

F.A.S. TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

The Other Side of the Looking Glass FASD and Co-occurring Disorders: Part II

Jocie DeVries

I have always loved books. As a stay-at-home mom for thirty years, I learned to entertain myself by reading books, magazines and newspapers every chance I got and attending writer's conferences a couple of times a year. I was interested in people and loved examining cultural developments in our community, state, country and world.

By 1990 Michael Dorris had written his best selling book, *The Broken Cord*, and I started making friends with people who were raising children disabled by prenatal alcohol exposure. My full-time role as a mother included raising my four children and baking cookies and pizza—not only for my kids, but for other kids in the neighborhood whose mothers “worked.”

My discernment and understanding of kids came from watching them interact together, solving problems, building castles in the woods, or using log rafts to keep them safe and dry during their pirate battles on the seashore near our house. So, by the time my four kids and all their friends grew into and out of their teens, I had been around the block a few times with counselors and therapists and their various approaches to mental health care.

During the following twenty years of child and family advocacy, I've learned that there are 3 elements needed to actually help families. These three elements were the ones that we focused on as we examined FASD and co-occurring disorders at the September 2007 consult: Research, Clinical Practice and the Collective Family Experience (common wisdom of practice from the parents). An underlying principle we also knew was important is a statement about interventions from Dr. Kenneth Lyons Jones (one of the two doctors who first identified FAS as a syndrome to the medical community in 1973): “Although there is a broad spectrum of defects associated with prenatal alcohol exposure, the developing structure most sensitive to alcohol is the brain, and the resulting neuro-behavioral abnormalities have the most profound and lasting consequences for affected individuals.” Because we parents know that alcohol is primarily a neurological teratogen which is commonly displayed in dysfunctional behavior, we wanted to bring a group of people together to study the state of the FASD field through this lens.

During the past few months as we have been busy organizing and analyzing the data gathered at the consult, I suddenly had the feeling that I had been standing in this place before. I had all but forgotten that we have been working to separate FASD from other behavioral issues since 1990. One day as I mentally processed that feeling, I remembered this was the same subject we were discussing in the fall of 1991. But now we are observing it from a completely different vantage point. It was as if I had looked at FASD and co-occurring conditions from one side of the looking glass in the beginning, all those years ago, and today I'm looking at it from the other side. Eighteen years later...same issues, different sides.

My experience in public advocacy began in 1991 when we organized parents to testify before the Washington State Juvenile Justice Hearings, which had been convened by the state legislature to find out what citizens thought about why so many of our youth were exhibiting antisocial behavior. My personal testimony centered around the agonizing decision my husband and I were faced with: trying to raise a teenager with FAS when the professionals (in our case it had been 24) didn't have a clue about how to separate the FASD behaviors from other problems, including what looked like anti-social behavior.

Even today many people don't know that it is a neuro-behavioral condition because so much attention has focused on the FAS face. But in 1991 it was so misunderstood that we had to literally give custody of our son over to the state in order to access appropriate services. The emotional trauma this gave our boy (who had been adopted out of multiple foster care placements) was unspeakable.

Ever the curious investigator, before I wrote my own testimony, I followed the Senate Juvenile Justice

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Committee to every corner of the state where they were holding hearings, and listened in. The citizens testifying at the hearing were by-and-large desperate parents of teens who were involved in the juvenile justice system (exhibiting anti-social behavior) or they were professionals who provided services to these teens. Most every profession was represented: law enforcement officers, teachers, health care providers, coaches, lawyers, social workers, therapists and counselors of every variety were there.

As I listened to the public testimony, it occurred to me that the professionals were describing five basic intervention models that were being used to help get these teens back on track. I heard them describe a variety of perfectly good services and treatment programs. But those of us parents who were listening knew one thing for certain: the programs and services they were describing were not helping our teens in trouble. We knew that not only weren't they helping, they were at times making things worse and were often destructive to family attachment and bonding. (Even the research community admittedly didn't know anything at that time about caring for those with FASD.)

By the time the hearings came to Seattle where our group was to testify, we were prepared. My testimony was based on my personal story, woven around the point that there were 5 intervention tracks that I'd heard about through the other testimonies, but none of them were appropriate for teens with FASD. (See p. 3 for full testimony.) The television cameras were rolling and the newspaper reporters were scribbling in their notebooks as I finished my testimony.

