

Fetal Alcohol Spectrum Disorder Awareness Day 2010

Helping Your Child Succeed

Featuring Dr. Kathryn Page, Ph.D.



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Biographical Sketch

Dr. Kathryn Page's work currently focuses on policy changes regarding substance exposed children; research and services for the homeless in Sonoma County; and a host of training and consultation activities that take her across the nation and into Mexico. Over the last 15 years she has come to concentrate on Fetal Alcohol Spectrum Disorders (FASD) and its overarching but invisible relation to societal difficulties.

Kathy did her predoctoral internship in the Stanford Psychiatry Department's AOD treatment center, and received her Ph.D. from the Center for Psychological Studies in Albany, CA. in 2001.

She has worked as a school psychologist in public schools; served as 504 (disability) coordinator in Santa Clara County's juvenile justice system, written curricula for and served at-risk teens and adults with AD/HD and other neurodevelopmental issues; obtained significant grant funding; participated in the formation of Juvenile Drug Treatment Court (Santa Clara County); run a small nonprofit organization and served as Clinical Director of two fetal alcohol-related agencies. Dr. Page founded FASD Diagnostic Clinics in the county hospitals in Santa Clara and Lassen Counties.

Kathy co-founded the State Task Force on FASD and serves on the Sonoma County Task Force for the Homeless, the national Interagency Coordinating Council on FASD, and the Citizens' Advisory Council for the UC Davis Center for Excellence on Developmental Disabilities.

She has published articles for the National Council of Juvenile and Family Court Judges and the Judicial Council of California as well as a variety of more local publications, and wrote a chapter in a book on adult neuropsychology of FASD. She helped make three videos and organized a training series available to all Santa Clara County employees on FASD.

Together with the Assistant Warden and State Supervising Parole Agent, Dr. Page created and began a mentoring project with in a prison in Susanville, California. Both the AW and the PA had become convinced that a great many of their charges were fetal alcohol-affected, and with better understanding of this condition, both prison and parole could become more positive for inmates and community as a whole.

It is her mission to raise professional, policy and individual awareness of FASD to a level that will trigger the resources this condition warrants.

FETAL ALCOHOL SPECTRUM DISORDERS (FASD)

Fact Sheet

At least **one out of twenty-five** of us has some degree of brain damage from exposure to alcohol in the womb ⁽¹⁾; such exposure is the single **largest known cause of mental retardation** ⁽²⁾, although there is a **wide range of severity** ⁽³⁾. At least **75%** of the victims will have **none of the recognizable facial features** of Fetal Alcohol Syndrome ⁽⁴⁾. With or without facial features, the damage generally falls into the following categories: ⁽⁵⁾

- Symptoms of Attention Deficit/Hyperactivity Disorder (disorganization, impulsivity, distractibility and hyperactivity—or occasionally underactivity)
- Neuromotor impairment (balance, coordination, oversensitivity or undersensitivity to stimuli, poor perception of sounds, visual input or social cues)
- Executive functioning (the ability to judge, plan, empathize, estimate, delay gratification)
- Speech problems (sometimes generally delayed, often a much better talker than listener)

If not properly identified and treated, FASD results in the following “**secondary disabilities**”, at the rates indicated: ⁽⁶⁾

- Mental Illness: 90%
- Expulsion or Dropout from School: 60%
- Trouble with the Law: 60%
- Inappropriate Sexual Behavior: 50%
- Dependent Living (inability to live on one’s own) 80%

Drinking during pregnancy is common and any amount can be dangerous:

- One out of ten babies born in California in 1992 had alcohol and/or illegal drugs in their system at the time of birth—this doesn’t count the babies exposed during the rest of the pregnancy. ⁽⁷⁾
- One drink can cause impaired cell adhesion: migrating brain cells slip off their destination. ⁽⁸⁾
- 1-2 drinks a day doubles the chances of low birth weight. ⁽⁹⁾
- The number of children with discernible mental handicaps doubles with one drink a day. ⁽¹⁰⁾

This damage is 100% preventable.

- Women who drink should avoid getting pregnant; pregnant women who drink must be effectively supported to stop drinking.
- Children with brain damage from prenatal exposure to alcohol must be identified and treated in order to avoid wasted lives and future generations of alcohol-exposed babies.

