

NEW WRITING

Reflections of a Year 11 school leaver with Asperger's Syndrome: an interpretative account

By Pat Bennett

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Summary

John has an autistic spectrum condition and was admitted to a mainstream school during Year 8 after a number of exclusions from other schools. This essay reports John's memories and opinions of his experiences in that school and identifies factors which helped him cope with his identified problems. John left at the end of Year 11 with some GCSEs and a place in the local FE college.

Introduction

This article considers the memories and opinions of a young adult, John, (not his real name) who has an autistic spectrum condition as he reflects, at the end of Year 11, on his experiences of mainstream secondary school.

The purpose is to explore his identified problems in school and then explore what helped him to cope with these, develop improved staff and peer relationships and

eventually leave in Year 11 with a handful of predicted middle-grade GCSEs and a place in the local FE college to study Information Technology. The extent to which John's placement can be regarded as a success will be discussed and, against a different professional opinion, I shall argue that this was a desirable outcome.

John's insider account and his interpretations of his behaviour in school contribute to professional understanding of his thoughts and feelings. In this way, non-professional knowledge becomes incorporated into, enriches and changes professional discourse.

Biography and Background

At the end of Year 7 John's parents had been asked to remove him from the independent school – which his siblings continued to attend successfully. Before that his parents had also been asked to remove him from an earlier independent primary school where they had initially enrolled him.

At some time during primary school John had received a medical diagnosis of ADHD (Attention Deficit Hyperactivity Disorder) and been prescribed Ritalin. An independent educational psychologist, appointed by parents, had reported that John had a Verbal IQ in the very high ability range, a Performance IQ in the average range and specific learning difficulties on the dyslexic/dyspraxic continuum.

John arrived at Countytown High School (not its real name), a local comprehensive school, in the summer term of Year 8 having been out of school for six months while parents had sought a school place elsewhere for him. Within days, troubled staff and peer relationships emerged.

The SENCO (Special Educational Needs Coordinator) talked to me on a number of occasions about John and I originally tried to hypothesise and work within the framework of the existing information. However, nothing I did or suggested improved the deteriorating situation. Over time, and at a multi-disciplinary review in school with the psychiatrist and psychoanalyst from the Child, Adolescent Mental Health Centre, a consensus was reached in Year 9 that John's behaviours only made sense if interpreted through the lens of autism. The school submitted a request for statutory assessment, I provided psychological advice, and John eventually received a Statement of Special Educational Needs. There is no doubt in my mind that without this he would have been excluded.

With the Statement provisions in place I had telephone and face-to-face consultations with staff, attended reviews, and delivered in-service training both to the whole staff and, separately, to the support assistants and to some individual teachers. There were many times in the period that followed when I felt at a loss, deskilled and drained of ideas which might support both the staff and John, who, I feared, were beginning to lock into a cycle of mutual negative recrimination. However, it was always my firmly held opinion that this school was where John should remain given his age, previous educational experiences and the likely alternatives. Parents veered between voicing support for the school and bitterly criticising it. It seemed to me that this behaviour probably reflected their own confused, frightened, angry and occasionally belligerent emotions as the waves of staff criticisms of their son threatened to overwhelm their capacity to cope with the situation.

A period of time then passed during which I received no further communications from John's parents or school. When next in school on other business I asked after John. I remember feeling a distinct urge to run and hide, expecting a catalogue of complaints. So it was with pleasure, and, I admit, surprise that I heard that John was

doing much better. Things were calmer at school and major incidents of confrontation were increasingly infrequent. There was not much time to talk in greater depth on that occasion but I remember asking the SENCO if she could identify a reason for this. She could not say except to comment, *'He just seems to have made his mind up to conform'*.

He just seems to have made his mind up! Of all the possible answers I had anticipated, this was not one of them! It is a phrase that has lingered in my mind and led me to investigate further.

I arranged, with John's parents' permission and with his explicit agreement, to interview him at home prior to his leaving school in Year 11. There were many different ways in which I could have chosen to interpret the resulting rich data, but I have concentrated here on themes of John's interaction with his broad educational environment and the meaning of success in such an environment. The reader will no doubt be able to find in John's words other meanings which I have not considered.

