

TODAY'S DECISION MAY BECOME A LEGACY

(Living with FAS/FAE – Fetal Alcohol Syndrome/Fetal Alcohol Effects)

By David Hambleton

Kids are wonderful! Some in some ways, others in other ways...

I'm writing to help us all understand one another. Nope, this is not a political issue. I'm sure that is a disappointment for some and blessed relief for many others. In ways, I hope I'm not alone among our delightful family in some understanding coming from my recent preoccupation/avocation of learning about some of our kids. In other ways, God forbid we need to learn any more than has been learned, for the learning is most certainly at the dear expense of people least deserving of paying the cost.

I'm writing because some (many) of my kids are paying horrific prices for their birth-parents' choices. These birth-parents, in their own turn, and with far less understanding within or without, often were/are still paying for their parents' decisions. I'm writing so some of the young among us may understand in real terms and with real faces that life is an endurance race and it is dreadfully important that we keep that perspective, because we never know when today's decision may become a legacy.

Mark and Rob were my "friends" in 7th Grade. Not that I was a fan of the arrangement. On the first day of school, the veteran teacher called me out of the class, gave me a front row seat, and sat Mark on my right and Rob on my left. They couldn't understand what was being taught. Both of them were impulsive to a fault. Neither could focus on anything for more than a few minutes at best. Their favorite pastime was physically attacking one-another, and when that wouldn't work, anyone else would do. They could be scary-quick-witted, though lacked the foresight to get anywhere beyond a spitball or sneaking behind me to slap the other on the back of the head – with a shot at me in the mix, which they thought was the funniest thing in the world. After months of this abuse, I asked the teacher one day why he'd set me there with my "wingmen". He told me point-blank that I was the largest kid in the classroom, and he needed help controlling them. Would I please go back to my seat? And, no, I could not strike back. Dangit! I learned a lot about what I would come to know as long-suffering that year. In retrospect, I was in training.

It is difficult for some kids to sit for more than a few minutes. It is common for children to rock themselves to sleep, and even to bounce their heads off headboards once in a while. Once in a while kids don't get social cues and need to be told point-blank to blow their noses, bathe, change clothes, or even eat. When kids have caused a problem for themselves and gotten hurt, they'll first find something or someone else to whom they'll shift blame. Kids lack cause-and-effect reasoning skills. Kids usually have trouble with associative and correlative concepts. It is normal for a child to need to be told a few times to avoid a hot stove.

These are all perfectly normal behaviors and should be expected of any child. If you haven't had any yet, you have this training to look forward to, and it is a parent's incredible reward to see your child's (or, for teachers, your charge's) light come on. It is the repetitions that start you wondering...

Meet Mark and Rob! Minutes for other kids are seconds for them – they can't sit still. They rock violently as though to shake or knock something loose that is jammed in their head – helmets are authorized, and may not last... Social cues must be blatant and explained again and again and again and again, and usually these kids stop taking offense to being told to clean themselves because they just don't get that they should – let alone why. Counting can be tough enough, but algebra is just out. Or trigonometry and calculus may be easy as pie, but spelling and sentence structure are permanent roadblocks to education. Dyslexia and other physiological cognitive challenges are common.

Caught red-handed knocking a picture off the wall does not mean the child did anything wrong. It was the picture's fault for being there. And why are you picking on the child again?!! The fit of anger can take out walls and last for a few minutes, hours, or weeks. (There IS associative reasoning there – it is just misdirected.)

You've seen this family in WalMart. They're the one with the child running eyes-closed from end-to-end of the aisles bouncing off displays and carts singing something about being free. Around the next corner the parent is holding a loose grip around the child's wrist; and the child is flailing away trying to break the hold while yelling, "You're hurting me! You're choking me and I can't breathe, you monster!!! You're not my mommy!!! Why are you taking me away!? Security! I'm being kidnapped!!!" Yes, that is the child on the porch yelling obscenities at the top of her lungs about how wrong and cruel the parents are. Parents of these kids are likely to be reported to the authorities and even jailed upon fantastic stories of abuse, purely fabricated by these children in fits of brilliant uninhibited impulsive rage. (Only selected parts of this paragraph are my actual family – so far... We haven't been to jail yet.)

Eight pencils in one hand take a full five minutes for a ten-year-old to count. But that figure has no relationship to that same bundle split evenly in front of the child, with a concurrent description of the process. "See, I'm taking four pencils in this hand and four in this hand. Now how many pencils do I have?"

"Um... (Three minutes of scowling)... Fourteen?"

Regular daily reinforcements with different quantities of pencils and a week later the same pencils in the same parent's hand starts out as "1, 2, 3, um... 4... seventeen?!!"

Even on the hundredth iteration, there is no reason in the world to anticipate the same outcome that has happened for 99 in a row. The blisters on the fingers are from the (same) stove.

