FAS/E: A Standard of Care for Adults
The Dysfunctional Years

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My final year of denial that something was wrong with my son, Rusty, began in September 1989 when I enrolled as a student at The Art Institute in Seattle. It all seemed so innocent and natural at first. I had spent 24 years as a stay-at-home mom raising four spunky kids. My baby had entered high school so my husband and I started to prepare for an empty nest. I did really well at The Art Institute (3.7 GPA) but understood quickly that I had much to learn. One day as I was admiring an illustration that another student (young enough to be my child) was working on. I said, "That is exquisite! How did you learn to draw like that?" He looked at me like I was crazy and said, with the arrogance of a great artist, "First you need to learn to observe." At first I was really annoyed and thought he was just being sarcastic, but the more I thought about it the more I realized what a truthful statement he had made.

Of course with me too busy to provide firm structure for Rusty and Cheryl, they took off in separate directions generating clouds of chaos everywhere they went. My hope for an art career vanished like dew in the morning sun as I realized that something was terribly wrong on the home front. I was upset but had spent too many years as a full-time mom to fret about a lost art career. My children's future was in jeopardy and I was determined to discover why. As my husband says I am very easily amused (and I have always liked my own company) so I dropped out of art school and began the journey on another learning curve trying to figure out what made my children tick. I started reading everything I could get my hands on regarding the human brain and what makes us different from other mammals.

Raising four kids on one paycheck didn't leave a lot of "research" money so I bought myself new brain books as Christmas presents from my husband, Don. His job was to write something romantic to me in the front of each book. One year the book's title was The Brain, so in this one he wrote, "I hope you like this book about me." The next year the brain book was entitled, The Amazing Brain, and he wrote, "Merry Christmas to my honey who has a mind of her own." Then one day I heard something on TV about a book detailing new research on the two different sides of the human brain and how this could help us understand and learn more easily. I was impressed that this wasn't some crackpot idea because the scientist, Roger Sperry, had won a Nobel Prize for his proof of the split-brain theory which says "that our problem-solving skills, physical and mental abilities and even personality traits are strongly influenced by our habit of using one side of the brain more than the other side." I also learned from Jacquelyn Wonder and Priscilla Donovan in their book, Whole-Brain Thinking, that brain bias explains why one person is a math whiz while creative types often flounder when trying to balance their checking accounts. (This is a book I enthusiastically recommend.) They go on to say, "the ideal person has strong skills in each hemisphere and can move into the appropriate one when that skill is needed." I was hooked. This solid scientific research also seemed to give validity to the 4-temperament theory that I had been using to build self-esteem in my kids.

I began reading everything that I could find on how to utilize and explain this theory of brain function and learning. I read Thomas Blakeslee's, *The Right Brain*. This book (also highly recommended) details the brain's "two languages." "Since the left and right brains are organized differently, it is easy to see why the memories of one side are not useful to the other. The left brain handles complexity by sequences of small logical steps. The right brain's holistic feel for throwing a ball on a windy hill is likewise of no use to the left brain. The two kinds of brain organization simply store knowledge in a different form - almost like a different language." Nobel Prize winner, Roger Sperry, and his colleague, Michael Gazzaniga, continued this line of research proving that something called the corpus callosum serves as a bridge between the two halves of the brain, letting the right hemisphere of the brain know what the left hemisphere is doing.

My husband, who is a tennis player, told me that if I wanted to understand how to put this theory into practice that I should read Timothy Gallwey's book, The Inner Game of Tennis. Being a stubborn cuss, I thought to myself, "Now what could a tennis book teach me about the brains of my children?" Later, however, when I saw a TV interview with the author, I went to the library and checked out his book. I was totally thrilled with what I learned and promptly purchased every book he had written. One book review read, "Tim Gallwey is the most interesting writer on tennis to appear in many years. It can be stated without doubt that reading Gallwey literally reveals you to yourself." (Jack Barnaby, past president, U.S. Professional Tennis Association) Reflecting back to that period in my life, just before Rusty was diagnosed with FAS, I did discover that a tennis book could indeed teach me a lot about my children because it taught me how to observe.

The basics are these:
1. The human brain is put together sort of like a walnut. There are two halves, called hemispheres.
2. Each hemisphere picks up information from our environment through our eyes, ears, nose and sense of touch.
3. The bridge between the hemispheres is called the corpus callosum. Its job is to integrate all the information so we can have a complete picture of what is going on around us.

