



The FEN Pen

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If I had one wish.....

Patricia Cameron
Coordinator

If I had one wish it would be that every parent/caregiver had the ability to look after his/her child like a mother bear protects her cubs. In the wild, the mother bear's knowledge and understanding of the world around her, along with her intuition and primitive instincts, is sufficient to protect her cubs from danger, most of the time. In the human world, protection of the young is much more complicated, and many parents find themselves powerless when it comes to protecting their child with a disability.

This is not to say that caregivers do not have the right instincts or intuition to protect their young. The wild is much more predictable and orderly than the human world. The human world is made up of a complicated maze of interstate highways to access medical, social, mental health, educational, therapeutic and recreational services. Parents of children with FASD find themselves in the middle of this maze where they find many closed doors and uninformed professionals who have nothing to offer. Navigating the maze of service systems is more like a mother bear helping her cub across the Atlantic Ocean than across a stream in the woods!

You can imagine their despair and helplessness.

Advocacy is the prescribed course that parents and professionals must navigate to access the services on this interstate highway. The Oxford American College Dictionary defines advocate as a "person who pleads on someone else's behalf."

The act of pleading is a very stressful state for a caregiver and is a far cry from protecting.

Webster's New World Thesaurus offers these synonyms for the word protection; certainty, safeguard, assurance, stability and strength.

How do we reconcile the roles of pleading and protecting? A protector, just like the mother bear, is knowledgeable about the world in which he or she lives and can use this knowledge to anticipate and act accordingly. Educating parents and caregivers about the systems they must encounter to access services will empower them to take actions that protect the safety and well-being of their child with FASD.

Education is the first system parents find themselves navigating through. Many parents do not have a good understanding of the education system forcing them to play an ambiguous role as their child's protector in this arena. In an ideal world, professionals would partner with the parents/caregiver and together they would come to a consensus of how best to pursue interventions that would address the needs of the child. But I see situations where the professionals disregard parents/caregivers suggestions and focus primarily on standardized assessments to determine whether or not special services will be offered. I see parents who are confused and intimidated by the language of standardized test scores, statistics and percentages and whose intuitions about their child are not taken seriously.

I do not like the idea of parents in the role of advocates. Advocacy is the act of begging for something from a more powerful entity. I can see advocating on someone's behalf in front of a judge in a court of law.

Teachers, principals, and school psychologists should not be judges that parents must come before to receive a verdict. This model prevents a collaborative working relationship among parents and professionals and puts parents in a subservient role.

I would rather use the term *parent collaborator* to depict the preferred relationship between school and home, where everyone is working together, listening and learning from each other with an open minded attitude about potential opportunities and partnerships.

One of FEN's missions is to provide resources that parents can access to become informed about the systems that they will encounter as their child grows. Besides a library of written materials, FEN also provides the FASTeN Teleconference monthly and the FASTeN listserv. Both the teleconference and the listserv provide a forum for parents to share information and gather support for the difficulties they encounter in the service systems. They often times find professionals who are willing to help but who do not have the tools to do so. In such cases, parents find they have to "educate" their child's teachers, counselors, and others on the characteristics of FASD and interventions that have shown to be effective.

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FASTeN Telephone Network



The Family Empowerment Network (FEN) sponsors a telephone support network for families affected by Fetal Alcohol Spectrum Disorders (FASD). On selected Thursday evenings, you may dial in from anywhere in the United States to share ideas, receive (and give) support, or just hear that you are not alone!

DATES FOR 2005:

April 21 st	May 19 th
July 21 st	August 18 th
October 20 th	November 17 th

TIME: 7-8 p.m. Central Time

You must pre-register to receive the Wisline number and access code.

To register for the FASTeN Teleconference:
call: 1-800-462-5254 or email: fen@fammed.wisc.edu

ADULT MALE FASD RESIDENTIAL FACILITY BENEFIT

August 21, 2005

Benefit for Know Him Ministry Adult Male FASD Residential Facility in the Chicago area.

