

Our Lived Experience of 14 years of ABA – Jane and Johnny McCready



Our son Johnny was diagnosed as autistic at age 2 $\frac{3}{4}$. We had a pretty good idea even before then as one of my stepdaughters is also autistic, though very much at the higher cognitively functioning end of the spectrum. Soon after the autism diagnosis Johnny was also given a diagnosis of severe learning disability by the Maudsley autism unit.

We were advised by the paediatrician to enrol Johnny pronto in an autism nursery which used the TEACCH method. We were also advised to try Speech and language therapy (SALT) and Occupational Therapy (OT). All these we did, paying privately for most as the state pretty much offers nothing for autism before school age.

After about 6 months, then drifting into a year, it became clear nothing much was changing. Johnny remained non-verbal – and not just non-verbal but also unable to *understand* anything said to him, not even simple words like “shoes” or “juice”. He was incredibly hyperactive, climbing on unsafe things, trying to flood the house, high-pitched screeching 18 hours a day, posting food down the plughole, eating Playdoh, biting, pinching and kicking anyone who didn’t do exactly what he wanted (and how would we know what he wanted, as he had no means of communication?). The worst bit of all was when he would punch his own little head – hard – or bang it on concrete if stressed at all, even by something like being offered a dinner he didn’t fancy. That dinner would end up thrown at me, and anyone in the way might get bitten.

The speech therapist we'd hired, with autism expertise, said sadly that she didn't think he would ever be able to talk and we should move to signing. He was only 3. I was a teacher once way back, 3 seemed too early to give up on speech.

I asked the nursery too for help with his aggression and self-injury. They had not much to offer – *“praise him when he's **not** hitting you”* was the best they had. This was a child who did not understand speech. Let alone a sophisticated double negative like that.

At our wit's end, another mum recommended I try ABA, which had worked so well for her autistic boy. *“No, no”* said I, *“for I have heard dark and terrible things about it, how it creates little robots and is cruel”*. Luckily for me she did not mince her words: *“you are talking rubbish and have been misinformed, you should try it”* she said.

What did I have to lose? We reached out to the same supervisor she was using, a jolly and easygoing young chap called Matt. I remember him turning up on day one with a rucksack full of squidgy and spinning toys.

Right away, I could see Johnny start to respond to ABA. The first tool an ABA practitioner has in their teaching armoury is something called “mand training”. It means learning how to request for desired items (or making **demands**). Simply put, an autistic child who cannot imitate and who does not yet “get” what speech is for, will probably not just start speaking or communicating out of thin air. And of course imitation skills aren't just about speech – they're also vital for learning signing, or pretty much everything from doing up a zip through to reading. So first they taught Johnny to imitate actions – *“do this”* for copying clap hands, stamp feet, hands in the air. All with huge use of fun and motivation to encourage him to copy the actions – they call it reinforcement. So for Johnny his reinforcement was a huge push on the swing or a play with a squidgy toy. It would be different for another child, has to be tailored to what motivates the individual.

Just three weeks after starting, they moved from non-verbal to verbal imitations and Johnny actually said his first word. Not very clearly, not all that well, but it was a word all the same. He had learned that making the mouth shape *“puh”* got him the best thing in the world – a *“push”* on his beloved swing.

They then moved on to other sounds, words, mands.

Meanwhile they were teaching him so many other skills, like walking down the road to the shops (he'd previously insisted on the car or buggy even for 10 yards). They had started to redirect his aggression and self injury into better ways of expressing himself – for instance, using his words, or squeezing his fingers together tightly instead of self injury. If you start early on this stuff you can change habits, teach them to “self-edit”. All much harder when habits are entrenched and they are twice your size.

One of the key things they also taught him back then, which no-one talks about much but which is absolutely crucial for all learning is to sit still. First for 10 seconds, then 20, then a minute. If you cannot sit and listen for a bit, you cannot learn.

I wanted Johnny to try the mainstream primary at the top of our road, which one of his 3 big sisters, then age 6, was already attending.

So with evidence of great progress, and with the help of a fine legal advocate, I managed to get ABA onto his Statement of Special Educational Needs, and Johnny started in their nursery class. At first it was just a couple of afternoons a week, always with his ABA tutor at his side, then lots of work back at home with his ABA team working on skills to feed back into school life. The local authority started to chip in for the ABA.

We'd been advised he was really "too severe" for mainstream, but I wanted to try it. And he loved it from the start.

There were two things the ABA tutors could do that a non-ABA shadow couldn't (we tried). One was they knew how to motivate him to learn - using his reinforcers, breaking tasks down into their smallest composite elements, giving him short bursts of learning followed by a big play with his toys. A whole raft of techniques.

The other was that they knew how to redirect any challenging behaviour - crucial in a busy and manic classroom of 30 other tots. Without this, he'd have entered the woeful autism school exclusion stats fairly quickly for being disruptive or even aggressive.

