

The following story was written by way of therapy. It is the story of my journey of discovery with my son which ends (or begins?) in a diagnosis of FASD. It is the tip of the iceberg and I am sure that I could write a story every day for the next month and still have plenty to say about this disability. If I could give one piece of advice, it would be to seek out people and information to help you. Read, research, learn and understand everything you can about FASD. If Knowledge = Power, then Understanding = Peace. What has been important for me is to change my own expectations of what can be measured as success for my son, without losing hope. Hope, that together we can provide the support our son needs for a full and happy life. Hope, that what I have learned along the way can help other parents on their own journey through this mine field that is FASD.

Names have been changed to protect identity.

## **Don't Let the Good Stuff settle on the bottom**

We adopted our son Adam from Pskov in Russia in 1999. He was 18 months old. From the moment I saw him my heart was flooded with love for this wee boy who did not smile and looked at us suspiciously. He had been a ward of the state for 9 months. For three of those months he had been hospitalised due to severe neglect. His court files made reference to his mother drinking and “neglecting the child”. He was about the size of a nine month old when we got him. On the train journey from Pskov to Moscow I recall he just lay stiffly in my arms staring at me, expressionless. Still, to me, he was the most beautiful thing I had ever seen. Through my rose-tinted glasses, I had no idea of the journey we were about to embark upon.

By school age Adam had flourished in our care. He had grown like a weed. He was a “chatter box” and naturally inquisitive. I loved this about him. He was interesting and funny. He was constantly on the move, climbing, running, jumping. Never sticking with any one activity for long. For his 5<sup>th</sup> birthday his Nana gave him a tool box with real screw drivers, spanners and hammers. He spent the rest of the day covertly taking handles off kitchen cupboards and loosening the bolts of our outdoor furniture! It was lucky that our sense of humour had remained in tact and that his personality was one of a “likeable rogue”. We would spend many hours in those early years repairing items that Adam had needed to pull apart or investigate.

Adam loved hanging over our fence and chatting with our neighbour, Dave. One Sunday when Dave was about to go to the service station to get petrol for his lawn mower, young Adam asked if he could go for a ride in the car with him. No problem. He was buckled into the back of Dave's car and off they went on their 10 minute journey. When they arrived home, Dave came over and said “I don't know how you do it. It's like having an outdoor motor constantly running in the back of your car!”. I guess we had just gotten used to the never-ending chatter.

Adam was on a collision course with the education system. Teachers through primary school either seemed to love or loath him. Comments common on his primary school reports were:

“Adam often finds it difficult to accept responsibility for his own actions”

“We look forward to Adam achieving independent work habits”

“Adam is easily side tracked in his work and the next step for him is to work on his concentration. He sometimes struggles to start written work”

“Adam can be very helpful and polite but sometimes lets himself down by becoming too carried away. He is easily distracted and can be a distraction to others”

Adam's primary school years were at the small country school at the end of our road. The school had only 75 students and went through to year 8. However, we decided that, in order to prepare him for High School we would send him into an Intermediate school in town. This was a school with a good reputation and a roll of about 600 students.

His first day at Intermediate was nerve racking. He felt sick in the car on the drive to school and as we walked through the gates he said "I don't know about this". I told him he would be just fine. His reply was "how could you possibly know that?". Little did I know it was going to be one of the worst decisions I could have made. He was gobbled up by that school and nobody seemed to care. He had lost the security of his small country school and was just like a fish out of water. He began to get into trouble for bullying and defiant behaviour. He, and I, spent way too much time sitting outside the Principals office. He also began a pattern of being "sick" and needing time off school. It would be a sore stomach or a head ache. We went backwards and forwards to our local GP who assured us it was normal teenage anx. Adam had also begun chewing his finger nails until his fingers bled.

I would go to all and every Parent-Teacher interview and as was the case with Primary School, when I suggested that I was worried about his basic reading, writing and spelling skills, I was told it was "a boy thing", he was doing OK and I should not worry. One lovely teacher did however suggest that I needed to attend parenting courses in order to "modify Adam's behaviour".

Again, the school reports read that he was more than capable but needed to work on his planning and time management skills in order to achieve.