I invited John to tell me about his school experiences before he arrived in Year 8 at the mainstream comprehensive school. Referring to his first and second schools:

John: *Oh, well, er, before Countytown, I started off at (independent primary) which was, er well, I don't **actually** remember a lot of it. I can remember...pretty much my last day. That's about it.*

Me: *Tell me about your last day then.*

John: *I can remember **very, very** little about it.*

Me: *Ok.*

John: *I can remember when I first went to judo in the lunchtime club and that's where I first went to judo... and I had a few friends there I made in...erm...in school before then.*

Me: *Right. Is that in the nursery?*

John: *Yes...I...er...I made a few friends there and I'm still in touch with a few people from there. Erm...as far as I can remember... I think I liked it there...but you don't tend to remember the *dreadful**

parts. You remember the bits that you enjoy.

John: *Then I went to (independent all age school) in Year 4 for a year...and erm...the school was quite good then (description of the school and John's opinion of the headmaster). Erm...I left that school halfway through Year 7, I would say, and I was off school for six months.*

Me: *Oh, how did that happen?*

John: *Well, I'm not exactly certain myself. In the...um...the thing I remember...the very last thing...there was a letter in school...I think...Someone was calling me names or something from the back of the room and just in...in anecdotal evidence, I told the teacher what he was saying, and I got in trouble for swearing and I don't...I still don't understand it.*

Me: *Had there been previous incidents like that?*

John: *Not really...erm...I remember I wasn't the most co-operative of people. I was...people always said that to me.*

Me: *Co-operative in what sense?*

John: *Well, I was often in trouble for being... what the teachers saw as cheeky...but what I saw as...just being me...and erm...just forgetting stuff and being disorganised generally. Erm...yes...that pretty much sums up my life before coming to Countytown.*

Themes from the above contribute to my understanding of John's later experiences at Countytown High School as follows.

Firstly, I find John's account remarkable in its omission of detailed description or personal anecdotes. Many authors note the excellent rote memory skills of children with autism. However, research on memory processing in individuals with autism suggests that, *specific* difficulties in remembering are common. Additionally, they are known to have more general difficulties involving processes related to the self. If children with autism have problems in encoding information about themselves, then this could result in what Millward et al. (2000) describe as a deficit in personal episodic memory. Episodic memory is an individual's record of the personal incidents that have happened. It seems to me

that some of the staff's frustrations with John's failure to understand/remember his own contribution to certain unfortunate incidents in school, while he remembered what other pupils did very well, could, arguably, be attributed to a difference in the way that young people with ASD lay down and organise episodic memory. This might then lead to John's very different interpretation or complete lack of understanding of certain consequences of his behaviour, as in fact happened.

Secondly, John talks about not remembering 'the dreadful parts'. Another remarkable aspect (to me) of our conversation in total was the almost complete absence of words describing any emotions experienced at school. This omission is surprising given the occurrence (at one point daily) of fairly serious incidents arising between John and school staff or between John and his peers, during which emotions ran high on all sides. John was certainly capable of feeling and demonstrating through his behaviour a range of very intense emotions. Was it possible that he simply 'forgot' these feelings after the moment had passed, or had he buried those experiences deep in his subconscious as a mechanism for defending himself against their painful effects? During his first year at Countytown, John had been attending the Child, Adolescent Mental Health Service clinic, where, in addition to occasional appointments with the child psychiatrist, John saw the psychotherapist on a weekly basis, usually during school hours. Despite a reference in our conversation to the psychiatrist, John never once alluded to the psychotherapist.

Williams (1996) has some revealing insights into the use of psychotherapy with people with autism.

Although people with autism may be subject to a much higher degree of stress than most people, an information processing problem may actually rob a person of meaning and personal significance, which are two of the key elements in becoming psychologically or emotionally ill or disturbed in any focused or complex way. Mental illness is primarily about attributing too much personal significance to things. That is the very problem that some people with autism might wish they had...low thresholds for

information overload can result in shutdowns in processing, happening so frequently that the meaningful impact of anything highly disturbing doesn't have a very prolonged effect. (p.82)

Interestingly, however, she goes on to note that the above may be different for some people with Asperger's Syndrome because, although they do experience information processing problems, some go on to process consistently what is seen or heard and gain some degree of consistent personal significance. Debate continues in professional circles as to where boundaries lie between Asperger's Syndrome and high-functioning autism. For John, it seemed as if the weekend acted as a giant eraser, which metaphorically rubbed out the emotional memories of the previous week. Each Monday was, in a sense, a fresh start. During all the time I was involved with John, during the 'darkest' moments, staff and parents never once reported to me that John was unwilling to attend school. He was often late, itself a cause of friction with his parents and with school staff, but that was for other reasons (namely, sleep disturbances resulting in his being reluctant to get out of bed in the mornings). He never became a 'school refuser'.

