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Crash the Clinic

David Steare and Amanda

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Abstract

This is an edited transcript of the 4th Autism and Systemic Practice Conference 2023 presentation in which David asked Amanda some questions and Amanda shared the story of her family trying to get her for their family. David shared some of his responses to the wider issues in stanza form. Amanda is a parent of two young women and David is a retired systemic practitioner working voluntarily to support local families with neurodivergence. Amanda's words are in ordinary font and David's are in italic.

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Amanda's Story Part One with David's brief comments

My name's Amanda and I'm a late diagnosed autistic ADHD (Attention Deficit Hyperactivity Disorder) person age 45 and parent to two young autistic women age 21 and 17. My mum was diagnosed probably incorrectly with bipolar disorder as she was probably also neurodivergent and experienced long term problematic mental health including being on a section when I was a young child, she passed away sadly at age 48.

About me, I didn't perform or manage particularly well at school but I do have a first class degree now having gone to university in my 30s when I had two young children to juggle. My degree is in HR (Human Relations) and Marketing which is important to me as I'm very interested in both equality and communications, I enjoy investigating possibilities and outcomes for neurodivergent young people and adults as they are underrepresented and marginalised in our current UK workforce. I am particularly interested in encouraging SEND (Special Education Needs and Disability) parents also, who may feel unable to work in a traditional paid role out of the home, but have so much to offer.

I volunteer as a parent peer supporter for local families who've experienced barriers to education and I also help plan and deliver events supporting women and girls causes in my spare time. I've been self-employed as a consultant and job coach. I never really sit still, my brain's always on the go, lovingly described by my ADHD coach is a constantly revving Ferrari brain. I did always wonder why I struggled with certain aspects of my life, socially at school and at work. I didn't manage to stay in work environments for more than two to three years, and I always felt as though I would find out why that was and there would be some explanation of the restlessness and dissatisfaction. The answers I got of being autistic and having ADHD were not what I was expecting.

So today I'm going to talk about my daughter, my youngest daughter's journey who is now 17 and how things began to unfold for her in 2019.

Thank you, Amanda. I can't remember when we first met, so I think I think we met in early late 2019 or early 2020 at the parent carer forum for our local Authority. Can I just ask you what was what was it like for you and your family before you tried to seek help?

We had a very normal family life, very happy, two very quirky children who are very specific and independent and knew exactly what they wanted. Everyone in our home has always been quite literal and eccentric. We've always trod our own path as a family, we were never really authoritarian; we were quite relaxed. Our kids never stopped asking questions all the time which we encouraged. Our youngest daughter was very high energy, highly athletic, sociable, and very determined. She would do several things at once, looking back this was a need for stimulation.

Once she went to her large catholic academy senior school, the wheels completely started to come off about nine months in and school contacted us in June 2019 to tell us that our daughter had written in a book that she didn't know who she was, was living a lie and wanted to die. Prior to this nothing was ever on the radar for us of in terms of either mental health or neurodivergence, we thought that they made a mistake and had the wrong student. I couldn't even believe the phone call later after this asking us to come collect her as things had had escalated to self-harm with scissor blades, and following this she made firm covert plans to end her life age 13. By this time, she was involved with the NHS (National Health Service) because we'd have lots of incidents at school including self-harm on their premises, but no one was listening and there was no urgency or concern. The only thing the health provider would say is that they thought she was autistic, but we were also told we might be able to tell you that in two to three years, this was in January 2020 around the time we also thought Covid was something that was happening to somebody else across the world.

So how did you experience this response to your daughter and to you as a family?

Then it was really hard, it was it was really difficult. We didn't know what to do. We started looking around for other options in terms of diagnosis because we couldn't wait two to three years. She was already crashing as it was, and we just needed some certainty and some help really.

David’s poetic provocation entitled ‘psychogenesis’

In the beginning the clinic created pathology and autism.

And autism was without diagnostic criteria, and lacked research evidence;

and controversy was upon the gateway of health.

