



Carrie Grant

SPECIAL
EDUCATIONAL
NEEDS AND
DISABILITY (SEND) IN
UK SCHOOLS

A Parent's Perspective

Education Studies

Collection Editor

JANISE HURTIG

LIVED PLACES
PUBLISHING



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This book is dedicated to David and our children. Your stories are my world.

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A message from the author

A message to the learners, the curious and those who care about our young people.

I, and many parents like me, are desperate for you to be the best educator you can be. We are willing you to lead in fully understanding our children and giving them the best education they can possibly get. We champion you from the sidelines to become all you can be, working alongside us, so our young people can become all they can be. For the future is in their hands.

Carrie Grant

A note on language

In this book, I have chosen to use the most up-to-date preferred language in the United Kingdom, which is identity-first language – for example, I describe my children on the ASC spectrum as autistic instead of as people with autism. I also use Autism Spectrum Condition (ASC) to avoid the “Disorder” of ASD (Autism Spectrum Disorder).

Abstract

This book explores the experience of children who have special educational needs and/or disabilities (SEND) in UK schools, from the perspective of a parent. Through recollecting and reflecting on her own experiences and the experiences of her four children, the author sets the scene of the current educational context; reflects on the necessity of leadership as a skill; explores how collaboration does and could work in a school setting; considers the purpose of an individual strategy for each child; recounts the tools and strategies that have worked for her children; and questions what the future of education might look like.

Keywords

SEND, SEN, Special Educational Needs, Education, Parent Participation, School Experience, Inclusion, Disability, Teaching, Diversity

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Introduction

When they think of school, most people imagine a classroom with 30 children, a teacher, and a teaching assistant. Work is led from the front with the children listening, following, and working to a greater or lesser extent and at differing speeds. What we may not think about is that nearly one-fifth of the children in that class have Special Educational Needs (SEN) – also sometimes called Special Educational Needs and Disabilities (SEND). This could be a physical disability, a neurological difference, or a mental health challenge.

We also know that there are many children with SEN who are not in school, having been off-rolled¹ or permanently excluded. Add to this the 100,000 children in the United Kingdom who did not return to school after the pandemic, and it makes for an alarming landscape. SEN children have become collateral damage in the race of schools to get to the top of the league tables – or, at the very least, to avoid being shamed by finding themselves in the lower half of the league table.

This “all children learning happily together” image is the one I had when I started on my journey as a mum. I have four children, two in their twenties, one teen, and one pre-teen. Three are birth children and one was adopted, and all have additional needs, often referred to as Special Educational Needs. Even these words are problematic for me. My children are considered to have “needs” because they are outside the range of what is defined as “normal”. But who decides what normal should look like? Our

culture, history, traditions, our faiths? What about children who are considered “normal” – do they not have needs too? Why are needs seen as a bad thing to have? Would my children still be considered “needy” if we redefined “normal” and broadened the definition a little?

In 1966, early studies of autism showed a prevalence of 4.5 per 10,000 children (Lotter, 1966). If we jump to 2013, that figure was shown to be one in 50 (Blumberg et al., 2013). It could be argued that if this prevalence continues to increase, autistic people could be the new “normal” – they would then be the predominant neurotype.

Not being able to fit into a neurotypical world means those who are neurodivergent will always be expected to change and cope, and will often need adjustments made for them. When something is judged as working for the majority, it is very hard to get institutions or wider society to open up their thinking and consider another, more inclusive way of doing things. The irony is that in my experience, the institution of school – the one that should be the most open to learning and change – is actually the most rigid of thinkers.

SEND in the United Kingdom

The concept of SEND was first talked about in the late 1970s, replacing the term “handicap” that was used in the 1944 Education Act (Hodkinson, 2015). The first Code of Practice came some 50 years later (DfE, 1994), so it has been a slow process. But what of teacher training in SEND? Until recently, Initial Teacher Training

(ITT) in the United Kingdom did not have to include autism training at all, and the time given for learning about *all* SEND was limited to approximately two days. The 2016 Framework of Core Content for Initial Teacher Training made this training mandatory in 2016, and embedded practice began in 2018 (DfE, 2016, p. 17).

We still have no compulsory SEND training for the police force and in a 2017 report, more than one-third of general practitioners (GPs) (39.5 per cent) reported that they had never received formal training on autism – either during or after their qualifications (Unigwe et al., 2017). Learning disability and autism training for health and care staff is only now in the consultation stage. Even autism training for staff working with children in young people’s mental health inpatient units only started being delivered in 2021 (DHSC, 2019).

