

Fetal Alcohol Spectrum Disorder Awareness Day 2010

Behavioral Health Approach

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/>.

Clients with Fetal Alcohol Spectrum Disorders in Mental Health Treatment: *Recognizing the signs and tailoring your approach*

You have seen many clients on the fetal alcohol spectrum, but probably none you've known about. These clients will look, sound and seem quite normal at first. They may come with a variety of mental health diagnoses, most commonly AD/HD and Bipolar Disorder, but they will run the entire gamut. (FASD predisposes a person to mental illness along with the developmental issues.)

These clients will likely be among your most frustrating. They get appointment time and date mixed up over and over, blur boundaries, and may take things very personally. In spite of good intentions to the contrary (and no doubt great counseling by you) they may live from crisis to crisis, apparently unnecessarily, and seem to be unmotivated, self-defeating, or weak in character. Their emotions, thinking, perceptions and actions are much younger than their chronological age, even with average or high IQ.

These clients will be different from each other in many ways, but they are likely to have this in common: despite much talk, the work isn't getting traction out in the world. Jobs are still lost, relationships broken, money misspent. The client may be able to say all the right things about making progress, articulate the steps and generate insight, but the behaviors will remain the same.

If your work is client-centered, your sessions might be spent circling in dizzying tangents. If it is more structured with behavior change as the object, you will tread the same ground over and over. This client, even if he or she is of average or higher intelligence, will show poor judgment across most situations. Moods will plummet or soar at the drop of a hat, and be difficult to rebalance.

Sending your frustration into overdrive, a client with FASD may have trouble distinguishing truth from fiction. Your client may tell you what he or she wants to be true, or fears is true, or thinks you want to hear, or hopes will help avoid trouble. This is frequently in spite of clear evidence to the contrary, visible to all concerned. When you try to reverse this habit you have no luck, and the lying continues, often bafflingly transparent and sometimes with no point at all.

In mental health, we depend on more or less accurate self-report. Feelings, thoughts, fears and hopes are the stuff of treatment. Getting to an accurate sense of the inner reality of the person with brain damage from prenatal alcohol exposure sometimes requires a kind of x-ray vision, infinite patience and careful scaffolding of the person's narrative.

We also depend on a therapeutic relationship. Trust is gained and becomes the foundation for the rest of the work. But if we don't recognize our client's behaviors as coming from neurological impairments, our own reactions may be contaminated with anger, rejection, mistrust, even contempt.

This article, together with other materials distributed in this packet, is meant to help fit clinicians with the neurobehavioral lens that lets us see fetal alcohol damage for what it is, and to provide some key principles of FASD-informed treatment. While this condition is more treatable the

earlier it is identified, the rare counselor with some understanding of FASD can be an infinite blessing to affected families and individuals of any age.

Remember: between 2 and 5% of us are dealing with fetal alcohol damage, and as difficulty “keeping it together” is the hallmark of this condition, FASD is not distributed evenly throughout society. Agencies of public assistance or incarceration have high concentrations of fetal alcohol-affected clients, and almost no one is getting recognized. San Luis Obispo is an exception, and you are among the agents of this change.

Red Flags for Fetal Alcohol Spectrum Disorders

- Poor self reflection OR good insight but with little progress
- Tangential talk, sometimes lots of it
- Your input doesn’t register—although it may seem like it at the time
- Misdiagnosed as AD/HD, ODD, Bipolar
- Little awareness of own actual needs
- Little awareness of feelings
- Can sound—and be—insightful but targeted behavior doesn’t change
- Truth often confused with fiction, sometimes subtly
- Difficulty with time, dates and money
- Boundaries blurred (intimacy assumed, “new best friend”)
- Client pledges (*wants!*) to put changes in place, rarely follows through

If a client seems to match this description, your next move is to check other symptoms of fetal alcohol-type brain damage. Probably unnecessary caution to mental health practitioners: we can’t diagnose without a) a little further training, and b) standardized tests that check a variety of domains. Neuropsych testing would be ideal at this point, but in most counties that is unavailable. So it’s up to you to continue the investigation.