It works like this: your left side (left brain hemisphere) is typically used when speaking or balancing your checkbook. The right side (right brain hemisphere) is the part of your brain that has instant recognition of the face of your best friend when you see her walking toward you at the mall. You know immediately if she is fatter, skinnier, or more wrinkled. Your right hemisphere is also quicker than the left side–you may have a "hunch" something is this way or that, but you have to "engage" your left hemisphere in order to "figure it out." The right brain communicates with you by flashing images into your mind. For example, if I ask you, where is the information desk located in your community library, how do you find the answer to that question? Most likely a picture of the room just appears in your head. That is how your right hemisphere talks to you.

However, we have a problem. The problem is that the left side, the verbal side, can be very critical of the information that is picked up and processed by the quiet right side. This becomes even more difficult when we want to work with individuals with FAS/E because our talkative

left hemisphere keeps interrupting or interpreting what we are observing (based on our education, experience with other children, etc.). But to understand a person with FAS/E, we need to learn to create a quiet zone inside of our heads and observe for long periods of time without giving ourselves a running verbal commentary on what we are seeing. Learning to see, while refraining from inner self talk, is not an easy thing to do.

But if we can master this type of observation, we can interpret our disabled children in a very interesting way - by trusting our instincts and intuition on a very deep level. For example, after many years of observation and experience, some parents gradually come to realize that the behavior of their children with FAS/E is not based in evil, defiant or predatory intent. (This information is very valuable to the person who wants/needs to represent an individual with FAS/E in a legal arena.) In reality, their behavior is a direct manifestation of their neurological brain damage. This damage results in a short circuit of their brain functions–in difficulty receiving information from their senses and analyzing and integrating that information. So learning how to observe is important for two reasons. First, individuals with FAS/E usually have a lot of issues and it takes intense observation in order to understand and separate them. Once you have identified the issues, then the next task is to explain all of this to the disabled individual. There are many ways to accomplish this goal. I used cartoons, such as the one below, to explain these complex issues to my children.

Everyone has a Hurting Place
I called the black hole the "Hurting Place" which often makes us hug ourselves or rock back and forth when we're in emotional pain. Sometimes I just talked to my children about the fact that when the black hole opens up (like the shutter in a camera lens) and the pain is so intense and distracting, nothing else seems very important, such as going to school that day. At other times we talked about the black hole itself–that it is really a puzzle made up of many different pieces.

Some of the puzzle pieces of pain may come from sources such as the following.
* early (and sometimes ritualistic) sexual abuse
* deprivation and neglect, e.g., not having enough food as an infant
* loss and grief from the "sudden" disappearance of their birth mother, grandparent and/or dad
* not understanding why they continue to get into so much trouble

Learning to help individuals with FAS/E also means understanding your own strengths and weaknesses and how to be extremely effective in the use of your own brain. This is the second reason it is so important to develop good observation skills. You must learn to observe and know yourself so well that you can trust yourself enough to establish your own boundaries. Since our children with FAS/E have no boundaries of their own, we parents must set them. For some, the day will come when you say to yourself, "I really can't do this anymore." If you do get to that point you must be mature enough to have confidence in your ability to make good decisions. We also need to understand the stresses that burden our spouses and discern the effects on our other children.

Sometimes it's OK to say this kid is outta here (usually during the teen years when they get bigger than you are) and place him in residential care. Sometimes its OK to say this child is going back into state foster care. Sometimes it's the best decision to place the teen in inpatient

psychiatric treatment. Sometimes as they reach adulthood, it’s OK to say, "I love you with all my heart and will help advocate/interpret for you, but you and I cannot live in the same house." In any of these situations, the family should maintain contact with the child, if at all possible, in order to continue the bonding process that takes so long in our kids. People don't all have to live in the same house to be a family. Sometimes living in separate houses actually improves the relationship.

Today when I look back and think about my experience at The Art Institute, I giggle to myself as I remember that kid and his remark about learning to observe. It was such a great moment because he made me really stop and think. It may take me a while to figure things out, but I love it when many sources converge to make the same point.

As you read this issue about the adult dysfunctional years, grief may open up your hurting place again. But that's OK. Only after grief has been acknowledged and expressed, can the healing begin. Then your energy will return and it can be directed to helping your child once again.

[The complete Standard of Care is available by itself or in our book, The Best of FAS Times. Please see publications page for details and ordering information.]