

Finding Strengths and Building Self Esteem in Children with FAS/E

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When my husband and I adopted our kids in 1978, we didn't know they had developmental disabilities. However, I do remember one odd trait that really stuck out and I now realize it was our first clue to identifying FAS/E. About the time Rusty came to live with us I was deeply involved in reading and studying about family relationships. One book that someone recommended to me was called, *I'm OK; Your OK*. I have no idea what the intellectual elite and/or academic scholars thought of the premise in the book but I thought it was kind of interesting. Somehow it had a practical bent to it which was probably the reason pop-psychology became so important during those years. And with three adopted children with hidden disabilities, I needed practical. I had a houseful of four busy children, plus my husband and I who had totally opposite personalities and backgrounds. It was a zoo.

Logically speaking, Rusty should have been easy to understand. He came from a neglectful birth family, passed through 8-10 different foster placements, suffered severe abuse and clearly had an attachment disorder. His personality should have been a "textbook case" of non-existent self-esteem, but somehow he was different. All of the social workers, therapists, psychologists, psychiatrists and various medical doctors were very kind and sympathetic but their advice didn't add up; there was a missing piece. Of course we now know the missing diagnosis was FAS **but there was an early clue that pointed to the missing diagnosis and I found it in the book, *I'm OK; You're OK*.**

According to what I remember about the premise of the book (and don't mess my memories up with facts) people's early background/history determined their basic outlook on life. In the 1970's, personality was thought to be the result of environment. Considering Rusty's history he should have had debilitatingly low self esteem. But oddly that wasn't the case. The therapists claimed to see problems with self esteem but they didn't see him at home. He was a very cheerful little guy and his attitude was cooperative and pleasant until something came along and we would try to teach him personal responsibility. He seemed to think he was a god or something. In fact, my subconscious mind came up with a nickname for him, the crown prince. Rusty was my little prince. It upsets me when I look back and remember these things because we were so alone when we were trying to figure this all out. I didn't want to change him, I just wanted to understand who he really was. So instead of fighting his "natural" perspective of himself and the world, I just accepted it. His attitude was puzzling of course considering his background. But as long as he liked himself and had cheerful, healthy, sharing interactions with his siblings, I didn't care if he thought he was the crown prince.

Now we know from the collective family experience that his behavior and attitude is common. Developmentally, persons with FAS/E remain very immature and always think they are the center of the universe. It's not that they spend a lot of energy keeping others revolving around them. They think they already ARE the center of the universe and they deserve preferential treatment and privilege. They think other people should follow rules and will be the first to notice when others aren't in compliance. But something about the disability convinces them that they are always the exception to the rule. This self/others view normally occurs in an early stage of development (about the ages of 2-4) but **if it is grossly exaggerated and the child gets perpetually stuck in this stage, then it can be a big clue to identifying FAS/E.** This self/others view can be described as, "I'm ALWAYS OK; what's your problem?" Sometimes therapists insist this describes an attachment disorder but parents learn the difference after the child is medically diagnosed and they understand the core disability traits of FAS/E.

A second discovery which helped us understand and sort out self esteem as it related to trauma, abuse, and attachment in Rusty and Cheryl came again as we stopped depending on the environmental theory of personality development and began concerted efforts to increase their self respect. Although it was not

until years later that the four temperament theory of inherent personality traits was scientifically documented,¹ I became fascinated with it in the 1970's because it was so practical. It worked. **The four temperament theory offered another reliable way to understand Rusty's personal perspective and view of the world around him even without the diagnosis.** It became a compass which taught him about his own strengths and weaknesses. It also gave him a simple way to understand that his brother and sisters, mom and dad all had strengths and weaknesses, too. And it gave us all insight into how to laugh and play fairly together even when having a difference of opinion.

In this issue of *FAS Times* (our second on FAS/E: A Standard of Care for Children) we are providing more detailed information and specific tools which parents have found helpful as they raise their children into healthy, happy adults. The first tool we want to share is this theory of the four temperaments. It came to be so important to our family in helping our disabled children see where they fit and what their strengths were, that I want to share it with our readers. It was the ONLY tool I found that helped self-esteem without having an accurate diagnosis because it grounded them with a true explanation of their own identity. It wasn't that I increased their self esteem by flattery or false praise. It helped them become aware of their own deep talents and recognize the truth within themselves. So I have developed illustrations for a little cartoon parable that I used with my own children, which parents can use to help their children find their strengths.