1st prize: 2006 Harley Davidson or \$14,000 cash
2nd prize: \$250.00 cash
3rd prize: \$100.00 cash

Contact: wteichen@comcast.net

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Bureau of Mental Health and
Substance Abuse Services*

Fetal Alcohol Spectrum Disorders *Training of Trainers*

June 7-10, 2005

The Friedrich Center
University of Wisconsin- Madison

This training is offered at no charge to Wisconsin service professionals to serve as local FASD resource persons; advocating for families and individuals who experience the effects of prenatal alcohol exposure.

Space is limited. Call now!

For more information contact:
Family Empowerment Network at
1-800-462-5254

Sponsored by:
Wisconsin Treatment Outreach
Project & the UW Department of
Family Medicine

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"If I had one wish...."

FEN's resources have been helpful in equipping parents with the tools they need to effectively collaborate with the professionals that serve their children.

FEN is doing everything it can to make my wish come true. Parents are welcome to call or email anytime. Together we can become "protectors" instead of "advocates," so that the ocean of systems we must navigate through will feel more like a mother bear helping her cub across a stream in the woods.

"Navigating the maze of service systems is more like a mother bear helping her cubs across the Atlantic Ocean instead of across a stream in the woods."

Check out these books written by a mother and her daughter with FASD:

Our FAScinating Journey: Keys to Brain Potential Along the Path of Prenatal Brain Injury

By: Jodee Kulp
Cost: \$24.95

The Best I Can Be: Living with FASD

By: Liz & Jodee Kulp
Cost: \$12.95

To order either book:

Web: www.betterendings.org
Contact: (763) 531-9548

Sibling Issues and Concerns Relating to FASD

Jenny Dunne Palmer, BA
Student Intern

Having a child with Fetal Alcohol Spectrum Disorders (FASD) affects the entire family. While there may be resources and services available to help parents and children with FASD, siblings are often left out. This is unfortunate because siblings commonly have the same concerns and questions as their parents. It is essential that their concerns be addressed because they are too important to be disregarded.

There are some common concerns that many siblings of children with developmental disabilities typically face. The Siblings Project (Strohm, 2001) lists several:

- A need for clear, appropriate information about FASD
- Fear of developing or having the condition that resulted in FASD
- Pressure to overachieve to make up for the limitations of the sibling with FASD
- Pressure to be a “good” child and protect the family from any more distress
- Feelings of guilt about not having FASD
- Feelings of resentment towards the sibling with FASD
- Feelings of shame about the negative feelings they may experience
- Feelings of loss and isolation
- Embarrassment about their sibling’s appearance or behavior
- Concerns about the increase in responsibilities and care giving demands
- Concerns about their future and their sibling’s future

Parents can help offset the limited resources available for siblings by addressing their concerns in various ways. The following are some suggestions from the Arc’s sibling support project:

1. Provide accurate, developmentally appropriate information about FASD. This information may change as siblings ask more questions and matures. It is important to remember that parents are their children’s role models. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes.
 2. Allow for open, nonjudgmental communication between parents and siblings. This can be a few minutes in the morning, at bedtime, or while driving in the car. Parents should plan one-on-one time with them, so they know that it is their time to talk about anything, and that their parent is there for them.
 3. Encourage the development of coping skills to address the feelings of grief, isolation, resentment, guilt, and embarrassment. Parents can encourage independence with all of their children and it will benefit everyone in the family. Also, it may help relieve some negative feelings.
- “Celebrate all family members’ achievements and milestones in life.”
4. Find opportunities for siblings to meet with other peers who have a sibling with FASD or another disability. They will find out they are not alone and that it is okay to have both positive and negative feelings. It also provides them with a safe place to share their concerns.
 5. Ask siblings if they would like to go to meetings or appointments. Let siblings become a member of the team. Furthermore, siblings often have questions that can be answered by service providers. Siblings may have great opinions and ideas to share with service providers.
 6. Expect typical behaviors from siblings. These include teasing, name-

be hard to witness, it is a beneficial part of normal social development. It is important to allow these conflicts because siblings with or without a disability need to have a life where they sometimes misbehave, get angry, and fight with their brother or sister.

