

# F.A.S. TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

## The Collective Family Experience Yields Sole-Source Products

Jocie DeVries with Ann Waller

In 1990, there were no referrals or clinicians available who could educate parents about taking care of children or youth with FASD and its peculiar behavior pattern, *especially those with IQ's in the normal range*. In fact, Dr. Sterling Clarren from the University of Washington (the dysmorphologist who diagnosed our son) told me that he did not expect interventions for FASD to be identified by scientific research for at least another twenty years. I told him we couldn't wait that long—my son would either be dead or locked up in jail for the rest of his life before then. I walked away thinking, even if researchers don't know what to do, surely families do because this problem has been around for a long time. So my husband and I realized the only real option we had was to find other parents raising children with FASD who were willing to share what they knew and blaze this trail with us.

There had to be other parents somewhere out there, who had raised or were raising children diagnosed with this disability. So we decided to find these families and to document the behaviors, events and interventions *most common* to them, which we call the Collective Family Experience on FASD. If we could do that, we would be able to provide the critical component missing from scientific research—practical wisdom for FASD education and training of families and professionals.

As we connected with other families, we discovered that most of them lived in isolation. They weren't sure if anyone else on the planet was experiencing the same unexplained things they were. They knew whatever they tried, it didn't work for their affected children the way it did for others. They knew what was happening in their own homes, but they didn't know how to describe it, much less what to do about it. When parents tried to explain the unexplainable to professionals, they felt like they were speaking a new foreign language unknown to anyone else. Some families describe life with FASD as living in the Twilight Zone—things aren't as they appear to be and they are living with behavior that is irrational and indefensible.

This is why parents know there is a behavioral phenotype for FASD. The first time they meet with another parent of a child with FASD, there is an instant connection. When one parent describes a crazy situation, the other parent can match it with a similar story. Finally, they've found someone else who speaks the same language! They may still be living in the Twilight Zone, but at least they now know other people who live in the same place! Until we had our son's diagnosis from a medical research specialist and had time to interact with families of other diagnosed children, we had no way to effectively know how to address his behaviors and challenges. (See page 3 for more on the importance of a diagnosis.)

### A Sole Source Provider

We knew other parents needed what we needed: the practical knowledge and expertise gained by parents experienced on the front lines and in the trenches, people who knew and spoke the same language. We also soon realized that professionals needed this same practical information. This is the one foundational strength on which we base all of our educational products: the collective family testimony on raising children with documented prenatal alcohol exposure and solid medical diagnoses from preeminent medical scientists.

So we formed our non-profit educational organization (the FAS Family Resource Institute) and we began to gather information from parents of diagnosed children through personal interviews, surveys and formal working retreats. This information was analyzed, organized and sent back to the families for review and revision. As we came to new stages and discovered new issues, we added to our body of knowledge. Once we began to pool our information and identify what most families with diagnosed children were experiencing, we were able to begin serving as mentors for other parents, advisors to public policy makers

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## FAS TIMES

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and educators for professionals. The result of this ongoing effort is a sole source body of knowledge, the Collective Family Experience, which has been gathered over the past seventeen years.

### **Early On: The Need for a Practical Behavioral Description of FASD**

As our little organization grew and we began to gather the Collective Family Experience, we quickly discovered that the first thing we needed to do was describe the behaviors that most of us saw in our disabled children—behaviors that were commonly misinterpreted if they were not understood as part of a disability. So we decided to produce a brochure that parents could present to doctors, counselors, psychiatrists and other service providers, as they went about trying to find services for their affected children.

One of the major problems that parents ran into (and still do) is that professionals tend to not believe that the problems and behaviors they are seeing in undiagnosed persons with FASD are based in brain damage, especially in those with IQs in the normal range. But if parents could show professionals an educational brochure that described the behaviors of FASD in practical terms that matched the characteristics of their children, then they might be taken more seriously. (We have been thrilled to see how successful all of our educational products have been in doing this.)

When we produced our first educational brochure, we asked and were granted written permission from Michael Dorris to quote his behavioral description of FASD. (See companion article on this page.) Although we came to understand later that the basic issue underlying the apparent lack of conscience and remorse was a cognitive deficit in understanding cause and effect, it was Mr. Dorris' words that connected with parents and generated the first real tidal wave of public awareness on FASD.

So in our first educational brochure, "We Love Children," we acknowledged the hard truth that Michael Dorris declared on the 20/20 broadcast in April of 1990, namely that heavy fetal alcohol exposure leaves it's victims without an ability to tell right from wrong, without remorse and void of conscience. Then we expressed the gut wrenching, emotional pain that this truth causes family members.