I learned later from the Secretary of the Washington State Department of Social and Health Services (who was one of the panel members of the committee) that our testimonies prompted him to hire a point man to investigate the issue of fetal alcohol exposure and its effect on state programs. Twelve years after my testimony, when he became the Washington State Director of the Office of Management and Budget, he told me he still remembered my son's story and he even remembered that his name was Russell. There are too many positive outcomes that came out of that experience to list them, but one service delivery system in particular moved forward. The Division of Alcohol and Substance Abuse set aside funding for this disability, including support for the phone line, trainings, and educational prod-

ucts of our family-run group; the Iceberg professional newsletter; and other projects as they were proposed and accepted.

The reason I share the concept of the Looking Glass with you is to emphasize how hard it was and still is for families to live in the FAS Lane and be constantly pushed by the necessity of family preservation to translate and separate these behaviors so they can explain them to the gatekeepers of critically-needed services. The issue is multidimensional. Along the way we have learned that getting systems of care to understand the significance of separating FASD from co-occurring disorders is an epic struggle; but our point has been consistent with the 1996 Institute of Medicine's (IOM) report to Congress, "In understanding how to meet the needs of individuals with FAS, it is first necessary to describe the behavioral characteristics."

However the misunderstanding regarding FASD and co-occurring disorders continued to reign supreme throughout the years in spite of the IOM report. Families would call us puzzled over the fact that the state was spending what seemed like excessive amounts of money trying unsuccessfully to treat their affected children in psychiatric hospitals or warehousing them in prisons or jails, while practical interventions that parents requested and would have helped were denied. As we struggled to reverse this policy, our efforts led us on a fifteen-year journey in, through and around eight service delivery systems in the state of Washington and even to Washington, DC.

By 2006 we had formed many partnerships with other family-run mental health and disability groups, so we decided to host a legislative reception in Olympia in honor of all the volunteer work that was being done by these groups. Once again the perfect opportunity opened up. Another organization had the Washington State Rotunda reception room reserved for an opening day reception for the 2006 legislative session. For some reason their plans didn't work out and they had to cancel at the last minute. Coincidentally, this was the exact day we wanted to hold our reception, so we were able to secure the Columbia Reception Room in all its glory. We visited all the legislative offices and gave the legislators and their staff invitations to our lunch reception. During the reception a staff member for Senator Jim Hargrove sent word to us that we could meet with him in his office after the reception. So we

went up to see him. The first question out of his mouth was, "Where have you guys been?! You haven't been to see us (at a legislative hearing) in a long time!"

We told him we had been working with members of Congress to get a federal appropriation for states to have funding to provide services to individuals with FASD. He asked us how it was going. We told him there is now an FASD appropriation, but the money isn't being utilized for intervention services like we'd hoped—it is mostly being used for research and administrative costs and we are really disappointed about that.

As we continued, we began to explain the core behavioral phenotype and some of the case histories where our state's Mental Health Division (MHD) had wasted so much money funding services that weren't appropriate for those who had neurological brain damage from prenatal alcohol exposure. As our meeting concluded he said, "I want you to work with MHD and train them to identify the core behavioral phenotype. Don't worry about all the possible variations and peripheral issues—just get them to understand the FASD Core Behavioral Traits."

After our conversation with Senator Hargrove, Vicky and I called the new Director of the Mental Health Division, Richard Kellogg, and asked for an appointment to come in and talk to him about FASD. Our presentation to him focused on the same principles that we always talk about. Vicky gave her basic presentation about the importance of a diagnosis, the basic elements of FASD and the inability of social workers to understand that antisocial behavior could be caused by this pattern of neurological damage. As always, my basic presentation was based on the difficulties that affected individuals have in relating behavior to consequence and that the five intervention directions typically used by his agency are not only ineffective for individuals with FASD—they are in fact, unnecessarily costing taxpayers exorbitant amounts of money.

We ended our presentation with a proposal for us to provide social service personnel in the Mental Health Division with training to learn how to identify, understand and care for affected individuals on the basis of separating FASD from the co-occurring mental health disorders that are listed in the Diagnostic and statistical Manual (DSM) for mental health professionals. After our initial meeting with the director, he invited us to come in and present to his staff at mental health headquarters

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Why Good Programs Don't Work for Those with FASD

Jocie DeVries' testimony for Juvenile Justice Hearings, 1991

Mr. Chairman and Committee Members:

I come before you today on behalf of my son, Russell. As you know I have attended many of the Town Hall Meetings and have watched as you have sought to identify why so many community youth are exhibiting antisocial behavior. I've noticed that most of the testimony falls into five categories of youth. To help me remember the categories, I've given each a name that starts with the letter T. You've heard testimony about:

1. **Traumatized Teens.** Youth who have experienced a severe emotional shock during their youth or childhood.
2. **Tipsy Teens.** Children and youth exhibiting antisocial behavior from current alcohol or other substance abuse.
3. **Truant Teens.** Youth from families who have not taught them that antisocial behavior has unpleasant consequences.
4. **Troubled Teens.** Youth who have a mental disorder such as schizophrenia, ADHD or Bipolar Disorder.
5. **Treacherous Teens.** Youth who are persistently aggressive and predatory toward others.

