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## LIVING WITH FASD: Meeting Expectations

As a young lad, I grew up in post war London and learned at an early age that there were a lot of expectations that I was being groomed to meet.

Firstly, I had to do well in school, stay out of trouble, get my homework done (preferably on time), get to school on time, keep my room clean and help with the housework. With the passage of time, those expectations got expanded to include passing enough "O" level GCEs so that I could become an architect, lawyer, accountant or the like. I also had to get a job and pay rent as well as pay for my own vacations, clothes, entertainment, etc.

Well, fast forward 20 years to that early morning call in May in 1983 where we were informed that our bouncing baby boy was awaiting us, and that he was eight days old. Our joy was manifest, and henceforth, I would now have a son of my own, and yes, he would have to meet my expectations.

Oh what proud parents we were, for our son (Simon) was a very good looking baby. The first couple of years of parenthood were quite uneventful. As Simon grew, we noticed that he was quite active and was frequently out and about in the neighbourhood looking for something to keep him entertained. At three years old, he put my wife's car into gear whilst she was talking, and by the time she found the brake, the garage door was demolished. Somehow at four years old, with the car off and the keys in my pocket, he put my car into gear on a sloped driveway and reversed through four lanes of traffic at Yonge and Lawrence during the rush hour and was untouched. (I was horrified watching this in slow motion.) Ah, we've got an active one, we thought. Not meeting expectations yet, this lad.

By the time he was six years old, we were called to the Elementary School to meet with Larry and Larry (School Principal and Class Teacher). We were advised, in no short order, that our son was "unique." He didn't like to work, nor did he want to work. I ventured forth that they meant he was different. "No," they said, "unique."

We suspected that our child had ADD or ADHD and we trotted him off to Sick Kids Hospital for the battery of tests that they undertake on boys. Sure enough, they said "classic ADHD": time to fill him with drugs. They helped somewhat, but they made him very angry as the daily dosage wore off.

The next few years passed, and armed with the ADHD diagnosis, we prepared ourselves for our son's maturing. He continued to not meet any of our expectations except at sport, where he was quite good, but many a coach's nemesis.

High School arrived, along with the first telling signs of drug use, lies, theft and belligerence. Failing grades, bad attitude, disruptive behaviour and lack of structure and organizational disarray were our daily diet. Boy, this ADHD is a lot worse than we imagined. By now, we had lowered our expectations, but lying, drug use, theft – these were just unacceptable. Where had we gone wrong?

Well there was no quick fix for all of this behaviour, so after much hand wringing, analysis, and discussions with friends and “experts,” we selected the path of a military school; boot camp by any other name.

Our son obtained his high school diploma, but what would his future be? Could he hold down a steady job, and be a productive citizen? Of course he could, after all, he only had ADHD. Or did he? My wife began to suspect there was something more at play here. After all, how many kids lose six cell phones in 18 months without remembering anything? Why was he never on time? Why couldn't he get a resume together and look for a job? Every job lasted only two weeks. Why was his room (then, apartment) always a mess? Could our expectations get any lower? Would we have to support him forever? Of course not, after all, he only had ADHD.

On a regular basis, we gave Simon a daily dose of negative feedback. How did you manage to lose your jacket? You lost another cell phone. How is this possible? Can't you take care of anything? You lost the \$50 we just gave you. Where? And so on and so on: negative begetting negative. Get a job. Why are you calling at 2 a.m. in the morning? What do you mean, you've been arrested?

Eventually, my wife found out the truth. The birth mother of our son was drinking during the pregnancy. The father was an alcoholic. The diagnosis was FASD. Our son had no short-term memory to speak of, hence losing stuff, forgetting meetings, etc. He couldn't organize, plan or execute. He was very bright and great at concepts, but getting to the finish line was beyond his capability.

After the FASD diagnosis, much changed. Our expectations were drastically revised. We now realized that he was almost unemployable

with his condition, but, in us, the change was profound. We now realized that many of the expectations that “normal” kids are expected to meet were too difficult for him to meet, because he didn't have the brain chemistry to succeed.

My wife and I discussed the implications of the new diagnosis and realized that our son needed our love, support, organization skills, life skills and financial assistance. What he didn't need, and in hindsight didn't deserve to have, was our continued negative feedback about his latest misadventure.

We couldn't change the past; however, we could take giant steps together in a new beginning. We tried by helping his dignity (he now had a one-bedroom apartment of his own), by providing enough money to have a social life of his own for someone of his age (we no longer expected him to contribute by earning money through a steady job), and helping him do what he was good at (music). We also assisted by getting his driver's license back and eventually getting him a car. Dignity and freedom came with a price, and our son is no more, but he enjoyed the latter part of his life better than the expectation-driven earlier part of his life.

Had we had the correct diagnosis earlier, what would it have changed? With the benefit of hindsight, it would have significantly reduced the daily family conflict about what he was or wasn't expected to do. It would have reduced our expectations of him down to a much more realistic level, which would have meant a more peaceful life for him and receiving a lot less of a negative diet surrounding many aspects of his life.

Would an earlier diagnosis have changed the end result? We will never know, but for sure, he would have had a much more positive environment in which to grow up. So much for meeting expectations – just let them enjoy life to the best of their capabilities.

*Author Note: Stephen Clifford is a businessman in the private sector living in Toronto, Ontario. He and his wife Trudy adopted their son Simon as a baby. Simon received a diagnosis of FASD as a young adult after many years of searching for answers. Trudy is an RN and worked as an Intake Coordinator at Surrey Place Centre. She also coordinated the FASD Adult Diagnostic Clinic there.*