On the last day of Intermediate School, after the final bell, he waited for a boy who had been in his class to leave the classroom and punched him – hard and in the head. The school phoned to tell me what had happened but as it was after school it was out of their jurisdiction – I think they were just glad to see the back of Adam. When I spoke to Adam and asked him why he had attacked this boy his reply was, "you get told every day for a year that you are dumb, and see what you do". I phoned the other boys mother to check that her son was OK and was received with about 20 minutes abuse down the phone of how out of control my son was. I accepted this and assured her that I made no excuse for Adam's behaviour which calmed her down. She then confessed that she had already been and filed a complaint with the police. This was Adam's first brush with the law. He still did not seem to understand that what he did was wrong. I guess in his mind, he had simply dealt with the cause of his pain and didn't quite know what all the fuss was about.

2011, High School. Adam was enrolled at an all boys public school with a roll of about 1300. This is where our journey of discovery really begins. We noticed almost immediately that Adam's anxiety levels had increased. He continued to chew his nails, increased fidgeting and rapid eye movement were all signs that he was stressed. He also began swearing without control or remorse. He did no homework and when prompted responded with abuse. Nothing we said made any difference. Trouble at school was also escalating and he was stood down for fighting and swearing.

Parent-Teacher interviews towards the end of Term one were enlightening. It appeared that he was also doing nothing a school. He was getting detentions on a daily basis for not completing work and sent out of class for being disruptive. One teacher smiled as she flicked through her notes and said "Oh, Adam has done nothing in my class". I was horrified that a child could be in a classroom for ten weeks and that the teacher would just smile and say that he had done nothing (what was her job again??). I let her know how I felt. I also wrote a letter of complaint to the school and made an appointment to see the Principal.

I took all of Adam's books with me to the meeting and showed him that there was virtually nothing written in them, that the school was not providing an education for my child. The Principal

suggested that we call Adam in so that he could have a chat. Adam arrived in the office, nervous. He sat and spoke in his usual articulate and polite manner. The Principal explained to him how lucky he was to have parents that were interested in his progress (Teachers really need to learn how condescending that comment is), and asked what he was going to do to make improvements to his school work. Adam had all the right answers – listen, concentrate, complete work etc. He was then dismissed from the meeting. He stood, shook the Principal's hand and said "thank you sir". With a look of superiority, the Principal said, "he will do just fine, he looks a man in the eye when he shakes his hand". At an all boys' school, it seemed that was just as important as reading and writing!

By the end of the second term, many many detentions later, Adam's Dean wrote in his report: "Some real concerns in Adam's report. High School students should not be silly in class and need to be socially isolated. Improvements required"

At home, he was beginning to get more and more out of control. He had been in more trouble with the Police – going along with another lad who thought it might be fun to smash windows at the local community centre, he had stolen money off both his Nana and his Aunty. Arguments escalated and he began to take his aggression out on things around him. Many holes were punched or kicked into walls. He tore up his school uniform and all of his school books. He snapped all of his pens and pencils in half. He was having trouble sleeping and began to have paranoid thoughts that his father was trying to murder him. After one argument I went into his room to smooth the waters, he was sitting on his bed, one tear rolled down his cheek and he said, "mum, I'm broken and you can't fix me. I want to kill myself". I have wept so many tears over that line. For the first time in my life I felt that I could not cope and experienced a feeling of what can only be described as utter sadness. The grieving had begun, I just didn't know it.

The next day, we took Adam to our GP. He examined him and said that physically he was fine that maybe he was "having us on" with the talk of suicide and that teenagers will manipulate parents with such comments. We explained that we did not believe this to be the case and asked that he be referred for psychological assessment.

Within a week we learned that his referral to the hospital had been made but that the waiting list was 12 – 14 weeks (he was considered low risk). We did not agree so opted to pay to see a private Psychologist. We spent about an hour explaining Adam's history. At the end of the session, he said "Have you considered that he may have ADHD? We have a check list and from what you have explained, he ticks every box". We were lucky. The Psychologist we had met that Saturday, also worked in the Child and Adolescent Mental Health unit at the local hospital. He could see our distress, so arranged for a series of tests through the public health system to be conducted. This took about another eight weeks.

I was in constant communication with the school explaining that we were working through a process and asking them to bear with us. I advised expected diagnosis of ADHD. Still the school insisted on dishing out detentions and punishments. He was just one step away from being suspended. Out of frustration I went and spoke with the Deputy Principal who explained that they were "helping him learn to take responsibility for his actions". I cried, out of anger this time, and said, "you are sending me home a boy that wants to kill himself, don't you dare sit there and tell me you are helping him. You are destroying him. You are failing". I think I was labelled a problem parent at that point. I told myself that didn't care what they thought of me. In the most basic of maternal instincts, I knew that I needed to dig deep and save all my strength to help my son survive.

