

My son's not Rainman

John Williams on being a parent of 'The Boy' with autism

I'm a comedian. I've stood backstage at a comedy club on a Friday night hearing the noise of the baying crowd the other side of the curtain, knowing full well I'm about to be fed to the lions. Yet even when I look back at those moments, none of them seem as daunting as writing an article about autism for a professional magazine.

You see, I'm no academic. And I'm certainly no expert. My knowledge doesn't come through books or studying, it simply comes from living with one boy. My boy. And I suppose over the 12 years he's been on this planet if I've become an expert on anything, it's an expert on him. Just him. I've watched his continuous struggle to adapt and make himself heard in a world that neither of us will ever truly understand.

The truth is, autism to the two of us has in many ways felt like a battle. Just a long, laborious fight, both in the physical and non-physical sense. From a very young age The Boy (as I refer to him, just to save his blushes) learnt that if you want Shane's toy car, but Shane won't give you his toy car, and you can't find the words to be able to ask Shane for his toy car, then a short sharp bite to Shane's arm will get you that toy car. And if a quick bite doesn't do it, a push or pull will. The Boy has used this knowledge in too-many-to-count clubs, care settings and even schools.

And that's why I decided to tell our story. Because his life was forever shaped by his behaviours, and very few people could see past them. But I didn't want his behaviour to define him. He's so much more than that. The Boy who I laughed uproariously with at home, he was lost to the world at large. And the relatively few people in his life who have taken the time to look a little deeper have been rewarded with an amazing, fun, witty, charismatic boy just waiting to shine.

So I wrote a comedy show and an

accompanying blog of our life together. I called them 'My Son's Not Rainman'; just to try and dispel the myth that everyone with autism is some kind of a genius in



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some way. Wonderful though these skills are, The Boy has never sketched the London skyline from memory or memorised every bus route between Harlow and Portsmouth since 1904. He prefers the company of others, has no real interest in trains and his worst subject is maths. His greatest 'skill', if he has one, is just being him.

There have been a few hurdles to overcome with the show and the blog that I hadn't foreseen. The idea of using comedy and humour to tell our story

filled some people with horror. In the modern world, comedy is often seen as cruel, that there must be a target or a figure of ridicule in it all. For example, last year I was invited on to the Radio 4 *Today* programme to talk about 'comedy and dark subjects'. And on the telephone the young researcher eagerly asked me, 'What's the most offensive joke you tell about your son on stage?' It genuinely took me aback, that someone honestly thought I was going to stand up in front of a roomful of people and ridicule my own child in some way.

So if there is a target in the show, then it's other people's perceptions of The Boy and those like him. There is joy in our world, that's all our story is about. And from joy comes laughter.

Nobody will ever make me laugh more than him – he's made me look at the world differently, he's made me question so many things I took for granted, and above all else he's made me realise that socks are just a weird bit of material that you don't really need. What isn't there to be grateful for?

I didn't always see the positive in our situation, it's fair to say. For so many years it just felt like the never-ending battle I described earlier. It was forever about getting him the right level of support. Or any level of support. For us, the diagnosis of autism closed doors rather than opened them. 'It's because he's autistic' became the answer to most concerns raised, and now the medical community had a label its work was done.

For parents the frustration that schools and healthcare work so independently of each other can't be overstated. Here was a boy deemed 'unteachable',

excluded from two mainstream schools and a special school. Headteachers, educational psychologists, speech and language therapists – they all recommended CAMHS referrals. Yet still years on we have moved no further up the elusive CAMHS waiting list. Apart from one meeting to assess his suitability for medication, The Boy hasn't been seen by a medical professional with regard to his autism since he was diagnosed so many years ago.

That's the parental-moan-bit over

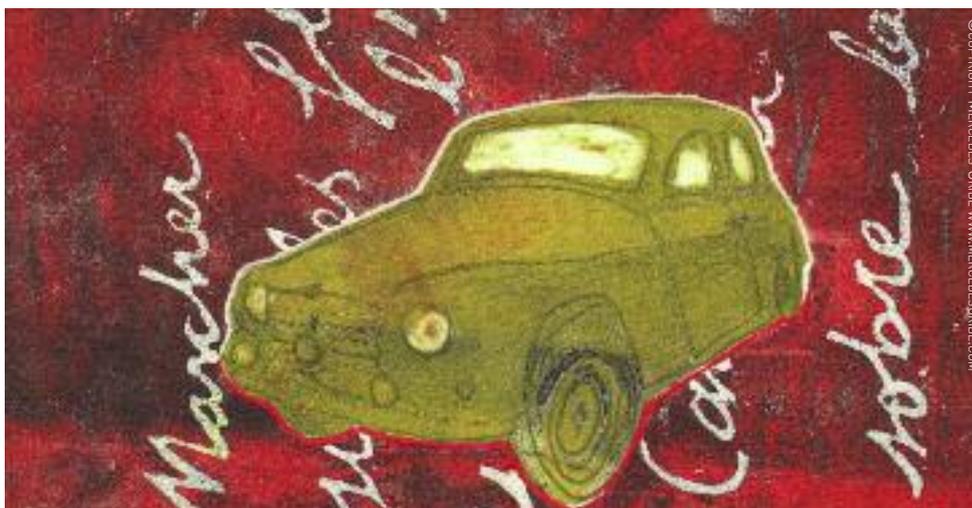
with. Apologies, it comes with the territory. I'm not even sure what it is I want that would make everything better – I'm not naive enough to believe that it will all go away one day. I suppose much of the concern is based on fear – we forever hear the horror stories of adult services, so for parents we think we have to cram everything in before they turn 18, because after that there's nothing.