And the professionalisation of the clinic moved upon the gateway of health spending.

> *And the clinic directed, "Let there be diagnosis": and there was diagnosis.*
>
> *And the clinic viewed the diagnostic process, that it was good: and the clinic distinguished diagnosis from controversy.*
>
> *And the clinic called diagnosis Health Care, and controversy the clinic called Irrelevant.*
>
> *And assessments and care pathways became obligatory.*
>
> *And the clinic directed, "Let there be policies and procedures in the midst of our health spending, and let accountability divide and rule."*
>
> *And the clinic made policies and procedures - dividing health spending which were under the policies and procedures - from government budgets which were above policies and procedures: and it was so.*
>
> *And the clinic called the policies and procedures NICE.*
>
> *And diagnostic assessments and care pathways were now beyond question.*

NB NICE. stands for the National Institute for Clinical Excellence, a British Quango (Quasi-autonomous non-government organisation).

Amanda's Story Part Two (with David's brief comments)

So to continue your story Amanda what was the experience of seeking diagnosis?

We had the door shut in our face by our daughter's school who literally said to us and I quote "no diagnosis, no help, nothing we can do for you until you've got a piece of paper that will tell us what to do". Of course nowadays we know that isn't true but as people that were new to this we just accepted what we were told by what we thought were the experts. Left with no option but a two-year wait, we had to pursue a private route for our daughter.

So can you tell me what you did next?

So for our daughter we sought out a private assessment with an independent psychiatrist who was able to provide her with medication to help bring her anxiety down. We used a doctor recommended by another parent who by complete coincidence had been through similar. Of course nowadays we know it's a familiar story up and down the country for women and girls who go under the radar to burnout in our outdated education system.

What happened on the day when you received the diagnosis?

So on the day we had our diagnosis, school texted us to tell her to tell us not to send her again because she had asthma. She was considered vulnerable to the new novel virus that we were all worried about in March 2020. So that happened on the exact same day that we were told she was autistic in the private clinic, we were also told she a had pathological demand avoidance profile which is something not a lot of people want to talk about but that's what we were given, as well as ADHD traits and sensory processing disorder. Our daughter was delighted she no longer had to attend the school site and was happy to do all her work from home.

We told those nearest to us about the diagnosis from this private psychiatrist and they didn't really seem to believe it because she'd always been so happy and well-adjusted, doing really well at school and it seemed like they didn't really want to accept that something like that would be in their family. Most people didn’t know what to say as they didn’t know anything about autism, except what was in the media, which didn’t correlate with our daughter’s presentation and personality. There was even an element of parent blame, but the suggestion of autism and assessment had come from the NHS, it was never even on our radar.

We honestly didn't really care what the answers were, we just wanted some help however that looked, just to be able to manage and move on from the escalating self-harm and suicidal thoughts that our daughter was having.

David’s second poetic provocation entitled ‘diatribe according to David’’

> *In the beginning was the medical narrative, and the medical narrative was with the clinic, and the medical narrative was the clinic.*
>
> *The same was in the beginning with the clinic.*
>
> *All concepts were made by the clinic; and without the clinic was not any medical or therapeutic narrative made that was not made.*
>
> *In the clinic was correctness; and correctness was the people’s guidance.*
>
> *And the guidance shineth in controversy; and controversy comprehended it not.*
>
> *There was a person sent from the clinic, whose name was Kanner/Asperger.*
>
> *The same came for an expert, to claim authority of neuro-correctness, that everyone might believe.*
>
> *Kanner/Asperger was not that neuro-correctness, but was the author of that neuro-correctness.*
>
> *That was the neuro-correct power and truth, that corrects every person that is born into the world.*

Amanda’s Story Part Three (with David’s brief comments)

So to conclude your story Amanda: following diagnosis what was life like afterwards?