We also included our first attempt at describing the behavioral phenotype as

generated by the Collective Family Experience. Since our information was based on "practice-based evidence" (the pool of information from parents on the front lines), we wrote that this behavioral phenotype was generated *through the eyes of parents*.

The brochure also detailed the types of resources we began providing to parents and professionals in the early 90's. We are the sole source for these resources and educational products since all of the information in them is based on the Collective Family Experience. These resources include:

- ◆ FAS Times newsletter and other FASD educational materials;
- ◆ Toll-free phone line for information, mentoring and referral;
- ◆ Professional development training; and
- ◆ Advocacy training/mentoring for parents and service system providers.

Starting in 1993, as we distributed our "We Love Children" brochure to a wider and wider audience every year, parents around the world called and wrote to us to express appreciation for this unique tool that could be used for educating professionals working with their families.

As the years went by, we were able to utilize and add to this body of information, while together we helped each other raise our disabled children into their adult years.

### **The FASD Behavioral Screening Tool**

By 2002, we had created and published numerous additional educational brochures targeted to specific audiences, all based on the behavioral phenotype. Unfortunately, at the same time in the medical community, a growing disagreement evolved on

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## **FAS\*FRI: In the Beginning**

Fetal Alcohol Syndrome (FAS) has remained diagnostically difficult and conceptually elusive for parents and professionals ever since the original description by Jones et al., in 1973.\* A major breakthrough in describing the disability to parents came in 1989 through the book, *The Broken Cord*, by Michael Dorris, which gained nation-wide attention. In the Spring of 1990, on the ABC news program, 20/20, Mr. Dorris was interviewed about the enormous impact of his best selling book. He reported that he had received thousands of letters from parents who identified with the description he had written: "Individuals with FAS are without a conscience, without remorse and cannot distinguish between right and wrong." Eighteen months later when ABC rebroadcast the interview, they reported that they were still receiving over a hundred requests a day from parents and professionals for video copies of the program. Because of Mr. Dorris' courage to speak out, thousands of parents could put a name on the problem they had been struggling to identify. His information was particularly helpful in linking a cause (prenatal alcohol exposure) with the peculiar range of behavioral difficulties

parents were seeing in their own children and in helping them to better understand the course this disability typically takes over the life span. This widespread publicity also legitimized FAS in the public consciousness.

Within the next two years, parents of children diagnosed with this disability teamed up with interested professionals to organize the FAS Family Resource Institute (FAS\*FRI). This educational [family-run] organization has now devoted [about 17 years] to their mission to identify, understand and care for individuals with FASD and to prevent this disability from occurring in future generations. Their mission has necessitated the identification of a behavioral phenotype for [FASD], the development of a professional training curriculum, and operation of a national family advocacy and mentoring network. By adding their own families' experiences to the information gathered from thousands of other families with diagnosed children, they have accumulated enough experiential, front-line reports which are similar enough to serve as their research science base.

Abstract and Introduction  
FAS Through the Eyes of Parents  
J. DeVries, A. Waller  
*Addiction Biology*, June 2004

\* Jones KL, Smith DW, Ulleland CN, Streissguth AP. Pattern of malformation in offspring of chronic alcoholic mothers. *Lancet* 1973; 1(7815):1267-1271

# Diagnosis: The First Step to Success

Ann Waller, M.Ed.

I couldn't believe my ears. The facilitator of the Education Workgroup had just told me that one of the main topics of their meeting was whether or not a diagnosis was needed to properly educate students with FASD. This was her second time to lead this working group of the federal Interagency Coordinating Committee (ICC) on FASD and she was frustrated that they had not made much progress.

I sighed as I lamented the unfortunate fact that I had not been able to attend her meeting and give practical input from the Collective Family Experience. (I couldn't attend it this time because I needed to give a presentation in the concurrent meeting of the ICC workgroup on Juvenile Justice.)

Since she was relatively new to this workgroup and I had been with it since it's inception, I told her this was an old controversy that seemed to arise at every one of these federal education meetings.

Now she couldn't believe her ears. "Every meeting?!"

"Every meeting."

In fact, the critical importance of a diagnosis was the topic of a presentation Jocie and I were asked to give by the former Education Workgroup facilitator for an Early Childhood conference *four years* ago. In all fairness, much of the membership of these federal workgroups is transient, with different members new to the discussion at every meeting. Consequently, it's easy to get caught in repeating the same conversation over and over again.

In our experience, the majority of educators and researchers start out believing all they need to know is the students' academic deficits so they can be remediated. But we know through the Collective Family Experience that regardless of how much students with FASD can and do learn, it doesn't change the way their damaged brains work and that's usually what interferes with the educational process.

