

# The FEN Pen

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## Hidden Disabilities in AODA Treatment: Recommendations for the Treatment Community

Georgiana Wilton, PhD

Prenatal alcohol exposure occurs at an alarming rate and is a leading preventable cause of physical and cognitive birth defects in the United States (Committee on Substance Abuse and Committee on Children with Disability, 2000). Even moderate alcohol use by pregnant women has been associated with adverse effects (Kesmodel et al., 2002). Unfortunately, Wisconsin leads the nation in reported frequent alcohol consumption among women of childbearing age at 25.26%, (BRFSS 2001) placing this state at a high risk for alcohol-exposed pregnancies, and fetal alcohol spectrum disorders (FASD).

FASD represents the range of effects that can result from prenatal alcohol exposure. Fetal alcohol syndrome (FAS) is the most recognizable and publicized of these effects. Characteristics include a) small size and weight; b) distinct facial features; and c) central nervous system effects such as cognitive challenges (Stratton, Howe, and Battaglia, 1996). If an individual has some, but not all of these features, they may be diagnosed with another condition under the fetal alcohol spectrum of disorders including *partial FAS*, *alcohol-related neurodevelopmental*

*disorder (ARND)* or *alcohol-related birth defects (ARBD)*.

Unfortunately, many women go undetected and unserved due to a lack of accurate, easily accessible information. Difficulties in recognizing and diagnosing FASD have prevailed since the conditions were first identified, (May, 2001). These difficulties are due in part to the subtleties of the physical features, their tendencies to change over time—especially in adulthood, cultural and ethnic differences, and the varying degrees of severity (Aase, 1994).

An especially alarming risk to individuals with FASD is the associated rate of alcohol and other drug problems. Research has shown that adults with FASD were three times as likely to experience alcohol and other drug abuse as the general population (Streissguth, 1996). Additional risks include mental health problems, dependent living, and problems with employment. These secondary characteristics can be equally

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800-462-5254

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**Website**  
[pregnancyandalcohol.org](http://pregnancyandalcohol.org)

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## Healthy Choices: Personal Steps to a Healthier Lifestyle

### Women Ages 18 – 44

- Do you have questions about your health habits?
- Do you use even a small amount of alcohol?
- Would you like additional information?
- Would you like strategies to help you assess your health habits?

To request your own self-help guide, please call the:

**Healthy Choices Line**  
800.752.3157

#### Online

[www.pregnancyandalcohol.org](http://www.pregnancyandalcohol.org)

*This line is staffed from 4:00 – 10:00 p.m. Monday – Thursday.*



**Healthy Choices**  
*Personal Steps to a Healthier Lifestyle:  
A Self-Help Guide*

University of Wisconsin School of Medicine and Public Health  
Department of Family Medicine and  
UW Population Health Institute

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devastating, and are all known risks to substance abuse recovery.

Given these risks and the difficulty in diagnosing FASD in adults, many women currently in AODA treatment or recovery may be affected but remain unidentified. This lack of identification jeopardizes a woman's treatment and recovery outcome. Therefore, the following modifications are recommended for women-specific treatment providers as they work with adult women at risk of FASD:

- ◇ Training on FASD for all treatment staff and ancillary service providers

**Wisconsin leads the nation in reported frequent alcohol consumption among women of childbearing age at 25.26%.  
-BRFSS 2001**

- ◇ Screening for FASD and other cognitive limitations as women enter AODA treatment programs
- ◇ Flexibility in treatment requirements (e.g., homework assignments, group vs. individual counseling, etc.)
- ◇ Development of an *Individualized Life Plan*

These recommendations for individuals with disabilities in treatment highlight the need to eliminate barriers (including physical and attitudinal); assess for hidden disabilities; and maintain a strengths-based approach to recovery. Not only are treatment modifications and accommodations required, aftercare and recovery support accommodations must be considered to fully support an individual with a disability in their sobriety.



## You and Your Child's Education: Building blocks for a healthy, working relationship between school and home

By: Patti Cameron, M.S.

With the blink of an eye, the school year is upon us, leaving us with fond memories of a wonderful Wisconsin summer. Summer is a time to put interventions and strategies on the back burner – a respite of sorts - however, the relaxed daily routines and the outdoor activities of summer can still be very therapeutic for parents and children alike. I hope your summer was therapeutic for you as well as your children.

