

# F.A.S. TIMES

FETAL ALCOHOL SYNDROME / FAMILY RESOURCE INSTITUTE NEWSLETTER

Discovering Alternative Mental Health Approaches

## Creating a Culture of Recovery: Part II

Jocie DeVries

The FAS Family Resource Institute began gathering the Collective Family Experience in 1990. Today, seventeen years later, we are going to introduce you to two young adults (who as youngsters were diagnosed with FAS and co-occurring mental health conditions) whose stories will soothe your furrowed brow and give you hope for the future of all affected children. We will begin with Shawn. Shawn was born into a two-parent family. Unknown to his dad, his mother drank quite heavily during her pregnancy. Shawn's mother was diagnosed as being Manic Depressive (now typically referred to as a Bi-Polar Disorder). She was also diagnosed with ADHD. Shawn's uncle was also disabled, having been diagnosed with Schizophrenia many years earlier.

Unfortunately Shawn inherited the genetic predispositions of the Bi-Polar Disorder, ADHD and Schizophrenia in addition to getting heavy prenatal alcohol exposure. By the time Shawn was five years old, his behavior was so unmanageable at home, school and church that his parents were exhausted, so he had to be admitted to a psychiatric hospital. He was so out of control, the hospital would only keep him overnight and took him by ambulance to a neighboring state where he was in residential care for almost a year. This tragic circumstance was repeated five more times before he reached thirteen years of age.

Shawn spent fourteen years in and out of psychiatric hospitals and residential treatment centers and was heavily medicated throughout his childhood. At one time the Mental Health Division (through the Regional Support Network (RSN) was spending over \$5,000 per month on this child and not having any success in helping him. But Shawn had parents who loved him and would not give up. Shawn belonged to a larger, extended family (FAS\*FRI) and we wouldn't give up either. This included a good adult mentor and a therapist who were FAS\*FRI board members.

One day about the time Shawn turned fifteen, the therapist, Ken Dunning, discovered neuro-feedback. Ken was trained to incorporate this therapy into his practice. Because Shawn was "one of his kids" he gave him therapy on a sliding fee (and sometimes free). Shawn started getting better—you could talk to him, he could listen and he could *think*. Ken worked with Shawn for three or four years. One day in spite of many fears and reservations from his family and the other professionals in his life, he threw away the pills and refused to take them anymore. Although the transition was a bit rocky at first, he soon stabilized. Today, because of one dedicated therapist who searched until he discovered a practical alternative to "talk" therapy, Shawn is in his mid-twenties, takes no prescription medications, has a job in a quiet structured setting, and is a very enjoyable person to be around.

Our second young adult, Dwayne, was five years old when we met his mother. He was adopted and living with his mom, dad and little brother. Dwayne's mother was energetic and absolutely determined that Dwayne was going to be successful. He had been adopted at 18 months old and diagnosed with FAS when he was three years old. Soon after his diagnosis, his mother attended one of our Intervention Touchpoint Seminars where we described how to document her child's medical and mental health history and events and how to advocate for her son.

We didn't hear too much from Dwayne's mother for about 10 years because she was a *very efficient* advocate. But one day, about the time he turned 15, she called, saying she was at her wits' end. Although Dwayne had been under the care of a good counseling center and receiving Mental Health therapy under the auspices of the mental health Regional Support Network, he was not only not getting better, he was getting worse. He was starting to hit and strike out at people at school and at home. The professionals in Developmental Disabilities, Mental Health, Juvenile Justice and at his school had placed him in residential care five times during the previous two years. During that time, he had garnered a dozen mental health diagnoses in

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### FAS TIMES

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addition to the original FAS diagnosis he received at three years old.

Most recently he had been arrested twice and was currently sitting in jail waiting for another evaluation to see if he was able to assist in his own defense at trial. His mom asked Vicky McKinney and me to come advocate for her and her husband at the Interdisciplinary Team Meeting to help see what was going on and if we (FAS\*FRI) had any additional recommendations.

Of course the first thing we ask parents when we're invited into this type of situation is to review the medical, mental health, juvenile justice and education records. We had to laugh because the first thing she said was, "Oh, yes. I remembered what you taught me ten years ago about documenting everything that pertained to his developmental progress. And I have everything documented." Consequently, that made our job a lot easier. When we went into the meeting the first thing we noticed—which is quite common—was the disrespect and condescending remarks toward the parents. "They aren't consistent enough." "They're too grouchy and negative." "They're too lax." "They need more parenting classes," etc., etc. That was a big red flag in my face.

So after reviewing Dwayne's records (with his permission) before the meeting and then hearing the criticism first-hand that the parents were getting at the Interdisciplinary meeting, Vicky and I asked, "OK – now you've put this kid in five mental health treatment centers in the past two years, he has been arrested twice and failed the Competency/Capacity Evaluation on both occasions and the charges are always dismissed because he is incompetent to stand trial. Have you ever given this kid a neuropsychological evaluation?"

The team—very nice people I'm sure—looked stunned and stammered, "No."

So we asked, "Then how do you know what kind of neurological conditions are underneath his behavior? How do you know whether or not he's having unidentified seizures or voices giving him commands?"

The point we are trying to make here is that even though we have all kinds of professionals taking care of these affected kids, they do not have the training needed to sort these co-occurring conditions out.

So the result is to either blame the exhausted parents or label the kids as incorrigible. This actually points back to the professionals as having a lack of training from the Collective Family Experience.

The eventual outcome was fantastic, although it took us a while to get there. Every time the Interdisciplinary Team met, we went with the parents so they were never left alone and undefended. Every time someone said a word of criticism, we jumped down their throats. We insisted that the child be hospitalized immediately and we worked closely with Dr. Alan Unis at Sacred Heart Hospital in Spokane to have him appropriately evaluated. Within three days they had identified significant neurological damage. As a result, a Superior Court Judge ordered Dwayne into *Involuntary Treatment* for six months. He was placed in residential care with 24/7 supervision by a rotating, rested staff.

