

F.A.S. TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

Key to Education: Identifying Innate Strengths & Talents

Jocie DeVries

Last night I attended a totally delightful concert at my grandson Matthew's elementary school. It was wonderful because the music was so unique, the production was so creative, and the children were both excited and proud to participate. I had been wondering what, and who, was guiding Matthew's taste in music, because a few weeks before the concert, he had created a surprise for me on my computer.

He frequently stays at our house after school. As he got up to go back home one day, he said, "Grandma, go look on your computer. I made a surprise for you!" Since he had never done anything like that before, I was very curious, and went to check it out. He had created a button right in the center of the computer screen that said, "Grandma! Check this out." When I clicked on it and opened up the file, I heard the most incredible music.

Now, since I attended the concert last night, I understand a little of the impact that a good teacher can have on the dormant talent that lies buried in the heart of a child, in a way that I've never understood before. The song on my computer was hauntingly beautiful, and very similar to the concert music, a duet between a flute and a clarinet.

Matthew's mother is my daughter, Loree. In 1967, when she was born, we lived in San Francisco, where my husband worked for United Airlines. The minister and his wife at our church were working to help a young single woman who was pregnant. She decided to give the baby up for adoption, and we became the adopting family. It's a long story, but the birth mom disappeared almost immediately, so we were unable to get any of her family or medical history. Thankfully, she never had any medical emergencies or anything like that, but there were big holes in our knowledge of her heritage.

One notable issue involved her apparently genetic appreciation of music. Not having any musical talent myself, I was not aware of what type of inborn clues and signals to watch for, and encourage. But when she was in the fifth grade, she came home having decided she wanted to be in band, so she asked for a flute. I really didn't understand the whole musician concept until she was almost grown, and we spent the summer in Santa Barbara, California. My husband was on a special aircraft project for the Department of Defense. We rented a furnished house, which happened to have a piano. All summer long she sat and fiddled with that piano. I didn't pay much attention until one day, I noticed she had taught herself to play the piano with both hands, and could play any piece of music she picked up.

Finally, I understood the clues that were before me all along. She was always a very busy child. Yet every afternoon, when she came home from school, starting with the 5th grade when she first got that flute, she would go right up to her bedroom and practice for an hour. That was how she dealt with the stress, and strain of the school day. It was such a natural part of her daily rhythm that I thought all kids were like that... I never understood that some parents have to force their kids to practice! These lessons helped me understand my grandson Matthew, as he was growing up. He has never been a rough-and-tumble child. His interests are much more methodical and focused. For his age, he is a computer, math, and science genius. He is a master at video games and loves the martial arts; he likes chess and, of course, music.

Last night, I thought I was going with him to a band concert; but when he didn't take his trumpet, I asked him why. He told me it wasn't a band concert, but a special concert with weird instruments. Then he shrugged his shoulders and said, "I just love music!" I felt so happy, not only for Matthew and his mother, but for my husband and me too. Learning to recognize their musical gifting has given them both back some of their heritage that was lost when my daughter was adopted.

This is a problem that other adoptive families may share. And there are many adoptive families raising

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children with FASD. According to data from at least two major FASD clinics and the Collective Family Experience on Fetal Alcohol Spectrum Disorders (FASD), about 83% of the affected children coming into their clinics for evaluation are not living with their birth parents—most are in foster or adoptive homes. In our view, it is always better when children can live with their birth parents, if they can be healthy and safe.

However, we see our advocacy and education role as not only helping birth parents create a safe and healthy environment, but to provide education and mentoring to all parents who want to nurture their children. Our overall goal is to help adult affected individuals, parents, and professionals produce resiliency and self esteem in the hearts and souls of every disabled person.

If you would like to talk to someone about any of these issues, please call Vicky McKinney at (800) 999-3429 or e-mail her at vicky@fetalalcoholsyndrome.org.

This issue of FAS Times is devoted to current topics relating to students with FASD in the field of education. From the interesting potential of fish oil's effect on behavior, to the confessions of a psychologist mom trained in behavior modification, and ending with the bus dance, we hope you will enjoy this issue even though education can be one of the most challenging fields for our affected children and youth. ♥

Fish Oils Sooth Severely Troubled Boys

Felicity Lawrence
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Experts on Omega-3 fatty acids said yesterday there was an urgent need for properly conducted scientific research on the impact of diet on the brain, amid claims that fish oils have dramatically improved the behavior of boys with some of the UK's most severe emotional and social problems.