I expressed concern that if the workgroup cannot take a stand on diagnosis, it will never make any progress toward setting or meeting goals. And a lot of time and federal money will be wasted again and again on nonproductive activity. She agreed.

These federal meetings are not the only forums where this progress-halting contro-

versy is surfacing. One research study (n=5) reviewed in the March 07 issue of *Iceberg* concludes that an early diagnosis does not improve outcomes for children with FASD—the opposite of what Dr. Streissguth, et al, documented in the landmark 1996 research study (n = 415) on secondary disabilities and the opposite of what most families report to FAS\*FRI. How can this happen?

A closer look at the 2006 study reveals a big clue: the narrow scope of its research inquiry. The researchers seem to have asked whether an early diagnosis *alone* would make a difference. **This is a far different issue than whether or not it is necessary to diagnose and understand the impact of this disability in order to serve those affected.** We agree that at this point in time (at least in the U.S.) a diagnosis alone does not automatically make anyone eligible for services. And without *understanding* the diagnosis—the brain damage caused by prenatal exposure and the way that manifests itself in the behavioral phenotype and cognitive dysfunction—it is a given that no one will know how to support and intervene appropriately. It is true that a medical diagnosis without practical interpretation has extremely limited usefulness. In fact, it can actually be harmful if it is misunderstood to the extent that affected people are written off as inherently bad and hopeless.

This is precisely why the FAS Family Resource Institute is a family-run *educational* organization dedicated to helping others *identify, understand and care for* individuals with FASD and their families. It is not enough to just name the cause of the disability. Parents and professionals alike need to understand the havoc this type of brain damage can wreak on schools, homes, public systems and society in general. Unfortunately, even 34 years after the disability was identified in the U.S., the level of knowledge about the practical implications of FASD is still extremely low. Even now, I talk to professionals who believe all people with this disability are mentally retarded. So it often falls to the parents to educate themselves, the teachers, counselors, social service providers, etc., what the diagnosis means for their children in each arena.

According to the Collective Family Experience, a diagnosis or acknowledgment

of FASD is just the first step in the journey of identifying the underlying issues and individual composite of disability and challenges for any one person. But it is a *critical* first step, without which the journey cannot *proceed* in the right direction.

Of course, this is not to say that all people with FASD will respond to the same interventions or be successful with the same supports. But we do believe (based on the Collective Family Experience) there are many generalizations that can be drawn for those with this disability which provide the starting place for assessing and understanding each individual. Then, and only then, can appropriate supports and interventions be put into place.

Without a diagnosis, or at least acknowledgment of the presence of FASD, the inappropriate, inconsistent behaviors look willful and are thus misinterpreted to mean that affected individuals (especially those with IQ's in the normal range) are lazy, uncooperative, undisciplined, or defiant. As a result, a typically successful intervention or consequence is used to extinguish the behavior or help them "unlearn" it.

When that doesn't work, the consequences become progressively harsher and/or they are imposed for a longer period of time. Things continue to spiral into worse and sometimes more dangerous situations because the disabled person is being punished for repeating behavior that is based in cognitive deficits and vulnerabilities, which cannot be changed. Consequently, without a diagnosis of brain damage and neurological disability caused by prenatal alcohol exposure, professionals, parents and service providers simply cannot meet the unique needs of these disabled individuals.

Another huge problem is that a lack of diagnosis can often exacerbate bonding and attachment problems. It is hard for parents to bond with children who seem to be willfully disobedient and uncaring about how their actions affect other family members. But when parents realize that brain damage and disability are the underlying causes of their children's behaviors, the anger level within the family greatly decreases, making way for bonding and attachment to grow.

An additional complication that makes

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# Snapshots: Part II

Children featured in our Nurture book with current updates

**Christina's** birth mother was a teenager with a history of binge drinking. Christina was diagnosed with FAS when she was 8. At 16, she struggles with depression because she is often excluded in the activities of her peer group.

Her charming expressive language skills mask her naivete and social vulnerability. As is typical with FASD, she has great difficulty remaining focused, handling money and choosing safe friends.

Luckily, she has energetic adoptive parents and two grown-up sisters to help her stay involved in community events. Her self-esteem is excellent due to her many talents. She is a skilled illustrator and musician. Christina is very coordinated and excels in figure skating, winning many medals in the Special Olympics, including the bronze medal at the 2002 World Games in Anchorage, Alaska.