When I first came to listen to the testimony, I came with my notebook and pencil to take notes on all the inefficient and useless programs that the state is funding. However, as I listened I realized that each category of antisocial behavior has good treatment programs.

Adolescent Treatment Programs

- There is therapy and intensive mental health treatment for traumatized teens who are haunted by painful memories of physical or sexual abuse.
- There are adolescent drug treatment programs for tipsy teens that are chemically dependent.
- There are community diversion programs to teach behavior and consequence to truant teens.
- There are psychiatrists and psychiatric hospitals to determine if medication is appropriate for troubled teens.
- There are residential treatment programs or incarceration for treacherous teens.

The problem is that there is a form of

organic brain damage called fetal alcohol syndrome which is caused when a pregnant woman drinks alcohol during pregnancy and it can cause a youth to exhibit antisocial behavior because they don't have the cognitive ability to connect cause and effect.

We first learned about this condition as we watched ABC's 20/20 program in April of 1990. We were totally shocked to learn from the announcer that FAS is a type of brain damage that can leave a person without a conscience and unable to tell right from wrong. We immediately sent for our son's medical records from the adoption archives, found documentation of prenatal alcohol exposure and he was diagnosed a few months later at Children's Hospital.

The only recommendation the doctor had for us was to give our boy *limits and protection like a three-year-old* even though he was over six feet tall, had a completely normal IQ level and might not be willing to live inside those boundaries. The point of my testimony is that we have a lot of good treatment programs to help youth with antisocial behavior but we don't have any programs for youth who have the organic brain damage of FAS. ♥

Interventions That Work in 2008

From the FASD Wisdom of Practice

Before any program or service can be successful, FASD must be diagnosed or at least acknowledged as highly likely and then taken into account as modifications are made. Assessments need to be made as to whether or not more than one "T" issue is involved.

1. Traumatized Teens with FASD

When a youth has problems that severely interfere with daily life or they repeatedly display disruptive behavior without any obvious predatory intent, a complete mental health evaluation needs to be made to determine the cause of the presenting issues, whether it be abandonment, current or past abuse, and/or some other trauma. Standard approaches to

healing these memories may work. Some parents report excellent results with alternative/complimentary approaches that work through the subconscious.

2. Tipsy Teens with FASD

Outpatient treatment programs may work for a few teens with substance abuse problems, as long as they are cognitively able to understand it *and* willing to cooperate with changes in their environments, activities and friends that have contributed to the situation. If not, or if withdrawal is a concern, inpatient treatment program may be necessary. Either way, long term supports, like supervision and accountability will be needed. 12-Step programs can be helpful, if they connect with a trained mentor.

3. Truant Teens with FASD

Diversion programs can be very effective with realistic requirements, good supervision and accountability, with the understanding that if they violate the terms, they will go to jail for a few days. If school truancy is involved, then their academic and school-based social issues also need to be addressed. Many times the reason teens with FASD fail in school is more social/behavioral than academic.

4. Troubled Teens with FASD

When co-occurring mental health disorders are suspected, we recommend a full neuropsych evaluation, done by a neuropsychologist who understands FASD. Follow-up therapy can be provided by any mental health professional who understands FASD and co-occurring disorders. It works best when professionals gather information from and consult with the family in this process. Based on the evaluation and consultation results, professionals can recommend the type and length of medical treatment and/or psychiatric therapy with specific timelines and goals, not to just "stabilize them" and send them home with more medications and no behavioral supports.

