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It's not Autism. It's Your Parenting. An Autoethnographic Exploration of the Relationships Between Professionals and Parents of an Autistic Child in the UK

Barbara Mitra

The aim of this paper is to chart the journey of parenting an autistic child (referred to as AJ) in the UK context, drawing on diaries, records and notes kept during his primary school age (5-11). Using autoethnography, I explore the continued disbelief I faced by professionals regarding the link between autism and behavior. Instead, our parenting was continually questioned and assumed to be ineffective. This was despite an official diagnosis for the child at age seven, initially of Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder, and later, at age eleven, changed to Autism Spectrum Disorder and Pathological Demand Avoidance tendencies. It was also despite having an older child (four years older) who functioned well throughout his education and was considered to be a model student. The purpose of these vignettes is to explore how engagement with professionals actually traumatized us as a family and caused us untold stress and pressure.

Methods: Autoethnography

Autoethnography uses “the researcher’s personal experience as a source of data” (Tavella, 2018, p.59) and connects “the personal to the cultural” (Hughes, 2012, p.95; Ellis and Boucher, 2000). It can reveal valuable insights into informal and real-world aspects about particular situations and circumstances. It is about gaining deep insights from the broader stories. Autoethnography draws on insider perspectives, using ourselves as research subjects, reflecting on our experiences and using what Humphreys (2005) calls “vignettes” to generate innovative and evocative texts (p.842). These stories are based on records kept throughout the diagnostic process and beyond (focusing here from when AJ was aged 5-11 years old). These fieldnotes (which are ongoing), provide rich accounts of the interactions with

professionals relating to the autistic child, primarily from my own viewpoint as a mother, but encompassing opinions, comments, and details from all those involved. These stories are “grounded in particular moments” (Carless, 2012, p. 607) but add knowledge and insight regarding the impact that professionals and organisations have on parenting an autistic child.

Pathological Demand Avoidance (PDA) and Parenting Stress

While I was given much information about autism as a “lifelong developmental disability” (McCafferty & McCutcheon, 2009, p.1; Leveto, 2018, Miranda et al., 2019), no professional mentioned Pathological Demand Avoidance (PDA). Listening to my own “gut” feeling that the ADHD diagnosis did not quite fit—particularly as AJ was able to concentrate and focus for long periods of time and was not hyperactive—I continued to explore different aspects of autism. As a result, through my own extensive research I came across PDA, a term coined by Newson et al. (2003) to describe “children within the autism spectrum who exhibit obsessive resistance to everyday demands and requests” (O’Nions et al., 2016, p.407). When I read about the characteristics of PDA, which included “manipulative behavior, difficulties with other people, harassment of others, fantasizing, lying, cheating, stealing and socially shocking behavior” (O’Nions et al., 2016, p. 408), it was like a lightbulb being turned on, as it seemed to describe much of AJ’s behavior. I also knew that the classic strategies we were being told to use did not work and often resulted in major meltdowns which increased my own stress, as well as the anxiety and stress of AJ himself.

Stress involves “a mismatch between perceived resources (e.g. knowledge and self-efficacy beliefs) and the actual demands of the parenting role” (Morgan et al., 2002, p.219). This results in negative feelings towards the self and the child, attributed to the demands of parenthood. The difficulties associated with raising an autistic child and more specifically a PDA child, results in chronic stress (Miranda et al., 2019; Hutchinson et al., 2016). I found the process of getting a diagnosis (which was drawn out over a number of years) as well as misdiagnosis and disbelief of issues actually resulted in higher levels of stress (Epstein, 2007; Crane et al., 2018). It is often the case that disruptive behavior is one of the most common reasons for referrals of children with autism (Epstein, 2007). Indeed, I came with worries and

concerns about AJ's behavior which had already led to several school exclusions and was viewed negatively by other parents and professionals (Hutchinson et al., 2016). This led to us being excluded from social activities with other families (McCafferty & McCutcheon, 2020, p. 7) which made us feel isolated and alone.