When I started my parenting journey, I was just as unenlightened. I knew next to nothing about autism, Attention Deficit (Hyperactivity) Disorder (AD(H)D), adoption, dyslexia, dyspraxia, dyscalculia, non-binary gender identities, transmasculine identities, demi-girl identities, queer identities, gay identities or dysphoria. I knew nothing of self-harm, suicidal ideation, absconding or child-on-parent violence. I knew nothing of Special Education Needs Coordinators (SENCOs), Child and Adolescent Mental Health Services (CAMHS), local authorities, or Education and Health Care Plans (EHCPs). I knew nothing of mainstream provision, reasonable adjustments, special schools, pupil referral units (PRUs) or home education. I also knew nothing of the exclusion, the isolation, or the judgement that can accompany

any or all of these things. This book will explore the stories of how I learned all about this stuff – often the hard way. In working with many parents and professionals over the years, as well as being a professional coach myself, my aim is to share and suggest – never to tell you what to do. These kinds of learning best happen by sharing best practice rather than rule making. So often I find myself saying, “Give me someone who knows more than me.” I am desperate for insights from professional experts or experts by experience. And this is what I am: an expert by experience. I sincerely hope you have a few lightbulb moments while reading this book and, more than anything, I hope you take the lightbulb moments and expand them into beautiful experiences in your own landscape.

One final thought before we begin. This book describes everything I didn’t know before becoming a parent to SEND children, and everything that you might not know about education for those with additional needs. What I do know, though, is equally important and worth remembering as you read the stories that follow: my family is incredible and my children are outstanding. My home is full of people – the people we have chosen to gather: the misfits, the marginalized, the creatives, the quirky. These are our people. Our village is in our home, and it works. We have joy, laughter, pain, tears, and a whole heap of mess. Our home is full of love, and acceptance, and the celebration of small wins. It is a culture of noticing every breakthrough, learning and growing, listening, and constantly evolving – for all of us, but crucially for us as parents, shapeshifting into everything we need to be to parent our amazing children.

Learning objective: Language about diversity

To begin to understand the breadth and depth of the diversity in humanity and the language used to talk about it, and to begin to develop a mindset of openness and curiosity.

1

The landscape

We live in a postmodern society. By this, I mean we live in a society that no longer adheres to one belief or one big-picture story. If we understand there to be one overarching story, it follows that we are all a part of that story: we all know our place in that story, we perceive our history through the same lens as one another, we all live by a shared moral code, we toe the line, and we understand where we fit – whether it is fair and equal or not. During the late nineteenth century and the early part of the twentieth century, philosophers and psychologists were challenging the truths and motivations that created the story of their time. These challenges struck at the core of society’s foundations, changing the way we think and ultimately leading to a rise in new concepts of equality and inclusion.

One story versus many stories

In our postmodern lives, we face a relatively new challenge. Should we all live with an “each to their own” attitude? Do we all hold an individualistic outlook that says, “This is my story. This is my truth”? Perhaps the world of home-schooling may have some of this underlying belief – I will explore my family’s experience of home education a little later in this book but, on the surface, the idea of every child learning in their own home

feels very individualistic. Should we all return to the one story instead? The institution? It has always worked before, after all, so maybe we should return to “common sense”. Or does the story need to be rewritten to include other voices, telling other stories that until now have not been heard – for instance, the feminist voice, the Black voice, the disabled voice, the LGBTIQ+ voice and the neurodivergent voice?

Bearing all of this in mind as we turn to the dialogue around SEND, you will hear the voices of these worldviews. You may notice the dominance of the “let’s return to one story” voice. By raising the voices of those who were previously excluded, we threaten the status quo and challenge the perceived natural order. We make those leaders who have the one-story worldview feel as if their dominant voice is being threatened, and is at risk of being lost.

The increase in the number of children being diagnosed with SEND has led to many voices being raised that challenge the status quo. As you speak up on behalf of a child with SEND, here are some sentences you may hear in response:

“We never had all these children with autism and ADHD when we were kids. There were kids who didn’t fit in but we all just got on with it.”

“Why do we keep labelling these children?”

“If parents got on with parenting properly we wouldn’t have all these children misbehaving.”

“ADHD is just an excuse for bad parenting.”

“Generational trauma is causing this upsurge.”

“Diet is causing this upsurge.”

“The environment is causing this upsurge.”

“Vaccines are causing this upsurge.”

“Kids are spoilt and have no resilience, so they develop mental health problems.”

“Kids need greater discipline.”

“Smack them into submission.”

“Neurodiversity is a sickness.”

“Why should we make adjustments for your child – who do you think you are? Who do they think they are?”

“We cannot change. If we do it for one, we have to do it for all.”