Vicky and I did one staff training for them and mentored them closely for three

*...the Collective Family Experience is a very important data base that has been used to sort out FASD from other co-occurring mental health conditions for over 16 years...*

or four months. Once they really understood and met Dwayne's needs (protected him from his vulnerabilities caused by neurological damage), the staff that was working with Dwayne saw remarkable changes in his behavior. He now likes himself (and the staff like him!) and he actually laughs again. The staff has seen a complete turnaround in this youth.

One thing that we had to make very clear to them from the beginning was that because of Dwayne's particular situation with FAS and co-occurring mental health and neurological conditions (which is not uncommon in youth with FASD) it would not have been safe for him to reunite with his family after being released from the hospital. So the main responsibility of the group home staff was to establish the least

restrictive environment in which Dwayne could live, safely and happily. In fact, it worked so well that he voluntarily signed himself in to stay at the facility when his involuntary time had ended. He said, "I'm just not ready to leave; I understand what my needs are and I can think." His medical and mental health events and issues are still being documented by professionals who will know how to work with the parents when he is ready to return home.

I share these stories with you for a reason—the Collective Family Experience is a very important data base that has been used to sort out FASD from other co-occurring mental health conditions for over 16 years now. We share Shawn's and Dwayne's stories with you to give you reasons for hope. We don't try to erase the disability because that isn't possible. But in our experience, you can't have hope until you understand the baseline of behavior and the permanent nature of the disability, and then grieve over what might have been. And that takes time.

A few weeks ago Vicky, Linda La Fever and I were presenting at the Washington State Co-occurring Disorder Conference in Yakima. After my presentation, a warm and lovely woman waited off to the side to talk to me. When everyone else had gone, I went over and sat down beside her. As she started to talk, she said, "I wanted to tell you, thank you. I should have told you many years ago. I heard you speak back in 1993. I am a chemical dependency counselor and when you and Linda presented, I was so shocked I couldn't speak—because you described my own daughter! You see I'm a birth mom and I had never understood my daughter until I heard you speak on FAS. No one—in all my training—had ever taught me anything like that... I went home and cried for three solid days. Not out of grief, but out of joy and thanksgiving that I could finally understand her. I know it's long overdue, but I wanted you to know—that presentation changed my life."

What is it that they say about the truth? The truth shall set you free. With this in mind, we share the following articles and information about potential therapies, new approaches to mental health support and intervention and some people who have the knowledge to help you—and help your children be the very best they can be. ♥

# Creating Compassionate Care... by Establishing the Least Restrictive Environment

# OPTIONS

## Out-of-Home 24-Hour Group Care Options

**CHILD/ADOLESCENT PSYCHIATRIC HOSPITAL** \$24,000  
 Cost per day: \$600 - \$1,000.  
 Average cost per month: \$24,000.

**PRISON**  
 Average cost per month: \$4,500

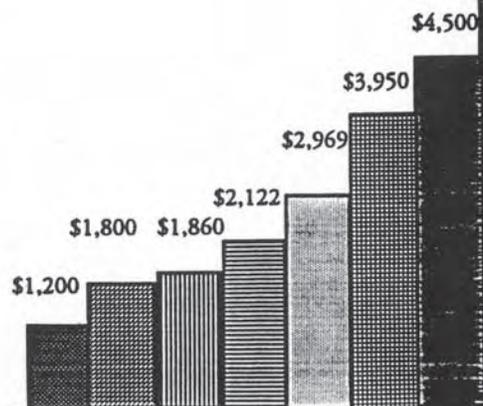
**STAFF SECURE FACILITY**  
 Fire setters  
 Highly sexually aggressive  
 Average cost per month: \$3,950

**RESIDENTIAL TREATMENT**  
 Severe behavior problems  
 Chronic runner  
 Severe family conflict  
 Medically fragile/D.D.  
 Average cost per month: \$2,969

**LEVEL III**  
 Behavior problems  
 Family conflict  
 Aggressive  
 Alcohol/substance abuse  
 Average cost per month: \$2,122

**LEVEL II**  
 Minor behavior problems  
 Delinquency  
 Average cost per month:  
 \$1,860

**MINI-GROUP HOME**  
 Specialized programs  
 Fetal Alcohol Syndrome  
 Sexually aggressive  
 Developmentally Disabled  
 Average cost per month:  
 \$1,200 - \$3,400



Source: Washington State Department of Social and Health Services

## Governor Gregoire Speaks Out on FASD

Jocie DeVries

Vicky McKinney and I first met Chris Gregoire in 1992 on her first day in office as the Attorney General of Washington. She graciously listened as we told her our stories of adopting children who were eventually diagnosed with fetal alcohol syndrome (FAS). After we finished our public awareness spiel, she told us that the subject was very interesting and then asked what we wanted her to do. We told her that affected children sometimes need support services and residential care to keep them and their communities safe—and we knew these things cost a lot of money. So we said, “We want you to sue the alcohol industry to pay for critically needed services.”

We had no idea of the difficulties and complexities involved in our simple plea for help until we saw her mouth drop open in shock and surprise. After quickly recovering from our audacious proposal, she indicated that she was going to have her staff start researching the possibility. We left her office feeling that we had been heard and trusting her to seriously consider our request. She eventually decided, for many reasons, that filing a lawsuit was not the best action to take. But her interest in FAS and her support of our work had been sparked.

Since then, she has worked with the FAS Family Resource Institute on several FAS public awareness events, including when she was a featured speaker in A Woman’s Forum on FAS in 1993. In January of this year, we contacted Governor Gregoire about the possibility of making a public service announcement (PSA) on FAS and she readily agreed to serve as a spokesperson to bring this children’s crisis to the attention of the citizens of Washington. We felt that if anyone in the state could call attention to the importance of FASD prevention, it would be Governor Gregoire.