It was at this time that we sought the help of a psychotherapist whose first question to me was "Was he a wanted child?" We had suffered a miscarriage before AJ was born, and I told the psychotherapist that AJ was clearly wanted. We were desperate to understand AJ's behavior and thought seeking some counselling or therapy might help, especially because the NHS Child and Adolescent Mental Health Service had rejected our request for support. The therapist told us that we had to be extremely strict with AJ and that he must sit up at the dinner table to eat dinner and we had to enforce this rule. AJ still remembers being traumatized by us making him sit at the dinner table to eat a meal with us after seeing this therapist, and recent research suggests that autistics exposed to ABA therapy may be at increased risk for PTSD symptoms (Kupferstein, 2018). After three hours of AJ sitting at the table, we decided that the approach really was not working. Needless to say, we decided to find out more about the PDA strategies to see if they were going to work. AJ also asked not to see this particular psychotherapist again. Rather than supporting us in our parenting, this all placed extra stress and strain on us as a family, as well as traumatizing AJ by employing strategies that only heightened his anxiety.

Our stress was also exacerbated by professionals and family members who continually told us that "more effective discipline" (McCafferty & McCutcheon, 2020, p.7) was the issue, as well as by family and friends who continually questioned the autism diagnosis (Iadarola et al., 2019), suggesting "he's not really autistic" based on stereotypes, perceptions and misunderstandings of autism. This made the process of even asking for referrals difficult. The headmistress of AJ's school initially said, "I don't know why you want to have AJ assessed" until his behavior became so disruptive with violent meltdowns that there were clearly issues. This led professionals and family members to question our parenting styles rather than supporting us through the diagnosis process. Nor did professionals seem interested in helping us find suitable strategies to help our child function well in different contexts. Instead, this continual questioning of our parenting styles

exacerbated the stress, trauma, difficulties, and anxieties that we already had coping with AJ's behavior.

It also added to the stress and anxiety AJ himself was experiencing: the parenting strategies actually aggravated AJ's behavior as they were not applicable for a child with PDA tendencies. For example, instead of consistency, AJ needed flexible strategies and changes of routine and structure to engage him. We were told we had to be very rigid with the strategies we were using, such as reward charts. As parents, we knew that reward charts would not work but we were told this was what we had to use. AJ would come home and rip up the reward chart every time we made one. This added to both his stress and our stress as parents resulting in AJ having protracted meltdowns. As noted by Iadarola et al. (2019) parents' ongoing concerns about their child tend to be ignored, often stemming "from a perceived lack of respect of parent opinions" (p. 26). Having to implement a strategy that I knew would result in distress for AJ, was equally distressing for me. It also led to low self-esteem and self-worth in our abilities to parent AJ, despite our older child functional well at school and home.

Vignettes About AJ at Primary School: Raising Concerns

During Year 1 (UK, English system), when our son was five, we began to raise concerns about his behavior at school and at home. This often resulted in violent meltdowns which lasted up to two hours (or longer). Alongside these meltdowns were violent episodes at both home and school, which included throwing things, hitting, kicking, scratching, verbal disruption and sometimes running away. We asked for meetings with the headmistress and when this was eventually agreed, the headmistress commented "Did you drink [alcohol] while you were pregnant?" I was stunned as I had been extremely cautious about both what I ate and drank throughout pregnancy and beyond. Additionally, I had been a parent who had regularly attended parent/teacher meetings for AJ and also for our older child. I was always present, engaged, and clearly health conscious. There was no obvious reason as to why I should be asked about whether I had drunk alcohol. This was the first of numerous accusations about us as parents and this kind of interaction set the tone for interactions with other organisations where parental blame seemed to be the first concern of those we met.

As AJ continued during year 1 (5-6 years) and year 2 (6-7years), school began to send AJ home whenever his behavior was too much for them to cope with. The bottom line was that if he hit a teacher, he would be sent home. From AJ's perspective, this meant that once he had had enough of school, he would hit a teacher so that he could go home. These informal exclusions became very frequent, even when I pointed out that "informal" or "unofficial exclusions" were unlawful according to IPSEA (Independent Provider of Special Education Advice, 2021). These led to formal exclusions and exclusion letters—over 27 of these during years 1 and 2 alone). These exclusion letters detail "You have a duty to ensure that your child is not present in a public place in school hours" along with expectations about what the child is expected to do. For example, one such letter noted "As I informed [father] for the remainder of this afternoon AJ is expected to write his own version of the Easter story . . . this should be returned to school for marking."