The brain has been pickled. This is a crude but oh-so apropos analogy for the process by which these children arrived here. Fetal Alcohol brains are shockingly smaller and less developed under CT scan than normal brains. In the womb, the baby is infused with alcohol when the mother takes a drink. (There have been reasoned claims of fathers' contributing to the cause as well, physically and of course

socially.) What has been observed is that babies carried by women under the influence of alcohol actually spasm as though reacting in pain to the burning of their developing bodies by the alcohol within and surrounding them in their blood streams and in the amniotic fluid. These babies after birth will often be missing their survival “fall reflex” to spasm and flail their arms and legs outward when released. The synapses between right and left brain are stunted and cannot reach where they should. This, some say, causes the children’s impulsive, seemingly unfeeling, forgetful, dissociative natures and inability to cope with confusing and busy environments while at the same time driving confusion and busy-ness. Maybe it is because of all the internal busy-ness and confusion that these people have a very hard time dealing with external sources of the same. Doctors frequently mis-diagnose this as ADD or ADHD and treat with inappropriate psychotropic drugs that mask or add to the child’s challenges.

These challenges are not always apparent at birth. A small head, microcephaly (due to the shrunken brain mass) is often unnoticed unless compared on a chart to norms. A flattened nose bridge, small eyes, pronounced palpebral fissures (flaps on the nose-side of the eyes), a smooth philtrum (the ridges between lip and nose), and a thin upper lip are characteristic, but all may be hereditary features in the child’s genetic line. If alcohol abuse is endemic to the family for generations, who can know? Some whole families have thought for generations they just genetically had trouble with reasoning, and that it is “in the family” for them to have a “life-line” that goes straight across their palms without drifting or breaking. These babies are also frequent fliers with cleft palate, shortened or stunted bones, heart murmur, and fissures between left and right heart chambers.

How horrific to learn that while they cannot be cured, all these birth defects, obvious and subtle alike but all debilitating on many levels, can be so easily prevented. I wanted to write something to show where the playing field lies for some of our kids. You should know that while they have some of the characteristics I’ve written about above, ours are relatively mild cases. They will probably grow up to be fully or near-fully-functional adults, though more than one will probably need a “second brain” or someone to assist them with remembering things like turning on the alarm clock, taking a shower, going to work, or eating lunch. That being said, many of them are brilliant students and some are talented athletes. Most have vibrant spiritual lives that are the envy of “normal” kids.

Some of our kids have struggled through and overcome abuse and neglect that would have left others by the way. Suffice it to say they are plucky, strong, and admirable overcomers, achievers, and victors already in their short lives. Others of our kids suffer with them as they sometimes reiterate, relive and hopefully resolve what they’ve been through and, what they’re going through now. They are not less strong, and will have some incredible perspectives on life and what is important in it as they grow to adulthood. All that suffering and struggling, and you would never know it most of the time for the togetherness, smiles and joy we share as a family. I guess when they’re that tough it is that much better when they grin.

I have an image that, knowing full-well how inhibited is our ability to comprehend, our ability to feel, our ability to restrain our impulses, our ability to sit still and concentrate, our ability to refrain from attacking one another; our Creator nonetheless stepped out and took a chair between us, just so we could sit on either side of Him tossing our spitballs or sneaking around him to slap one-another on the

back of the head for the fun of it. Knowing that I am Mark and Rob to Him, I find it all humbling joy that I am invited to share the pleasures of knowing my amazing children, and being their Daddy and unworthy husband to their amazing Mommy. One veteran of an unmerciful childhood and (typical) years in jail resultant from what he only lately understands was caused by fetal alcohol has, as a young adult, produced videos on Vimeo where he assures us that while his brain and body may be irreparably damaged by his mother's drinking, he is now living (with an assistant) very well, and his spirit is alive and well. I think very well, indeed.

Fetal Alcohol Syndrome (FAS) is a catch-all name for issues also known by a number of different titles, but this one is general and basically self-descriptive. Sometimes the little brother, Fetal Alcohol Effects (FAE), is discussed, mostly because it bears a less restrictive definition. Please know that these effects are absolutely preventable. Mostly it takes young people being conversant as to what can and does happen when bad decisions start to pile up. A bad day begs for a release. A celebration wants a drink. A drink leads to a bottle. How easy is it to conceive a baby in a literal toxic soup?!! A pattern of marginally-consequential legal "adult" behavior means that fertilization could be done by a damaged sperm and/or a newly-fertilized egg could lay in a maiming cocktail for days, weeks, or even months before a mother realizes she's pregnant and starts taking care of herself and the baby. So this is a plea for my nieces, my nephews, and my own lovely children to remember that today's choices may well be tomorrow's legacy. Make them good ones you'll be proud to share.

Some days some of our kids are FAS kids, and some are FAE, and some are perfectly abnormal like the rest of us; but all of them are far above average in their own Lake Wobegonian ways.

FAE/FAS Links:

http://www.medicinenet.com/fetal_alcohol_syndrome/article.htm

http://en.wikipedia.org/wiki/Fetal_alcohol

<http://vimeo.com/2823156> - the video I mentioned above

Blogs – some brilliant day-in-the-life-of accounts of adoptive parents:

<http://thefinalmaze.blogspot.com/>

<http://coffeecatharsis.blogspot.com/>

<http://www.welcometomybrain.net/>

<http://looneytunes09.wordpress.com/>

<http://urbanservant.blogspot.com/>