“The way we were educated worked for us before, so why can’t we continue to educate in the same way?”

“I’m here to teach, not be a therapist.”

“The problem is people with all these ‘woke’ ideas.”

There is a battle going on between those who, for whatever reason, are invested in the status quo and those who are begging the system to adapt so their children can be included equally.

Equity versus equality

Let us not confuse equal provision with equality. Equality does not mean “the same”. Equality may mean that my child needs more provision than yours – this is a concept sometimes called “equity”.

This is an important difference, because sometimes it might appear that equitable and inclusive provision is not “equal”, which can be upsetting for some and can lead to push-back. The world right now is geared towards the neurotypical – those

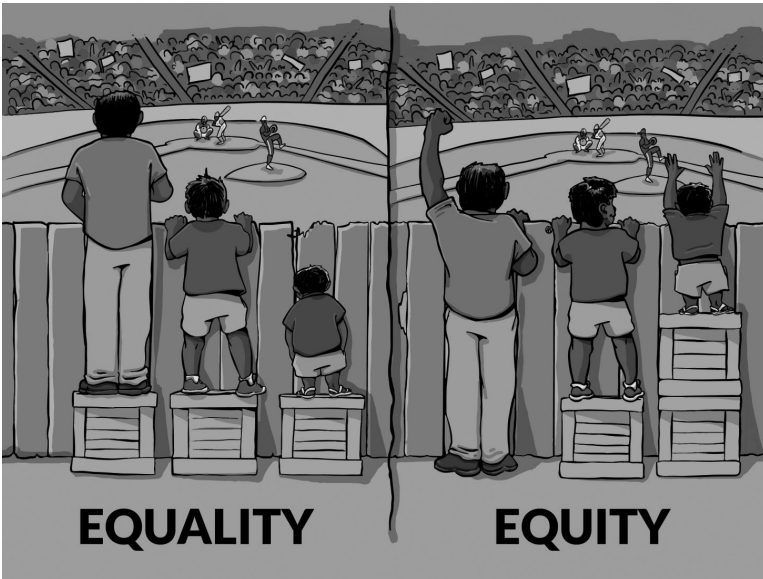


Figure 1 Equality vs. equity. Source: Interaction Institute for Social Change | Artist: Angus Maguire.

who have been declared “normal”. When a group decides to reach for inclusion, the whole system changes – and this can feel uncomfortable for those who have always benefited from the system, because it can feel as if something is being taken away (whether or not it actually is). When those who feel challenged look at equitable provision, it can feel vastly unfair when they notice that it is not “equal” – that is, that they are not getting the same assistance as those who need more help. For the privileged, equity can feel like oppression.

Deconstruction is painful, and the institution of education may resist the challenge to its institutional thinking. But it is important: we cannot build something that works for everyone without first deconstructing what is there already. If we are struggling with the uncertainty and the change, we must remind

ourselves of the bigger picture – what we are working towards – and remember that the *reconstruction* phase will come.

So why do we need to deconstruct what's there? Because even where it may be *equal*, it is not *equitable*. Not every voice can be heard right now, and one of the voices that is missing, or at least obscured, is the voice of those who have SEND, together with the voices of their families. It is not for someone who has never experienced being neurodivergent to tell our neurodivergent people how they experience the world, and therefore judge what is right for them. We need to make the space to hear these voices – my children's voices, and my voice, and those of my family, so they can be taken into account to positively expand my children's experience of life and education – this is equity. If we care, then it is also our job to facilitate these voices being heard, and not rely on these voices being able to clearly speak as part of the status quo. Some struggle to find words, some will never have words, some speak other languages, some make art instead of verbalizing, and some speak with actions and behaviours. It is for those who can hear – those who care – to find a route in for these different voices.

The same goes for us as parents and carers tunnelling one way to raise the voices and tunnelling the other to reach our children. Finding the route into our child is one of the wonders of being a parent. For those who parent children with additional needs, we are challenged to reach deep into ourselves to find resources and capacity we never knew we had.

Who are my children?

Let me introduce you to my children. My children have a huge number of intersections in their identities, so I will try to outline who they are here, and tackle more of the detail in each area as I move through the book.

Here I'd like to offer a word of caution: to help readers keep my children clear in their minds, I have given each a pseudonym (Ch1, Ch2, Ch3, Ch4) and provided a bullet-point list of identity words that describe each individual. However, children are not their labels. They are wonderfully complex and are so much more than the sum-total of all their descriptors – or their behaviours, for that matter. My children can no more be reduced to a bullet-point list in reality than any other human on the planet.