Going Deeper

- History of school difficulties
- Always losing track of belongings, projects, plans
- Sensitive to environmental stimuli (lights, sounds, crowds)
- Often feels like something is being forgotten
- Trouble finishing things
- Many jobs, relationships
- Main: did mom drink? Any reason to think she didn’t? Were you in foster care?

At this point you have a working hypothesis. Share it with your client, to the degree possible and with the utmost respect. He or she will almost certainly be visibly, tremendously, relieved. “I think a lot of your troubles with school, relationships and work might be a matter of wiring, rather than you just not trying hard enough. We can put some supports in place to help with that.”...this comes as a tremendous relief to most. Bringing up mom’s drinking is optional, but this too has been helpful. It gives it a name, points to a whole raft of useful resources, and allows the client to be a partner in problem-solving.

Assuming you don't have access to a neuropsychological evaluation, you can do some informal screening to sort out strengths and weaknesses. Clients often enjoy this process. This may be the first time your client has ever had someone name these difficulties in anything but a punitive, shaming, resentful spirit. You may wind up laughing together.

Informal Screening Suggestions—you will think of your own as well.

- Visual memory: “Without looking, tell me--what’s the color of the walls in the waiting room”?
- Auditory memory: “I’m going to say a couple of sentences. See if you can repeat them.”
- Kinesthetic memory: “Where did you park your car?” Do you often forget what you went into another room for?”
- Narrative cohesion: “Tell me about your day yesterday” (Listen for logical beginning, middle and end, not jumbled or tangential story.)
- Sensory issues: “Do the tags on your shirts bug you? Do you get overwhelmed in Costco? (shut down, feel agitated)
- Abstract thinking: play 20 questions. Listen for quick, concrete answers.

Adaptations to treatment

Aims

- Positive and consistent sense of self
- Self regulation
- Ability to get along with the rest of the world

Process

- You structure the session—client-centered is wheel-spinning.
- Stay sympathetic with the true self. Together you are allies against a wayward brain.
- Don't take client's word at face value.
- Keep bringing client back to priority.
- Always connect therapy to actual behavior rather than verbal report or insight.
- Acknowledge difficulty w/truth. Walk back through a doubtful report. Get prior permission to double-check important stories.
- Arrange supports for memory regarding appointment times or medications.
- Remember: this client is younger than he or she appears or sounds. Often much younger. You're the grownup here.
- **KEEP STEPPING BACK FROM YOUR AVERSIVE, IRRITATED REACTIONS.**

Content/Focus

- Focus stays on the realities—not so much theory, but specifics—of client's life.
- Help clients come to understand the effects of their particular pattern of brain dysfunction.
- Basic areas of focus:
 - Relationship
 - Work
 - Self care (including addictive behavior)

- Teach client how to recognize feelings in self and other.
- Teach assertiveness (as distinct from passivity or aggression) and self-advocacy
- Keep looping back to client's positive identity—not asking, but reinforcing.
- Build in support for client's CNS: reinforce simple principles of nutrition, exercise, fun and relaxation. Check for sleep disorder. Insist on it. This will make a huge difference.
- Think “external brain”: where client has gaps in neural functioning, arrange for a source of help. Memory, sensory issues, planning, follow-through can all be supported, and life gets much simpler.

I conclude with my enormous gratitude to you for taking the time to learn about this common, devastating condition. You are now among the very few clinicians who will be able to help and individuals dealing with FASD. Please consider passing this information on to your colleagues.

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.

O'Connor, M.J., and Paley, B. (2009) *Psychiatric conditions associated with prenatal alcohol exposure*. *Developmental Disabilities Research Reviews* 15: 225 – 234.

Paley, B. and O'Connor, M.J.. (2009) *Intervention for individuals with fetal alcohol spectrum disorders: treatment approaches and case management*. *Developmental Disabilities Research Reviews* 15: 258-267.

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/>.