5. Treacherous Teens with FASD

Since violence and predatory behavior are *not* core FASD traits, if this type of pattern exists, a secured facility will be needed to keep themselves and others safe until the co-occurring disorders can be addressed and treated. The most important things to remember are (1) just because they are violent at this time, it doesn't automatically mean they can't change with appropriate treatment and (2) it is critical that a family member or someone continues to love them through this process. Unconditional love makes miracles possible! ♥

A Diagnostic Protocol for ARND

Jocie DeVries

According to the weather bureau, the community of Everett, WA is the convergence zone of the Pacific Northwest because the sky over that city is where the various weather systems merge after blowing in from the Pacific Ocean and moving up, around and over the Olympia Mountains. After the September consult on FASD and co-occurring disorders, I will never quite listen to the weather report in the same way because the Convergence Zone was exactly the process we experienced listening to 24 hours of workshops from the state of the field of FASD.

I felt a little sad for the speakers who had to come and go so quickly and couldn't stay for the whole process because they would have loved to hear the sum total of the outcome. It was so full of hope. In this process we heard from the people in the state of Washington who have been—in our experience—the most sensitive to the needs of affected individuals and their families. *The take home value for families is that the neurological brain damage of prenatal alcohol exposure can now be medically documented in everybody from newborns through adults.*

Doctors Ann Streissguth, Fred Bookstein and Paul Connor from the Fetal Alcohol and Drug Unit (FADU) at the University of Washington shared the culmination of their behavioral research. We learned about the new science of detecting affected adults through

MRI imaging of the corpus callosum and we learned that newborn babies who have corpus callosum damage can be identified through ultrasound images of the fontanel. These remarkable discoveries provide concrete evidence of brain structure abnormalities and are critical to psychiatrists and neuropsychologists who have the job of trying to professionally separate those individuals who “only” have mental health conditions like Bipolar, ADHD or Post Traumatic Stress from those who have structural brain damage, developmental disabilities or some combination of these conditions. The Collective Family Experience that we provide, helps the family sort and sift through the child's family history and behavioral and medical records as a basis to provide advocacy, mentoring or referral, as needed.

Since the consult I have interviewed Kay Kelly, Director of the Legal Issue Resource Center at FADU. Kay works closely with the four specialists who have developed a forensic assessment team (FASD Experts) to diagnose FASD conditions in individuals who are legally involved in serious capital offenses. After the initial intake, Dr. Natalie Novick Brown begins a sequential 4-step diagnostic process that involves an extensive functional and behavioral assessment of the client's history, including analysis of the extent of prenatal alcohol exposure (Step 1). Some tests (e.g., for adaptive skills) and

collateral interviews are also conducted. If the results indicate problems due to fetal alcohol damage, Dr. Brown refers the client to Dr. Paul Connor for neuropsychological testing (Step 2). If his results also indicate the likelihood of FASD, all data are provided to Dr. Richard Adler, the team's psychiatrist, who does a physical exam of facial abnormalities and growth deficiency.

After reviewing all data, including reports from Drs. Brown and Connor, Dr. Adler renders a diagnosis (Step 3). If the diagnosis involves FASD, Dr. Fred Bookstein conducts a computerized statistical analysis of the client's corpus callosum. (Step 4). If damage is found, a case can be made for FASD as a primary factor in the client's criminal behavior. Once the entire process is complete, the team testifies about their findings in court. FASD Experts is the only known diagnostic team in the world that specializes in forensic assessment of FASD within the legal context and one of the few assessment teams that specialize in adolescents and adults with FASD.

According to the Collective Family Experience, this type of process* is the most efficient and cost effective method to diagnose both FAS and ARND that there is to date. The convergence of this body of information gathered at the 2007 consult is a state of the field that is hopeful and helpful to families. ♥

* For similar diagnostic criteria and protocol, see *FAS Times*, Spring 2005, p. 9, or the Appendix of our photo book, *Nurture: The Essence of Intervention for Individuals with FAS* for a review of an article published by Dr. Eugene Hoyme and his diagnostic research team.

Dr. Fred Bookstein Speaks Out on Measuring the Corpus Callosum

Keynote Speaker at Consult, Sept. 24, 2007

There are many reasons why it's a good idea to measure the corpus callosum (CC):

- It is easy to see and easy to trace accurately.
- Long before we started our actual quantitative studies (MRI scans) it was already known to be abnormal in FASD.
- There is a cogent explanation of how alcohol causes its damage, explanations richly confirmed in animal experiments in which the corpus callosum proves to be unusually sensitive to alcohol damage throughout gestation. This period of susceptibility corresponds to dates beginning about 40 days post-conception in humans, which is before some women are even aware that they are pregnant.
- It is specifically mentioned in the 2004 Centers for Disease Control report [on referral and diagnosis] as a source of valid information fulfilling the CNS* abnormality requirement of an FASD diagnosis by way of the “structural abnormality” prong.