Now that summer recreation activities have come to an end, your efforts may be directed toward ensuring that your child has a positive experience in the upcoming school year. In most cases, your children will be finding their places in unfamiliar classrooms with new teachers and classmates. The beginning of the school year can be just as unsettling for you as it is for your children.

We would all agree that in a perfect world, every child is accepted and valued for their unique gifts that they bring to their learning community. I believe this is not too much to ask for in today's public (or private) schools whether your child is in special education or not.

Many parents are uncertain as to how to go about ensuring that their child has a positive experience in school. They don't want to appear "overprotective" but feel that they would like to be kept informed of their child's progress in

more frequent intervals than conferences or report card time. With this in mind, below are some tips to establishing a good rapport with your child's teacher and school.

One: *Give it some time.*

Give the teacher and students a few weeks to adjust to their new classroom. If your child has a history of acting up during this adjustment period, I would encourage you to write a brief note to the teacher before school starts describing the behaviors your child typically exhibits at the beginning of the school year and how other teacher's have successfully handled it. This note can be written in a cordial tone offering a suggestion of what has worked in the past as opposed to a request for the teacher to use a specific strategy.

Two: *Communication isn't a given.*

Don't assume that your child's previous year's teacher and the present teacher have communicated. Often times, teachers do have the opportunity to meet before the school year begins to discuss specific student's learning needs but this isn't always the case. If the teacher's teaching style and the student's learning needs were not compatible, the information given to the next year's teacher could be skewed. This would be another good rea-

son to communicate with your child's teacher at the beginning of the school year.

Three: *Teachers teach differently.*

Although most schools do not allow you to request a specific teacher, it doesn't hurt to write a note to the school principal before the end of the school year expressing your joy/dismay with their current teacher's teaching style and your hope or expectations for the following year. If you have an understanding of your child's learning style and you believe the school doesn't, I would include in the note to the principal, the teaching style/classroom that is best suited for your child's optimal learning.

Four: *Be a support to the teacher.*

Don't forget that teachers have many demands placed on them during the day. It has been said that in any given classroom, the range of the students' abilities can be represented by as many as 5 grade levels. Volunteering in or out of the classroom is one way to help out.

Five: *Be brief.*

Written communication with the school should be brief. Set up a meeting to discuss the details of your concerns. Many schools are agreeable to using daily communication logs between home and school but the information shared by teacher and parent in these logs should only be a sentence or two.

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## A Visit to our State Capitol

By: Paul Joles, President  
ORCHIDS FASD WI



On Monday September 8, 2008, in honor of FASD (Fetal Alcohol Spectrum Disorders) Awareness Day, FEN and ORCHIDS families met at the state capitol in Madison to talk with their state representatives about FASD. As our legislators listened intently, we told our stories of hope and the challenges we face as parents raising children and adults with an FASD. Some of us have older children still living in the home because that is the safest place for them at this point in time.

This event marked the first time since 2000 that an organized group of parents from Wisconsin met with state legislators to educate them on the issues surrounding FASD. We want to thank the Wisconsin Children and Families (WCCF) for helping us define our role as “advocates” and for the helpful materials and handouts.

It is only through advocacy that parents and community members associated with FASD can truly make a difference in the lives of individuals with an FASD. Policy makers and legislators need to hear from families like you! Please consider joining us next time as we strengthen our collective voice to participate in this valuable empowering experience!

Save  
the  
Date

## National Fetal Alcohol Spectrum Disorders Conference (FASD)

Friday–Saturday, May 1–2, 2009 • Preconference: Thursday, April 30, 2009

American Family Insurance Headquarters, Madison, Wisconsin

Sponsored by:

University of Wisconsin–Madison, Department of Professional Development & Applied Studies

Conference speakers will include **Edward Riley, PhD**, San Diego State University, and **Dan Dubovsky**, FASD Center for Excellence. The two-day conference will address the impact of prenatal alcohol and other drug exposure across the lifespan, and include nationally recognized keynote speakers, skills-building sessions, program sharing, poster session, and exhibits. Day-long preconference sessions will be held April 30.

More information will be available soon. Thanks for your interest in FASD and related issues.

Visit: [www.dcs.wisc.edu/pda/fasd/conference.htm](http://www.dcs.wisc.edu/pda/fasd/conference.htm) and receive conference updates by subscribing to our conference listserv. To join, send a blank e-mail to: [join-fasd@lists.wisc.edu](mailto:join-fasd@lists.wisc.edu)

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## **FASTeN: Fetal Alcohol Syndrome Telephone Network & Listserv**

FASTeN is a telephone & Listserv support network for families affected by Fetal Alcohol Spectrum Disorders (FASD). On selected Thursday evenings, you can participate in a family teleconference to share ideas, receive (and give) support, or listen to people who will share valuable resources for families. The Listserv is open to a registered group of families to allow them to pursue topics from the teleconferences or other issues related to FASD.