The Cotswold community school in Wiltshire, a residential school for boys who cannot be handled in mainstream care homes and schools, has treated its children with fish oil supplements for 20 weeks and measured changes in their behavior. A nutritionist, Jackie Stordy, analyzed records of the boys' behavior, using school logs of the number of times the children had to be restrained.

The children's scores for hyperactivity, impulsiveness and oppositional behavior were also compared before and after.

After 20 weeks the number of times staff had to restrain the boys had dropped by 46%. The length of time they had to be restrained dropped by 42% and their scores for impulsiveness and hyperactivity improved by 20%, said Dr. Stordy.

For nearly all the boys there was a small but significant improvement, except two who did not take the fish oil and showed no improvement. Three showed dramatic improvements. "Their scores moved into the normal range for the population, which is remarkable," Dr. Stordy said.

The claims being made for fish oil's effect on children's learning and behavior have become controversial, with experts criticizing supplement manufacturers for overstating the evidence from unscientific research.

But it was the Cotswold community school that approached manufacturers Efamol for supplies of its fish oil-based essential fatty acid supplement Efalex. Dr. Stordy said the work made no claim to be a proper trial - only 19 boys were involved. There was no placebo.

Michael Crawford, an expert on essential fatty acids and the brain at the London Metropolitan University, said this sort of evidence was little more than anecdotal. "What we need is serious research." John Stein, professor of physiology at Oxford University, where much of the UK research on Omega-3 fatty acids and learning and behavioral difficulties is based, said: "Some of these studies are little more than an advertising exercise. But our own research has shown a link between nutritional deficiencies and behavior. It all cries out for a large, properly designed trial but people won't stump up the money because you can't patent nutrition."

The school head, Andrew Thomas, said the fish oils were just one of a range of techniques used to help the children, including improving their diets. "Fish oil supplements seem to be making a genuine difference to the roller coaster of emotions they face every day." NCH, the charity that runs the school, may extend use of supplements to its other homes. ♥

SAVE the DATE!

February 23, 2008

9:30 am - 4:00 pm

Understanding the Special Education Process

\$15 per family (for materials)

Best Western Alderwood Hotel
19332 36th Ave W., Lynnwood, WA 98036

Contact Person: DaNae Ware, 877-279-1416
E-mail: danaeware@verizon.net

Statewide Parent Training Program
Sponsored by Washington PAVE

Discussion Topics: Special Education Laws including IDEA 2004 changes, Evaluation, Individualized Education Programs (IEPs), 504 Plans, Strategies and remedies to use in working with school districts, discipline, inclusion, communication, and more.

Registration Deadline: 02/15/2008

Washington PAVE

is a parent-directed organization that works with families, individuals with all types of disabilities, professionals and community members. Since 1979, PAVE has provided information, training and support for over 1,000,000 individuals with disabilities, parents and professionals. WA PAVE was one of the first State Parent Training and Information (PTI) centers in the U.S. There are PTI programs in every state.

www.washingtonpave.com

Report Card on FASD and Education

Vicky McKinney

I remember an excited little boy anxiously waiting to go to school. So excited and full of spark...mostly to see friends, but he did like some of the schooling. Most days I would get a call to come get him because he was "out of control" and disrupting the learning of others. Again I would bring him home and he would dash into the house where I would find him hiding in his closet crying his eyes out. He would say, "I hate school and I hate recess because I always have too much fun and I always get into trouble. I don't understand what they want me to do." He still gladly went back to school each and every day. After years of trying, they finally snuffed the spark out of him. He gave up, saying, "All school does is make me feel stupid."

This heart-breaking letter shows one mother's frustration trying to make sure her child who has FASD gets a good education from her local school system. I would like to tell you that this is an isolated incident, but according to many parent reports to FAS*FRI, this is the norm.