## Update from Christina's Mom

My heart breaks as I re-read Christina's story and look at her pictures in the photo book. Where did that bright, energetic, determined girl go? We had such high hopes that she was going to be in a "better place" when she reached her current age of 21. Not long after these pictures were taken, she was manipulated by two classmates and sexually assaulted. Her disability traits and vulnerabilities were not understood by those who were trusted to watch over her. Since then she's attempted various forms of suicide several times, has gained over 50 pounds, and lost her enthusiasm for music, art, and figure skating. Her self-esteem plummeted. She is desperate to be liked and loved, which tends to make her more naive and vulnerable than ever.

On a positive note, last year she was thrilled to graduate from high school and "walk" with her class. For a graduation gift, she requested a cat, so off to the animal shelter we went. She rescued the sweetest feline, named Lucy. She also recently got her first job at a pet store and she's very happy cleaning cages. Her goal is to gather up the courage to hold a tarantula. We think she'll make it. AND, perhaps best of all, she is now in an apartment with 24/7 staff and enjoying

some autonomy from Dad and Mom.

Christina has a strong desire to fill a useful place in the world. It's going to take some time for her to heal from her trauma, but we have faith that she will. Her inner storm continues, but she knows she is loved by many and she's beginning to know a measure of peace and success once again. ♥

**Tony's** history includes prenatal exposure to alcohol and he is well-known for having survived the highest level of cocaine exposure ever recorded in the county where he was born. At the age of three, he was diagnosed with FAE and ADHD.

At 13, Tony's impulsive energy and thrill-seeking behaviors are legendary. Often described as the hyperactive Disney character, Tigger, by his patient family members, he makes friends easily. Unfortunately, he does not notice when they need their personal space or need a break from his intense personality.

He strongly resists taking part in team sports and physical education, due to his difficulty in processing information, as well as being easily over-stimulated and overwhelmed by "chaotic" environments. Educators are all too aware of his need for a full-time aide to monitor his unpredictable mood swings. The aide is absolutely critical to keeping Tony on track, academically. Tony has great coordination skills which have been nurtured by his parents, because they understand that meeting his sensory motor needs are critical to his well-being. Consequently, having the combined gifts of innate athletic talents and highly motivated parents, he is astonishingly skilled in acrobatic snowboarding, skiing, high diving and in-line skating.

## Update from Tony's Mom

For most of his life, Tony was our energetic "Tigger." On occasion, when especially frustrated, he morphed into The Taz (Disney's Tazmanian Devil). We were always exhausted as we tried to keep up with his boundless energy, yet we were always entertained by his athletic abilities and humorous antics.

School was always his most frustrating and painful experience. We greatly admired

his desire to go back to school each day. Because he totally lives in the moment, the miseries of the previous day were forgotten. He would excitedly head out for a brand new day of adventures.

As he has grown, the gap between Tony and his peers widened. Unfortunately, he is keenly aware that he isn't keeping up, no matter how hard he tries. His friends are getting their driver's licenses, while he grieves that he can't remember what he's just read in the driver's education manual.

Because his disability is so masked, the demands of his teachers continued to be far greater than he could possibly achieve. Tony was especially excited to have classes in auto tech and welding earlier this year and he poured himself into them. So it was a crushing blow when both teachers admonished him for not using his potential and gave him failing marks. After years of valiant effort, he gave up, saying, "All school does is make me feel really stupid."

Choosing safe friends eludes him, everyone is a friend to him...the more exciting, the better. This has gotten him involved with the juvenile justice system. His first offense was just after he turned 17—it was April Fool's Day (how ironic). He spent 27 days in juvenile detention for carrying some nifty brass knuckles that belonged to a friend. While in detention he made more friends who told him they would always watch his back and if he needed a job they would give him one. The new friends were incarcerated for dealing and using drugs.

As time goes on, his healthy friends have fallen away and been replaced by those who have dangerous influences on him. He resents the tight supervision we strive for in our efforts to keep him safe. Our relationship with him is strained and we rarely get to see his sensitive and humorous nature any more.

In the state we now reside, the justice system holds parents accountable for their child's actions. We have managed to educate the court, who now accepts the fact that we have a mentally ill and emotionally unstable son. But in spite of our efforts, the court is holding us legally and financially responsible for all of his actions until he is 21. Each time he is incarcerated, the daily fee goes up. The financial and emotional burden is overwhelming.

During this especially turbulent time, the few service providers involved with him began notifying us, saying, "Tony will soon

be 18—do you have need of our services?” (Tony was still eligible for nearly a year of services). It was disheartening to realize they were anxious to bail on us after we’d provided so much documentation and information to everyone regarding how chronically needy he is! After all these years, it’s hard to believe that so many professionals have such little knowledge of fetal alcohol issues.

