Fetal Alcohol Spectrum Disorder Awareness Day 2010

Educational and Child Care Approaches

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.)

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 Managine Children with Fetal Alcohol Syndrome/Fetal Alchol 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/. .

Educating the Child with FASD

(A companion piece to FASD: Some Overarching Patterns and Principles of Support, also in your packet)

You have had many children with fetal alcohol damage in your classroom or child care facility; most of them did not come with a diagnosis and you may have had no idea which ones they were. This article is meant to give you: 1), a quick lens to recognize the signs of possible Fetal Alcohol Spectrum Disorders; 2), common neuropsychological functions involved; 3), a sense of what it's like to be an affected person; and 4), some principles and specific suggestions to help manage behaviors, maximize learning, and reduce the shame and upset that so badly interfere with both. There is an enormous amount of good work available online with detailed suggestions for managing all aspects of behavior, classroom environment, attention, cognition, speech…in short all the aspects that fetal alcohol can cause trouble with. A few of the best of these are listed at the end. This article will just cover the basics.

Children with FASD are undoubtedly among the most frustrating in your classroom, and some can be the most endearing at the same time. The following behaviors can wreak havoc with classroom management, and certainly make it hard for the child to learn. All together, these behaviors look like rudeness, disrespect, selfishness, lack of motivation, disobedience…sometimes they are given the official diagnostic stamp of Oppositional Defiant Disorder. They may have a diagnosis of Attention Deficit/Hyperactivity Disorder as well, as the symptoms of AD/HD are one of the core clusters of FASD.

Classroom Behavior

- Trouble respecting boundaries: interrupting, grabbing other children's materials, talking over others. Taking belongs of other children or teachers.
- Hyperactivity: difficulty sitting still, waiting in line, staying in seat or participating in physical activities.
- Trouble with rules: always breaking rules, in spite of repeated warnings or explanations.
- Difficulty playing either independently or with others. Meltdowns frequent.
- Disconnect between actions and consequences: consequences are rarely thought through, and disciplinary consequences have no impact.
- Lying and exaggerating, sometimes when it would be just as easy to tell the truth.
- Emotional reactivity: tantrums, rages.
- Immaturity: functioning at a level perhaps half one's age.

It is true that there are other causes for patterns of behavior like this: trauma and neglect alone can accomplish this wreckage. It is rare that a child is exposed to abuse without alcohol also being part of the picture, however, and together these two assaults on the brain just make it that much worse.

Neuropsychological Impact

The following are measurable, testable capacities directly related to aspects of brain functioning frequently impacted by prenatal alcohol. Each affected child is different, and the pattern of brain damage is different—it depends on the dosage, timing and frequency of mom's drinking; the genetic vulnerability of both the mom and the child to prenatal alcohol; other substances the fetus is exposed to; the condition of the mom overall—stress, illness, nutrition all play a role.

- Cognition – Reflected in IQ, comprises verbal comprehension, perceptual reasoning/organization, working memory and processing speed. Connections between all parts of the brain misfire, leaving one part functioning fine in some cases, or several parts, but "putting two and two together", "getting the big picture", "making connections" and acting on information stored in the brain are where it falls apart. IQ is usually higher than achievement scores in FASD.
- Attention – Constantly distracted by either external or internal stimuli, to the point that felt priorities keep shifting. Relative importance of these priorities is not determined by the demands of classroom tasks, but by the punch that's packed by the various other items entering the child's perception: the fly buzzing, the feeling of the tag on the back of the shirt, the lunch coming up. They can all FEEL more pressing than the task of the moment.
- Executive Functioning – Ability to combine pieces of information, enables reasoning, judgment and planning. Child may be unable to keep more than one piece at a time in mind, and it's usually affected by the emotion of the moment.
- Communication – While the mechanics of speaking are often ok, impacted areas include auditory processing and the ability to communicate actual thoughts and feelings. Asking this child an "essay" question may result in a blank stare or deflecting behavior.
- Memory – Working memory is often severely impacted., affecting children's ability to learn, and especially their ability to learn from mistakes. This is why typical rewards and consequences have so little effect. Memory may fluctuate from one day to the next.
- Sensory issues – Hypersensitivity to incoming stimuli like lights, sounds, textures, smells and the general hubbub of transitions at school. The child is probably unaware that these are setting off internal alarms, and may act out with aggression or meltdowns, or might shut down altogether.

From the Inside Out

If we think developmentally, we know that children go through stages where certain milestones are met and major life tasks are completed. Each stage lays the groundwork for the next, and if one is not adequately completed the next stages will not have the necessary foundations. The first stage is basic trust of oneself and other people, where we learn that we can get that thumb or bottle into our mouths (trust of oneself) and that someone will come and make us comfy when we cry (trust of others). FASD can interfere: our own coordination and memory impairments will make it harder to acquire

skills, and with our sensory issues and poor memory we are rarely entirely comforted—and when we are we don't remember it.