The educational system is the system most reported by parents of children with FASD, to be failing them. The reasons are many:

- The Federal Government caps the amount of funding for students with special needs in our schools here in Washington State at 13% of the population of each district. We all know that there are many more than 13% that may need extra help/services in their educational process.
- No Child Left Behind has added more stress onto students and teachers to meet a certain "standard" with no funding to do it. This in turn has caused our kids with FASD to fall through the cracks at a much higher rate than ever before, as they cannot meet the expectations of the "norm."
- Many school districts have yet to recognize and adapt to "other" teaching methods. There is an amazing amount of scientific information on the varied learning styles of children/adolescents with disabilities, yet school systems are years behind.
- Even though over 80% of the students in the educational system do not go on to college, the one goal of the educational system is to get them ready for college. Vocational programs, where a student

with FASD could find success, are being eliminated.

There are many other reasons the educational process is failing students with FASD. But instead of blaming the educational system, *let's get busy and start demanding fair and just treatment for our children* with neurological disabilities from prenatal alcohol exposure, so they can access an appropriate education.

In order to get your ducks in a row, here's where you can start:

1. Gather your child's medical, developmental disability and mental health documents together so he/she can be recognized as having a disability and understood as having neurological damage rather than being willfully disobedient, uncooperative or bad.
2. Give all of this information to the school as proof that your child qualifies for an Individual Educational Program (IEP).
3. Get your child qualified for the IEP under the category of Health Impaired. This category recognizes neurological disabilities, the root of the problem that disrupts the learning process.
4. Read and understand what your child is entitled to under the federal laws of IDEA (Individuals with Disabilities in Education Act). There are many wonderful organizations in the U.S. to help you do this. Call 1-800-5PARENT to find one in your area. Also an excellent Internet resource for disability and legal issues is www.wrightslaw.com.

...let's get busy and start demanding fair and just treatment for our children...

If you have trouble getting an IEP for your disabled child, call me at (800) 999-3429 or e-mail me at vicky@fetalalcoholsyndrome.org for help and/or referral to resources in your area.

When you do get an IEP in place, make sure you are a part of the planning team. Do not let the IEP be written without your input. Because you have worked with your child from infancy, you know your child better than anyone. By now you instinctively know what will and will not work. Be sure to address the

following areas or issues in the IEP:

- Possible multiple diagnoses and how they affect the learning process.
- Any fine or gross motor problems that make it difficult for the child to write and may require another form of communication.
- Memory problems, short and long term, that may look like non-compliance but are actually processing problems and the inability to find the information that's only sometimes there.
- The issue of IQ verses functional ability. The IQ is not a good indicator of functional ability. They may have the ability to repeat information back to you (some days are better than others) but do they have the wisdom to know what to do with this information? They almost always test higher than they function.
- Sensory problems that can make the school day a nightmare for kids with FASD. The majority our kids work so hard during the school day to hold it together and fit in, that by the time they reach the safety of home, they fall apart and we are left with an over stimulated, exhausted, non-consolable child that is required to have homework done by the next school day.
- Behavioral problems that are almost always caused by the child's inability to understand abstract reasoning, or cause and effect.
- Open and daily communication between the classroom professionals and the parents. This may include the para-professional, teacher and any other person involved with the education of the child. This may be e-mail or a daily journal.
- A teacher who is structured but not rigid—someone who is willing to limit transitions, use consistent language, keep the routine predictable and use developmentally appropriate goals.

It must be understood by parents, as well as educational professionals, that even with all these interventions in place, you may not get consistent educational outcomes. The most successful parents and educational professionals are the ones who have the ability to "tweak the program" to meet the needs of individual students, on a daily or even minute-to-minute basis. ♥

US Department of Ed Finds WA State in Need of Intervention

With the reauthorization of the Individuals with Disability Education Act (IDEA) in 2004, the US Department of Education established new monitoring procedures and levels of intervention they feel a State may need to ensure implementation of Part B of the IDEA. The US Department of Education makes a determination of the State's performance based on a number of factors. These include:

- State's annual performance report that each State must submit to the Department of Education
- Information obtained through monitoring visits, and
- Any other public information made available.

A state will receive one of four determinations based on the information:

1. Meets requirements and purposes of Part B
2. Needs assistance in implementing requirements of Part B
3. Needs intervention in implementing requirements of Part B
4. Needs substantial intervention in implementing requirements of Part B

The State must fall within the "needs intervention" category for three or more consecutive years before significant action is taken including the withholding of Part B funds. However, as a part of the review the US Department of Education, Office of Special Education Programs (OSEP) identifies all areas of concern and what action must be taken. If the concern is something OSEP feels can be accomplished in one year, it will be stated in the report back to the State and will include what action the State is expected to take and how they are to report back on that action.