Without support services in place, Tony collapsed into failure. He began experimenting with drugs and alcohol. His last incarceration resulted from being caught with four friends who possessed a pipe and marijuana. Tony thought it was awesome that none of them would narc on the other to the police. What good friends...

With Divine intervention, my husband’s company changed medical insurance providers, which helped us place Tony in a residential treatment program. We are relieved that he is finally in a safe, supervised environment where he is getting cognitive behavioral therapy and enjoying some academic success (because he is being taught the way he learns), which will provide the opportunity to again believe in himself and reach for his best potential. We know there is no magic cure for our son, but he is trying so hard because he now realizes his life depends on it. We feel hopeful again. If he stays there until December, he will have his high school diploma!

Living with fetal alcohol behaviors and crises for so many years has had a huge impact on our entire family, including our two healthy daughters, one a pre-teen and the other a young teen when we adopted Tony and Christina. Although we would never choose to live with this disability again, we are thankful that FASD hasn’t been able to crush us. It has actually mobilized us to do all that we can for our children and others like them. The grace of God and our faith in Him have been our encouragement for each day. Eric and I are so thankful for all our friends who have journeyed with us and allowed us to journey with them. ♥

**Ashley** was separated from her siblings for two years in foster care, where she was severely abused and neglected, but she was eventually adopted and reunited with her three biological brothers. She was diagnosed with FAS at the age of 7.

At 11, she is often misunderstood by her teachers as being lazy. Her poor organizational skills cause her to misplace or forget to hand in her school assignments. She often

displays chameleon-like behaviors and is easily influenced by whomever she’s around. Consequently, her family worries about her future and her vulnerability in social situations.

However, returning to live with her natural siblings has been a great comfort to her and she has learned to communicate exceptionally well with them, which is helping her recover from her traumatic past.

Now 14 [in 2005], she sings like an angel, plays the violin, loves to draw and illustrate, enjoys tumbling and dances jazz ballet and tap.

Update: Ashley did not benefit from the same early nurturing as her brothers. Multiple attempts (residential treatment, weekly therapy, strong school environment) have not been able to consistently help her maintain her performance.

Ashley has lacked consistent approaches to her academic development, and school seems harder for her now than earlier. Her father simply hopes that she will be able to finish high school and find something productive to do with her life. She has a tremendous sense of style, so he hopes she will complete the two-year cosmetology program offered through the school (even though it means taking an extra year to graduate).

Ashley continues to need a firm but supportive parenting approach. She shuts down immediately with any approach that she perceives is too harsh.

At least several times per week, Ashley is not able to handle the general education classroom and spends time in the resource room. The general education teachers continue to see her time in the resource room as not trying and being lazy. This element of special education needs definite attention. Ashley is in 11th grade.

She has been involved with the juvenile justice system for fighting at school in sixth, seventh and eighth grades. She never instigated a fight, but got lured into the conflict.

Ashley has had multiple hospitalizations and a four-month stay in a residential treatment center.

Since Ashley has been inappropriate sexually, her father finally consented to [birth control] to avoid pregnancy. Ashley does not want a child. She and her Dad have talked extensively about this topic. ♥

**Andrew** was born to a mother who consumed alcohol to the point of blackouts

throughout her pregnancy. Andrew was not diagnosed with FAS until the age of 4.

He is the brother of Ashley, Michael and Brandon who have all been reunited in a stable adoptive home. He shares his brother’s problems with food allergies, including gluten (wheat), cassein, and artificial additives. Andrew does very well in his home environment, which is very structured and predictable. But he experiences difficulties at school on a regular basis. Andrew’s poor expressive language skills are his greatest challenge.

In spite of these problems, with diligent coaching at home, he has learned to read, spell, and do simple math. At age 11, after six productive years in the same elementary school, he has made a successful transition to middle school, where his teachers are familiar with the family.

Andrew has learned to play the violin through visual and auditory memory. He is a great helper at home and remembers the routine better than all of the other children. He has developed into a gifted runner who loves the routine of practice. Andrew will do well with an employer who builds upon his work ethic and who provides adequate supervision and training.

Update: Andrew is a shining star. For a teenager with an IQ of 65, he has surprised everyone in his ability to attempt school work in the regular classroom. He is a sponge and soaks up everything. He completed algebra. His school success has maintained his self-esteem. With supervision and support, Andrew will always find success. His dad reads all his assigned novels to him and works with him at the keyboard to write his papers. He certainly can learn, but he needs extensive support. He enjoyed learning about the Holocaust. They both enjoyed The Diary of Anne Frank and Night. ♥

**Michael** has been diagnosed with FAS and Bipolar Disorder. When Michael and his siblings could not live with their birth mother, they were traumatized when they were sent to live in separate foster homes. The good news is that all of the children were eventually reunited in a loving adoptive placement. Unable to function without medication, Michael suffered from many failed attempts to find the right combination of drugs. This was one of the biggest challenges for him and his family. Further

complicating his life are his food allergies, including gluten (wheat), casein, and artificial additives.