The letters made no references to AJ's heightened emotional state of distress and the fact that while immersed in a long and protracted state of anxiety, AJ would not be able to focus on completing schoolwork. These exclusions were often followed by extreme behavior at home, including intense feelings of guilt, shame, feeling "bad," and worst of all, substantial self-harm which could last for two-three hours and sometimes longer. AJ was too young at this time to understand his own behavior. He certainly wouldn't be able to write an Easter story following such an exclusion.

Another exclusion letter (24/06/2014) noted "He was excluded for this fixed period because he scratched a member of staff, following this with an extended period during which he kicked, grabbed and scratched at staff who were keeping him safe and preventing him from setting [off] the fire alarm. AJ also attempted to bite more than one member of staff and tried to punch another in the face. The length of this exclusion reflects the increasingly dangerous nature of AJ's behavior." It continues "I must remind you that, during any period of exclusions, you have a duty to ensure that AJ is not present in a public place during school hours, unless there is reasonable justification for this. You may receive a penalty notice from the local authority if he is present in a public place during school hours on the specified date." Clearly, the description of AJ in the letter shows a child who is anxious, distressed, agitated and distraught, resulting in his extreme behavior. School did not offer any discussions or suggestions as to why

AJ was behaving in this way and they did not offer any support to discuss possible diagnosis. Instead, we were made to feel that we, particularly our parenting styles, were to blame for AJ's disruptive behaviors, again adding to our own stress, anxiety and feelings of inadequacy, even as we tried to support and help our son.

Vignettes About Parenting

In one of the fortnightly meetings with school in 2013, it was noted "It is felt that in school AJ has learned that "no means no" and has a better understanding of boundaries. Staff are being consistent with expectations and strategies" and "he needs structure, visual support, calm environment and routine." Between fall and summer, though, AJ had 27 formal exclusions, suggesting that school were still struggling with AJ's behavior, despite their consistent expectations. Another meeting with school noted, "Recommend [father] uses repetitive language. It's home time now." The attitude of school seemed to suggest that if parenting was clearer and stricter then AJ's behavior would improve.

School was not interested in understanding why AJ was engaging in disruptive behaviors. There was a chasm between what school were interested in (AJ to behave in a non-disruptive manner) and what we as parents were interested in (finding out what was causing the disruptive behavior and addressing the underlying causes). By ignoring any underlying causes and assuming that parenting was at fault, school continually undermined our parenting with phrases such as "act like you're cross" and "put on a show to show you are not happy with his behavior" or "You're not cross enough." In fact, the words "ineffective parenting" were mentioned at various meetings. We continually worried about doing and saying the "wrong" thing as parents at home and at school. In fact, AJ would respond to us being "cross" with further meltdowns and self-harm, which greatly added to our anguish and caused particular trauma for AJ.

One of the clashes with school strategies was that AJ was not always showing classic autism traits and did not respond well to classic autism strategies. It was during the next few years (2014 to 2016) that we became aware of Pathological Demand Avoidance (PDA) and started investigating this for AJ as

it seemed to fit his profile. This led to more questioning and comments about ineffective parenting.

Things came to a head regarding parenting when a child protection conference was called after an incident when AJ refused to go to school. The paperwork for the conference confirmed the lack of respect for parents due to inaccuracies in the paperwork, such as ignoring my ethnicity (mixed race) and giving incorrect details about AJ (his eye color was incorrect). The conference began,

There are on-going difficulties with AJ's behavior. He is still having a tendency to run when he is unable to cope with situations. He shows high levels of anxiety and frustration when he is unable to communicate. His response to distress is shouting, hitting, biting and even turning tables over at school" (Community Pediatrician Report 12/29/2015).

However, once other professionals began to question our parenting during the meeting, the same pediatrician was quick to add that "Parents have never put boundaries in place, therefore I would be very cautious about saying AJ has PDA. Behavior may be a result of parenting." In that moment, the pediatrician changed her stance from supporting us to challenging us, reinforcing the headmistress' opinion that "AJ is allowed to act inappropriately without boundaries at times...an example is AJ running around the car park at home time, when this would potentially cause a hazard to him."