In a letter, dated June 15, 2007, addressed to Dr. Bergeson from OSEP, the department outlined the areas in which they had found Washington State in need of intervention. The State was found in need of intervention "based on the totality of the State's data in its State Performance Plan (SPP) and Annual Performance Review (APR) and other publicly available information." OSEP has 15 indicators that are used to evaluate a state's performance on

national standards that are part of the state's performance plan. The letter states that the specific factors affecting OSEP's determination of needs intervention for Washington were: (1) the State did not provide any data on correction of noncompliance identified through monitoring of Indicator 15 (General Supervision system); and (2) the State did not provide valid and reliable baseline data for indicator 11 (Percent of children evaluated within the prescribed timelines for the State).

Specifically OSEP found that the State did not comply with indicator 15 because it provided no data documenting correction of its noncompliance in the 2005 report. The letter stated, "Although the State reported that it had identified 109 findings of non-compliance through monitoring in FFY 2004, it provided no data documenting correction of this noncompliance in FFY 2005. The State's failure to provide any data confirming timely correction in FFY 2005 of any of these 109 findings identified through monitoring in FFY 2004 is inconsistent with the State's obligation to demonstrate to OSEP and the public that the State monitors the implementation and enforcement of Part B of the IDEA."

For indicator 11, the letter stated, "that the State acknowledged that it did not collect data on the number of students for whom parental consent to evaluate was received and who were found eligible within the State-established timeline, but reported that it began collecting that data in the 2006-2007 school year."

In addition to these two indicators, OSEP identified additional areas for which the State will need to provide information in their next Annual Performance Review, due Feb. 1, 2008. They also identified indicators that the State has met or exceeded their target for improvement. This was especially apparent in the area of students on IEPs who participated in regular assessments with or without accommodations, as well as those who participated using alternate assessments, and in the decrease in the percent of students on IEPs who were removed from regular classes for a percentage of their day.

The State has the opportunity to request a reconsideration of OSEP's determination through a hearing. This letter would be due to the US Department of Education by the 15th of July.

For more information regarding the

letter to Dr. Bergeson or the accompanying chart, go to the following websites:

* www.ed.gov/fund/data/report/idea/partbspap/2007/wa-aprldr-2007b.pdf

* <http://www.ed.gov/fund/data/report/idea/partbspap/2007/wa-aprtbl-2007b.pdf>

Washington PAVE contacted OSPI Special Education Director, Dr. Douglas Gill for a response to the determination of a "Needs Intervention" rating for the State. His response follows. "We believed we sent the required data for Indicator 15 to our liaison on October 19, 2006. When we were notified of the rating and the claim that we had not submitted any data, the data were sent within minutes. However, it was, of course, too late to change the rating. Indicator 15 was the single most important data in separating a 'needs intervention' rating from a 'needs improvement' rating." ♥

[Editor's Note: For FAS Times readers from other states, you can find out how your state was rated online at: www.ed.gov/policy/speced/guid/idea/monitor/factsheet.html.]

Washington State Announces Rules for Implementing IDEA

Washington State has completed the process for revising the Washington Administrative Code (WAC) for the provision of special education services. This process was necessary to comply with the Reauthorization of the Individuals with Disability Education Act, (IDEA). The Office of Superintendent of Public Instruction, (OSPI) adopted the final regulations on June 29, 2007 and they took effect on July 30, 2007.

Washington PAVE strongly suggests that when attending your next meeting for the development of an IEP or when either participating in initial assessment or reassessment, ask for an updated copy of your procedural safeguards.

To get more information or to download a copy of the new regulations or the concise explanatory comments regarding the changes in the regulations go to the OSPI website special education web page at: <http://www.k12.wa.us/SpecialEd/default.aspx>. ♥

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Reflections of a Former “Rat Runner”

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[Editor’s Note: Although the author does not refer to FASD, she is talking about using behavioral modification with conditions that have a neurobehavioral basis. Enjoy.]

Did My Professors Lie, or Did They Just Not Anticipate My Kids?

