Fetal Alcohol Spectrum Disorder Awareness Day 2010

Social Workers 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 UCDavis 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										
	Gets "stuck" on perceptions or actions										
Speech	Chatterbox (excessive)										
	Delayed speech										
	Articulation problems										
	Better talker than listener										
	Repetitious										
"Moral" issues	Lying										
	Stealing										
	Cheating										
Emotions	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.)

Working with Adults with Fetal Alcohol Spectrum Disorders:

Some of Our Most Difficult Clients in Social Work

- Recognizing the patterns
- Understanding the implications for your work
- Tailoring your approach

Background

Some clients leave us feeling exhausted, irritated, disappointed and at times hopeless. They are the ones we're really pulling for because they seem like good and well-meaning people. But the broken promises mount, the fibs get found out, the rules get ignored and the blowups do not help either. Despite all the right words about getting the kids back, moms will show up late to visitation, bring the wrong food or toys, and generally treat their children in ways that continue to worry us.

These clients may well be dealing with brain damage from their own mothers' drinking, and no one has ever recognized it. You will almost certainly be the first to consider the possibility. (A study released this year on 1.400 kids in foster care showed that over a third of the mothers of these kids were themselves fetal alcohol affected….but none of them had been previously diagnosed.)

Fetal Alcohol Spectrum Disorder (FASD) is a wide array of behavioral, intellectual, communicative, regulatory and medical difficulties stemming from brain damage caused by exposure to alcohol during gestation. These difficulties can co-exist with a normal or even high IQ. According to longstanding estimates, FASD is experienced by at least one out of a hundred people in this country, but recent research suggests that between 2 and 5 percent is more realistic. Across the globe, almost none of these individuals' difficulties are accurately diagnosed.

This condition is largely invisible, often masquerading as simple disobedience or immaturity in children and poor character in adults. Except for the small percentage with characteristic facial features, people with FASD are usually punished and shamed for failures that are—without a little help—beyond their control. Or allowed to flounder with no structure, limits, or challenge.

In Childhood

Children with the dysfunctions associated with FASD do sometimes come to clinical attention (adults more often come to correctional attention), and usually emerge with a diagnosis of AD/HD, often with Oppositional Defiant Disorder or Reactive Attachment Disorder as well.

But without recognizing the fabric of brain damage that underlies the behavior of a child with FASD, interventions will misfire and tensions continue to rise. "Secondary disabilities" begin to set in, according to a large longitudinal study, in the following proportions:

Mental illness: 94% (mostly depression)
Trouble with the law: 60%
School dropout: 70%
Dependent living: 80% (over the age of 20)
Substance abuse 60%

FASD is the only disability that results in such dramatic dysfunction, partly because it is unrecognized, prompting tragically unrealistic expectations. Partly also, of course, because parents with drinking problems tend not to parent very well—but children adopted in infancy also experience this level of difficulty unless their disability has been accurately identified and treated. Identification is so hard to come by at this point that most families raising children with FASD have no idea that that's what they're dealing with.

Children with FASD go on to become adults with FASD—it doesn't go away, and in fact the impairments generally become more obvious and more significant as more is expected from the chronologically maturing adult. As Ann Streissguth says, "The girls get knocked up and the boys get locked up"—unless we identify this disability and provide interventions.

Adults

Adults with fetal alcohol damage—even in the absence of substance use—can seem to function like drunks. (This is no surprise neurologically, since the parts of the brain that are most affected prenatally by alcohol are the same as the ones that are affected temporarily by a few glasses of wine, or permanently by 20 years of hard drinking.) A spectrum disorder like alcoholism itself, FASD covers a wide range of severity: from mental retardation to a mostly-manageable level of problems of memory, planning, sensory integration and so on.

At whatever level of severity, however, judgment is almost always affected by prenatal alcohol damage, often to an astonishing degree in the context of a person's IQ or other measure/estimate of "intelligence".

Planning ahead, taking consequences into account, managing time and money, learning from mistakes, delaying gratification, keeping track of obligations or possessions, managing emotions—all these are problematic for the alcoholic. ***Equally and devastatingly so for someone who has not touched a drop since gestation.***

Nevertheless, there is a veneer of normalcy over this welter of difficulties, often maintained with a great deal of energy. Unless you're looking for it, it may never occur to you that your most frustrating clients may be dealing with this deeply affecting condition. They do look and sound normal—especially with the peculiar-to-FASD quality of speech that is more coherent than their actual thinking or behavior.