### **Dates: 2008-2009**

<b>September 25<sup>th</sup> (adults)</b>	<b>February 19<sup>th</sup> (school-age)</b>
<b>November 6<sup>th</sup> (school-age)</b>	<b>April 23<sup>rd</sup> (adults)</b>
<b>January 15<sup>th</sup> (adults)</b>	<b>May 14<sup>th</sup> (school-age)</b>

### **Times:**

**Adults: 7:00—8:00 pm Central Time**  
**School-Age: 2:00—3:00 pm Central Time**

**If you would like to register, please call or email FEN for the dial up instructions.**

**1-800-462-5254 608-262-6590**  
**fen@fammed.wisc.edu**

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If you need to discuss an issue at length, you should indicate this in your daily entry log and ask to set up a time to meet.

Six: *Seek other parents for support.*

Ask the teacher if she knows of another parent in the school with a child that is having similar difficulties (academically or socially). Having someone to meet for coffee or getting the kids together after school or on weekends is a way to alleviate stress and at the same time develop friendships with others with whom you have common interests. Volunteering for school activities is another way to network with other parents. No one should feel alone with their challenges in life – parent or child.

Seven: *Disagreements are a natural part of people working together for a common goal.*

When school and home disagree, set up a time to meet with school staff. Always begin the discussion by identifying things that the school/teacher have done to encourage learning and positive social experiences for your child. Put together a brief list of your concerns to handout at the meeting. Contact state advocacy agencies for additional suggestions and strategies. DPI has parent advocates on hand to discuss ways to negotiate the challenges you are experiencing with your child's school.



Helpful websites:

<http://dpi.wi.gov/sped/wsems.html>

<http://www.dpi.wi.gov/sped/hmparents.html>

<http://www.specialednet.com/Resources.htm>

## Wisconsin FACETS Free Telephone Workshops

To register call: 1-877-374-0511  
(please register 1 week in advance. Workshop materials are mailed to you)

WI FACETS offers information, referrals, individual assistance, advocacy supports, workshops and support groups for families of children with disabilities at no charge to Wisconsin residents.

### October

7th 12-1 pm

22nd 12-1 pm

27th 7-8 pm

30th 12-1 pm

Communication Strategies

Dispute Resolution Options

IEPs Part I

IEPs Part I (Spanish)

### November

5th 12-1 pm

13th 7-8 pm

17th 7-8 pm

20th 7-8 pm

Bully & Harassment

Dispute Resolution Options

IEPs Part II

IEPs Part II (Spanish)

### December

4th 7-8 pm

12th 12-1 pm

16th 12-1

Transition

Dispute Resolution Options (Spanish)

Section 504

## Practical strategies for living with someone who has a disability

By: Lyric Dold, LPC

Although it is fairly commonplace in today's families to be living with a person with a disability, it is rare to find much information on how to not only cope with such a situation but, moreover, make the best of it. The situation can be highly stressful for caregivers and family members as they focus on their own responsibilities as well as those of the person with a disability often "filling in" for them, being sensitive to their perspective, and bearing the brunt of their behaviors and coping mechanisms.

The stress can be expressed in both emotional as well as physical burdens often jeopardizing the health of the caregivers. And, the health of the cohabitor/caregiver is precisely what needs to be maintained to sustain the health of the entire.

The following are summaries of ways the cohabitor/caregiver can attend to reducing stress and increasing harmony for themselves, the individual with a disability, and the family.