As a psychologist who trained in the 1960’s and early 1970’s, I grew up in a generation and program that was heavily behaviorally oriented. B. F. Skinner was my “god,” and while my presumably misguided clinical brethren talked about the “unconscious,” I was busy learning schedules of reinforcement and how to arrange contingencies and events to alter behavior. My colleagues and I “ran rats,” we “ran pigeons,” and of course, we “ran” college students. And even though I was a bit of a renegade in the sense that I always had a fascination with neurology and physiology, I still focused on manipulating external contingencies to alter behavior.

Secure in my knowledge of my behavioral skills, I not only taught courses on behavior modification to graduate students in psychology, but I served as consultant to a center working with severely and multiply-handicapped children. And I continued my research, switching to “running” Japanese quail and impressed as all hell with myself that I could shape a quail to key peck in less than 10 minutes. Life was good and all was right in the world. Years went by, and eventually, I had the joy of becoming a mother. And things were still right in the world.

My son flourished, and was a joy to parent. A bright, curious child, he taught himself to read before he was 3 years old, soaked up the world as if it was a huge playground created for his delight, and had adults marveling at his sensitivity, creativity, and good manners. Compliments were tossed freely at me, and while I publicly denied any real responsibility for how well he was turning out, secretly I was thrilled, and wondered why everyone talked about how hard parenting was. After all, all one had to do was provide a nurturing environment with lots of stimulation and some structure and limits to help the child learn

wrong from right, and voila.... a happy and wonderful child -- right?

A few years later, as my son began to struggle with the symptoms of Tourette’s Syndrome, Attention Deficit Hyperactivity Disorder, and Obsessive-Compulsive Disorder, and as our family began to get stood on its head, I reminded myself that I was an expert in behavior modification. Kicking myself into my professional mode, I sat down and generated a behavior modification plan for my son, which I then posted on the refrigerator so that he and my husband could consult it.

After a few weeks on the program, it became clear to me that while there had been some benefit, there was still a lot to be desired. Recognizing that part of the “problem” was my son’s interactions with his younger sister and that she had as much responsibility as he, I put her, too, on a formal behavior modification program whereby they each could earn “rewards” for cooperating with each or being nice to each other. Her plan joined his revised plan on the refrigerator, next to their school schedules and all the usual reminders that find their way to the refrigerator door.

Somewhat strained sibling relationships inspired yet another failed behavior modification plan...

By a few weeks later, it was clear to me to me that this simply wasn’t working as well as it should because my husband wasn’t sticking to the program. He’d forget to record things or forget to administer rewards promptly (I, of course, was perfect, but you probably knew that already). So one night my husband came home from work to find the children giggling, waiting for him to notice that there was now a third behavior plan on the refrigerator -- one that was geared to getting him to administer the children’s programs.

After a few more weeks, I came to some realizations. First, I was spending a huge chunk of my time writing and revising/fine-tuning behavior plans, printing them out, and administering them. Second, I was spending a lot of time talking to my husband about why he wasn’t doing his part in administering the plans for the children. And third, I realized that if this continued, I was going to need a bigger refrigerator door.

And so it slowly dawned on me that the kinds of formal behavior modification programming I was used to were just a drop in the ocean when it came to dealing with the

kind of widespread dysregulation I was seeing in my children and my husband. Their ADHD, compulsiveness, and tics could not all be “targeted” and neatly defined into clear objectives when the problem was so much more pervasive. I needed to find another way.

My growing recognition of the limits of behavior modification was reinforced unexpectedly by an unhappy incident a few years later. My son, who was by then pretty severely dysfunctional, was placed in a special education class with others like him. The school hired a consultant to work with the teacher on behavior management. Unbeknownst to the parents, the teacher had conveyed her distress over the children’s language to the consultant, who developed a behavior modification program for her to use. The parents were never consulted before the plan was implemented to find out if we had ever tried such a plan before, and if so, with what results.

Within a week of the new plan being implemented, I noticed my son deteriorating significantly. He was angrier and more emotional in the home. Since it wasn’t a time of waxing tics or seasonal allergies for him, I was puzzled at the apparent deterioration, and called another child’s parent to ask how her son was. She informed me that her son, too, had been getting worse that week, and she couldn’t figure out why. We called the other mothers, and sure enough, they reported the same problem. The next day, I contacted the teacher to find out if there had been any changes in school, and that’s when I learned about the change in the behavior modification program. I ran a quick literature search and discovered that there were one or two anecdotal references to children whose symptoms were actually worsened by inappropriately applied behavioral contingencies.