So given that we've been told this at the beginning of 2020 things move really slowly, everything was closed we didn't really hear from anybody for a while because as you all remember life just stopped. The health service put all of our daughter’s mental health issues which were actually largely school based emotional trauma and deliberate gaslighting down to autism so they could offer no help and say we are not commissioned for autism. They wrote us a letter which was a complete avoidance saying everything that she's ever experienced is because of her autism, which simply wasn’t true. So we ended up going back to the private doctor who prescribed anti-anxiety meds and sleep medication to help, we had to pay for all of this, which the bill ran into thousands of pounds just to see somebody, because there just wasn't anybody helping.

I had to attend A&E (Accident & Emergency) in the early hours with my daughter right in the middle of Covid in June 2020 which was horrific as she escalated and needed urgent assessment. It's not something I'll ever forget because we were scared to go to hospital to ask for help with a mental health crisis. But because of what was lurking potentially at the hospital, and our daughter was clinically vulnerable with asthma we were told to shield her and not take her out, but we didn't have a choice. I had a child who didn't want to live, who needed to be assessed by health professionals and I had to take them into an emergency setting to see staff who were understandable genuinely terrified of contracting covid, it was one of the worst days ever.

Whilst everybody else went to school in September 2020 in the safety bubbles and covid safe strategies to separate students, she went back and was just edged out gradually and strategically by school staff who didn't want to know, as they had too much of an ego after being asked by parents how they were helping and what they were doing to support. She didn't make a month of attendance, by the end of September she was out of school, they wanted her gone, they didn’t like being asked what they were doing but seemed ok with accepting the funding through her EHCP (Education, Health & Care Plan). So they bullied her, exaggerated the tiniest bit of behaviour they could, phoned home and fed back whatever they could in order to paint her in as worse light as possible, in the hope we would agree. I assume so they could pack her off to a PRU (Pupil Referral Unit), except we knew our daughter and we knew, as desperate as she was, there was no way any of this could be labelled as behavioural choices.

School staff had honed in on her on the first day back in September, in fact, the morning she went back, citing her socks (with trousers) as an issue, pulling her individually out of class, knowing that all this had happened to her and how vulnerable she was. All interaction was designed to either provoke her so they could cite poor behaviour, or just in general grind everybody down. Eventually it just it had to stop as she was making herself vomit and said she would end her life on the premises if she was forced to continue attending, as the staff made her feel so hideous and ashamed. So, we ended up with no school place for 12 months.

Our daughter's a very smart capable academic young person who wanted to learn, who'd always wanted to learn, she was never on anyone’s radar for misbehaviour and school simply didn’t know how to label her, so she became a problem they could misrepresent and degrade to get her out, until she could take no more. For her own safety we refused to send her and she was too ill to attend, directly because of the school’s behaviour and failure to support, despite having all the funding from her EHCP.

We had to take our Council to the SEND Tribunal in the middle of all this, whilst supporting our very poorly daughter as well. It took some doing but we sourced a place at a really fantastic school that had a lot of experience with PDA (Pathological Demand Avoidance) which happened to be on our doorstep through sheer good fortune, but we'd never heard of it. The independent specialist school was very expensive and there was a lot of reluctance on the council's part to fund the place but finally she was somewhere she could recover, rebuild, and have some peace, with staff who wanted to help and understood the challenges.

The cost to mine and my husband's marriage really was that it was at the point of collapse and we continue to struggle and recover from the fallout not to mention the debt, since I had to give up my job to focus on the home crisis. Having to take your own Council through an imbalanced arduous legal system just to get a school place is entirely ridiculous. Especially when the local authority have their own legal team and hire a barrister to oppose you, using the public purse, whilst you can't afford any legal representation. My husband continued to work through all these challenges, in a really stressful job as an RMN (Registered Mental Nurse), whilst also juggling an extremely difficult situation at home and all the artificial barriers we found ourselves up against when we needed to access something other than mainstream education for our very academically capable daughter.

Young people who are academically capable but can't manage in mainstream settings are an afterthought in our education system. Both of our daughters are incredibly intelligent, one had a difficult mainstream experience in a different secondary school, which ruined her mental health but she is now finishing a Master's degree age 21 and starting a doctorate. Our other daughter's senior school marginalised her when she was at her poorliest and she has continued to recover fully and struggle ever since. The only people interested in genuinely helping her, was us. If it wasn't for our determination in holding budget holders to account, she would still be out of education.