Michael is a very sensitive person who displays deep empathy for others. But he could be easily destroyed without the constant advocacy of his family at school and in community settings. He has trouble with generalizing information and he usually needs assistance in retrieving information. He also needs help getting started on school work and expressive writing is very difficult for him.

At age 10, Michael is one of the top spellers in his class and is motivated to work on spelling and other assignments at the breakfast table with his Dad. He has successfully completed therapeutic behavior camp and enjoys tap dancing for fun. He also plays the violin and has an ongoing fascination with learning everything he can do with his hands (taking digital pictures, using the computer, cooking, etc.).

Update: Michael's bipolar disorder on top of the FAS has been difficult. Watching him run in front of a moving car was terrifying. Michael takes enormous amounts of medication and sees one of the top psychiatrists in Indianapolis. Diet continues to be incredibly important also. Michael may never be able to eat gluten or casein. ♥

**Brandon** was diagnosed with FAS when he was 2 years old. He also developed food allergies, including gluten (wheat), casein, and anything artificial in food.

He is extremely sensitive to facial expressions and negative comments from those around him. Brandon's central nervous system is very fragile. When he gets over-stimulated, he becomes extremely agitated, shuts down and is unable to verbally respond to people or to his environment.

In school, Brandon's success is dependent upon careful coaching by his teachers. He has received special education services since he was three years old. At 9, Brandon has succeeded in passing his third grade required testing in math and language arts.

He is very coordinated and he has strong athletic skills. He is very talented in tumbling and tap dancing, which uses some of his excess energy. Brandon plays the violin and is a talented artist and creative thinker.

Update: After a rough fourth and fifth grade experience in which teachers could not connect with Brandon, he has blossomed

in sixth grade at a highly structured charter school. Routine and structure are imperative for Brandon's success. He continues to be easily overstimulated when "too much" is thrown at him. ♥

Additional Thoughts on Ashley, Andrew, Michael and Brandon from their Dad

After five years of violin lessons, the program fired the instructor, and the new person did not have the patience to work with Andrew, Michael and Brandon. They came to hate playing, so we stopped the lessons. On the other hand, all three of them have taken tumbling and tap from the same dedicated woman (owner of the studio) for seven years. She loves these boys and has even participated in case conferences to share their abilities, rather than disabilities.

Andrew, Michael, and Brandon are in a highly supportive environment at a charter school that tries to approach education with accountability and common sense at all times. All three boys easily surpass their IQ potentials. Michael and Brandon have IQs in mid-80s. Ashley's is in the mid-90s.

The new WISC IV, which measures both processing skills and working memory, has been very helpful in understanding Michael's academic needs. While his verbal and non-verbal scores are in the 80s, his processing skills measured 70, and his working memory measured 62. I have used this information extensively with teachers to help them understand why Michael cannot listen and take notes at the same time, cannot remember the steps to a math problem without consistent repetition, and will always need tests read to him and interpreted, if necessary. Helping the boys with homework is a full-time job.

Andrew, Michael, and Brandon attend school regularly. Andrew is in 8th grade, and Michael and Brandon are in 6th. Michael was retained in fifth grade at my request. Now he and Brandon are in the same classes all day long at the charter school. Brandon is Michael's external brain throughout the day and takes the responsibility very seriously. They both understand each other and advocate for one another.

Michael has had three psychiatric hospitalizations and Brandon had one.

There is no alcohol or drug use among my children to my knowledge. Ashley and Michael have been able to talk openly about their birth mother's drinking and how it has hurt them. All medications and cleaning supplies are locked up in our home. No

over-the-counter medications are purchased. After attending a panel of recovering teens and how they could get high for a dollar, I made the choice to not have money in my children's hands. I am the bank.

In rereading their original stories, I still see the preciousness in each of my children. They are so loving and innocent, but can easily be overwhelmed. I have never stopped believing in their potential and giving them high expectations. ♥

**Bekah** tested positive for alcohol at the time of her premature birth; she was eventually diagnosed with FAS at age 3. She is communicating very well with her family even though the doctors originally thought she would never speak. Her medically fragile condition (including other complex diagnoses) has led to many surgeries and intensive care needs. Bekah's exceptional care costs have been a financial hardship for the family as her extensive and complicated needs cannot be met with Medicaid dollars.