Through the diagnostic process, Adam was sent for a Cognitive/Achievement Assessment. This document was our first introduction to what could really be going on. It showed that he had average IQ of 94 but that his academic achievement did not reflect this. He had a non-verbal

learning disability and was categorised as dyslexic. The report summarised:

“Adam has a definite discrepancy between his verbal and non-verbal standard score on the Stanford-Binet. The 13-point discrepancy is indicative of a specific learning difficulty associated with processing.... He does have a specific reading and spelling disorder associated with phonological processing and decoding that would place him in the category of dyslexia. Adam has a specific learning backlog centred on lack of attention; his auditory perception and his poor writing skills. Adam demands a structured programme”.

In her summary, she also suggested; “It may be worthwhile to have Adam thoroughly assessed by a Paediatrician to determine whether he does present as a learner with FAS. Many of Adam's learning difficulties appear to be linked to the characteristics of a learner with FAS”.

The ADHD diagnosis was confirmed and we began a medication programme for him. However, it soon became evident that whilst the medication helped a little, we continued to see behaviours that suggested he had no apparent ability to understand his actions and consequences. Angry rages were still common place.

The first year of High School was behind us and we had decided that the following year we would move Adam to the smaller country school closer to us (roll of 300). During the summer holidays he discovered the joys of alcohol. He decided to sneak out of his Grandparents house and go to a party where he got drunk. He did stagger home at about mid-night to a Nana and Poppa who were out of their minds with worry. He did not seem to understand that he had up-set them or done anything wrong. He just wanted to “have some fun”.

Medication and talk therapy were reaping very little reward and the Social Worker assigned to Adam to help with his ADHD suggested that he be assessed for FASD. A newly trained multi-disciplinary team had just begun assessments and was funded to do one a month.

On enrolment at his new High School, we presented the Principal and Councillor with the Cognitive/Achievement Assessment and explained the ADHD diagnosis. We were still trialling medications at that stage and explained that we were working through this process. They seemed extremely understanding and compassionate to our plight.

However, the school offered no support and in the end we opted to pay for a Teacher Aide ourselves for five hours a week. We began to see the benefit of this one-on-one attention in his school work. We thought we had nailed it.

But, issues were boiling outside of the classroom. Seven weeks into term one and there had been five disciplinary incidents:

1. Swearing/abusing another pupil
2. Wearing an earring, repeat offender
3. Swearing at a Teacher
4. Eating in class and being disruptive
5. Videoing a school ground fight

We went to meet with the Principal and Councillor where they explained that Adam's behaviours were “entrenched” and that he needed an intervention for behaviour modification. The Principal went further to say that he was not “normal”, that his constant pulling at his hair (his new stress indicator) drove her “nuts”, that he did not listen and was defiant. He was sent to an alternative education centre in town.

Although at first he did not want to go to the Centre, he soon found it to be a place where he could

succeed. The environment was such that it provided very clear boundaries and expectations. The programme was limited to a very small class size and designed to focus on just Maths and English and that academic work was carried out each morning with physical activities scheduled for afternoons. The combination was perfect for Adam. When I asked him why the Centre worked for him his response was:

“Its quiet and I can think. I like the activities. I like that I can work on the computer and get an instant answer in whether I am right or wrong”. As part of the programme, they also insist that each child writes a letter to their teacher explaining a bit about themselves and why they are there. This is Adam's letter:

*Dear Teacher*

*My name is Adam and this is my first year at the Centre. I'm coming to the Centre so I can change my behaviour towards my schooling and behaviour in general. If I stayed at High School I would get kicked out and if I get kicked out of school I wouldn't get an education. I live with my mother and father and my little brother. I have ADHD, I get angry over the little things like when I can't land a trey flip on my skate board. My music helps me relax. When my parents take my ipod off me I get angry. I want to change my behaviour.*

*I go to piano lessons on Mondays. I like piano because I like to learn new pieces and I just enjoy music.*

*When I leave school I don't know what I want to be. I want to do something hands on, not office work like my mum.*

*I'm hoping to change my behaviour because I'm hurting my family and myself.*

*I'm not a bad kid, I just do some bad things.*

*Yours sincerely  
Adam*

At this time, Adam had also made it to the top of the list for the FASD assessment and he began the six weeks of diagnostic testing. Although we had a fair idea of what the outcome of the diagnosis was going to be, it still hit us hard to hear that Adam had permanent brain damage as a result of prenatal exposure to alcohol. I suspect his early neglect and deprivation also added to his condition. He was diagnosed with Alcohol Related Neurodevelopmental Disorder (ARND) with a co-morbid condition of ADHD. The report states;

“Impaired attention and impulsivity are among the most common mental problems associated with brain damage including brain damage associated with an FASD diagnosis. Stimulant medication is generally quite helpful for treating the symptoms of ADHD including ADHD associated with FASD. However, where ADHD and FASD are comorbid, stimulant medication tends to be less effective in mitigating the symptoms. This is reported to be the case with Adam...”