A Lesson Learned

That experience, combined with my growing dissatisfaction with traditional behavior modification approaches for symptoms of TS+ led me to almost totally abandon behavior modification. I realized that **if we make demands on a children that they can’t comply with because of their dysregulation, we will increase their stress levels** and we may actually make their symptoms worse and trigger new problems. [emphasis ours]

Like other children, children with neurobehavioral conditions are motivated to

obtain rewards and avoid punishment. If what we are trying to alter is truly an involuntary symptom, they will try their best to modify it, but at what cost? In the next section, I will try to provide a brief overview of a neurobehavioral approach that I think may be more effective, although I don't know that I can quite do it justice in a short synopsis of this kind.

A Neurobehavioral Approach

It's one thing not to know right from wrong or how one is expected to behave and another thing to know the expectations but not have the ability to consistently comply. Most children with neurobehavioral conditions seem to know right from wrong and know how they're expected to behave but their ability to comply may be diminished. Some of the sources of the diminished ability are neurologically-based disinhibition and regulatory problems that impact their motoric levels, attention, thoughts, and/or mood; learning disabilities that impact their ability to "read" nonverbal social cues such as body language, facial expressions and tone; difficulty in generalizing a rule learned in one setting to another setting; neurocognitive deficits that may make it difficult for them to make easy transitions or follow multi-step sequences; and/or ability to retrieve information about how to act when they are in a state of heightened arousal or frustration.

When a child is experiencing dysregulation, they are emotionally vulnerable and in a state of discomfort. And just as we seek to escape discomfort, they will, too. But how can they escape discomfort quickly? Their reaction may be to try to get someone (a trusted adult) to solve their problem for them – regardless of whether the problem is doing their homework, being unable to find their belongings, getting another child to play what they want to play, etc. At that moment, nothing matters as much as obtaining relief from the discomfort.

At the same time that the child is feeling an increased sense of vulnerability, the parent or teacher is also feeling an increased sense of vulnerability -- our self-esteem and 'ego' tend to be tied to how the child behaves. We feel like incompetent or "bad" parents or teachers when we cannot apparently do our job well -- and our assessment is based on how the child does. So we seek relief from our discomfort by trying to get the child to behave or func-

tion in a particular way. This is like saying, "I can only be OK if [my child] does [this]." So we put pressure on the child -- pressure that doesn't help the situation and only leads to more discomfort for the child.

At some point in that thinking, we have lost some measure of control and sense of responsibility for taking care of ourselves. It is much healthier, in my opinion, to say, "I wish that [my child] would do [this], but I can be OK even if my child is not doing that." This is particularly important when we find ourselves, as parents, being so concerned about what family or friends or even strangers will say that we land up feeling extremely stressed out and starting to yell at the children to "behave!" And the more our vulnerability increases, the more demands we may make on the child so that we can obtain relief from our discomfort. At the same time, the child is seeking relief from his/her discomfort by making demands on us. *Out of all the people in that triad -- the child, the parent, and the teacher -- the traditional approach has been to try to change the child. But when you think about it, we are trying to change the one individual in the relationship who has the least ability to regulate him/herself.*

Instead of trying to change the child, let's talk about how to change ourselves in ways that will reduce our own vulnerability and that will enable us to accept and support the child. Let's talk about how we can work on ourselves so that we can create a climate of acceptance and support that will enable the child to regulate him/herself. Yes, all children need limits and limits will be set, but we begin by becoming what we want our child to be: someone who can regulate himself or herself and who can model self-regulation.

Perhaps an example or two might help at this point. I was talking with a new patient, and during the initial interview, I asked the mother what her goal was for therapy. Her response was immediate: "My son is totally out of control and I am spinning totally out of control with him." Rather than starting with trying to change her son's behavior, then, we began with her working on herself to understand her child's experience, join with him, develop empathy, and validate him -- without feeling that she had to "fix" him or control him. By establishing that bond with him, she would be in a better situation to communicate calmly with him, dialogue, and model self-regulation for him. As another parent once commented, "How

can I control my child when I can't seem to control myself right now?"

Altering cognitions (thoughts) and behaviors are nothing new to those trained in or experienced with cognitive-behavioral therapies. Extending them and applying them to children with neurobehavioral dysregulation and their parents has been a challenge. As a professional who has always valued cognitive-behavioral approaches, and as an individual who has used them in her own personal life, I was willing to explore them. But what really convinced me of their potential value was one of those personal experiences -- something that happened with my son.