When we first organized FAS\*FRI in the early 1990s, we were overwhelmed with newspaper and TV reporters, who wanted to do stories on FAS because it was such a hot topic. However, in the last few

years, the methamphetamines epidemic, the war on terror and illegal immigration have dominated the news headlines, and rightly so. But the problem with FAS still remains. It is currently estimated that as many as 1,000 babies are born in the state each year with Fetal Alcohol Spectrum Disorder (FASD), according to Doug Allen, Director of the Division of Alcohol and Substance Abuse. (FASD is the latest term used by federal agencies, which incorporates all the physical and cognitive disabilities caused by prenatal alcohol exposure.)

Since FASD is a lifelong condition, many thousands of adults today are living with this type of permanent brain damage. Although there is a common set of behavioral traits, each person with FASD has his or her own special needs, problems and capabilities and will need some level of lifelong support. Many of these individuals have FASD and co-occurring mental health conditions, which exponentially drain state fiscal resources. FASD is like an avalanche crashing down and overpowering state agencies. But when we realize that an avalanche is just a bunch of snowflakes that nobody paid any attention to, the task of keeping everyone safe seems more manageable.

Therefore we need to raise public awareness on FASD so that it can be prevented and the avalanche can be stopped. Governor Gregoire concurs with us that the most valuable resource in our state is our children, so it is critical to have public policy and practice, which promote children’s health, safety and nurture.

Now that her PSA is finished, we are working with radio and television stations

to give the Governor’s message as much prime airtime as possible. Although the media effort has just started, the PSA is already playing on ABC TV in the Vancouver area. It has been posted on our website. It will also be used in FASD educational seminars and plans are in process to make it available to chemical dependency treatment centers and various school districts to share with their high school students. If anyone has other ideas to reach the public with this prevention message please e-mail [Vicky@fetalalcoholsyndrome.org](mailto:Vicky@fetalalcoholsyndrome.org).

By working together, we (the Governor, public agencies and family-run organizations) can stop FASD from impacting future generations and help those children and families already affected. Washington State’s Division of Alcohol and Substance Abuse (DASA) leads the nation in providing compassionate, chemical dependency treatment programs that are specifically designed for pregnant and parenting women. The FAS Family Resource Institute (FAS\*FRI) has been gathering and sharing the FASD Collective Family Experience (the foundation of our frontline educational information) since 1990. In 1995, DASA began ongoing funding of FAS\*FRI’s educational trainings and products. And now, we are delighted with this latest opportunity to work with Governor Gregoire on FASD issues and to share her very important message with the citizens of Washington State. ♥

FAS Family Resource Institute  
1-800-999-3429  
[www.fetalalcoholsyndrome.org](http://www.fetalalcoholsyndrome.org)  
[Vicky@fetalalcoholsyndrome.org](mailto:Vicky@fetalalcoholsyndrome.org)

DASA 1-800-562-1240  
<http://www1.dshs.wa.gov/dasa/>

Federation of Families Annual Conference

## Improving Outcomes Through *Practice-based Evidence* Youth and Families Speak Out!

Dec. 1-3, 2006 ♦ St. Louis, Missouri ♦ Cost: \$350 for non-Federation members

For more information or to register: [www.ffcmh.org](http://www.ffcmh.org)

## Ken Dunning Karin Reep

April 27, 2005 Meeting  
Notes by Jocie DeVries

In the spring of 2004, the FAS Family Resource Institute was asked by Skagit County Youth and Family Services to conduct a needs assessment with families raising children with FASD for a grant that they had been awarded from the FASD Center for Excellence. The **most critical need identified by families was training on the FASD behavioral phenotype for professionals** in the following five fields: Mental Health, Education, Juvenile Justice, Developmental Disability and Guardians ad Litem.

The next three most crucial needs that were identified were to:

- ◆ Create a position of Advocate Liaison between juveniles (and their families) and the primary systems listed above;
- ◆ Conduct FASD peer-to-peer advocacy training and mentoring for affected youth and their families; and
- ◆ Provide extra supervision for affected youth at home and at school.

The families participating in the Needs Assessment also identified two therapists who were knowledgeable about FASD and successful in helping affected children and supporting their families: Ken Dunning and Karin Reep. As a result, Jocie invited them to a two-hour brainstorming session on effective strategies that would meet the needs identified by the families. The following are summary points from this discussion:

- We agreed with the families that the professionals in the systems listed above need general training on FASD and specifically on the FASD behavior phenotype.
- Youth with FASD in the juvenile justice system need to have a comprehensive medical evaluation (as in an EPSDT\* available through Medicaid), including vision, receptive and expressive speech, hearing, complete physical exam, screening for possible seizure disorders and referral for a full neuro-psychological evaluation.
- Mental health counselors need to understand the following issues:
  - Traditional counseling methods (talk

therapy based on insight) will only be effective on a short-term basis, at best.

- A high level of supervision of a youth with FASD (above the peer norm) is comparable to the need for a prosthesis in order to be able to function well.
- Parents need to be supported in their search for alternative therapies, not criticized. Since parents are not finding effective medical and mental health “treatment,” they are constantly searching for ways to improve their children’s brain functioning. Many professionals criticize parents for this. Parents need to be respected as front line researchers instead.
- Many parents of affected children get more and more isolated when trying to keep their families intact, so their social life and personal friendships are practically non-existent. In this situation, offers to have someone to come in the home to provide respite or take the child outside the home may be more trouble (disruptive) than it’s worth. When this type of help is refused, the family may seem to be withdrawing more and more into themselves. Parents may even appear to be “withdrawing” more from the community if they need to home school their children to keep them emotionally stable and to make academic progress. So when a professional comes to a family to help, he/she needs to listen to the parents and understand the situation in light of the disability, before developing a therapeutic treatment plan and recommending interventions.
- Parental burnout and physical health should be major issues to address in a therapeutic plan, taking into consideration the unyielding demands of a child with FASD. There may be many contributing factors involved in the parents’ health conditions, including their children’s sleep disorders (causing sleep deprivation), frequently re-occurring crises, need for high levels of supervision for safety, etc.
- The child with FASD may have a form of brain dysfunction which can cause behavior that appears to manifest itself as Oppositional Defiant Disorder,

Conduct Disorder or other mental health conditions. In truth, many of these behaviors can be the manifestation of damage on the cellular level caused by prenatal alcohol exposure, so these children may not respond well to medications or interventions designed solely for other mental health conditions in persons without FASD.