7. Give siblings their own personal space and allow for safety concerns to be addressed, especially if the sibling with FASD has challenging behaviors.
8. Celebrate all family members’ achievements and milestones in life. One sibling’s needs should not overshadow another’s achievement or reaching of a milestone. Families who seek resources, are flexible, and are creative, can help assure that the accomplishments of everyone are celebrated.

It is important to remember that siblings often have concerns similar to their parents, but fewer resources are available to them. Parents play an important role in developing the sibling’s feelings and attitudes towards their brother or sister with FASD. By listening to their concerns, including them, celebrating them, and letting them act their age, parents can develop a solid, trusting relationship with their children.

References:

The Sibling Support Project. What siblings would like parents and service providers to know. <http://www.thearc.org/siblingsupport/>

Strohm, K. (2001). Programs and practice: Sibling project. *Youth Studies Australia, 20*, 48-52.



FASD & The Criminal Justice System

Julita Jankowska,
Research Intern

The functioning of individuals with Fetal Alcohol Spectrum Disorders (FASD) can impose great and demanding challenges in systems of care. When their needs are met, they function quite well. However, when their needs are not met, they can have inappropriate and unacceptable social behaviors that can lead to trouble with the law. Some individuals with FASD may end up in the corrections system. Prevention of secondary disabilities can be one strategy but sometimes despite all preventable actions, some individuals may get involved in the criminal justice system.

Some common behavioral characteristics of FASD are particularly problematic, such as impulsivity, inability to learn from previous mistakes, inability to make an association between cause and effect, having poor relationships, and/or being easily influenced. In addition, individuals with FASD are often unable to completely understand abstract thought. This can result in difficulties understanding social rules and expectations. Further, adults with FASD often give the appearance that they are very capable but in reality they may lack the ability to follow through on tasks.

Some individuals with FASD tend to have a high need for interactions, but lack the social and interpersonal skills needed to establish safe, mutually satisfying long-term relationships. They may have difficulty distinguishing between strangers and friends. Emotional immaturity coupled with a strong desire for inclusion, poor judgment, impulsiveness, and low frustration tolerance increases the risk of crime and criminal gang involvement. Finally, they are especially vulnerable to be taken advantage of by others, and of becoming victims of crime or witnesses to a criminal act.

The estimated prevalence of the diagnosed FASD cases in the United States corrections system indicate numbers similar to prevalence rates in community settings, about 9.1 individuals out of 1000 individuals (Burd, Selfridge, Klug, & Bakko, 2004). According to this study far less than 1% of expected cases of FASD have been identified in the United States correctional system. The findings suggest that the US corrections system has many undiagnosed cases and the real rates of FASD remain unknown.

Caregivers and providers involved in lives of adults affected by prenatal alcohol exposure fear that the criminal justice system has not met needs to screen, identify, and treat offenders with FASD. Burd et al. (2004) emphasizes that the identification of these conditions in the corrections systems is essential. The study stresses that FASD represents a barrier to learning and may affect individual's ability to participate in rehabilitation programs offered in correctional settings. Furthermore, it impairs generalization of skills acquired during rehabilitation that takes place in the corrections system.

Burd et al. (2004) concludes that the United States corrections system has a need to develop basic awareness programs focused on recognizing the basic characteristics of FASD in the prison population. The study also promotes the development of more suitable management strategies for inmates with prenatal exposure to alcohol.