* Central Nervous System

Survey Results: Diagnosed Co-occurring Disorders

Survey taken by parents at the Consult, Sept. 2007

(N = 22)

Diagnosed Co-occurring Disorders in Children with FASD

- Sensory Integration Disorders – 16
- ADD or ADHD – 15
- Learning Disorders – 14
- Neurological Disorders – 8
- Bipolar Disorders – 6
- Mental Retardation – 4
- Intermittent Explosive Disorders – 4
- Depression – 4
- Sleep Disorders – 3
- Borderline Personality, Suicidal, Anxiety & Substance Abuse – 2 each
- Opposition Defiant Disorder, Schizophrenia & Reactive Attachment Disorder – 1 each

WHY Separate FASD from Other Disorders?

Ann Waller, M.Ed.

As we were putting this issue of FAS Times together, it occurred to me that we had not yet described WHY we know it is so important to separate FASD from co-occurring disorders. We've written and talked about it and around it in many FAS Times issues and presentations, but I'm not sure we've linked all the pieces together so that it is clear. When Jocie and I discussed this, as she said in the lead article, we found ourselves going back to the presentations and testimony she first developed in 1991.

After reviewing all of that early material, we realized that we really have come full circle in many ways. We've come back (if we ever left it), conceptually and experientially, to that early foundational information from the Collective Family Experience—why many good programs and services work for many teens and adults, but *don't work* for those disabled by FASD. The reason for this common failure is because of the structural brain damage that is specific to prenatal alcohol exposure.

At a recent conference I attended, there was a keynote presentation which repeatedly referred to the “dysfunction” involved with this disability. During the Q and A after it, one of the participants protested the use of this term. He recommended that, out of respect for those with FASD, we should refer to them as “functioning differently” instead of being dysfunctional. We can teach them that we all have strengths and weaknesses, he reasoned, and that people learn in different ways. In other words, those disabled by FASD aren't dysfunctional, they just function differently.

After thinking through what he said for a few seconds, I decided that I didn't agree. Of course, we need to show respect in how we work and interact with those who have FASD. However, I believe that it isn't respectful to ignore their permanent brain damage or pretend it doesn't exist. If you follow this approach out to its logical conclusion, it implies that FASD deficits in reasoning, judgment and learning fall well within the normal ranges of individual differences. The fact is—they don't.

These children know they are fundamentally different from their peers, even if their IQs are in the normal range. They know they don't fit in and according to the

Collective Family Experience, it's usually a huge relief for them to get a diagnosis (the younger the better). When they find out they were born with some measure of brain damage, they realize that many of the troubles they've had, aren't their fault. This realization increases their confidence and self esteem. If the diagnosis occurs at a young age, parents have more time to help them understand and accept it and the children are more willing to accept the “extra”ordinary amount of support and supervision it will take for them to be successful.

To me, this is much more respectful than trying to convince them they are normal and teaching them if they need help, they can just ask for people to accommodate their learning styles. The structural brain damage involved in FASD is manifested in reasoning, judgment and learning deficits that distinctly set them apart from their non-disabled peers and often result in behavioral and social problems.

Simply put, the following are the reasons it's so important to separate FASD from other disorders and conditions.

1. It is structural brain damage that can be misinterpreted as laziness, rebellion, a different learning style, etc., or disguised underneath a co-existing mental health disorder and/or an addiction.
2. FASD must be separated from other disorders and conditions in order for it to be diagnosed.
3. A diagnosis establishes the underlying structural brain damage so it can be legally recognized and accommodated.
4. With the necessary accommodations and supports, teens and adults with FASD can succeed. (See p. 3 for Interventions.)

The interesting thing is that in the eighteen years since we started training professionals with this foundational information, scientific research on the brain (especially research on the brain structures of individuals prenatally exposed to alcohol) has actually documented what Jocie first theorized in 1991—that prenatal exposure to alcohol damages the corpus callosum which results in disruption of the normal flow of information back and forth between the left and right sides of the brain. This type of information processing is necessary to facilitate normal reasoning, judgment and learning. Consequently, the ability to connect actions with consequences and modify future

behavior based on experience (learning from consequences) is compromised.

Scientific research since the early 1990's has also proven that several other major brain structures are damaged by prenatal alcohol exposure, including the prefrontal cortex. This part of the brain is involved in planning, making decisions, exercising judgment, inhibiting inappropriate behavior, and controlling impulses, etc. This type of research gives us even more reasons why the brain damage specific to prenatal alcohol exposure results in a common behavioral phenotype. We certainly recognize that there is a spectrum of severity and individual differences, but they all, to some degree, fall outside the normal range for their non-disabled peers.