Another tool that is a more sophisticated companion to the cartoon parable is one Ann Waller found very helpful with her family. Cynthia Ulrich Tobias has written a book, *The Way They Learn*, which describes several types of learning theories, including the work of Dr. Anthony Gregorc. We have received permission to excerpt some of the basic information on four learning styles for parents and professionals to use as another method to find the strengths of the children under their care. When we can identify the strengths and natural style of our children we can more easily set them up for success and build up their self respect whether or not they have an FAS/E diagnosis.

The fascinating thing about the timing of compiling these intervention tools and the Standard of Care is that things are beginning to happen on the national level. I was invited to present a formal paper on "FAS/E: A Standard of Care" to a joint committee of the national Centers for Disease Control (CDC) and the National Institute of Alcohol Abuse and Alcoholism (NIAAA) in early September. This paper will be published in a monograph along with the other papers which were presented. What an honor for our collective family experience in raising children with FAS/E to be recognized in this national forum! Many thanks to Dr. Louise Floyd at the CDC for this exciting opportunity.

A second very dynamic development is the congressional passage of the FAS Prevention and Services legislation sponsored by Senator Tom Daschle (D) from South Dakota. As of this writing, it is on the President's desk awaiting his signature. This legislation sets up an FAS federal interagency task force (on which The FAS Family Resource Institute will be able to represent the FAS collective family experience and advocacy). This task force will help facilitate FAS/E prevention and intervention efforts on the national level. Funding is also designated for research, prevention and intervention projects.

Since we have compiled a Standard of Care for toddlers, children, adolescents and adults with FAS/E and our knowledge and expertise are now being recognized in federal agencies, **we will be working with policy makers and scientists to design research protocol which will document and evaluate not only demonstration projects for basic interventions, but actual methods of treatment.**

The reality of these unique events and their possibilities was recently validated through the evaluations of our conference in Everett, Washington on October 8 & 9, 1998, also entitled, "FAS/E: A Standard of

¹In 1981, "David Lykken, researcher at the University of Minnesota, studied [the temperaments of] identical twins who were separated at birth and reared apart in different environments." Brain Styles by Marlane Miller, p. 35.

Care.”² Participants said that they felt excited, supported, understood and hopeful about what they learned. In fact, on Monday after the conference, Vicky got a call from a very excited woman who told her, “You know my co-workers told me not to come to your conference because it would just be the same old material we’ve heard before. But everything was new! I can’t wait to get to work and show them all the wonderful handouts and brochures and tell them all the things that I learned!”

Other evaluations of the conference were equally as positive. A parent wrote, “It was joyous to be with so many people who loved FAS kids! I felt at home.” A teacher said, “This was an excellent conference! Well put together, organized and full of excellent information. Thank you! I learned a great deal about the disability. As an educator, I appreciated the information from a parent’s perspective—what works and what doesn’t.” A child/family advocate commented, “The family interventions, i.e., Standard of Care, will be very important in my advocacy work for kids. An excellent conference, we need it here in our area [of Spokane]!”

These are encouraging words but we must never lose sight that it takes extraordinary devotion and personal focus for parents to be able to stabilize children with FAS/E and boost their self-confidence. Self esteem is the icing on the cake. But the proper basic ingredients to make the cake itself must be available before the cake can be frosted.

According to Senator Daschle’s legislation, it takes over a million dollars to care for an individual with FAS/E. Many families still struggle alone with absolutely no help from social services. This situation must change if we are going to keep individuals with FAS/E and our communities safe. The conference in Everett provided a wonderful circle of support for all of us. We must use the energy it generated to continue the momentum to help all individuals with FAS/E and their families.

² We would like to thank the following organizations which helped the FAS Family Resource Institute present this conference: The Divisions of Alcohol & Substance Abuse, Developmental Disabilities and Mental Health in the Washington State Department of Social and Health Services; Northwest Indian College; The ARC of Snohomish County; Village Moms (an advocacy group); The March of Dimes; Snohomish County FAS Network and Snohomish County Human Services Alcohol and Drug Unit.