- Youths with FASD may expect to live as “middle class” or “rich” as they perceive their parents to be, but they are typically unable to maintain this level of life style on their own. This may be a major issue to address with youth.
- Mental health counselors will be more effective if they include complimentary therapies such as:
  - Supervised field trips to include role-playing on safety issues;
  - Neurofeedback treatment beginning as soon as possible;
  - Nutritional regimen to bolster the production of serotonin in the child’s brain and balance body chemistry as naturally as possible; and
  - Chiropractic care, including massage, focusing on acupressure sites.
- Group residential care can be a positive experience for affected youth who have deep-seated anger, such as in attachment problems or victimization, since peer confrontation and 24/7 supervision may be the last appropriate interventions to prevent endangerment of safety and/or incarceration.
- Caution needs to be taken when an affected youth pleads guilty. A guilty plea does not necessarily mean he/she is guilty. It may mean that it was perceived as the fastest way to get out of the immediate crisis situation (e.g., allowed to go home after an arrest and intense interrogation).
- Probation terms for youth with FASD need to be tailored to take into account the cognitive deficits involved in their disability. For example, they may not be able to comply with regular appointments or reporting requirements without reminders or other types of support.
- It might be helpful to explore whether or not the “Real Justice” method of intervention (culturally appropriate sentencing and restitution) would work for youth with FASD. ♥

\* Early Periodic Screening, Diagnosis and Treatment

If you want to change the world, start by changing the life of a child:

## It Only Takes One

By David Oliver Relin  
Parade Magazine, March 26, 2006  
Reprinted by permission

The world knows him as Denzel Washington, a dynamic actor who has won two Oscars and wowed audiences in films like *Glory*, *Malcolm X* and *Training Day*. But Billy Thomas remembers him as the excitable 6-year-old who walked into his Boys & Girls Club [BGCA] in Mount Vernon, New York, 45 years ago.

"Denzel was a little wild back then, always getting into everything," Thomas says. "He was a good kid but he needed a little guidance."

Billy Thomas provided it, becoming Denzel's mentor. "Billy was like a god to us," Washington says. "He was the mentor every child needs but few are lucky enough to have. Whatever success I've enjoyed in this life, I trace right back to Billy and the lessons he taught me at the Boys and Girls Club."

This year, the Boys & Girls Clubs of America celebrate a century of changing children's lives. In 1906, 53 facilities banded together to form the Federated Boys Clubs of Boston and gave birth to a national movement. Today, there are more than 3,300 clubs in all 50 states serving more than 4.4 million children. (In 1990, they changed their name to Boys & Girls Clubs.) The clubs often are equipped with basketball courts, swimming pools, computer labs and art studios. At the core of each club are caring adults like Billy Thomas who make time to become mentors.

Under Thomas' tutelage, Washington performed in front of a crowd for the first time. "My friends and I bought Beatles' wigs for \$2 apiece and won the club talent show singing, 'I Want to Hold Your Hand,'" Washington remembers. "I was such a ham back then that I had to be the star. I had to be Paul."

When Denzel made the decision to pursue an acting career, he considered Thomas' advice: "Billy always said that luck is where opportunity meets preparation, Washington recalls. "He said, 'You better pay now, put in the work now, or you'll have to pay later.' So I decided to study for two years at the American Conservatory Theater, learning the classics. That decision prepared me for the challenging roles I've taken on throughout my career. Sure, I can wave a gun around and talk out of the side of my mouth in *Training Day*. But I can also play Brutus in a Shakespeare production on Broadway." (The actor currently stars in Spike Lee's latest film, *Inside Man*.)

The clubs have helped to launch all kinds of careers, from athletes to politicians to news anchors. But sometimes simply providing a safe, well supervised refuge from the streets is their most important function. For Liberty Micheals of Everett, Washington, the club just one block from her house was a lifesaver. Liberty was 12 when she returned home one afternoon to find her mother attempting to commit suicide with shards of a broken bathroom mirror. Liberty called to her neighbors, who helped save her mom. Then she turned to her mentor at the Boys & Girls Club for her own healing.

"I could see Libby was suffering, so I zeroed in on her," says Ghvette Bergstrom, then a program director at the Everett club. "Her older brothers and sister were all in and out of prison and she didn't have good guidance at home. I just took her under my wing and told her I was there for her."

By eighth grade, Liberty was thriving and had set her sights on a career as a dentist. With her mentor cheering her on and helping to line up scholarships, Liberty Micheals became the first person in her extended family to earn a high school diploma and then graduate from college. At 25, Liberty is now a dental student at the University of Washington and volunteers at the Everett Boys & Girls Club. "I owe everything to Ghvette," Liberty says. "In her I found an example of the kind of stable, happy person I wanted to become. She was always there to guide, advise and just open her heart to me."

For 100 years, the special one-on-one relationships that Boys & Girls Clubs provide have been bringing out the best in young people. Take Eddie Armstrong: Eddie was 7 and living in Memphis when his mom picked up her children and left for Little Rock, Ark., to flee a bad family situation. "My mother made a courageous decision," Armstrong says. "But I was a confused kid with no clue about my future and no male role model – until I met Jim Weatherington."