Thirdly, John mentions having made a few friends in his primary school who had moved up with him from nursery and who attended lunchtime judo club with him. From my conversations with parents, I knew that friendships were difficult for John to maintain and that few peers, if any, ever called for John at home or telephoned him. John's understanding of having friends was not usually reciprocated. This was a particularly sensitive area, since John's sibling was reported to be both successful academically and also highly popular and socially skilled. Parents described a similar picture of John's second sibling. John's difficulties were undoubtedly compounded by his sibling relationships – which put additional stress on the family. John's peer relationships proved to be a major source of stress for him in school and also for his teachers, who spent endless hours trying to untangle incidents. These usually involved verbal abuse (real or perceived as such by John) and being shunned by peers.

Fourthly, the dialogue anticipates what was later to become another major cause of conflict

between John and school staff at Countytown High School. Behaviour which outraged and disbelieving staff recounted to me as totally unacceptable rudeness, John characterised as '*what the teachers saw as cheeky*' and explained with '*just being me*'. John explained later in these terms:

John: *...at this point (referring to the start of Year 9) a lot of teachers...I don't think...thought on the same level as me, if you know what I mean, there was a clash if you know what I mean.*

Me: *What sort of clash?*

John: *Well, because I often speak to people on the same level as they speak to me, I...er...I tend to speak to everyone as equals. I don't...erm... pay any particular respect to teachers...I pay what respect's due because they're teachers, but I don't...er...value them just because they're teachers. I value people if they're good teachers, or if they know their subject well...or if they're nice people...and...er...a lot of the teachers who I didn't get on with particularly well didn't like me because of it.*

Later in the conversation, referring to the comments in a behaviour diary kept by his teaching assistant, he reiterated:

...it had no effect on me at all...they still don't...because I don't feel they're worth anything...and so this would be handed up to a higher level of staff if I'd been ill-mannered...in their opinion...I never saw myself as being ill-mannered.

Finally, John talks about '*forgetting stuff and just being disorganised generally*'. Again, this almost throwaway remark fails to capture the enormity of the problems which subsequently ensued in high school as a result of his inability to remember deadlines and organise his work.

In reading through my interview with John, I am primarily struck by the contrast between John's matter-of-fact narrative and style of delivery, and my own memories of that same time-span. I have vivid episodic memories. They are of fraught meetings and reviews, of delivering some in-service training to school staff whose attitudes veered between outraged anger at

behaviour which they found totally offensive, blank incomprehension of its causes and panicky feelings of becoming deskilled – with corresponding loss of self-esteem and self-confidence in their professional abilities. By the time John was in Year 10, the latter emotions were also beginning to overtake me as I felt increasingly at a loss to provide further advice to staff on how to cope both with John's behaviour and with the intense emotions it elicited. The picture then is of a group of skilled, experienced professional people who had been reduced to feelings of anger and/or helplessness by John.

Within the opening lines of the interview, John had himself identified some of the issues which led to his removal from his previous schools and which also caused relationship difficulties in high school. Later, he identified a further point of conflict at high school, namely his putting his head down on the desk in lessons and refusing point blank to do work set – which he explained in terms of being either depressed and/or tired. He said:

I would spend whole lessons doing nothing...just have my head on the desk...and the teachers...wouldn't argue with me about it. They did at first but...because I did it so consistently...I think they just gave up on it.

On one level, John was able to identify the kinds of difficulties which he was experiencing at school. This knowledge throughout Years 8, 9 and 10 did not help John to change his behaviour. So, to return to the question which prompted this study, what was the change agent?