Her bright smile and sweet innocence melt the hearts of those around her, keeping them tightly engaged in making sure she succeeds.

Update from Bekah's Mom

This year has not been the best for Bekah. She is doing OK in school. In fact she is in the classroom for most of the day. She still continues with speech, occupational therapy, and pull outs.

She is still seeing a specialist for her gastro-intestinal problems. We continue to search for something that will help her digestive system work better. Her doctors have talked about surgery, but she is so young that they are wanting to wait a bit.

We have been dealing with finding the right type of medication that will help her the best for her mood/anger issues. She was on Risperdal and that was great; but after being on it for a while, it took a toll on her body—her lipids were all over the place and not good for her system. She has been on Geodon for the last few months but to no avail. She has become much more moody, with a lack of attention and has had way more violent outbursts, towards me especially... (not fun!)

We will be seeing a psychiatrist within the next month for med management to try and find a mixture of medications that will help...hopefully by summer or it is going to be a VERY LONG summer!! ♥

**Hannah** was prenatally exposed to alcohol and methamphetamines. She was diagnosed with Neurobehavioral Disorder, Alcohol Exposed, at age 3 and has since been diagnosed with the co-occurring disorders of ADHD, asthma and sensory integration dysfunction.

Her mother described her as the “sweetest baby in the world.” She slept 14+ hours a day until she was officially adopted. Then she woke up and has been going full speed ever since.

At age 7, Hannah is becoming a gifted artist who loves to draw and do craft projects. With a warm, beautiful smile, she has learned that she has the ability to totally charm anyone around her.

Hannah loves school but she struggles daily against impulsive tendencies, a very short attention span and a limited ability to maintain the friendships she develops. The stress of trying to maintain the focus and control required for the rigorous structure at school is often overwhelming for Hannah’s fragile central nervous system. When she returns home, the safe environment her parents consistently provide, gives her the freedom to emotionally crash and recuperate.

She is extremely bonded to her family. Hannah’s innocence and joy are infectious. Her parents thank God for her and cherish her every day.

#### Update from Hannah’s Mom

Hannah is doing well. She is in the fourth grade. For the past two years she has had wonderful teachers who understand her and her disabilities more and more. Her current teacher says he gets the most out of her when they talk about the subject; but when it is “pencil to paper” she loses the whole thought process. So he grades her most by hands-on teaching! Her outbursts at school have become minimal, which I believe is due to having an environment where she is safe and understood.

She has done very well with cheerleading and playing volleyball this year! She still struggles in maintaining friendships, primarily with other girls. But I believe that is a problem with ALL girls at this age! ♥

## Collective Family Experience...

Continued from p. 2

standardizing diagnostic criteria for FAS, especially on the facial dysmorphism.

This controversy was keeping the focus on the facial features and off of the challenge of identifying the majority of those who don’t even have the facial features. These people need to be identified by their behaviors due to the brain damage caused by prenatal alcohol exposure. Thus researchers and professionals acknowledged the full spectrum of disability, but no one knew how to practically describe the most common behaviors, except FAS\*FRI.

So we decided to create the FASD Behavioral Screening Tool (FASD BeST) to help identify those who might have been disabled by prenatal alcohol exposure, but do not have the facial features. About that time we met a university professor whose research background helped her understand the behavioral side of FASD. We began collaborating with Dr. Glenna Andrews, Psychology and Sociology Department Chair at Northwest Nazarene University in Idaho. Dr. Andrews had done extensive work and research with behavior related to agenesis of the corpus callosum (ACC).

Since 2002, Dr. Andrews has conducted some small research studies on the FASD BeST. Her data indicate there is a high correlation between scores on the FASD BeST and the Achenbach Behavioral Checklists (2002, ABC) scores. She was also able to determine a cut-off score on the FASD BeST, which produces a 90% hit rate, i.e., identifies 90% of those with a diagnosis related to prenatal alcohol exposure. She has compared data from the following groups: FASD, ADHD (Attention Deficit/Hyperactivity Disorder), ACC and controls.

Dr. Andrews concludes that the FASD BeST appears to be effective in identifying possible FASD (as a screening tool) and seems to be sensitive to behaviors associated with FASD. It is also important to note that she found no differences in scores for individuals diagnosed with FAS compared to those with other disorders caused by prenatal alcohol exposure.