“Fetal alcohol exposure is the single largest factor setting up physical and neurological conditions that predispose American babies to aggressive and violent behavior”. ⁽¹¹⁾

Citations

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FETAL ALCOHOL-TYPE SYMPTOMS As compared to age peers: **1 = no problem, 10 = extremely severe**

		1	2	3	4	5	6	7	8	9	10
AD/HD-type symptoms	Hyperactive										
	Distractible										
	Impulsive										
	Disorganized (either in behavior or "stuff")										
Immaturity	Overall immaturity—esp. social										
Neuro-motor	Poor balance										
	Clumsy										
	Poor or labored handwriting										
	Over/under sensitive										
	Easily over stimulated---meltdowns										
Executive functioning	Poor cause-and-effect										
	Consequences don't work										
	Poor memory										
	Low empathy										
	Poor judgment										
	Little sense of past or future										
Speech	Gets "stuck" on perceptions or actions										
	Chatterbox (excessive)										
	Delayed speech										
	Articulation problems										
	Better talker than listener										
"Moral" issues	Repetitious										
	Lying										
	Stealing										
Emotions	Cheating										
	Easily triggered										
	Poor recognition of feelings — in self										
	— in others										
	Flattened range of emotions										

Kathryn W. Page, Ph.D. 2004; Kathryn.page@sbcglobal.net www.fatcat.vpweb.com (This is NOT a complete list of FASD-type symptoms, nor is it diagnostic--it is only meant to assist with sketching out a profile of the more common difficulties found with fetal alcohol or other brain damage/dysfunction.)

FASD: Some Overarching Patterns and Principles of Support

A recent study has estimated that anywhere from two to five people out of a hundred are dealing with brain damage from maternal alcohol consumption. Almost none of these people are seen as disabled, although their passages through life are rocky and often strewn with failure.

There are some peculiar features to FASD which set it apart from other disabling conditions and which require special handling in order to help a child or adult live up to the true potential that gets tangled up in the underbrush of neurobehavioral impairment. But with a quarter-century of heartfelt help for families affected by FASD, we are seeing that this potential can indeed be disentangled, allowing the person's real gifts to come through...we're just not seeing it very often, as few have access to that help. San Luis Obispo, with Martha's Place and the community fabric that supports it, is changing that.

The following has been distilled from contact with hundreds of affected families, research, clinical observation and personal experience. It is meant to illuminate some of the features of FASD so we can see them coming, keep ourselves balanced as we navigate the choppy waters of this condition.

Patterns

~~ Appearance is better than reality, leading to unrealistic expectations that cause most of the upset experienced by people with FASD as well as those who love them and work with them:

- Talk is better than thinking is better than action
- Can say all the right things without really knowing or meaning what they're saying
- Can relate information, say what's needed in a situation, can even have insight about changes needed or problematic behavior
- But actions, behavior, in-the-moment decisions are independent of this apparent awareness.
- Normal physical appearance; only a few with facial abnormalities or very small stature
- Mimic other people's manner, clothing, words
- IQ is better than academic testing is better than achievement

~~ Everything shifts around from day to day, sometimes hour to hour:

- Capacity to think, stay calm, perform tasks, understand others
- Physical well-being, comfort level
- Sense of self—I am a person who_____
- Perceptions of outside world—safe, friendly, hostile, frightening
- Priorities—what is most important to do now? Little things seem big, big things seem small. And then they shift.

~~Easily overwhelmed and vulnerable to stress, causing precipitous drops in functioning

~~Physical vulnerability is a reality for most. The person might not be conscious of it, but may frequently act out the effects:

- Fatigue
- Weakness
- Pain in muscles, joints, head, stomach
- Sensitivity
- Discomfort
- Accident-proneness

~~Relation to truth

- Trouble distinguishing truth from fiction—what we say is the truth is often more what we fear or hope is the case, rather than what it actually is.
- Compulsive truth-telling with no attention to self-preservation, respect for others' boundaries, consequences

~~Inability to plan

- Can't put self in future past a few hours
- Can't put self in others' shoes
- Can't estimate time, amount, sequence, equipment

~~Gullibility and suspicion

- New best friends
- Hard to recognize trustworthy people
- Give away every thing they've got

~~OVERALL IMMATURITY

- Perceptions are colored by the emotion of the moment.
- Emotions are out of proportion to "reality". Tantrums are not uncommon.
- Can only think ahead a few hours.
- Can work with close supervision, not independently.
- Only one answer or solution.
- Always right, no matter the evidence.
- Benefit from "grandparent" types.
- May cherish stuffed animals into adulthood
- Scared and vulnerable.