What is so frustrating about adults with FASD? According to many who understand this condition and work with chronically marginalized populations, the most frustrating aspect is the discrepancy between everyone's expectations—most centrally the client's own—and reality. The veneer of normalcy is thin but perversely effective, allowing the whole world, client included, to believe that the run of failures is either deliberate (it's all my fault) or rotten luck (it's always someone else's fault). Neither stance is helpful in getting a life back on track.

This guide is a beginning attempt to help you identify—VERRRRY tentatively of course—adults in your client load who may be dealing with the odd and pervasive effects of prenatal alcohol damage. And then having a tentative hypothesis, you might find the next section useful for tailoring your approach informed by the principles of effective intervention with FASD.

Patterns of functioning among adults with FASD

Note: There is no cookie-cutter profile of FASD. Any given person with this condition will have a wide variety of strengths, weaknesses and quirks. However, if you see a more than half (this is just ballpark) of these patterns in a person whose mother drank during pregnancy and other causes are ruled out, chances are good that you're looking at FASD.

Discrepancies between expectations and reality:

- Speech: Can be quite fluent, with wide vocabulary and apparent common sense, wisdom or insight. Often parroted from others' conversation; little depth upon investigation. Expressive language better than receptive (better talker than listener). (Can also be very tangential.)
- Appearance: Can be carefully put together—first impression often very good. May fall apart on subsequent occasions, or may be obsessively tended.
- Intention: Many good intentions, sincerely believed but rarely completed.
- Promises: Promises agreeably and sincerely made and broken, with explanations that may not make sense, or "I don't know".
- Walk vs. Talk: Can describe and endorse rules, plans or principles, then immediately (and innocently) do the opposite

Management of life details

- Time: Time is elastic, difficult to estimate or sense. Often late or early, surprised when "the time comes".
- Money: Subject to the moment—with money in her pocket, the person feels like a rich person; when it is gone, she is mystified about where it all went (more than most of us).
- Relationships: Also subject to the moment—in good moods, relationship is valued, sometimes excessively depended on. In bad moods, the relationship is "trash". (So yes, this does look like Borderline Personality Disorder)

Logic/Executive Functioning

- Big picture: Can't see the forest for the trees, overwhelmed by—and stuck on—details.
- Black or white, no shades of gray: The most salient reality is that which carries the most emotion right now, and is absolute. (Example: If a person is afraid of being left and his partner doesn't call, he will believe with all his heart that the partner is faithless. When she returns and they make up, he may believe with equal fervence that she will be with him always. The next missed phone call will send him plummeting to the depths of abandonment again.)
- "Stinking thinking": Attributions stubbornly and mistakenly applied in spite of much evidence to the contrary. (Example: "I keep getting into trouble because I live in this town. If I move I won't get into any more trouble.").
- Priorities: Despite talk that reflects good planning, plans will be hijacked by whatever presents itself most immediately—person, substance, opportunity, mood of the moment

Emotions

- Easily triggered: Big reactions (usually negative) to small things, especially when there is a change from the predictable or expected.

- Hijacked cognitive circuitry: Already vulnerable logic goes out the window in the presence of emotion
- Acting out: Emotions are not readily identified or articulated—more likely instantly translated to action.

Memory
- Information: Memory for facts often much better than for actions or intentions.
- Spotty: Some things crystal clear, others distorted or missing
- Central: Memory problems are at the center of much of the person's difficulty

Neuromotor
- Fine motor coordination: Often poor--handwriting can be labored &/or immature, large motor often much better.
- Oversensitive: (Often without knowing it) to tags on shirts, fluorescent lights, ambient noises, smells, taste or temperature.
- Overstimulation: Easily overstimulated, can get agitated or shut down.
- Drivenness: Often there is a felt—and hard to deny--pressure to move and/or to talk.
- Clumsiness: The person drops things, bumps into people or things, spills food or drink. May leave a trail of clutter.

Immaturity
- In comprehension, reasoning, impulse control, emotional and other regulation.
- Sexuality—younger partners, easily victimized.