We are excited about the possibilities for this tool to identify those who might be affected by prenatal alcohol exposure, but don’t have the facial features and/or the growth deficiencies of the full syndrome. We are continuing to work with Dr. Andrews to refine this tool so it will be officially accepted as a valid screening tool for FASD. As part of this process, we are currently making the tool available for practitioners to use and report their findings to her. It can be

accessed on her website at the University: [www.nnu.edu/psych-research/](http://www.nnu.edu/psych-research/).

### Our Second Book Comes to Life

In 2005, another public awareness link in the chain of events unique to the Collective Family Experience was the publication of our book, *Nurture: The Essence of Intervention for Individuals with FAS*. This photo book was created to increase public awareness in general, but it is especially targeted to medical and mental health professionals to alert them to the critical need for diagnosing the full spectrum of FASD.

National estimates by the CDC, the NIAAA and scientific researchers around the country vary, but it is believed there are from 3 – 10 times more people who have disabilities caused by prenatal alcohol exposure, but do not have the facial features of FAS. Dr. Larry Burd, Director of the FAS Clinic at the University of North Dakota, estimates that currently only about 1-2% of those disabled by prenatal alcohol exposure are correctly diagnosed.

Regrettably, the controversy in the field about what diagnostic criteria to use has not lessened, but intensified. There is a researcher who believes that only those who meet strict criteria for the facial features of the syndrome (FAS) can be confidently diagnosed. It is further believed that if this facial dysmorphism is not present, then there is no way to be sure that prenatal alcohol exposure is the cause of the cognitive deficits and behavioral problems that are manifested. Of course, we totally disagree. We believe prenatal alcohol exposure causes specific brain damage, which manifests itself in the behavioral phenotype identified by the Collective Family Experience.

A more inclusive diagnostic protocol was outlined by the Institute of Medicine (IOM) in a report to Congress in 1996, which included a diagnosis of ARND (Alcohol Related Neurodevelopmental Disorder) for those who don’t have the facial features of FAS. In 2005, as we were finishing the photo book, these IOM criteria were revised and published in the *Journal of Pediatrics* by Dr. Eugene Hoyme, Dr. Kenneth Lyons Jones (the Father of FAS), Dr. Luther Robinson, Dr. Phil May and many others.

Because this article was published right before we finished the *Nurture* book, we added a review of it in the Appendix, including the revised IOM diagnostic criteria for FAS and ARND. Thus the *Nurture* book is a

unique educational tool for medical doctors, neurologists and mental health professionals because it showcases the sweet faces (some with dysmorphic features but most without them) and inspiring stories of our diagnosed children and ends with these diagnostic criteria. Through the information in this book, we encourage these professionals to consider FAS or ARND as a possibility for patients who have been difficult to diagnose.

We believe the FASD Behavioral Screening Tool is a good place to start the inquiry. It can be an effective instrument for professionals who are looking for a way to speak the same language with parents of children suspected of having FASD. A positive screen on the FASD BeST can pave the way for further testing to diagnose ARND through the Vineland Adaptive Behavioral Scale, MRI testing, a neuropsychological exam, etc. The distinctive thing about this screening tool is that it is complimentary with researchers' efforts who are working to further refine ARND diagnostic criteria and it is a way to cross check that diagnosis with a totally different body of information, i.e., the Collective Family Experience.

### **This Issue of FAS Times**

We are featuring a few stories and current updates on children and youths from our Nurture book who have diagnoses in the FASD spectrum from medical scientific researchers. These children and youths are growing up in families who have based their supports and interventions on the wisdom and expertise of the Collective Family Experience. They still admittedly have their challenges and struggles, but their parents readily confirm that they would not be nearly as successful as they have been without the benefit of a diagnosis, without understanding FASD and without mentoring from the Collective Family Experience. ♥

## **Diagnosis...**

*Continued from page 3*

matters even worse when the diagnosis is lacking or not understood, is when professionals blame the children's behavior on poor parenting. Of course, the prescribed remedy for this is parenting classes, regardless of the actual skill level of the parents. Only when the diagnosis is made by doctors

and understood by the professionals, can the focus be shifted from "improving parenting skills" to recognizing the type of brain damage involved and devising appropriate accommodations for it.

So, all things considered, once this disability is diagnosed *and understood* by all involved, the gateway to a chance for success is opened up. Then, and only then, can families bond with their affected children and all of them can be served by the educational and social service systems out of respect and compassion. Parents and professionals can work together to meet the needs of affected children. Admittedly, we have a long way to go in developing and funding appropriate services and supports. But the journey to success begins with that first critical step of diagnosis.

The challenges of children, youth and adults with FASD are extraordinary. But their only chance for success comes through getting a correct diagnosis; living with families who love, nurture and bond with them; and receiving compassionate services and supports from professionals who understand and accept their disability. ♥

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