Child 1

- Dual heritage – Black West Indian and white English
- Dyspraxia
- ADHD
- Non-binary
- Queer
- Fully mainstream schooling

Ch1 was born in 1994, eight years after my husband and I met and six years into our marriage. We were not people who desperately wanted children; we were loving our lives together without them. I think we were also concerned that because our marriage really worked, perhaps a child may change that dynamic, and we wanted to protect the “us” that we had found and created.

By 1994 we were having regular conversations about having a child and imagining what life might look like when our “us” was added to. We tentatively decided we would try ... and bingo, I became pregnant in the first month! We were earnest “about-to-be” parents, reading up on parenting and increasing our skills. Most parents (like teachers) have an ideology about how they will nurture their children. It is usually made up from experience of how they were parented: seeing their own parents as an example of how to do it or, conversely, how not to do it. My husband David and I, in those nine months, talked about the nuts and bolts of how we wanted to parent.

Later that year, Ch1 was born. Assigned female at birth (AFAB),² we were in absolute awe of this little baby! As with all first-born children, when Ch1 was born they became the baseline in my mind for how a child should be. They talked and walked ahead of their targets. They were chatty, funny, engaging, and very curious. Their entire world seemed to be processed through their mouth. Everything they could fit into their mouth went into their mouth. They would bounce and wave their arms to music and try to sing along. They made eye contact and cuddled everyone. I only realized there may be challenges when they started school. Often, when I went to collect them from school, the teacher would beckon me over for a quick teacher/parent chat. My child was a little too playful and distracted and found it hard to sit still.

By the time they were in Years 2–3 (aged 6–7), I was told this child was rebellious, intentionally inattentive, too loud, and lazy. This is where things can become super-nuanced. If Ch1 had been a blonde, white girl, would the first port of call have been to get the educational psychologist involved to get an assessment?

My child is mixed race (white and Afro-Caribbean) and when I think of the language that was used by school back then, I now realize it could well have been the language of tropes. Lazy, loud, and rebellious are all too familiar terms when it comes to the assessment of our Black and mixed-race children.

Recent studies in the United Kingdom showed Black Caribbean and mixed white and Black Caribbean pupils were noted as being over-represented in the Social, Emotional, and Mental Health (SEMH) area, yet under-represented in the SEN area (Strand and Lindorff, 2021).

This assessment – or even judgement – of my child seemed to be far removed from the child I had at home, who was generally compliant, loved to read, and interacted well, especially with adults. A child's identity is influenced by many factors, but this "naughty" label became problematic – because my child began to believe it.

Today Ch1 has a very strong sense of true north: they are a truth-seeker with incredible gut instincts. If at a young age a child is told the good they possess is bad, this can play havoc with their self-knowledge and the development of their identity. The outside world is in contradiction to the "felt space" in the gut. As a child, who do you believe? The adults are the people who possess the knowledge, so they must be right.

Sadly, as parents, we didn't help this. Having been brought up to respect and trust the school system, on too many occasions we went to town on our child, chastising them for their lack of attention, withholding treats in order to get them to do what the

school wanted. Too often we sided with the school, leaving our child supporter-less.

As one would expect, our child began to see themselves as one of the bad kids, so they spent their time with those children who displayed more challenging behaviours. Time and time again, we would be at the school being told our child had been close to something when things went wrong. They were never really the perpetrator, but they were always the bystander. That's clearly where they felt they fitted.

The other challenge was that their reading age was super-advanced but their writing was really behind. They were full of stories, colourful adventures with exuberant, complicated plots. The speed at which their brain would dream up these ideas was supersonic, yet the speed at which they wrote them was snail-paced. They were left-handed and held their pen hard to the page. Homework became a painstaking battle of wills with most of the time being taken up disciplining them; back in the days when we used the naughty step, they pretty much lived on it!

As Ch1 progressed through the school, they had a very good teacher in Year 4. He took me to one side and explained that my child had problems writing their alphabet even though they had an amazing vocabulary and reading skills. He asked if I would concentrate any homework on trying to get them to write their letters. I began by asking Ch1 to write the first few letters. They could manage a, c, e, h, i and so on ... but there were gaps. Anything with a tail was a challenge. I realized they were missing almost half of the letters. And so the painstaking task began to work on simply forming the letters on the page. This was, of course, totally frustrating for Ch1, as they were reading books

aimed at 12-year-olds at the age of eight. Recognizing words was easy; *writing* them was a problem.

They began to struggle with confidence. The inability to write well added an extra layer of disconnection to learning, and now they were even more easily distracted. Gazing out the window, they would be called to attention. Clicking their pen, they would be told to be quiet. This lack of clicking the pen meant they would turn their head back to the window. In utter frustration, the teacher would accuse them of wilful disobedience, and they would be called to the front of the class or, worse, sent out of the class.