Thus a diagnosis of FAS/ARND validates that the core behavior traits seen in affected individuals are actually manifestations of the brain damage specific to prenatal alcohol exposure. This behavioral phenotype is at the heart of what separates FASD from other mental health disorders and from substance abuse disorders. Even when a person has a combination of these disorders, the *key factor* that means the difference between success and failure is the diagnosis of FAS/ARND.

This is why we believe our work with Dr. Glena Andrews is so important. She has helped us refine our FASD Behavioral Screening Tool (BeST[®]) and prove its effectiveness to identify those who may have FASD through their behavioral traits. More recently, she has researched the similarities and differences between children and youth who have some form of FASD, those who have agenesis of the corpus callosum, those with ADHD and controls. Her presentation at the September conference on the results of her research was one of the most well received. She compared scores between these different groups on both the FASD BeST[®] and the Achenbach Childhood Behavioral Checklist (CBCL). She found that no one in any of the other groups scored as high on any of the BeST[®] items as did those with FAS or FAE. (See p. 7 for more results of her research.)

Indeed we know, and now have scientific evidence to prove there is a fundamental difference between FASD and co-occurring disorders. Consequently, we will continue to advocate for separating them, so our affected family members can be successful. ♥

Life in the FAS LANE

Dear Vicky,

Yesterday we received the information about fetal alcohol syndrome that we had requested from you. Last night I read most all of it. My husband read the collective families brochure this morning focusing on the parts for preschoolers and children, as that is the age of our four children right now. He is clinging to what Dr. Luke* said last summer at our children's evaluations. I told Dr. L that our children all manifest the behaviors of children with FAS, each one of them to varying degrees. (I had previously researched it on the web.)

So Dr. L did the evaluations, measured their faces, and said that they do not have FAS. His advice (verbally) was to never bring it up again, that with FAS comes a stigma, a label, that teachers have a hard time to get past.

That would be fine if the child doesn't have FASD, but what about our kids that look "normal" but are so emotionally crippled; can't talk about how they feel; feel they've done nothing wrong when they slap their brother in the face; don't know how to act with other kids; lie constantly, etc. You know what I'm talking about, right?? So, for kids that really have FASD, but don't look like it, a "label" would get them help.

The diagnoses he gave our children, if you could call them that, [included such things as screening-development problems, behavioral problems, sleep disturbance, temperament/sensory integration disorder, etc.]. Our youngest son, Jesse, is almost four, completely irritable, not potty trained, very small, and he has a flat philtrum, although Dr. L never actually measured his face.

I'm not against Dr. L; I thought he's very nice. But as you can imagine, I am frustrated and disillusioned. Last summer I thought we would be able to finally figure out exactly how to help our kids. It took over 6 months to get the appointments. And a whole year has gone since we had them and nothing came from it.

Well, that's not all true. We are firm believers in Children's Benadryl and melatonin now. Doctors and psychologists seem to get overwhelmed and mix up the facts with the

kids. I actually have good biological history documented on the kids. I have the lab reports on each child's meconium from their births showing the level of drugs in their systems. Alcohol was not tested for, but I'm sure she drank.

Last summer I documented the kids behavior. It only lasted about 3 weeks because it turned into nonstop typing for me. I gave all of this copious paperwork to Children's and they still got things mixed up. Time keeps going by, the kids aren't getting "better" and nobody has any answers or help.

Over a year ago I visited my own doctor (I feel my health and sanity wearing away). And he said the most callous thing: "You just have to raise them until they're eighteen, and then you can be done." **I still can't believe he said that. I was too stunned to speak. I love these children** and am fiercely protective of them, and not just until they're 18.

I am really scared, confused, sad, and of course worn out. **The collective families' description of their affected children is a perfect description of our children.** We don't know what to do, where to go, or how to help our children. My husband and I (especially me because I "take care of everything") feel extremely overwhelmed. We adopted all four children, full siblings, at birth as they were successively born.

The reason I contacted PAVE in the first place is the school wants to write Teri* (our 6 year old) out of her IEP. She's doing well academically, so they feel she doesn't need it. This is in spite of the fact that about once a month I get letters from the school about her hiding in the closet and nobody can find her, her refusing to come in from recess, running away, having meltdowns, etc.