School, the pediatrician and other professionals were clearly unaware of boundaries such as bedtime, bath routines, the internet being turned off, all methods we used to get AJ to behave. These professionals also seemed to be unaware that transitioning can be very difficult for autistic children. Instead, we were criticized and continually berated for our lack of ability to parent as the direct cause of AJ's behavior. As a direct result of the stress and anxiety caused, I began to suffer with migraines and dizzy spells. It also placed anxiety on us as a family, and our older child (HJ) later told us he felt he had to behave extremely well in order to compensate for his brother. I had talked through various scenarios with HJ about what to do during AJ's violent meltdowns, including to leave the house if he felt unsafe. Perhaps this was

one reason that HJ took up martial arts and is currently hoping to take his blackbelt in karate.

Parents at Fault

The child protection conference was very keen to put AJ on ADHD medication, noting “ADHD medication [had] been refused by parents. Children with untreated ADHD develop self-esteem [issues] because they are failing and don’t succeed.” The community pediatrician added to this noting she had “suggested treatment for ADHD which parents refused as they said they didn’t want to manage his ADHD with medication.” As parents, we had always thought the ADHD diagnosis didn’t quite fit because AJ was able to concentrate on tasks for extended periods of time and was not hyperactive. The psychotherapist whom AJ had seen three times was invited to the conference, largely because they believed “AJ does not present as a child with ADHD and parents are quite right to refuse medication.” If the psychotherapist had not been present, then the outcome of the conference would have been to insist on AJ being put onto ADHD medication. Parental concerns were not listened to, nor concerns about ADHD not fitting AJ’s profile.

Other interactions with professionals were given a negative spin at the meeting in a way that had not been present in other meetings. For example, it was noted “Parents say they have been asking for support for some time: in fact, evidence suggests that support has been offered and parents have been reluctant to accept. The mother was offered a positive handling course and she was not able to go due to work.” I had been offered this daytime course at short notice. We had attended as much as possible (a Triple P Parenting course; engaging with family support workers; Occupational health talks on sensory issues).

We also attended Pastoral support plans with all the schools that AJ attended (usually fortnightly) and made it a priority to attend any parent/teacher meetings. One of the phrases that cropped up was again referring to parenting needing to “go back to basics” and that our parenting needed to be addressed. This led me to keep detailed reports of trying to implement the suggested strategies and describing in detail the meltdowns that resulted. For example, we had asked for help with the bedtime routine. We were given the following instructions “Bath time 8.10pm. If you go up later than [this]

bath time should last 7 minutes or less. After the bath, AJ should go to his room to play and finish by 9.15pm and make sure any medicine [is] taken, ears cleaned, teeth brushed, bedclothes on, hair dry. In bed for story time to get to sleep by 10pm. After 9.45pm AJ will have to turn out his own light/story.” We knew that any direct command would lead to meltdowns and I started to keep a behavior diary so that we could not be accused of ineffective parenting. For example, one entry on 28/07/2016 at 8.45pm “AJ was talking about dying” and while we continued to try and follow the bedtime routine I noted that “it took about 45 minutes to stop AJ trying to open the window and to stop saying he wanted to kill himself.” Another diary entry included “AJ was refusing to go to bed and have his bath... and was shouting and screaming” and later “AJ was screaming and crying and running downstairs.”

Clearly the bedtime routine we had been instructed to use was not really working. As well as struggling with transitioning from one task to another, AJ also struggled with strict routine, a manifestation of PDA. We had to show that implementing the strategies that professionals suggested actually resulted in extreme (and sometimes violent) meltdowns. It was emotionally exhausting to see AJ harm himself and talk about suicide, but this was further impacted knowing that we had to use these strategies to prove to school and other professionals that they simply did not work with AJ. It was traumatic to put a child that you care for through such suffering and unhappiness because professionals believed it was all down to our own parenting. This was reinforced after the child protection conference when a child plan was put in place that included phrases such as “I am concerned about parenting strategies...We need some in place...what we wouldn’t want to see is parents becoming permissive” (11th October 2016, Social Worker). Early etiology about autism blamed parents, particularly mothers, for the condition (Haney et al., 2018) and this legacy, it seems, still influences professionals who work with parents of autistic children and post diagnosis parents are “often left to manage the situation alone” (Crane et al., 2018, p. 3761).