If I had a wish list, I would love to see a system where children are reassessed every five or ten years. The difference in The Boy and his peers as they age is fascinating – some making great strides, others far less so. Especially given that children are diagnosed even earlier nowadays, some reassessment at a later period in their lives would at least offer a glimpse into how the condition changes. And it may provide an answer why some do better than others.

Now I'm in the middle of my utopian dream, I'll carry on. Without being too altruistic, it would be good to see more support for parents too. The years of school exclusions, running the gamut of other parents in the playground every morning, the family members who even question you – it all takes its toll. I know what a pain in the backside parents can appear at times, but it's because everything is a fight. And at any point we expect the door to be slammed in our face again so we have to get in quickly before that happens. And, sadly, parents quickly learn that the system is now very much geared towards 'those who shout the loudest' rather than assessed on need.

That's it with the ranting and moaning now, I promise. For the most part, life is good. The Boy is settled in his latest special school, and they seem to understand him more than anyone has before. He's getting older, and as a result I never have to sit through another episode of *Ben 10* in my life. *The Rugrats* will remain a work-in-progress.

The last few years have been a steep learning curve, not just for him, but also for me. I have finally learnt that a positive outlook can make all the difference to both our lives. I spent so long trying to find out what was wrong with him, I forgot to look for what was right. He will forever be the person who has taught me more about what it means to be alive than anyone else ever could. He's made me question the human condition, make me realise that the lack of empathy and understanding often doesn't come from within the autistic community but outside it. And above all else, he's made me realise that in the darkest moments, there's nothing a multipack of barbecue flavour Hula Hoops can't make better.



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Driving Miss Daisy

The Boy has been travelling independently to school for a few weeks now. I was going to tell you about it earlier, but once again the fear I might jinx something that seemed to be going so well meant I left it for a little while, just to be certain.

I say travelling independently, he goes in a taxi. With an escort. But it's as independent as life will be for the moment, and he seems to love it. Mainly because apparently the car is better than mine. And although I miss our chats on the drive to school, I love this new found independence too. It's another opportunity for him to break away and be his own person without awkward, stupid Dad always stepping in and controlling things, even if it is with the best of intentions.

He travels each day with another lad from school, The Boy Who Always Carries His Teddy, the taxi driver and the escort (in keeping with the rest of this blog I was going to call her Mrs Escort, but that just seems wrong on so many levels... we'll settle for Mrs T). Each Monday follows the same routine, the week starts with The Boy and The Boy Who Always Carries His

Teddy sitting together on the back seat, with Mrs T and the driver in the front. By Tuesday morning they've been separated and The Boy sits in the front seat. (I don't ask the reason why any more, I've decided I'm better off not knowing some things).

Each afternoon when the taxi pulls up at the door to drop him off I hear The Boy and Mrs T chatting away together on the doorstep. Laughing. I know he likes her, and the bit that makes me happiest, it's very obvious that she likes him. As I open the door I'll interrupt their conversation mid-flow. The Boy will stop talking instantly, and I'm left feeling like I've gatecrashed the world's greatest party. Whatever they were talking about is of no concern to my prying ears. They can pick up where they left off again tomorrow. He'll say goodbye to Mrs T and step inside.

Her name will pop up now and then, but The Boy keeps their conversations to himself. And although it's taken some getting used to, I like it. I like that he's taking more and more steps towards a life outside me. I like that there are things going on in his world that

I know nothing about. Like the time last year he came home from school and suddenly declared he liked football and supported Arsenal, despite showing no interest whatsoever at home. Sometimes as parents I suppose letting go can be as important as holding on.

I did get one little glimpse into his new life. At Christmas, he got out of the taxi with a present from Mrs T. I could tell by the shape it was an annual. I guessed at Doctor Who or Minecraft, thinking that I'd suddenly discovered the topic of their conversations all this time.

Of course I was wrong. He opened it, it was a football annual. Manchester United.

'Yesssss!!!!', The Boy shouted. 'I thought you supported Arsenal?', I said confused. 'I do', he replied with a heavy sigh, feeling the burden at having to once more explain everything to someone so stupid. 'I support Arsenal at school... I support Man United on the way to school'.

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