Weatherington, director of the North Little Rock club, was legendary in his community for "rearing and steering" aimless young men, Armstrong says. "Jim recognized something in me that I didn't even know was there." With Weatherington's coaching, Eddie Armstrong won a series of speaking competitions and was named 1997 BGCA National Youth of the Year, which led to a meeting with President Clinton in the Oval Office. When he returned to the Little Rock airport, Armstrong was stunned by the hero's welcome Weatherington had organized. "Right at the gate, Jim had gathered my mother, sister and teachers and arranged for a high school band to play as I walked off the plane. And he had a police escort lead us home, sirens blazing."

A year after Armstrong's triumphant return, Weatherington died of cancer. "It was only after I lost him that I've truly been able to reflect on how much my life was blessed by this man," says Armstrong, struggling to discuss the loss, even a decade later. "I can't even put my hands around the riches, the college education, and the opportunity that came out of the jumpstart he gave me."

### *You Can Be the One*

You can become a mentor to a child by volunteering to coach a team, help with homework or lead an art class at your local Boys & Girls Club. Or help a child become a club member. Here's how to begin:

◆ Visit [bgca.org](http://bgca.org) to find the club nearest you, or call 1-800-854-club.

◆ Check out a local club during National Boys & Girls Club Week (April 2-8). All clubs invite the community to see what BGCA has to offer. ♥

## Choline Supplementation Shows Promise

Jennifer Thomas, Ph.D., Researcher, San Diego State University

One of the biggest challenges for researchers is to identify ways to reduce the severity of fetal alcohol spectrum disorders (FASD). Numerous behavioral and pharmacological interventions that might provide benefits to individuals with FASD, particularly benefits in cognitive and behavioral functioning, are currently being explored with the hopes of developing effective treatments. At the Center for Behavioral Teratology at San Diego State University, we have been using an animal model of developmental alcohol exposure to investigate whether choline, a nutritional supplement, may be effective in reducing fetal alcohol effects.

Choline is an essential nutrient that is necessary for normal brain development. Choline plays many roles in brain development and functioning. Choline serves as a precursor (the building material) for synthesizing the neurotransmitter acetylcholine (neurotransmitters are chemicals that transmit messages between brain cells); it serves as part of the cell membranes of brain cells; and it can even influence the expression of genes. Because of the importance of choline for development, it is recommended that pregnant and lactating women ingest adequate dietary levels of choline. Choline is found in a number of foods, including eggs, liver, nuts, and milk, and is now added as a supplement to children's breakfast cereals (e.g., Kashi Mighty Bites) and vitamins (e.g., Flintstone's multi-vitamins with choline).

Choline deficiencies can be damaging to the developing brain, but choline supplementation may have beneficial effects. The behavioral effects of choline supplementation during early development were first investigated by Dr. Christina Williams at Duke University. Dr. Williams and colleagues reported that

choline supplementation during gestation or early postnatal development in rats led to long-lasting cognitive enhancement and changes in brain functioning. Based on these findings, we began investigating whether choline supplementation would have similar effects in rats exposed to alcohol during development, that is, could choline supplementation reduce the severity of fetal alcohol effects?

At this point, it might be helpful to note that although both humans and rats go through the same stages of brain

Most importantly, we found choline to be effective even when it is administered after alcohol exposure is complete and during a period of development that would be equivalent to early childhood in humans...

development, the timing relative to birth differs. So, at birth, a rat is at the brain development stage of a human fetus at the beginning of the third

trimester. Therefore, **when we refer to "postnatal" choline supplementation in rats, it would be the equivalent of administering it to a woman (and fetus) during the third trimester of pregnancy.** Thus, early postnatal timing for rats would be equivalent to early in the third trimester for humans.

Using a rat model, we first reported that postnatal choline supplementation reduced the severity of working memory deficits associated with prenatal alcohol exposure. We later discovered that early postnatal choline supplementation in rats can also reduce the severity of spatial learning deficits and hyperactivity, but not motor alterations, all of which are associated with alcohol exposure during a period of brain development equivalent to late gestation in humans. These findings suggest that choline may be most effective on areas of the brain critical for learning and memory. Most importantly, we found choline to be effective even when it is administered after alcohol exposure is complete and during a period of development that would be equivalent to early childhood in humans, suggesting that it

could be effective in children with FASD.

We are currently investigating whether choline is effective when administered during a period of development that would be equivalent to adolescence or adulthood, to determine if choline holds promise for older individuals with FASD. We also have yet to uncover the mechanisms by which choline attenuates fetal alcohol effects, which may help us identify additional effective treatments. Although studies to answer these questions are currently underway, to date, there have been no clinical studies to test the effectiveness of choline supplementation in humans with FASD. Thus, we do not yet know if this will prove to be an effective treatment for fetal alcohol spectrum disorders.

Nevertheless, our data provide encouraging evidence that effective interventions can be developed to counter the damaging effects of prenatal alcohol exposure. We are hopeful that dietary interventions, like choline, may provide a relatively safe and effective means to improve the lives of individuals with FASD. ♥

### MAILBOX



Dear FAS\*FRI,

Please find enclosed our check for \$15 for membership into the FAS Family Resource Institute. We became court appointed guardians last November for two brothers, age 8 and 12. We could not figure out exactly what we were dealing with in addition to [their history of] a very poor home life and family structure.

Somehow we stumbled across FAS and were able to talk to the *Birth to Three Program* Nurse who took care of these boys. Our suspicions were verified and we are now trying to seek some help in getting these boys the help that they need and deserve.

We are still at the point of not knowing where to begin, but **your website gives us hope.** Thank you and we look forward to being able to use your resources.

Dean and Rhonda K,  
Kansas

## Creating Compassionate Care... through Parent-based Information and Training

### Sherry Mashburn

Washington PAVE

Sherry Mashburn works out of the Office of the Migrant Council as a Parent Resource Coordinator for Washington P.A.V.E.'s Parent Training and Information (PTI) program. These program services include the following.