It happened about eight years ago, during a period when my son was experiencing mild 'rage attacks' that were generally associated with periods when he was obsessed with something. He'd come home from school and tell me that I had to take him to such-and-such store to buy whatever he was obsessed with at that time. I'd struggle to figure out the "correct" response to such an urgent request/demand. If I said "yes," and took him, would I be reinforcing his obsessive-compulsiveness and making things worse for him in the long run? If I said "no," would I be pushing him past his limits to handle the discomfort he was so clearly feeling? So I had compromised. I would generally tell my son that our rule was no shopping during the school week, but that we could go get it on the weekend. Sometimes that worked, but occasionally it wouldn't, and another hole in the bedroom wall would result.

Then one day I tried a different response, based on another psychologist's suggestions to me. When my son came home and initiated the request to go to the store, I began a dialogue with him in which I mirrored him, showing him that I understood what he was saying, and gaining clarification when I didn't understand him. [This type of dialoguing technique is described in the book "Giving the Love That Heals" by Hendrix and Hunt, for those of you would like to learn more about it.] Whenever he'd ask me if I would take him, I'd simply mirror him, saying something like, "you want me to take you to the store to buy [...] because... do I have that right?" The conversation gradually shifted over to his experience of feeling "stuck" and the intense discomfort he felt -- a discomfort from which he sought relief by asking me

to take him to the store. We spent about 45 minutes talking about his feeling 'stuck' and his sense of discomfort. And I noticed that once my son settled down and was actually sharing his experience of what it felt like to be 'stuck,' he felt supported by my response, and the tension passed. I didn't feel that I had to make some crucial decision about "store or not-store." My role was to understand his experience and support him. And it became crystal clear that his "real problem" wasn't the store or the toy -- his "real problem" was that he was stuck with a thought he couldn't get rid of and it was tormenting him.

There was no rage attack that afternoon. The next time he came home that way, I was able to help him get back into dealing with the real problem -- his discomfort over feeling 'stuck.' My son never had another rage attack from the first day that I shifted gears into trying to understand his experience and support him.

In retrospect, there were things that I could have done differently in that first conversation, and I was probably too directive at times, but the main point was there: through my response, I let my son know that I was there for him and that I empathized with his sense of distress over feeling so "stuck." I didn't feel as vulnerable myself because I no longer felt responsible for solving his problem or talking him out of his distressed state, and once I accepted that it was his problem and that I couldn't "fix" it or him, my role changed. Both of us became closer because of that experience.

Oh, there are still all too many times when I lose my temper or get frustrated. As much as I know, my life tends to have a lot of stresses in it, and I can 'snap' sometimes, particularly when it seems that everyone in the household is going through a period of symptom worsening at the same time. But the basic lesson was learned: behavior modification may work for one or two specific behaviors, but if the real problem is that the child needs to develop self-management, then trying to control the child via external controls isn't going to be as effective as modeling self-management for your child, providing them with the supports they need to self-manage, and providing skills training in any areas where they need such training. My need was no longer to 'fix' my son or solve his problems. My goal was to support my son as he attempted to work through

his problems and to learn self-management strategies. And so now when I go out to talk to teachers and school psychologists, I try to share with them how they can reduce their own vulnerability and be more supportive of the child. We can't change the child. We can change ourselves. And in doing so, we can create the kind of supportive environment in which the child can begin to acknowledge how TS or TS+ is impacting them without fear of criticism. Where they can grieve and come to grips with the limitations they may be experiencing. Where they can learn to manage themselves.

If nothing else, it may save you from having to buy a bigger refrigerator. :-) ♥



Jocie,

I'm not sure you would remember me, but we met at [your parent retreat] in 2005. When I received the flyer about the [conference in September], I was disappointed that I could not attend, as the last one was invaluable.

To refresh your memory, I am the grandparent of Sean, a then 1 year old who was diagnosed at birth with FAS, as his mother drank to the point of passing out regularly for the first five months of pregnancy. At that time, his mother was allowed three hour supervised visits at my home, three times a week. After she force fed him, he refused most foods, was diagnosed as "failure to thrive" and way below anything on the weight and height charts. Our goal at the time was to hit the 3% mark anywhere by his second birthday.