So doubt and mistrust carry the day here, and all further tasks—acquiring a sense of self worth, confidence in our ability to start and complete new things, later on our ability to seek out a healthy community of others—are hampered by this beginning.

The inner life of the child with FASD who has not had skilled and knowledgeable parenting to help meet those developmental needs will be fraught with shame, doubt, and fear. On top of that, add the cognitive confusion that comes from the current neural glitches, and an onslaught of sensory discomforts. This child will sooner or later feel like an alien—something is different, and wrong. It can be exhausting just to get through the day, especially knowing that at every turn someone will be mad at you.

It's hard to see this vulnerability in many children with FASD since on the surface there is so much acting out, loudness, impulsivity. But it's just this ex-ray vision a teacher or child care provider will need in order to put supports in place.

<u>Supports</u>

Teachers and child care providers can't undo years of poor parenting, and they can't fix the brain damage. But they can provide a calming environment and activities that help keep a child organized internally, they can communicate in ways that are clear, respectful and effective, and they can manage unruly behaviors.

Environment

- Keep visual clutter to a minimum; only display task being worked on.
- If possible, swap out fluorescent lights for incandescent.
- Store materials out of sight
- Create separation: create "office" with an open, upended manila folder, a "thinking", or "chill" space—comfortable and welcoming.
- Keep auditory clutter down—music, extraneous chatter.
- Allow "wiggle" seats—therapy balls, seating of various heights and sizes.
- Provide pens and pencils of various sizes and shapes if possible.
- Allow movement breaks; give child tasks that use large muscles.

Communication

- Straightforward and simple—stay away from clever use of language.
- Get child's attention with a touch or eye contact before addressing him or her.
- Visual aids to transitions (series of pictures for younger children, lists for older)
- Visual addition to oral instruction, written homework instructions
- The fewer words the better; short sentences. DON'T ARGUE.
- Leave plenty of processing time: "10-second child in a one-second world".

Managing behavior

- Try to notice when misbehavior or meltdown is just beginning. Hand child an alternative, preferably one that is useful and physical: "Take this to the cubby", or "Please carry this box to Mrs. Jones".
- Make classroom rules clear, brief and do-able.
- Make consequences short, immediate and meaningful. If this child has memory problems, long-term rewards or consequences will evaporate.
- Reward often.
- Structure, routine and repetition are essential.
- Find short tasks for child that he or she can accomplish.
- Keep expectations realistic.
- Some children may not be able to handle this classroom or child care facility and need to go somewhere else.

Yes, there will be accusations that you're giving this child special attention, or making exceptions for him or her, or even reinforcing negative behaviors. What we need to keep in mind is that a child with FASD can no more "learn to cope" on his or her own than a child with cerebral palsy can just learn to speak clearly.

And last but ever so definitely not least: your own wellbeing. Teaching children with fetal alcohol damage is tiring and frustrating, and will take all your creativity, flexibility and patience. Give yourself some credit (a lot of it), and lean on your support network, or build a stronger one. Refresh yourself at whatever well does the trick. Music and art will raise your dopamine level; contact with good friends and pleasurable physical activity will raise your oxytocin. Eat protein three times a day and do whatever it takes to get a good night's sleep.

Know you have the great thanks and admiration of all of us who know what it's like.

Resources

Do2Learn, funded by NICHD and NIAAA, Divisions of the National Institutes of Health
http://www.do2Learn.com/

This web site provides activities to promote independence in children and adults with special learning needs. Be sure to check out their FASD Toolbox for Teachers section.

NOFAS's Site for Educators
http://www.nofas.org/educator/

Resources for teaching students with FASD, resources for teaching teachers how to address FASD, and a section dealing with special education.

Student Guides and Technical Assistance Guides, from the National Information Center for Children and Youth with Disabilities (NICHCY)
http://www.nichcy.org/stuguid.asp

These publications are how-to guides which provide step-by-step instructions and practical information on selected topics. Of special interest are "A Student's Guide to the IEP," "Helping Students Develop their IEPs," and "A Student's Guide to Jobs."

Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope, Alberta Learning Resources Centre, 2004
http://www.learning.gov.ab.ca/k_12/specialneeds/fasd.asp

This guide offers teachers information and specific ideas to better meet the learning needs of students with FASD. The five areas of focus are: what is FASD, key concepts for planning effective education programs, organizing for instruction, creating a positive classroom climate, and responding to students' needs.

Tin Snips, a special education resource
http://www.tinsnips.org

It contains tools for teachers of individuals with autistic spectrum disorders, related developmental disabilities, and children with special needs. Most activities are also appropriate for Pre-K and Kindergarten.

http://www.education.gov.yk.ca/publications.html