Within the context of a caring community school with an inclusive ethos, the Statement funding provided a teaching assistant and the school arranged weekly access to a teacher/counsellor in addition to the pastoral support already provided by the Special Needs Co-ordinator and the Year Head. Additionally, John was allowed to follow a reduced GCSE curriculum in Year 10, dropping two subjects which, for a variety of reasons, had proved to be particularly difficult for John to cope with. This meant that John could use those periods in the library to do homework and coursework. Failure to produce these had been a major source of conflict. John himself asked for, and was given, permission to use his own laptop computer

both in lessons and for homework. I and another Educational Psychologist provided two hours of in-service training to school staff. The school rules were allowed to be stretched almost to breaking point, with much staff energy being expended on explaining to other pupils why there was 'one rule for John and one for everyone else'. Computer and homework clubs provided a haven for John at lunchtime, which would otherwise have been a difficult time socially for him. His interest and skill with computers provided a basis for, if not close friendships, at least positive social exchanges with peers.

Without the provision of the Statement, the school could/would not have felt able to meet John's needs and he would have been permanently excluded, most likely in Year 9. So the very least that can be said is that the Statement provision 'bought' John time in school. Whether this in itself was a 'good' or 'bad' outcome, I shall discuss later.

John's psychiatrist moved on to be replaced by another. John was antipathetic towards him:

John: *...he immediately asked...started saying that I should go on some other drug. I didn't want to...because...er...I've been on Ritalin for years... and it hasn't helped...and...I felt in myself that I didn't want to change. Er...it was other people's opinions of me that...er...that...er...that weren't right...like teachers saying that I was cheeky or something...but in my opinion...I wasn't being cheeky...I didn't really want to start on some other form of drug...so I said to him...no. I didn't want to do that.*

John: *...and also, I didn't like the way he spoke to me. He spoke down to me, y'know, although it was unintentional...the way you speak to people in a wheelchair or something...who're mentally disabled (John gave a mocking imitation) He did it to me and it **really, really** irritated me...er...I've never found anything more annoying in my life...so I said to my parents, I don't want to go and see him any more.*

Me: *So...er...he gave you this label as it were. What do you understand by it?*

John: *Hmmm...I'm not sure of the ins and outs of it...if you know...why I have it and what causes it. But I know it causes...er...er...autistic spec...erm...disorder...causes interpersonal problems...er...like people not being able to understand what people are thinking...really...since I've read a book actually...just one of the many that I've read...erm...have you read it?...it's er...The Curious Incident of the Dog in the Night-time*

Me: *Oh yes.*

John: *I...I've read that...I understood it...I understood the person...er...the person in the story...it's written **really, really**, well...the thought processes...it's just the same...to a great extent...with the person in the book...because I only suffer from it mildly...but...er...it...it helped me to understand what the problem was.*

John had been given a reason for his difficulties in school, and his reading of the novel had struck a chord with him. At the same time, he was adamant that he did not want to be prescribed drugs when he had perceived no benefit from previous drug regimes.

Were the provisions of the Statement and his understanding of the diagnosis sufficient to account for the change in John's behaviour which happened from Year 11? No, but that is not to deny that all of the above in total did contribute to helping John to cope with school and, it has to be said, school to cope with John. Crucially, the combination and dynamic interaction of all these factors allowed him to survive in school to the start of Year 11.

John's Attributions of Change

John: *Towards the end of Year 10...I star...I think I started to mature more, and I started to think...right...I've got my GCSEs...I've got my goal at the end...I started heading for that. That's...I think that's when I started working better...and so throughout Year 11, I've had compliments from teachers...how much I've changed. I keep on doing well in work. I've gone up in sets in all my lessons and I've really started...I've got a goal now. I can see the light at the end of the tunnel...and I'm trying my hardest to get*

there...over the summer I went to visit ...College (a local college of Further Education) ...and I really...instantly I thought...I could be here in twelve months time...and this is exactly what I want to do...and since then...I've had a real goal. I've really tried to work hard since then.

Me: *What is it you want to do at College?*

John: *Oh well...I've been accepted for a B-TEC National in IT...on condition of my getting four GCSEs, which isn't particularly difficult and...you see...I've been accepted for that course...which should be good...er...it was the most advanced IT course I could choose at the time.*

John suggests two reasons for the improved situation in Year 11. Firstly, maturity and secondly, having a goal. Later, when the tape-recorder had been turned off and as I was leaving the house, a third reason emerged – that he had had a different support assistant with whom he engaged particularly well. I was not able, on this occasion, to investigate the particular qualities of the support assistant but her influence was clearly a contributory factor. I failed, on this occasion, to ask John to expand on what he meant by saying, 'I started to mature more' but contrast it with a later comment with regard to his improving relationships with some peers, 'I don't think anything in me changed...I think it was other people...I think other people grew up'.

