and it was hard for me to accept that, in spite of all my efforts, he would always need to be in the care of others to stay safe and well and living with a decent quality of life.

When I started my journey as John's mother, I was a foster parent for special needs babies, and John came to me a scrawny little thing a few weeks after his birth, only 4 pounds, with a diagnosis of FAS. As delighted as I was to have a diagnosis, it was not long until I learned that there was almost no information available regarding prognosis or intervention. His future was a big question mark, and I realized I might have to rely on my "whatever works" philosophy of intervention. After I adopted John, I followed Ann Streissguth's continuing studies on children and adolescents with FAS, and that helped me to know what behaviors to expect and what problems to try to prevent. As other parents know, day to day life was challenging, sometimes joyful, sometimes frustrating. And as John reached adulthood without the abilities to live as an adult, I felt discouraged that nothing I could do for him would reverse the physiological damage of FAS. Until my "awakening" to a new reality.

It was that September day in 1996 that Dr. Ann Streissguth revealed the results of her long-term studies on secondary disabilities associated with FAS disorders. I was sitting in the auditorium in Seattle with other conference attendees. Streissguth noted the primary disabilities associated with FAS – the delayed growth, the facial characteristics, the physiological anomalies, and the dysfunction of the central nervous system. I recognized that John had just about every primary disability that was mentioned. Then Streissguth talked about the secondary disabilities that the individuals in her study developed: mental health issues such as clinical depression that in 23% of adults led to suicide attempts; dropping out or getting kicked out of school, getting in trouble with the law, sexual assault, abuse of alcohol and other drugs. These are among the secondary disabilities that can result from having FAS disorders, more devastating than the primary disabilities, and all preventable! It was at that moment that I realized that John had reached the legal adult age of 18 without having incurred any of the secondary disabilities! Streissguth reported that the protective factors include early diagnosis, stable home environment, and appropriate support services. John came to me with the first, and I provided the others. The joy I felt, the pride that I must have done something right in raising John to have helped him get at least this far in his life with absolute success!

The strategies I had been using all the years John was growing up were not just haphazard ideas applied blindly, they were carefully thought out strategies based on what I had learned from Streissguth and other FAS experts. There was a method to my madness, and that method was something I decided to record and distribute for other parents to use as guidelines in helping their children achieve success as well. My model for intervention has been used by many other families with great success, according to the feedback I have received.

There are seven basic components that I apply, and they happen to form the acronym **SCREAMS**.

Structure: a regular routine with simple rules and concrete, one-step instructions

Cues: verbal, visual, or symbolic reminders can counter the memory deficits

Role models: family, friends, television shows and movies that show healthy behavior and life styles

Environment: minimized chaos, low sensory stimulation, modified to meet individual needs

Attitude: understanding by everyone that behavior problems are primarily due to brain dysfunction

Medications: most individuals can increase control over behavior with the right combination of meds

Supervision: 24/7 monitoring may be needed for lifetime due to poor judgment and lack of impulse control

Structure: Most people who know about FAS disorders are aware of the need for structure, but sometimes this is confused with control. While providing structure as a foundation, we need to offer choices they can handle, remain flexible, and remember KISS – Keep It Simple Sweetie!

Cues: Giving cues can be tricky, as we tend to only give verbal reminders. I call it cueing; John calls it nagging. Kids with FAS respond well to visual cues, to symbols and signs, to music and rhythm.

Role models: Children with FAS disorders learn behavior primarily by mimicking the behavior of others. This makes healthy role models extremely important. I am reminded of this saying: “Children learn by example; unfortunately they can’t tell a good example from a bad one.” We need to provide positive examples for dealing with frustration and anger, for appropriate social interactions, and for life styles that are healthy. Our kids need to be shown how to act in ways that will keep them out of trouble. John learned to walk away from being shoved or hit. He learned to express his anger with words that explain what he is feeling rather than words or actions that might hurt others. When we have observed unhealthy behavior, like inebriation or violence or disrespect, we talk about it and we play act healthy reactions to difficult situations that are likely to occur.

Environment: Behavior modification is not on my list, because it has not been reported to be very effective when dealing with FAS behaviors. Our kids might understand consequences, but they usually aren’t able to learn from them. Time-out may not teach them to change their behavior either, but quiet time can be used when they are overwhelmed or over-stimulated as an opportunity to self-calm before rejoining a group. Behavior mod implies changing the child. What works better for our kids is to change the environment. Avoid noisy, crowded places; reduce the chaos; and prepare in advance some coping strategies for unavoidable situations that might be too stimulating. One overlooked factor in environment is diet – avoid all artificial additives (preservatives, coloring agents, aspartame, etc.), which may increase behavior issues.

Attitude: Understanding the nature of FAS as a neurological disability helps to minimize unrealistic expectations. Dr. Calvin Sumner stated that the greatest obstacle our kids must overcome is chronic frustration from unreasonable expectations of others. I believe this attitude of understanding by all who are in the individual’s life could reduce the risk of depression and suicide tendencies later. The parents whose children experience the most success are those who have achieved an attitude of acceptance that their child may not fulfill their dream of “normalcy.” Again, unrealistic expectations for full independence might set the teen up to fail. The teens and young adults who enjoy the most success are those who have accepted the limitations of their disability and the need for protective restrictions.

Medications: Meds are usually initially prescribed for ADHD, but medications can help more than just reduce hyperactivity. The right meds or combination of meds can normalize the balance of brain chemicals, and can somewhat restore function and give the individual more control over behavior, increase memory and learning, and enable the individual to function more appropriately in social interactions.

Supervision is difficult to impose, especially as the child reaches the teen years and wants the same independence as they think their peers are given. Unfortunately, giving privileges due to an 18-year-old to a person with the judgment, conscience, and impulse control of a 6-year-old could result in total loss of freedom, if they end up in the hospital, on the streets, in jail, or in the morgue.

I have overcome criticisms of being overprotective and of not letting go. But my son is healthy and happy and productive, and I am proud of the success he has achieved. His quality of life is better than that of most non-disabled people. The only screams in our family are screams of excitement and joy. Especially now that John is pursuing a romantic relationship with a new female friend. But that’s another story!



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