- ◆ Assistance and information on disability issues
- ◆ One-to-one assistance in obtaining a free, appropriate public education for eligible children in the public school system
- ◆ Workshops on a variety of topics, such as disability laws, evaluation, IEP's, inclusion, transition and specific disabilities
- ◆ Support at meetings
- ◆ Resources and referrals
- ◆ Lending library of books, audiotapes and videotapes
- ◆ Free and low cost materials and books
- ◆ Website with discussion board at [www.washingtonpave.org](http://www.washingtonpave.org)
- ◆ Quarterly educational newsletter, the PAVE Pipeline

As a Parent Resource Coordinator (and the mother of a child with a genetic disability), Sherry assists other parents in their

advocacy. The PTI began in 1979 and now has seven offices across Washington State. When asked what circumstances drew her into the field, Sherry said, "My son is 36 years old and was born with Leighs Disease which is a degenerative neurological disease that is passed down from the mother, in this case me, to the child. My son was born in California and was so impaired that no one would allow him into the public school system. We were living a nightmare as you can imagine. But when he was about eight years old, Public Law 94142 was passed which is the Special Education Law and gives all students the right to receive a free and appropriate public education. By this time parents with children who were disabled united in a large public awareness effort and I was determined to be part it.

"You asked what's working from my perspective. Here are my answers.

1. We collaborate with a mental health organization that provides treatment and is accessible to some children and youth in the migrant community.

2. Medical coupons are available for some of these families, which is good.

3. We have mental health counselors who offer support services in the school setting. This is good.

4. We have drug and alcohol prevention and awareness programs that are available for both middle school and high school

students and their parents."

Sherry states that there are also some things that definitely need solutions. For example, if a child or youth does something and is suspended from school, the schools require the parents to find a therapist that will certify that the child will not repeat that behavior again in order for them to be reinstated in school. No therapist is going to put his/her professional reputation on the line by giving that kind of guarantee. So we are losing a lot of kids to the streets who have mental health conditions that could be alleviated through treatment.

Washington State has been given a D as far as providing help to school dropouts when compared to other states in the union. We do not have any mental health day treatment for troubled kids in our community. The only way kids can receive this type of care is to be sent away from his/her family to an out-of-state facility.

It would be so helpful if organizations such as Washington PAVE were fully funded to find these kids and families and mentor them in culturally appropriate ways to keep them from being permanently expelled which leaves them vulnerable to a life of drug and alcohol abuse typically related to gang activity.

Sherry Mashburn can be contacted at PAVE, 1-800-5-parent. ♥

## *FAS Times & FAS\*FRI Books and Articles*

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# Creating Compassionate Care...through Cultural Congruence and Collaborative Circles of Care

## Suzie Kuerschner FASD Specialist

Ms. Kuerschner is a child development specialist with intensive training and experience in Fetal Alcohol Spectrum Disorders (FASD). Her experience includes assessment, intervention, parent training, and the design of learning environments, for over thirty years. She has been an Early Intervention Specialist, special education coordinator, and program developer for schools, state, tribal and county programs, clinics and public and private agencies.

As a Youth and Family Services Coordinator at the Native American Rehabilitation Association of the Northwest, Ms. Kuerschner developed a Child Development Center and Family Resource Program within a residential and outpatient treatment center for chemically dependent American Indian families. From this context, she developed appropriate interventions, therapies and behavioral strategies for infants through pre-adolescents from alcohol and drug affected homes.

Ms. Kuerschner has also created collaborative partnerships to deliver strategies to adolescent and adult populations with fetal alcohol within public and tribal schools and clinics from the perspective of multi-generational, family focused models. As a child development and Early Intervention specialist and educational consultant of thirty-five years, she has delivered over 6,000 trainings to schools and related service provider settings, mapping effective prevention and intervention strategies for populations with cognitive and behavioral disabilities.

Her publications include many journal articles and a manual, [Beyond the Gloom and Doom](#), written for the National Indian Child Welfare Association, which addresses intervention strategies for populations with FASD from a developmental and culturally congruent native perspective. But she credits her daughter, gifted to her as an infant 19 years ago, as moving her from theory to function.

Suzie Kuerschner was not shy or hesitant when asked what appropriate mental health care would look like for native people. Her

response included the statement that mental health definitionally must be part of a collaborative circle of care, a system of multidisciplinary integrated delivery and inclusive of identified community leaders carrying the strengths of traditional, cultural norms and values. She said, "When we have the privilege as providers to serve and participate in the lives of children and families we are charged with the mission to engage in an approach that simultaneously embraces clinical knowledge and cultural congruence. At no time can we decide we have to choose between one or the other. To do so would not only diminish the chance for success, but be disrespectful and might eliminate the very tools that create resilience.

"In our family we were raised to believe that children should be 'invited' into this world, reinforcing the traditional belief that a child is a sacred gift. We were taught therefore that pregnancy should be planned—physically, emotionally, mentally and spiritually manifesting love that would flow from conception through pregnancy, birth and child development. These four components of physical, mental, emotional and spiritual health are considered to be essential to the holistic well being of native people and are one of the values shared by all our nations.

"My life has been gifted by many experiences from being raised in a household including my grandmothers, parents, brother and often aunties and uncles. Collectively we faced the challenges and struggles of addiction, suicide, premature death, teen pregnancy and divorce; but through it all we were encircled with the unconditional love that creates determination and resilience. This was perhaps my first experience with 'the circle of care.'

"Whether developing multi-cultural reading programs in special education or fighting the destruction of Celilo Falls and the relocation of native people, my mother was constant and consistent in her mandate that people should be met and respected where they are, rather than where others think they should be. Interventions should always be driven from a perspective that identifies strengths as the driving force to heal needs. When a way of life is

constantly being changed or destroyed for a people, it results in multigenerational trauma. Systems and the providers within those systems must seek to understand and provide services that are both multigenerational and multi-disciplinary, not just comprehensive, but truly holistic in approach.