Having a goal was, it appears, the essential factor in John's changed behaviour in school. The attribution of the SENCO that, 'He just seems to have made his mind up...' appears to have been correct. Other factors had made it possible for John to survive in school to that point, but it was only when John could actually imagine himself doing the computer course at college that he really understood what he needed to do in school. The verbal exhortations of exasperated staff had failed to make this crucial link between school work and future life opportunities. Once his future was concretised in this way, John became motivated to work more consistently and behaved more normally in class. This made improved social relations with peers possible and eventually created the virtuous circle of positive outcomes that characterised his final year in school. It was the

vision of a different life after school that was the spur to John's newly found motivation to succeed in school, but in that he is arguably not alone!

One possible theoretical framework to understand his behaviour might be expectancy-value theories which hold that people are goal orientated. Two factors make students want to achieve, firstly, that whatever the goal is, it must have value to the learner and secondly that the goal must be achievable. This certainly appears to have been true of John. It is interesting to speculate on whether or not this might be a characteristic motivational style for people with Asperger's Syndrome.

A Successful Outcome?

As reported to me later by the SENCO, John's psychiatrist, in a meeting with parents and school staff in Year 10 (at which I was not present) told staff that the biggest favour they could do John was to permanently exclude him, because mainstream education was unsuitable for him. He repeated this opinion in a letter to John's GP, copied to school but not to myself. There can be no doubt that there are a number of competing narratives about John; professional, educational, social, medical and familial. The concept of success is relative and open to different interpretations. I argue here, against a different professional view, that keeping John in mainstream school was appropriate and that this placement was successful.

Firstly, I was acting in accordance with the expressed wishes of John and his family for whom academic qualifications were considered important. Had John's GCSE curriculum been disrupted by his leaving school, it is uncertain that he would have been able to sit these examinations.

Secondly, exclusion (formal or informal) from a third school would have been perceived as failure in the family, exacerbating already strained sibling relationships and contributing to an unhelpful family discourse surrounding John. Knowing that he completed school in a similar way to his siblings has reduced John's sense of otherness within the family.

Thirdly, I was acting in good faith in that my actions in this case were congruent with my own genuinely held beliefs regarding John's best interests. Just as the Statement can be said to have been a means to an end, so the acquisition of GCSEs, admittedly a stressful process for John, opened doors for him, which would otherwise have been closed, and thereby increased his life choices

Fourthly, there is the human rights argument that John was entitled to an education consistent with his abilities and that he should not be denied that education on the grounds of perceived disabilities.

Fifthly, and from the point of view of the Children's Services Authority, the placement was successful in that John's needs were met in mainstream school provision without the need for out-of-school or out-of-county provision. Arguably, the experience of knowing John has benefited pupils and staff at the school by increasing their understanding and acceptance of difference.

Finally, I believe that, having experienced and survived mainstream secondary school, the chances are now greater of John going on to develop a career and becoming independent and financially self-supporting. This is consistent with the *Every Child Matters* agenda and is of benefit to society as a whole

Against these arguments could be put other arguments which point to the undoubted stress which John experienced in school, including some not inconsiderable bullying; his relative underachievement academically, given his high IQ; the emotional strain on the school staff who, in my opinion, have been nothing less than heroic in their efforts for John; and, conversely, the human rights argument that John had a right to an educational experience which was more appropriate to his autism.

It is possible to imagine an altogether less happy outcome for John when I recall some of the lowest moments of this particular journey. Given exactly the same decisions on my part, motivated by that same good faith, but with a different outcome determined by unintended consequences, my role and the success of the outcome might be judged differently.

John has the last word:

I've made friends in Year 11...I've got on top of work...I've got light at the end of the tunnel. It's a really...really brilliant part of my life...I've matured and got on with it.

References

Millward, C., Powell, S., Messer, D. & Jordan, R. (2000) Recall for self and other in autism: Children's memory for events experienced by themselves and their peers, *Journal of Autism and Developmental Disorders*, 30, 1, 5-28

Williams, D. (1996) *Autism: An Inside-Out Approach*, London, Jessica Kingsley