Increased awareness and education around the issue of prenatal alcohol exposure and its life-long consequences are key elements in successful rehabilitation of one's ability to plan or resist negative impulses. We can only hope as knowledge of FASD grows, and medical and behavioral interventions continue to improve that individuals with FASD receive more access to support and needed services in United States corrections system.

This article is not intended to provide specific advice but rather to outline key areas of concern. For assistance about specific legal issues family or other advocates should contact an attorney.

It is commonly known that it is the family that informs the law enforcement or corrections system about the incarcerated person's FASD condition. What can families do?

1. Provide all background information to the court (LaDue & Dunne, 1996). This information may include the following: place of birth/circumstances of birth/pregnancy, type of home the incarcerated person was raised, medical records, school records, employment records, participation in therapy or other special services.
2. Notify the medical provider, the jail medical staff or jail administrator about the diagnosis of the individual that is arrested; it is very important that medical care be continued during incarceration.
3. Contact the jail administrator, sheriff or the Public Defender to ask for assistance in getting a mental health evaluation if the incarcerated individual is showing symptoms of mental health problems.

Websites:

The Arc of the United States:
www.thearc.org
National Alliance for the Mentally Ill:
www.nami.org
National Organization for Victim Assistance: www.trynova.org
American Bar Association: www.abanet.org/crimjust
Office of Victims of Crime: www.ojp.usdoj.gov/ovc

Resources:

Burd, L., Selfridge, R. H., Klug, M. G., & Bakko, S. A. (2004). Fetal alcohol syndrome in the united states corrections system. *Addiction Biology*, 9, 169-176.
LaDue, R. A., & Dunne, T. (1996). Fetal alcohol syndrome: Implications for sentencing in the criminal justice system. *The FEN Pen*, 5(1), 2-4.
Streissguth, A. & Kanter, J. (1997). *The challenge of fetal alcohol syndrome: Overcoming secondary disabilities*. Washington: University of Washington.

Myths and Realities Surrounding FASD and Women's Alcohol Treatment

Diane Malbin, MSW

The following is an excerpt from a skills-building curriculum under development for women's alcohol treatment providers. The focus of the curriculum is to provide additional tools for counselors to address the issues surrounding Fetal Alcohol Spectrum Disorders in clients.

Why do we not include discussions about FASD in treatment? With an already full program, would other topics need to be eliminated to accommodate discussions about FASD? Since most program agendas are already full, this is an important question. It goes to the question about whether the value of including this information outweighs the challenges.

Implicitly, the question also indicates there may be reasons to not do so.

The following beliefs and myths commonly surround FASD, and when they are unexamined for their validity, pose as barriers:

Myth 1

The damage is already done, so talking with women/families about FASD only creates trauma and doesn't help any way.

REALITY

Recognizing the effects of alcohol is a beginning, not an end. Avoiding this topic reinforces shame and perpetuates trauma. Parents often already know that there's something different with their child – standard parenting techniques and behavioral interventions are usually ineffective. The crucial information about FASD prevents struggles that occur when there is not recognition of FASD. Parents are often already grieving, but have no way to resolve the grief since there is no understanding of the source. Identifying FASD provides a way for a grieving process and resolution to occur. Information on FASD is essential for supporting healing and effective advocacy.

Myth 2

Talking about FASD with women in treatment will cause relapse due to guilt and shame.

REALITY

Mothers of children with any handicapping condition feel responsible. Where alcohol is the cause, women often feel shame and guilt because of the stigma associated with drinking during pregnancy. These feelings are magnified by confusion over the addictive process, when alcoholism is seen as a moral issue rather than a biophysiological process. Treatment providers with their knowledge of how the brain is involved in addictions, how this is a disease process, are in a crucial role for helping women understand addiction-based behaviors, and to shift from blaming themselves. No other discipline possesses this knowledge, understanding and acceptance of women in recovery. Without this support, feelings of shame and guilt prevent grieving, and prevent the healing that is provided by completing the grieving process. Sensitively providing information is a powerful support for women in recovery.