We both really became carers, and our own mental health was in the floor, we found ourselves patronised, lied to and gaslit by the local Authority. They seemed completely out of the depth with our daughter 'othering her', so they tried to put her in a potential unopened alleged cheaper independent school planned which had no staff, no history of relevant provision delivery, no DfE registration, there was no due diligence, only budget management. This was a totally unsuitable suggestion which meant she couldn't have done any GCSE (General Certificate of Secondary Education) exams or had the therapeutic help she needed to recover. Our daughter now has long-term trauma from this adverse mainstream school experience and lack of mental health support at that crucial time when she was isolated, and she's only now just beginning to talk about it age 16. So today I just wanted to share that as parents we're exhausted, always compelled to repeat everything to everyone which compounds our own trauma from it, because no one reads the notes to explain what's happened. We are more often than not forced to focus on the deficits, the risks and the possible safeguarding issues, we just beg for the education crumbs everyone else's family is given as standard.

Everything's a battle, you have to evidence everything you ask for, I've never been in a process like this in my life, it's like being a lawyer who's working pro bono for somebody just to have their basic legal needs met. Nobody wants to talk about the things our daughter is fantastic at, all the talents that she's got, she's an excellent mathematician, she's a gamer, she has a natural way with animals, and so much empathy for other people. She's really funny and sarcastic and dry, there are so many things that she can do if she has the help from someone who understands, so thank goodness for the wonderful school she's still at.

We can look back on some of these days with our daughter during covid and we can kind of almost laugh with her at some of the stuff that we went through as a family because it was so ridiculous it doesn't seem real, and have a bit of dark humour about it because that's what we've always done. We have to be able to reframe it, put it in context and move on where possible. Probably the saddest thing about all of this and shared as someone that's trying to turn it into something positive to help other people, is that we are so very far from the worst story. We're actually quite a good example of working through this horrible system, surviving, and having a semi decent outcome. Things really do need to change, and quickly. Decision makers today ought to remember that the young people they tread on whilst they guard their budgets, are the future leaders and innovators of tomorrow.

Thank you, Amanda, for sharing your story and telling us about your daughter's journey.

David's third poetic provocation entitled

'A polemic from the Peak District' (where I live)

> *Do not judge or maintain thresholds, that you are not judged as having blocked diagnosis and/or service delivery.*
>
> *For with every assessment you write you can be assessed, and with the criteria you use it can be upheld against you.*
>
> *Why do you see pathology within anyone, but overlook the faults that others may see in you and/or your service?*
>
> *Or how can you say to your patient, 'Let my therapeutic intervention remove your pathology, but don't be concerned about my own practice?*
>
> *You! Clinician! First remove any idea of pathology from the concept of autism, and then you will become a person here and now - able to see clearly the neurodivergent person in front of you, needing something from you as a person as well as from you as a professional.*
>
> *Do not give your expertise to those who pay you, and do not throw potential pearls of wisdom before those who are wiser about the lived experience of autism than you, lest you get negative feedback and a sense of failure from them.*
>
> *Ask them what they need, and resources can then be offered to them; be curious and you will begin to understand them; reflect, and the collaborative way forward for you both will open up.*
>
> *Which of you, if your patient asks for diagnosis, will give them a lecture about autism instead?*
>
> *Or if they ask for advice, give them a list of other agencies instead?*
>
> *If you then, though you are a trained professional, know how to be useful to your patients, how much more will your patients give you positive feedback when completing clinical evaluation forms.*
>
> *So in everything, do to others what you would have them do to you, for this sums up the ethical basis of your profession as well as your humanity.*

Authors

David Steare is an independent systemic therapist and autism advocate.

Amanda is an autism advocate and parent of an autistic child.

E-mail: david.steare@gmail.com

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