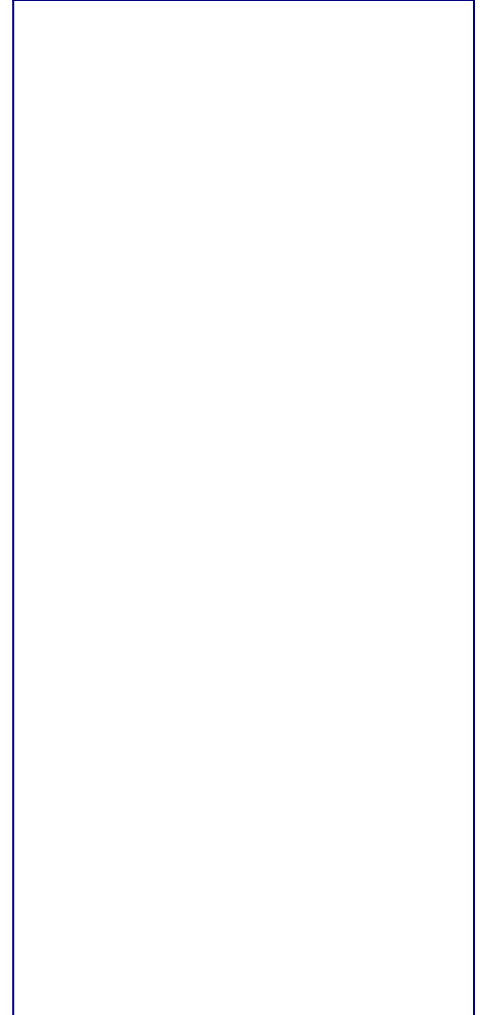
Lyric Dold is a Licensed Professional Counselor in Madison, Wisconsin who works with persons with disabilities and their families.

- ◇ Be clear on what you can reasonably expect
- ◇ Set limits and stick to them
- ◇ Leave well enough alone--avoid the urge for perfection
- ◇ In conversation, reflect (by restating) their feelings too
- ◇ Ask for clarification, don't assume you know
- ◇ Be specific—but not demanding—with any requests you make

### *And don't forget about yourself:*

- ◇ Find time for yourself--even in the moment--to avoid regretful actions
- ◇ Stay focused--avoid getting drawn 'off-track'
- ◇ Try to remain calm and composed
- ◇ When possible, schedule R and R into your life. This is essential!

These are a few "helpful hints" for the cohabitor/caregiver of a person with a disability. It serves as a quick reminder of ways to reduce the emotional and physical stress involved. It is important to periodically evaluate your own coping quotient and determine if professional help is needed. Working with a clinician with experience in the specific disability might be very helpful.



## *...UPCOMING EVENTS...*

<p>September 17, 2008 Solving the Social Equation in ASD Lakeland College Kellett School of Adult Education Liberty Hall Banquet &amp; Conf Center Kimberly, WI 54136 www.lakeland.edu/autism 920-565-1477 Cost: \$149.00 wierichsma@lakeland.edu</p>	<p>September 25-26, 2008 12th Annual Crisis Intervention Conference Chula Vista Resort &amp; Conference Cntr Wisconsin Dells, WI 53956 Scholarships available www.uwsp.edu/conted/conference 800-898-9472 Cost: \$200</p>	<p>October 8, 2008 Statewide Annual Respite Conference Holiday Inn Express Conference Center 3100 Wellington Place Janesville, WI 53545 Scholarships available 608-558-8204 Cost: \$25.00- family members \$40.00- professionals</p>
<p>October 22, 2008 4th Annual MHSAS Conference: Recovery: Promoting Dreams Through Evidence Based Practice Kalahari Conference Center Wisconsin Dells, WI UW Stevens Point Continuing Educ: 800-898-9472 Cost: \$160 (before 10/10)</p>	<p>October 22-23, 2008 MindQuest 2008: The Science and Art of Interpersonal Neurobiology La Crosse Civic Center LaCrosse, WI 54601 414-325-3016 nmalkemes13@lsswis.org</p>	<p>November 9-11, 2008 Children Come First Conference: Finding What Works Kalahari Conference Center Wisconsin Dells, WI 53956 WI Family Ties 800-422-7145 info@wifamilyties.org</p>
<p>November 12-13, 2008 WCCF: Unlocking the Mysteries: Adolescent Brain Development WI DOC Central Office 3099 E Washington Ave Madison, WI Open to the general public (\$75.00) 608-284-0580 (Mary Revoy)</p>	<p>November 20, 2008 T. Berry Brazelton &amp; Dr. Joshua Sparrow Luncheon Presentation: noon-1:30 Monona Terrace Madison, WI 53703 608-284-0580 Cost: \$40 mmcgrorty@wccf.org</p>	<p>December 3, 6, 2008 Reactive Attachment Disorders &amp; Challenging Behaviors 9:30—11:30 am Marcia Cogg's Human Services Cntr 1220 W. Vliet St. Room 104 Milwaukee, WI 414-289-6558 Cost: \$10</p>

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*Visit us on the web!*  
[www.pregnancyandalcohol.org](http://www.pregnancyandalcohol.org)