Dr. L wrote a general letter for me to bring out her sensory problems. (There is no Sensory Integration therapy available here, so the kids haven't had any, even though they all need it.)

Teri's psychologist said that he will write her a letter, too. Last week was only her second visit to him. She didn't want to go (because she didn't want to miss school) so she refused to talk. She just sat on the couch

curled up right next to me. He has diagnosed her with ADHD and is teaching her to breathe, etc. I don't feel that diagnosis fits, but don't know what to do about it, either. We are just grabbing at what we can at this point and trying to get the ball rolling.

Is there anybody that can help us know what to say during Teri's school evaluation to help the school see her needs? Even we don't know how to help her. Last year when she was in preschool, I asked the preschool teacher if she had any kids with FAS. She said, "No."

Although Toni*, our 8 year old, is an excellent reader, she has trouble in math and is a very poor speller. She acts very immature, aggressive with younger kids, lies, and is mean and crabby. She can't tell time, doesn't understand distance, cities, states, concepts. When I ask her teacher about it, she just says that she will get it eventually. I really feel like Toni should have an evaluation and some help. When I read that kids with FAS top out at age 12, I feel Toni should be prepared with an IEP if that's what's in store for her?? Toni was diagnosed with ADHD, RAD, Fetal Drug Syndrome, and poor fine motor skills last summer by a psychologist in Olympia.

We couldn't continue to see her because the drive was too hard, putting it mildly. So, what do we do to help Toni? Her behaviors with our family mimic oppositional defiant behavior; she also fits the FAS behavior and ADHD descriptions. At school it's only surfaced a couple times.

In your experience, can a child with FAS, learn to hide it from people if they want to? I talked to Toni's teacher at the beginning of the year about her special needs, and she says that Toni doesn't fit at all what I described. But, she does at home.

When I volunteer in the class, I notice that Toni immerses herself in books in her spare time. She doesn't have friends, doesn't interact with kids, is very disorganized. She still has very extreme sensory issues. How do I ask for the school to evaluate her when they don't see any problem??

Anything you have to offer will be so appreciated. ANYTHING. I don't want to ever give up on our kids. I actually feel like moving to Mossyrock, so that I could get the kids into Pope's Place after I read about that in one of the pamphlets you sent.

I look forward to hearing from you.

Very Sincerely,

Anna S., WA State ♥

* Name changed.

The Top 8 Strategic Recommendations from the Consult

For Governor Gregoire's Mental Health Transformation Workgroup

As we discussed in the lead article, it is the medical opinion of Dr. Kenneth Lyons Jones that it is the resulting neuro-behavioral abnormalities of prenatal alcohol exposure that have the most profound and lasting consequences for affected individuals. The Institute of Medicine's 1996 report to Congress and the Collective Family Experience are both in total agreement with his viewpoint. It is with this in mind that we sought funding from several state agencies, including the Governor's Mental Health Transformation Workgroup, for the consult on FASD and co-occurring disorders.

In the Winter issue of FAS Times (page 6) we published the discussion points from the small groups, which analyzed the information that was presented from research, clinical practice and the collective family experience. The following eight recommendations were the top issues that surfaced through analyzing and synthesizing the small group summaries and recommendations from the final consult session.

We will present these recommendations to Governor Gregoire's Mental Health Transformation Workgroup later this summer. We believe these recommendations—when implemented—will result in a fiscally sound, compassionate and effective public policy for individuals with FASD.

- Mandate and fund FADU* ultrasound screening of the corpus callosum for high-risk newborns.
- Emphasize that the ARND diagnosis is based on an anatomical, psychological and behavioral phenotype. MRI imaging research has established that there is little or no difference between FAS and ARND.
- Replicate the assessment and treatment protocols, services and family advocacy partnerships as practiced by Dr. Alan Unis, Dr. Gayle Fay and Dr. Glenna Andrews.
- Ensure that FASD consumer and family-run groups have a voice at all levels of program development and in their own

* Fetal Alcohol & Drug Unit, Univ. of WA

individual treatment plans.