More often, women in recovery are blamed for their children's behaviors. When children have undiagnosed FASD, this often results in multiple diagnoses, therapies, and behavioral deterioration. Parents are accused of inappropriate parenting by professionals. Exhaustion, depression, alienation, and despair are common, and women despair that even in recovery, their children are still COA; their parenting abilities seem fatally flawed and relapse is not uncommon.

Identification provides a different explanation for children's behaviors; women are able to come to terms with the fact that drinking during pregnancy caused FASD, and when this is addressed, women are often empowered to become stronger in recovery and powerful advocates for their children.

Myth 3

Identifying FASD in children and talking with children about FASD will harm the relationship with their parents and compromise healing in the family.

REALITY

FASD is not the result of an uncaring act. No one intentionally harms their child; no one causes FASD on purpose. There is no blame. FASD is the by-product of addictions or lack of knowledge. In some cases, if parents themselves have FASD, the association between drinking and pregnancy may not occur.

In more cases than not, relief is the first emotion following information about FASD. Things make sense. Parents and their children are able to process FASD, grieve and heal together, and move beyond trauma.

Myth 4

The diagnosis doesn't matter, you don't do anything different.

REALITY

No myth could be more wrong. Identification of FASD is pivotal since it means identification of an underlying primary physical disability. Identification of this handicapping condition is as crucial as for those with other physical disabilities -- blindness, hearing loss, paralysis, and others. Identification of brain dysfunction underlying behavioral symptoms redefines the meaning of behaviors, redefines the nature of the problem, and redefines the focus of interventions.

Like the adage in recovery: Recovery's simple. All you have to do is stop drinking. And change everything in your life. The same is true for FASD. All you have to do is to identify FASD. And change everything in your thinking and actions. People with FASD have a physical disability. We get to change.

Myth 5

Alcohol isn't the problem; other drugs, like methamphetamines, are more harmful.

REALITY

The effects of alcohol on fetal development are more damaging than all other drugs studied so far, including cocaine, methamphetamines, heroin, and other drugs. Usually a combination of drugs is involved, i.e. alcohol and tobacco, cocaine and alcohol, etc. Longitudinal studies have not been conducted on the effects of many substances on pregnancy outcomes, for example huffing gasoline, other solvents, and prescription medications.

Myth 6

Only chronic late stage alcoholics give birth to children with FASD.

REALITY

Social drinkers have given birth to children with full FAS, and not all alcoholics have. Research has found no safe lower threshold for alcohol exposure, or, there is no amount of alcohol below which there are zero effects. Typically the greater the alcohol consumption, the greater the effects. However, dose, peak blood alcohol level and other variables cause wide variability of effects. Timing is also crucial: The window of exposure to cause the facial features required for the medical diagnosis of full FAS is between days 18-21 of gestation. Drinking prior to or after those days may cause changes in the brain structure and subsequent function, but the facial features will not be present.

Myth 7

Drinking beer while breast feeding helps milk let down.

REALITY

Research by Julie Menella indicates that alcohol passes into breast milk, and infants' brains are growing exponentially in early infancy, and may be affected by alcohol.

Myth 8

FASD is an issue only in minority populations.

REALITY

While it is true that drinking amounts and patterns vary, it is also true that wherever people drink during pregnancy there is FASD. It is still often seen as a population specific problem more common to populations— Native American, African-American, under educated and poor families. This myth is a particularly effective form of denial, essentially relegating FASD to an "other" status.

Studies have found that the higher the academic degree of white, well-educated women, the greater their alcohol consumption. It may be that there is still a prejudicial differential rate of identification: the Native child may be diagnosed with FASD, the white child with the same prenatal history for alcohol may be more likely to be diagnosed with ADD/ADHD.

Myth 9

It's easy to identify a child or adult with FAS or FASD.