In summary, the report states;

“Central Nervous System Issues. On testing, Adam's cognition is estimated to be within the average range. Adam however presents with significant delays in academic achievement. Adam also presents with severe deficits in adaptive function. Adam has a deficit in attention and has been diagnosed with ADHD”

I spent hours reading and researching everything I could lay my hands on about FASD. I joined on-line support groups and had regular email contact with another mum who was walking the same track. I wanted to not only equip ourselves with techniques to manage Adam and his environment but also pass knowledge on to others that will work with him- in particular, the school.

Things have calmed considerably at home. We have made that paradigm shift from “he won't do it” to “he can't do it”. We have employed techniques such as giving only one instruction at a time. Setting boundaries very clearly and instead of berating him when he makes a mistake, we provide a supportive, understanding environment when he slips up. We demonstrate what we can and repeat things many many many times. We have learned that we need to be patient (saint-hood is likely in the mail)! We have also learned to celebrate success even over the little things... like when he says “fudge” instead of “fuck”....

Present day – 8 July 2012. Adam is to return to High School next term. We have met with the school and explained the diagnosis. The FASD assessment team have been very supportive in this regard and spent two hours explaining the detail of the condition to some of the teachers and the school councillor. We took a parent advocate to this meeting, my sister, who took notes and made observations that we could not. It was a good decision as we were so emotionally invested in the situation, that it was invaluable to get another perspective.

We have now been offered an RTLB and Teacher Aide resource. Why this was not offered to us on enrolment is beyond me, but I have to let that go. The school have agreed to an initial half-day programme for Adam where he will focus on Maths and English with some Drama and Music thrown in for good measure. .

I am concerned that the school do not fully understand the condition. They still make reference to him learning appropriate classroom behaviours and being self-monitoring. At the IEP meeting I took some reading material and a summary sheet of Adam's condition. I also suggested some strategies that could help them manage Adam and lower his stress levels. I was told that I was giving too much information to the teachers that my communication level was unacceptable (our correspondence had apparently taken up one third of the councillor's East-light Folder and Adams's special needs were “not as severe as others at the school”, that it was “normal” for them to deal with such children). I was told to “back away, take care of myself and my family and trust the teachers to do their job”. Given the history and our experience with the Education system, this is a tall order.

A paragraph in the book “Damaged Angels” touched me. It was written by an adoptive mother.

*“It's not something you can do on the side – it's a full life commitment. They don't accompany us on our life's journey, they sweep us off the path and down their own rocky roads with a flash flood. We grasp at sandbars along the way; find temporary high ground only to be swept away again by the tidal wave of FASD. Our consolation is that, together, this child might survive those rapids. Alone, they drown along with the sorrows of their birth mothers in the alcohol that has condemned them. Can we teach them to swim? Maybe. Can we keep them alive? Maybe. Can we let go and watch them drown alone? Impossible.*

Will I throw the most precious thing to me back into the system and “back away”? Impossible!

Adam was right when he described himself as “not a bad kid”, in fact he has a lot of the good stuff too. He is inquisitive, interesting, friendly, energetic, witty and generous.

Will I be able to save him and all his “good stuff” from sinking to the bottom of the education system? Maybe. What is for certain is that I will give that system a damn good shake up along the way. No regrets.

There is so much more to write about:

- The impact this has had on our family
  - How his brother copes
  - The pressure on our marriage
- The inconsistencies of this condition – good day/bad day
- The on-again, off-again job he has at the local café
- How fixated he becomes on “today’s shiny object” – short term obsessions.
- The real friendship he has forged with the local policeman
- How to go about educating family and friends of the condition
  - How they have coped, reacted, supported.
- How disloyal it feels to write a police “alert” about your own son
- How difficult it is for him to keep friends
- How to read situations and understand that he is over stimulated
- How to change your language to “concrete” instructions
- How to laugh with him, not at him (particularly when he is very literal)
- How being a peace-keeper and constantly running interference is an exhausting past time.
- How we can help others.