- Develop, fund and implement programs for the Department of Corrections to identify individuals with FAS/ARND so that appropriate re-entry plans can be made for disabled offenders.
- Recognize the urgency of separating the behavioral phenotype of FASD from other co-occurring disorders so service providers can learn to identify permanent disability without solely relying on IQ scores or the FAS facial features.
- Mandate and fund training (to include consumers and parent advocates as trainers) for all service providers. This is necessary because the FASD Behavioral Phenotype is still not currently understood by the large majority of state service providers. List of trainees should include Child Protective Service workers and Adoption Support case managers.
- Support the process to include ARND in the next version of the DSM (mental health diagnostic manual). ♥

Dr. Andrews Compares FASD to Other Disorders

Glenna Andrews, PhD, MSCP, is a clinical neuropsychologist, professor and chair of the Department of Psychology at Northwest Nazarene University (Idaho). Her research is based on interhemispheric transfer and bilateral field advantage in persons with corpus callosum damage and other brain irregularities. Her research (as reported at our consult in Sept. 07) indicates:

1. Children with FASD under age 5

- Can display behaviors similar to children with Pervasive Developmental Disorder (PDD), ADD/ADHD, or Oppositional Defiant Disorder (ODD)
- Yet they will
 - Score higher on the BeST¹ (meaning they have more and/or worse behaviors)
 - Score higher on the CBCL² externalizing and internalizing behaviors

2. Children with FASD between 5 and 7

- Score higher on the BeST¹
- Score higher on the CBCL on externalizing behavior
- Score similar on the CBCL on internalizing behaviors

3. Children with FASD above age 6

- Experience more anxiety than both ACC³ groups
- Are similar to ACC groups in somatic complaints
- Appear more withdrawn
- Demonstrate more aggressive and delinquent behavior
- Exhibit more behaviors on the BeST¹

How is this information being used?

- ◆ Educating parents in the behaviors of prenatally exposed children
- ◆ Using the BeST¹ to screen for the FASD behavioral profile in
 - ▶ Mental health clinics
 - ▶ Schools

- ◆ Educating professionals who work with children and teens with FASD on the behavior profile
- ◆ Assisting in developing behaviorally based IEPs for children with FASD ♥

Special Thanks

We wish to thank Dr. Gary Waller (Yes, he's Ann's hubby and she's proud of it!) for providing us with the ideas and format to create this unique event. His role as facilitator of the consult was encouraging, efficient, well received and very much appreciated. The innovative and comprehensive recommendations that came out of it are a tribute to his professionalism and expertise. ♥

¹ Screening Tool from FAS*FRI and Dr. Andrews: www.nnu.edu/psych-research/

² Achenbach Childhood Behavioral Checklist (CBCL)

³ Groups with Agenesis of the Corpus Callosum (missing) and partial ACC

The Other Side...

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in Olympia. A few days later we gave these same PowerPoint presentations to his staff. When we finished, the room was stone-cold quiet, except for a polite “thank you” from the director.

So we left, not understanding anything about the staff’s response to the information they heard. After I got home, an email was waiting for me from one of the director’s staff. He gave us this response to our presentation: “We’ve always said that FASD does not belong in the mental health system because it is not recognized as a mental health condition in the DSM. But the information you presented to us convinced us otherwise. In fact, we now understand that we have folks with FASD in our system and on our caseloads who we haven’t recognized as having organic brain damage.” The interagency funding that supported the September consult was a direct result of these meetings with MHD and with other state agencies and policy makers over the years.

As I reminisced about our public awareness presentations before the Juvenile Justice Committee so long ago, I remembered that the goal then was to find the reason that state intervention programs were not curbing the antisocial behavior of many youth in our state. The public awareness presentation for the Mental Health Division was much the same, but more sophisticated because of the scientific research that is now available. During the interim, research has documented that heavy prenatal alcohol exposure can cause corpus callosum damage that typically manifests itself through poor judgment and unacceptable behavior.

Suddenly I felt like I was stepping from one side of the Looking Glass to the other to find a wonderful new world of hope. Parents are still looking for diagnostic protocols and interventions that take into account the core behavior pattern. However, now that we have the medical evidence from the MRI research to document the structural abnormalities of the corpus callosum and other brain structures, the way is opened for our affected children

to be on the same playing field with other people who are born with brain damage and predispositions for co-occurring mental health disorders.

The current state of the field of separating FASD from other co-occurring disorders is firmly rooted not in the myriad of psychological theories¹ but in good medical and mental health care that recognizes structural brain damage as a critical component. Consequently, psychiatrists and neurologists now have the tools they need to distinguish antisocial behavior that is caused by other conditions/situations (as viewed in 1991) from the innocent delinquency of those who have the common structural brain damage from prenatal alcohol exposure (2008). Truly we have lived to see both sides of the Looking Glass and that is very promising to those of us who advocate for interventions that are rooted in the core disability traits of FASD. ♥

¹ See “Psychology 101,” *Newsweek*, March 27, 2006

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