Supporting a person with FASD

Goals:

1. Positive and realistic sense of self
2. Self regulation
3. Ability to get along with the rest of the world

Principles:

1. We cannot change fetal alcohol affected people. We have to change their world. This always includes arranging for “external brain”.
2. Each person with FASD is different.
3. Consistency, routine and help are the essential elements.
4. Creating ongoing supportive structure, attitude and environment is (infinitely) more helpful than reacting to problems as they arise.
5. But when we have to intervene: ABC’s:
 - a. Stop action
 - b. See what’s wrong
 - c. How can I help?
6. Our own emotional reactions are
 - a. Wired in
 - b. Usually not helpful
 - c. Crucially important
7. Caring for someone with FASD is hard.
 - a. Other people do not understand.
 - b. Infinite patience is required.
 - c. Knowledgeable professionals are hard to find; those who don’t understand FASD can do harm.
 - d. It takes resources to provide assistance, structure and environment.

Resources

Online: fas-link@listserv.rivernet.net Faslink is an online community of support with hundreds of families who chime in with questions, experiences, wisdom, and complaints that no one else would understand; a safe place for families as well as people who suffer from FASD.

Book: Recognizing and Managing Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects: A Guidebook by Brenda McCreight, published by the Child Welfare League of America in 1997. McCreight is an adoptive mom of many, and a licensed counselor in Canada who has helped thousands of families find success and joy with their affected children. This book is warm, sometimes humorous, eminently practical and sympathetic to both caregiver and child. It takes the reader through the developmental stages of a child with FASD, describing the range of experiences and needs of child and family and offering solutions along the path to successful adulthood.

University of Washington Fetal Alcohol and Drug Unit, home of Drs. Ann Streissguth Sterling Clarren, Susan Astley. A well-organized and rich website with many links to other resources, articles, research—always up to the minute. Also under this umbrella is Kay Kelly, who runs the legal issues section of FADU. <http://depts.washington.edu/fadu/>.

Parenting the Child with FASD For Foster Parents, Grandparents, Bio Parents and other Caregivers

(This is a companion piece to “Overarching Patterns and Principles of Support”, in your packet)

Parenting any child is not easy, as the path from total dependence to total independence always involves challenges, dangers and disappointments. But neurologically typical children are practically guaranteed to reach independence, with plenty of triumphs and delights along the way. Children affected by prenatal exposure to alcohol have behavioral characteristics that make parenting extra challenging, and--unless we are realistic and prepared—extra dangerous, disappointing, and often exhausting. If we ARE prepared, however, these children will also triumph, in deeply moving and rewarding ways.

Children with FASD are often dealing with several layers. First, the brain damage. Second, the emotional trauma that comes when the brain-based behaviors are misunderstood as “bad”, and punished rather than supportively managed. Third, as a result, developmental needs don’t get met, so the individual may stay forever ashamed, scared, depressed and lonely. And fourth, any abuse or neglect they may have faced have further scarred their ability to grow into happy, healthy (and taxpaying!) adults.

Brain Damage

Since alcohol causes the developing brain to lose cells, there will be mistakes in the structure and chemistry of that brain. If these mistakes aren’t enough to kill the fetus outright, they can result in a wide range of problems with thinking, reacting, coordination, and getting along with others. Depending on the timing and quantity of the alcohol, genetic vulnerabilities, consumption of other drugs including tobacco, and the other stresses in the mother’s life, these problems can be extreme, practically nonexistent, or anywhere in between.

Although every child is different, the characteristics listed below are some of the common ones that beset our affected children (and adults):

- Disabilities: academic, AD/HD, speech/language, information processing (including abstract concepts, societal rules)
- Poor impulse control
- Inability to connect behavior to consequence—poor judgment
- Poor short-term memory
- Hypersensitivity to incoming stimuli
- Emotional reactivity over small things, may not grasp the big things

Emotional Trauma

We get mad at anyone who chronically disregards the rules, lies, steals from us, destroys property, and seems not to care. We are especially put out when this person then gets mad at us, accuses us of mistreating THEM. When they are our children, foster or otherwise, we generally punish them for this behavior, and hope for the best, though if it really is chronic, our hopes are dim and our despair is deep.

And it is exactly this chronic, unshape-able quality that should tip us off to brain damage...but it hardly ever does, unless we recognize the signs.