Discussion

The professionals, clinicians and teachers involved with AJ during his most formative years tended to begin with “ineffective parenting” (Iadarola, 2019, p. 25) as their starting point, despite the fact that we had a high achieving and well-behaved older child. Each agency reinforced the other with this

opinion where information was being selected to reinforce pre-existing notions (Kappes et al., 2020). The various agencies clearly believed they had the best interests of AJ as their focus, but they were very quick to resort to a “blame narrative” (Davis & Manago, 2016, p.80) which added to extra stress on us as parents already trying to understand and manage AJ. Our concerns and requests for support were rebuffed with, “you don’t take up our support” and we were clearly told we needed to have clearer boundaries, and our parenting needing to be assessed.

Feeling unable to help AJ and frustrated by the lack of support from clinicians, teachers and professionals, I researched numerous conditions to see if anything applied to AJ. After much investigation I came across PDA on an autism website and the PDA strategies seemed to work much better than the ones we were being “told” to use. I also kept records of all interactions, emails and comments in order to make it much harder to blame us for parenting and to show that we did have clear expectations and boundaries documented. An emotional burden was placed on us to “prove” that we had expectations of AJ in relation to his behavior. The record keeping was quite intensive, as I would document every daytime, pre-school and after school incidents and meltdowns. Bearing in mind I was working full time with a demanding job at the same time which led to feelings of being overwhelmed and frustrated at the lack of support and help for AJ and also for us as a family.

Instead of criticizing parents and assuming that they are to blame, it would be much less stressful and more supportive for parents to “receive help through family-centred support services that offer counselling in order to decrease their stress levels by using appropriate coping strategies and other resources” (Miranda et al., 2019, p. 10) to improve family life. It seems that on our journey of parenting an autistic child, instead of the support and help we needed, our parenting skills were continually questioned, adding to our stress, which in turn impacted on the stress on AJ. The family support workers did not have training in autism and were learning about PDA from us. The strategies suggested by the family support worker were often for neurotypical children rather than someone with a PDA/ASD diagnosis.

Parents in a heightened state of stress and anxiety are going to find it more difficult to engage with behavioral issues in a positive manner (Osborne et al.,

2008, p.69). Not only does parenting a “child with ASD places considerable stress on the family” (Bhagat et al., 2015, p. 405) but having to deal with additional concerns from professionals, clinicians and teachers exacerbate that stress, leaving parents in an emotionally weakened state. Alongside this, being asked to implement strategies that we knew would result in meltdowns with AJ expressing suicidal thoughts and self-harming was even more distressing. I am fortunate that I am a well-balanced, confident person who has not struggled with mental health issues or low self-esteem. It is not hard to see how someone who has less confidence, or someone who struggles with anxiety or stress, may find themselves with overwhelming distress about their own parenting. This, in turn, would also then impact on the child, adding to the child’s stress and anxiety, intensifying any behavioral issues. It is also easy to see how someone who is unable to raise issues and counteract inaccuracies would be left with very little self-worth regarding their parenting. It seems that despite it being more than 50 years since Leo Kanner first described his classic autism syndrome, there is still a legacy of blaming parents for an autistic child’s behavior (Haney et al., 2018).

Conclusion

Autism is a lifelong developmental condition and is complex, with children exhibiting different characteristics that play out in terms of behavior. Parents themselves are often under great stress and want to help their child. Childhood is a formative time for children, but stress and trauma are often exacerbated for both the parents and the child, particularly due to professionals questioning parenting styles, rather than focusing on the links between autism and behavior. This autoethnography highlights the particular stress and trauma we faced throughout the primary school years of AJ as we were labeled “ineffective parents” and blamed for our child’s behavior and disbelief about PDA. There was also a general lack of awareness by all professionals about how autism might impact on AJ’s behavior. Parental concerns were often cast aside and not heard, so that we seemed to be in a continual battle with professionals, rather than working alongside as partners. I hope, that by documenting these stories that it will help professionals, who themselves are often inundated and extremely busy, to begin by listening to parental concerns. I also hope that more training could be given to professionals who are working with parents going through various diagnosis, especially when parents believe a specific diagnosis doesn’t

quite fit their child's profile. If such perspectives could be included in training programmes for clinicians, teachers, occupational therapists, psychologists, family support workers and others, it might go some way to mitigate the stress and trauma that these professionals add to both parents and the autistic child themselves.

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