Frequent questions

How do you know this behavior isn't just a product of current drug use?
~~~Ask if it was always like this—trouble in school, forgetting things, etc.

How do you know if this behavior isn't simple manipulation? ("lies")
~~~Does the behavior "work", by and large?

Is there a quick way to confirm executive functioning issues? (besides observation)
~~~Play 20 Questions and see if the answers are concrete or wild guesses.

Can we really boil this down to a few tip-offs?
~~~The Doofus Factor. Little tolerance for discomfort. Sensory issues. Memory. WAY overpersonalization.

Can anything be done to treat this condition?
~~~Think of it like diabetes, only with mostly emotional/behavioral symptoms. Manage CNS—keep stress and confusion down, simplify life, find "external brain" wherever possible. Sleep, nutrition, exercise more important than with most people. Help person become aware of strengths and limitations. Meds may address some symptoms.

Tailoring Your Approach

Discrepancies between expectations and reality:

1. Make no assumptions! Don't take the person at face value. Double-check what you think you heard, and ask for details. Ask the person to repeat what he or she thinks you said—always maintaining a respectful and supportive stance..
2. Set yourselves up for success: Instead of taking the vast promises or plans for granted (and then getting disappointed when they don't come true) break tasks into very small chunks, walk through each one, celebrate accomplishing each step, and YOU keep a copy of important records.
3. When plans fall through, try to remember BRAIN DAMAGE. Getting upset is one of the most common, and least useful, reactions—second only to taking it personally. But don't let it go unmentioned either!
4. Stay away from general or abstract advice, even profoundly wise advice. You'll think you did a good thing and may not notice your client's eyes glazing over.
5. If intentions are chronically waylaid, look for what link in the chain of events is not working. It may be something very simple—go back to your checklist. Memory? Sensory issues? Logic? Poor receptive language? Too much stress?

Managing life details

1. Time--Walk around client's dwelling, put clocks and calendars in several places. (You can get a little stick-on clock for $2.)
2. Go over calendars together, talking through upcoming events, down to the smallest.
3. Call her before important events (like a court appearance).
4. Orienting to longer-term passage of time--Talk about the season—what does she like about spring (when it is spring) and so on.
5. Money—try to recruit someone reliable to handle client's money.
6. Get all possible bills on autopay, and set up overdraft account.
7. Relationships—make sure your half of the relationship between you stays calm. Remember mutual regulation—extra true with the skittish CNS of FASD.

Logic/Executive Functioning

1. Stay concrete. Don't get hooked into long, pointless (and inevitably circular) arguments. Clear and simple is best, with firm limits. "Nevertheless" comes in handy (as in: "I know it seems unfair to you that your probation was extended. Nevertheless, we can't go outside the city limits.")
2. And yet more concrete: liberal use of simple drawings, charts, graphs (really simple) can keep the verbal/auditory slippage to a minimum.
3. Reinforce—celebrate—moments of logic.

Emotions

1. Try to help client predict bumps in the road.
2. Teach calming techniques (simple slow breathing has been a favorite).
3. Name emotions, help client gain skill at recognizing feelings.

Memory

1. LISTS!!!!!!!
2. Do not set person up to lie. ("Where were you the night of…")

3. Help the person really acknowledge memory issues—with humor, support and respect for whatever internal and external turmoil these issues have caused.
4. Strategize “external brain”—post-its, friends, phone calls that can serve as memory supports.

Neuromotor

1. Look for—and name, sympathetically—issues with coordination, sensory integration, drivenness. (This may the first time these aspects have NOT been a source of shame, but rather understanding.)
2. Strategize sensory remedies (examples: carry heavy things to calm agitation; chew gum to organize energy; stay away from crowed places to avoid overwhelm).
3. Foster self-advocacy—gradually help person to recognize regulatory states and to practice remedies.

Immaturity

1. Main thing is to keep in mind that this is the behavioral manifestation of a physical disability.
2. Put behavior into context of a much younger person—try to assign a behavioral age (in your own mind). Try to find a balance between respect for the individual and the fact of much younger functioning. (Example: even tough adults with FASD seem to love stuffed animals.)
3. If appropriate for the relationship, address sexuality, including birth control, masturbation and victimization.

Resources:

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/.

The website for the SAMHSA Center for Excellence on FAS has a wide variety of good, basic information including posters and brochures available for downloading. Website: www.fascenter.samhsa.gov