REALITY

The facial features of full FAS are often subtle. If there is no alcohol exposure between days 18-21 of pregnancy, those facial features will not be present. Most with FASD have few or no observable physical features; theirs is an invisible physical disability.

Myth 10

People with full FAS are at greater risk than those with FASD.

REALITY

Streissguth found that the diagnosis of full FAS is a "protective" factor. Those with FASD are rarely diagnosed with a physical disability, and are instead punished for symptoms of their underlying neurocognitive disorder.

Myth 11

All people with FAS are retarded.

REALITY

Of the 473 people in the secondary disabilities study, only 27% with full FAS had IQs ≤ 70 ; 9% of those with FAE had IQs ≤ 70 (Streissguth, 1996). The average IQ for FAS was 79; the average IQ for FAE was 90. IQ is the least reliable measure of level of functioning since some with IQs in the "normal" range are unable to perform consistently at levels indicated by their IQ.

Myth 12

Other professions are responsible for diagnosing and providing information; Addictions professionals don't need to do this.

REALITY

FASD is nearly 100% under diagnosed. Most professionals have little training either about alcoholism/addictions in general, or about FASD in particular. Addictions professionals are in a crucial position to provide useful information, and are in the appropriate position to take the lead among professionals for recognizing, supporting, and contributing to eventual prevention of FASD.

Myth 13

A diagnosis is required in order to begin to provide services for those with possible FASD.

REALITY

Just as it would be inappropriate to withhold services from others with physical disabilities, it is equally damaging to withhold services from those with FASD. Asking "what if" and approaching people "as if" will not harm nor limit; in fact, the approach for working with people with FASD is appropriate for all people. This approach starts with the idea of brain function, which is relevant for everyone. Also, to wait until diagnoses are in place may require an additional generation, a delay that translates into perpetuation of trauma and compromised prevention efforts. This is not diagnostic, it is about exercising an alternate approach.

...*UPCOMING EVENTS*...

<p>Circle of Life Conference 2005 Wisconsin's annual conference for families of children with disabilities and professionals who support them. Date: April 28 & 29, 2005 Location: Middleton, WI Web: www.wfv.org/circle</p>	<p>Finding Better Ways: Addressing the Mental Health Needs of Children, Youth and Families Date: May 2-4, 2005 Location: New Orleans, LA Contact: Naomi at (617) 769-4003 Email: Ngoldman@cwla.org</p>	<p>Building Brighter Futures for People with Developmental & Learning Disabilities: 26th International Conference Date: May 9-13, 2005 Location: New York, NY Contact: Amy at (212) 273-6255</p>
<p>FASD Forward: Innovative Approaches to FASD in our Families and Communities Date: May 13 & 14, 2005 Location: Lexington Convention Center Lexington, KY Contact: Jackie at (859) 936-9419 Kellie at (859) 254-2412</p>	<p>Research Society on Alcoholism Conference Date: June 25-30, 2005 Location: Santa Barbara, CA Contact: (512) 545-0022 Email: debbyrsa@bga.com Web: www.RSoA.org</p>	<p>International Foster Care Organizations (IFCO) The conference will focus on foster care, adoption, permanence, reunification, and other related topics. Date: August 7-13, 2005 Location: Madison, WI Web: www.fostering.us/ifco2005</p>
<p>"Being our Best with FAS": A Conference Camp by for Individuals with FAS/ARND and Their Support Person Date: August 19-22, 2005 Location: Camp Henry Newaygo, Michigan Contact: JoCindee at (231) 883-1088</p>	<p>Fetal Alcohol Spectrum Disorders: Into Action Date: September 22-24 Location: Portland, OR Contact: (503) 621-1271 Email: dmalbin@fasnets.org</p>	<p>Conference on Late Adolescents and Adults with FASD Date: May 4-6, 2006 Location: Vancouver, BC, Canada Contact: (604) 822-0054 Email: ipconf@interchange.ubc.ca Web: www.interprofessional.ubc.ca</p>

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