"For native people, this means understanding the continual loss of lands, language and culture, as well as the boarding school era which devastated traditional child rearing practices. Further, for the native, indigenous person, it is not about the 'I' or individual self, but rather about the 'we' or collective community. Vine Deloria once said that as natives, we do not live in our communities but our communities live in us! This understanding helps us to remember and respect the prophesy that said there would come a time when there would be those born who would look different and in these differences they would change the People.

"This understanding of the 'we' rather than 'I' must drive the way clinical services are delivered. Equally essential to appropriate service delivery is an understanding and respect for the spiritual context of those being served. In all ways, services must be driven from this relational model.

"The global neurologic impact of an FASD also dictates this integrated service delivery. By adolescence and young adulthood, the frequent emergence of secondary characteristics, depression and/or behavioral issues converge in a way that requires interventions in multiple systems."

When asked to list the most important things to remember in serving American Indian children with an FASD and co-occurring, mental health conditions, Suzie responded with the following points:

- 1) Understand behavior as a means of communication.
- 2) Observe behavior from context of child and family; note strengths and skills that can be identified to address the particular needs of the situation.
- 3) Understand the mental concrete processing issues that impact language development and can produce significant discrepancies between expressive and receptive language, compromising the efficacy of "talk therapy."
- 4) Understand the presence of "echolalic

behavior”; script settings in which the focus is on creating positive behavioral maps showing what is being “done right.”

- 5) Identify eligibility for special education services and utilize the Individual Family Service Plan and the Individual Education Plan as vehicles for defining and delivering integrated, case coordination. Develop staffing patterns that mandate and insure multidisciplinary coordination, producing a seamless fit of education, mental health, and alcohol and drug services.
- 6) Seek to understand the person’s intergenerational cultural and spiritual context and identify these resources weaving them appropriately through all prevention and intervention strategies.

“The circle must reflect a collaborative consortium of care coming from families, elders, spiritual advisors, teachers, physicians, and community providers. This circle must also promote holistic healing through both traditional and developmentally appropriate techniques that address the physical, intellectual, emotional, and spiritual needs of people affected by prenatal exposure to alcohol. Proceeding from a family, community-focused, intergenerational, and multidisciplinary vision, all services must carry the mission and hope that we will recognize our place in addressing the strengths and needs of all of our people who are affected by FASD.

“In recognizing our place, we will recognize the interdependence and interrelationship of that place with others in the community. We will not, therefore, trap ourselves in issues of territoriality. We will also not ensnare ourselves with stigmatic, judgmental approaches that push our people away and create isolation and unsurpassable barriers of denial, guilt and grief. Of course, we will encounter each of these, but we must acknowledge and move through them.

“Our success will be proportional to our ability to define policy and work together as families, physicians, spiritual advisors, mental health therapists, educators, counselors, speech pathologists, occupational and physical therapists, juvenile service providers, and court and corrections professionals to create this circle of compassion, care and commitment to our people.” ♥

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# Life in the FAS LANE

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Pam Medgard

I have another **don’t** for our future book on raising FAS kids: Don’t track merchandise that they have purchased on-line. It all started with a respite worker who brought her 4-year-old son to work. He accidentally broke Alex’s remote control police car.

By the time we got home from church, Alex was very obsessed on getting another vehicle—*very obsessed*. I said, “No problem, Alex; we will buy you a new one.”

We went on the internet and he decided he wanted a helicopter instead. The price jumped up a few hundred dollars for a helicopter. We searched and found one for \$69.00. (What a deal!) My husband Harley was not very happy about buying an adult toy for a very uncoordinated boy. He said, “What are you going to do when the thing crashes?” All I worried about was the approaching melt down at the minute. I ordered the helicopter and then went down and bought a map of the US. I thought it would be a good learning experience, not to mention a way of showing him when it would arrive, so he wouldn’t be so apprehensive.

Good Idea. Right. I am sooo amazing.

Day 1: He woke me up early to find out where the package was. I got up and checked the computer for him. I went back to bed. He came in 5 minutes later to find out where the package was. I told him it would still be at the same location. He said, “No, it’s not; you are wrong...\*%#!#%\*”

I set up the computer so he could just check it himself. I weighed the situation—me going down every two minutes or take the chance he would get into porn (in which he has a master’s degree, without being able to read). It did keep him busy running down the stairs every few minutes to check the tracking status. A bit of a hassle, but it was still a pretty good idea.

Day 2: I am getting sick of the questions about if the driver is stopping for lunch, when he goes to the bathroom and when he sleeps. No matter what answer I gave,

he felt it was wrong. Just before bedtime I lost it and told him if he mentioned the blasted helicopter one more time, I would explode. (Actually in my brain the wording was more like one more time and I will choke you.) Maybe this whole thing wasn’t such a good idea after all. Maybe Harley was right.

Day 3: Alex’s anxiety was increasing. He wanted to stay home from school to track the helicopter. After a lot of convincing he took the map and tracking information to school. Unfortunately that afternoon when he got home, the UPS truck drove up the driveway. Generally UPS takes our packages to the PUD. There was a substitute driver. Alex flew out the back door. I yelled behind him, “No it’s not FedEx—remember your package is not on a UPS truck.” That was the final straw; he came back in calling me a \*%#!#%\*. The phone rang; it was Harley. When Alex told Harley he was going to kill the FedEx truck driver, and didn’t want the \*%#!#%\* helicopter, Harley started laughing. There went the phone. We finally got him calmed down. Later he apologized and said he wouldn’t kill the driver and would keep the helicopter.