So the child with the brain damage that makes it impossible to meet our expectations without help may try over and over to “be good”, or my have given up. In any case, he or she has accrued a sense of self that is slathered with failure.

Meeting the Child’s Developmental Needs (with thanks to Brenda McCreight)

The prenatally affected child has the same developmental needs as any other child, but will require skilled support, environmental adjustments, advocacy, resources and parental well-being to meet those needs. The following is a brief summary of the developmental tasks at each stage, the challenges raised by fetal alcohol damage, and suggested solutions. Ages are approximate.

Infancy and Toddlerhood 0-2 years

Task: Basic trust in self and other. I can count on myself to control my body, to learn new skills, to soothe myself; I can count on Mom to bring comfort and nourishment.

FASD challenges: Poor coordination, sensory issues causing chronic discomfort, poor memory affecting retention of Mom as good, and of learned skills.

Solutions: Help child (e.g. assist in bringing spoon to mouth if child has trouble; build blocks with child rather than leave alone to struggle; provide words rather than wait til child finds them) find ways to soothe (replicate womb-like conditions of dark, quiet, tightly-contained); maintain routine of schedule, environment, feeding and sleeping; gently touch as much as child allows.

Early Childhood 2-4 years

Task: Identity, strong sense of self. I am a separate person. My body and ideas are my own, and valuable. “No” is a sensible thing for the moment.

FASD challenges: Always getting into trouble because of poor memory, attention problems, difficulty learning from experience. Poor coordination, not learning to do things “on schedule”.

Solutions: Maintain routines and consistency. Consequences must be short, immediate and meaningful (logical? not a meaningful construct). Time outs will work over time, but with lots and lots of repetition. “Time in” often better—parent must supervise in any case. Sport activities should not be organized or team, but individual. Parents can use

supports like day care, but fully inform personnel. Try to find a support group. Keep fostering attachment with touch and attunement. Set up small successes.

Middle Childhood 5-7 years

Task: Initiation. I can start new things.

FASD challenges: Same as before, plus learning disabilities and speech problems become apparent; social connections are problematic. Disparity becoming more evident; child may be noticing difference between self and others.

Solutions: In addition to routine, consistency and help, consequences must become more creative. Added tasks often more effective than items removed (child forgets they were ever there, let alone the reason for their removal). Include child in problem-solving, behavior management. Share diagnosis; help child separate true self (feelings, preferences, humor, wishes etc.) from brain-damage-related behaviors.

Late Childhood 8-12 years

Task: Sense of industry, capability. I am competent and my efforts pay off.

FASD challenges: All the earlier ones, plus social, academic and sport venues and mates move the child out into wider, less protected circles. Still little sense of consequences, poor impulse control, difficulty following rules...but biological imperative toward independence. Many more opportunities for failure and self-loathing. May be drawn to “bad” friends as the only ones who will accept him or her; sexuality and substances appear on the horizon.

Solutions: Find activities where child succeeds, has fun, and achieves mastery. More individual sports like tennis, swimming, biking; art. Groups like Scouts where leaders are more likely to consider the child’s special needs. Help child to assume some responsibility for managing FASD behaviors, and recognizing the negative consequences to them: walk back through incidents, see what went wrong. Put alternatives in place (other ways to work out anger—physical, art). Keep looking for successes to praise and encourage. Sexuality: teach about the various aspects out in the world, enlisting help from Scouts or YMCA if you’re uncomfortable. Hygiene and clothing may need direct support. Keep close supervision (resist pressure!). Keep communication as positive as possible.

Adolescence 13-17

Task: Find your community. I belong to these people (different from my family); I am like them.

FASD challenges: Lacking social skills, teens can either become isolated or associated with kids who will exploit them and lead them into dangerous behavior. They may begin to feel real grief for the life they can’t have. Sexuality, substance abuse a real danger.

Solutions: Summer camp; support group esp. important for parents now. Provide choices of activities, but don't give child (the much-wanted) total freedom to choose. Be careful about babysitting and driving. Keep involving teen in managing behavior—if you've been together a while, this may be second nature by now. Provide long-lasting birth control. Positive self image is the best protective factor: stay as positive as possible, keep setting up successes. Musical activity like singing or drumming may help regulated the nervous system. If there is substance abuse, access treatment immediately (and inform providers about FASD). If teen won't go, change of placement may be necessary to protect siblings.

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