And then, with little knowledge of FAS or development, I came to Washington State to pick your brains. I soaked in everything like a giant sponge. I took the approach that EVERYTHING matters and so we will do everything.

Dr. Riley strongly suggested that exercise, choline and right-and-left brain work makes a difference so we hit all of these. A milk-based product with high calories and lots of choline and vitamins became a regular part of his diet. At first we could only get him to down 1-2 ounces a day, but we now supplement his diet with 16 ounces a day (yea!). The exercise part has also helped

me shed some extra weight (win-win), and we have been working with art, music, and dance as a fun part of our lives. We have almost exhausted the local library of children's books.

Dr. Streissguth stressed the importance of a set routine and a positive environment. She also told me personally to treat him as a normal child and deal with any matters that come up. DONE. Sean and I talk a lot about anything. He is a sponge for information and remembers EVERYTHING. All of the breakout sessions provided information, strategies and a possible look into the future for us. No information was ignored. My husband and I have read everything we could get our hands on concerning FAS, brain development, sensory Integration disorders (Sean's are a mix of many).

Sean is now 3 and 1/2, is in a regular 2 -day-a-week preschool and doing well. He has reached way beyond our imagination on the height and weight charts!!! He is now 50-50 on them. His head growth is consistent and he is at the 50% level for his age. He has a huge vocabulary and has great reasoning and problem solving skills. He appears to be very intelligent. And soooo cute. He tested out of the early intervention program at 3, after working with various OT's [Occupational Therapists] for 2 years. We have not seen any behavior problems whatsoever, but we remain cautiously optimistic. Sean is a very happy and very loved child. (He has not had any contact from his mother for nearly 2 years and no longer recognizes her pictures, although we have not removed them.)

Sean keeps us laughing...and young...and happy. I know it's only a beginning, but it has been a successful beginning thanks to all of our (collective) help.

Which brings me to the reason of this e-mail...the Elements of Success conference. Although I can't attend this time, I hope to make it to another one of these retreats, so keep me on your list.

Thanks again,
Angel W.

[Editor's Note: We are in process of collating and organizing the information we gathered at the Elements of Success conference in September. We anticipate publishing this information in our next issue of FAS Times.]

The Bus Dance

Vicky McKinney

Summers were never simple raising five kids, but the most agonizing moments were spent searching for appropriate programs and/or camps in the summer for my daughter, Abby, who was born with disabilities from fetal alcohol exposure. Back then, most summer programs were designed for children with physical disabilities, but my daughter, because of her disability in reasoning, judgment, and memory, required constant supervision. Abby's social opportunities were extremely limited, and by the end of the summer, I was exhausted, because I would end up being the social director, program manager, external brain and mom 24 hours a day – every day— for three solid months. Consequently, on the first day of school, my neighbors were all anxiously waiting behind their living room drapes to catch a glimpse of me doing my annual bus dance on the first day of school. I was always so

excited to see Abby climb on the big yellow bus that I would lift my chin to the heavens and dance while the raindrops splashed on my head!

I must tell you that the bus dance has a rhythm. First, of all you need to know that the beat of the music starts out fast and furious, because I am trying to change the behavioral pattern of a disabled child who has just gotten used to sleeping in. Oh, what joy it is to hear those wake-up calls! – well, actually, they are more like screams and groans. Next, the music automatically shifts to a rhythm of rap as the formerly slumbering child quickly conjures up 44 rhyming reasons why she can't possibly go to school or even get dressed for that matter. Then the rhythm winds up singing the blues, because "nobody likes me and so I hate school." When I finally get her dressed and out the door I have expended every ounce of emotional energy I had to

use for the entire day.

By this time, the bus driver is sitting in the driveway honking the horn, because my child is the one making them all late. All the way to the bus, she would be begging me to not make her go. And amazingly, on occasion, when she was out of my sight she would decide school isn't so bad and calm down. This is only after she set me up to worry about her all day.

So by the time the bus pulls away I am ready to do the most amazing funky chicken I can muster and I don't care who sees it.

When Abby graduated from high school I was a legend in the neighborhood, but I wasn't the only one. Because every afternoon when Abby's teacher finally got her on that little yellow bus – if Abby still had all her clothes on – **the teacher was doing the bus dance too!** ♥

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