Day 4: I checked the tracking site. The stupid, stupid helicopter was still in Seattle. Oh no, there was no way it was going to make it to our house! Oh gees, oh gees!! I called Harley and we prayed. I started trying to brace Alex for the helicopter not arriving. It didn’t go over well. About 2:00 pm a FedEx truck entered our driveway. Holy cow, it was on the truck!! How could that be? If it would have been later in the day I would have invited the driver to dinner! The last time I was that happy I had given birth to [my other son]. Life is so good! We waved good-bye, repeatedly yelling, “Thank you!!” as he drove down the driveway. I love that guy!

Do angels drive FedEx trucks? ♥

# Creating Compassionate Care...through Clubhouses

International Center for Clubhouse Development ♦ www.iccd.org

*The International Center for Clubhouse Development is a global network creating opportunities for people living with mental illness to be respected members of society.*

ICCD clubhouses are founded on the realization that recovery from serious mental illness must involve the whole person in a vital and culturally sensitive community. A clubhouse community offers respect, hope, mutuality and unlimited opportunity to access the same worlds of friendship, housing, education and employment as the rest of society.

In pursuit of this mission, the center promotes the development and strengthening of clubhouses; oversees the creation and evolution of standards; facilitates the creation and evolution of standards; facilitates the quality of training, consultation, certification, research and advocacy; and provides effective communication and dissemination of information.

## *The International Clubhouse Community*

Everyday throughout the world, people with mental illness face the enormous challenge of living with a condition that has interrupted their lives and often stolen their hopes and dreams. In every country, every city, and every town there are people with mental illness.

For many years these individuals had systematically been denied the opportunities due them as citizens in their communities, and were relegated to the margins of society. In recent years, with the advent of improved psychiatric treatment options and rapidly developing community mental health systems, this situation has gradually begun to change. We are finally coming to understand that people with mental illness can live, work, and participate in their community—just as any other citizen can.

In New York City in 1948, a small group of people who had been recently discharged from a state psychiatric hospital joined together to create a group known as “We Are Not Alone,” or WANA. WANA was a self-help organization that later evolved into a highly successful and innovative community-based program for assisting people with mental illness to re-claim their lost lives and aspirations. In the early 1950’s WANA with the help

of a few dedicated volunteers purchased a building and re-named their organization “Fountain House.”

Fountain House is still vibrant and growing today, and is widely recognized as a beacon of light, leading the way to recreating mental health systems throughout the world. The Fountain House program has become the template for the “Clubhouse Model” of psychiatric rehabilitation, now flourishing around the globe.

Today there are more than three hundred clubhouse programs operating in 24 countries around the world. A clubhouse is a comprehensive center of support and encouragement for its members (people with mental illness). Over the years Fountain House along with all of the clubhouses modeled after it, have continuously demonstrated that people with mental illness can successfully live and work in the community. Key to this success is an environment of support, acceptance, and commitment to the potential contribution and success of each individual regardless of the severity of his or her illness. Clubhouses are places to which people can “belong” as contributing adults, rather than as full-time “patients” who are there only to be “treated.” The clubhouse is a place in which members and staff work side by side in all aspects of the

days’ work.

Clubhouses also offer an array of specific services from which members can choose as their needs and life goals indicate. Members can take advantage of daytime programming, vocational rehabilitation, employment opportunities, housing support services, case management, social and recreational programs, supported education, advocacy and crisis response services.

In March 1994, the International Center for Clubhouse Development (ICCD) was created to serve and represent the rapidly growing and dynamic clubhouse community. The vision of the ICCD is that men and women with mental illness throughout the world will have access to the respect and dignity offered by clubhouses, and to the full range of clubhouse opportunities, as they rebuild their lives.

The mission of the ICCD is to promote and protect the rights, opportunities and future of psychiatrically disabled men and women who are members of clubhouses all over the world. Today, as mental health services delivery systems around the world are facing new crises, the ICCD is here to insist on a future with respect and opportunity for those who have been denied them for too long. ♥

## *What is a Clubhouse?*

A Clubhouse is a place where people who have had mental illness come to rebuild their lives. The participants are called members, not patients and the focus is on their strengths not their illness. Work in the clubhouse, (whether it is clerical, data input, meal preparation or reaching out to fellow members) provides the core healing process. Every opportunity provided is the result of the efforts of the members and small staff, who work side by side, in a unique partnership. One of the most important steps members take toward greater independence is transitional employment, where they work in the community at real jobs. Members also receive help in securing housing, advancing their education, obtaining good psychiatric and medical care and maintaining government benefits. Membership is for life, so members have all the time they need to secure their new lives in the community.

# Creating Compassionate Care...through Education

## *Nurture: The Essence of Intervention*

This beautiful, gentle book is a showcase of over 60 affected individuals of all ages and races. Each individual's personality is happily expressed in a collage of photographs, accompanied by a brief review of medical and mental health history as well as challenges and strengths. This photo book of individuals disabled by prenatal alcohol exposure is the first and only one available on the market. It's a "must read" for any professional who is serious about recognizing and helping people with FASD.

Cost: \$35 U.S.

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## *Fetal Alcohol Syndrome & ME*

This 2-booklet series was designed to encourage and build self esteem in children who have disabilities from prenatal alcohol exposure. Their cheerful educational message is rooted in the common behavior pattern unique to FASD, with a strong focus on the endearing qualities which make affected kids so loveable. The words are phrased in the gentle language of childhood and expressed by a happy little cartoon elephant.

The two booklets are entitled:

- "What's a Diagnosis?: Identifying a Disability" *and*
- "Free to Just Be ME: Understanding My Strengths and Weaknesses"

Cost: \$3.00 U.S. per set

## **Prevention/Public Awareness Poster**

This poster, featuring individuals from the photo book, has a very dramatic impact and is becoming a popular educational tool.

Available in two sizes:

- 8 1/2" x 11" Cost: \$3.00 U.S.
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