Three beautiful, inclusive years Johnny had at that primary school. Yes he was "too severe" but he loved it, and learned to be around the noise and fun and chaos of 30 kids. He had playdates and went to parties, he joined in all of it. I often had my heart in my mouth dropping him off, but not him - he bounced in very happily every day.

But as he entered Key Stage 2 at age 7, art and PE gave way to geography and fractions. It was pretty clear that - though he was talking more, reading a little bit, writing a little bit - he was just too far behind. And he wasn't quite as happy any more.

So we decided on a move to special school. An ABA special school not a school using TEACCH, as the evidence was clear that this was how he learned best. With another call or two on my legal advocate, Johnny won a state-funded place at the ABA school 40 mins away from us in central London. I offered to do the transport, and am still driving him there and back each day 9 years later.

When Johnny started at the ABA school, he had hundreds of single words - but not all very clearly enunciated.

Gradually over the years they have taught him to clarify his speech and to use little phrases not just single words. SALTs and ABA staff were now pooling their skills to help him, not working in separate silos.

The other day he commented to me unprompted “*nice warm floor*” when I’d put the bathroom underfloor heating on. May not sound like much? But for a boy I’d been told would never speak, that conversational utterance is a triumph akin to his big sisters getting into uni.

The Ofsted-outstanding ABA school has high expectations of how much Johnny can achieve. The best way to illustrate the sheer breadth is to pull out a few goals from his school reports. From reading signs in the community like “fire exit” and “drinking water” to writing, saying and typing his full name and address. Learning to do yoga and how to swim. Learning to play with his classmates and take turns in a game of football. Learning that using words isn’t just about getting needs met, but about having little chats. Understanding when the things he loves are going to happen – eg right now it’s all about “*disco in 2 weeks*”. Washing his hands in the most hygienic way possible, sorting out laundry lights from darks, saying a line in the school Christmas play. Academics and learning in a group as well as one-to-one. The list goes on.

ABA is generally only used on redirecting ‘stims’ (self stimulatory behaviours) when they are barriers to learning, or downright harmful (like his self injurious head banging). Some of Johnny’s stims fall into the ‘barrier-to-learning’ category and school have worked on redirecting them. For instance, his constant noisy shouting was a barrier not just to his own learning but to the whole class’s – no-one could hear a word anyone said. So he’s learned there are some times you *can* make huge amounts of noise and some you can’t. Same with bouncing – especially now he’s much larger. In some places it simply isn’t safe to bounce, like on a crowded tube platform, a precarious floor or next to a little old lady in Costa Coffee. If he’s not taught these things, his world would start to narrow down.

Then at age 10, another blow.

Johnny was diagnosed with Type 1 Diabetes. This means he needs 5 insulin injections in his tummy a day every day for the rest of his life in order to stay alive.

This was a boy who was deeply phobic of needles. Vaccinations had been an utter nightmare, with several people having to hold him down physically, blood everywhere.

But the BCBA (ABA consultant) said – “*let’s try and teach him to do his own jabs*”. They are so focused on independence skills in ABA – “just enough support” they call it – again contrary to many of the myths about ABA creating prompt-dependency.

Deeply sceptical about Johnny being able to handle a needle, I told them – “*you’re welcome to have a go*”.

Six months later, using forward-chaining, backward-chaining, reinforcement, prompting, task breakdown – so many tools from the ABA canon – he’s doing those jabs himself 5 times a day. Every day, with insouciance and flair.

At age 16 now, Johnny has so many skills learned via ABA. He's even got a job at an advertising and media agency – filling up and emptying their dishwasher, and putting paper in the printers.

He's learned to use the gym independently – and what else is a gym but the adult version of his beloved childhood swings?

He's learned to wet shave and to tolerate all sorts of health checks that accompany a lifelong condition like Type 1 Diabetes – eye checks, blood tests, the blood pressure cuff.

He is also a whiz on the iPad and with the Sky remote. He can follow a shopping list and recipe; use a contactless card to pay. He was toilet trained right back in the early days of ABA, but he can now also shower and wash his own hair independently.

He no longer uses his fists to express his needs, but his words. Or he can ask for a break if overwhelmed.

This last one is massive. I can see a “Sliding Doors” movie type of scenario, where if I'd never listened to that other mum and tried ABA, he would have remained aggressive and self-injurious to this day.

And since he's now 6 ft and 15 stone, those fists of his would be doing serious damage. To himself and others. Would an ATU be beckoning, breaking all our hearts?

A local authority bod said to me last year words to the effect – *“well, ABA can't be all that great if he still needs it after so many years”*. I think in that one statement are writ large all the misconceptions about ABA. That it's just for little kids, that it offers a “cure” or has a “normalising” agenda.

To us, to Johnny, ABA is just good teaching. And of course he will always need good teaching. Who wouldn't? He will, we hope, continue to learn right into adulthood, all the skills he needs for a better quality of life (skills which so many of us just take for granted). Living at home happily with us, his mum and dad.

The only actual cruelty in this story? Those who'd keep ABA from kids who need it, kids like Johnny for whom it's utterly life-enhancing.