Throughout this period, however, they continued to prosper at home, playing musical instruments, singing, songwriting, and engaging in many creative pursuits. And thankfully, when Ch1 turned 10, something happened to disrupt the cycle: they gained a professional role in a television drama. This necessitated time away from school for rehearsals and filming, and they instead received their education through on-set tutors, as rules for child actors dictate. Amazingly, when away from school, Ch1 excelled in their education, and was praised for their speedy learning and ability to take direction. When they returned to school for their final year of primary school, they were like a different child. Away from the continual pressure and feelings of failure, they had become confident. In being told they were good at something, their new confidence grew, and with it their ability also grew, across all subjects.

Ch1 was diagnosed with dyspraxia at the age of 11, and AD(H)D at the age of 18. This late diagnosis was a relief to our child, but also very difficult. By the age of 18, they had experienced

years of school judgement. They were demoralized, traumatized, and lacking in academic self-belief. The very institution that was meant to prepare them for life had instead disassembled them, mocking their enthusiastic curiosity and judging their difference as defiance.

No one thanks you for a late diagnosis. I have never met a person who wishes they had been diagnosed later. A diagnosis is the doorway to the discovery of that part of you that is outside of the box. There may be parts of the process that demand a rethink of who we are and where we fit in the world. Negative labels can be a heavy weight to bear, of course, but this is largely because the internet gives very negative views on neurological conditions. The truth is that there will also be explanations, revelations and wonderful, positive attributes that exist because of this neurodiversity.

Ch1 used the benefit of having intense interests to begin a journey of self-discovery through the lens of their AD(H)D. Suddenly things began to fall into place, frustrations were explained, anxieties more keenly understood. They recognized their ability for fantastic thoughts, yet the struggle they encountered trying to order those thoughts. Suddenly things began to make sense. Not only this, but they began to put things in place in order to assist themselves in the areas where they were struggling – really simple solutions like sending voice notes when they found it hard to reply to people’s messages, journaling their thinking, meditation, and most importantly asking for help. When in conflict, they began to slow down the conversation in order to be able to think, taking time out to process thoughts and feelings. Over time, life has become so much easier.

Child 2

- Dual heritage – Black West Indian and white English
- Autistic
- Dyscalculic
- Non-binary masculine
- Queer
- Fully mainstream schooling, with work undertaken at home

Born in 2001, our second child was the hidden child. Assigned female at birth, they were later to realize the correct pronouns to describe them are “he” or “they”. Ch2 was quiet and self-contained, and in our words would be described as “in their own world”. They would line their toys up, draw pictures all over their walls, and dance to their own rhythm, quite literally ... they could beatbox before they could talk. Visitors would say that this child could see “into them”; Ch2 could be unnerving in their habit of observing things and people around them. This part of them has never left, but the way we talk about it has changed: as an adult, we would say that they are unbelievably insightful about others’ feelings. They would later be diagnosed as being autistic. The sensory overload that many autistic people experience includes, for this child, the emotions of other people. Imagine walking into a room and feeling everyone’s emotions without being able to stop it: this is what Ch2 experiences.

Where Ch1 had jumped up for cuddles and run up for nestling into us, Ch2 was quite the opposite. They would come into our bed in the morning, lie next to me and wait. Instinctively, I knew I needed to create another way into my child’s world. It never occurred to me that they might be lacking in anything; I just

knew that this child had a different way of communicating and so I unconsciously used my parallel skills to enter the relationship. I would lay my hand on the pillow and tell Ch2 I was going to sleep but Mr Hand would like to chat. This would unlock a super-imaginative and loquacious conversation with my hand. In contrast to the quiet child lying next to me, their parent, they would be giggling, sharing, disclosing, hugging, and kissing my hand. Bit by bit, Ch2 would reverse into me as they talked to my hand, nestled and secure. I found the whole experience delightful and every bit as intimate as the hugs from my first child.

Again, it was school that changed our thinking about our child. At school, Ch2 was highly anxious, felt unheard, and found schoolgirl friendships far too complicated and risky. On constant high alert, they would hold everything together at school, and the minute school was over they would melt down at home. Suddenly, they could only sit at a certain part of the dining table, foods must not touch, and various fears and phobias arose.

Looking back, I think we normalized these changes. It wasn't until a few years later, when our third child was born, that things became a little clearer for me.

Child 3

- Dual heritage – Black West Indian and white English
- Autistic
- ADHD
- Non-binary: demi-girl³
- Lesbian
- Mainstream plus specialist autism school

“Do you think she may be deaf?”

This is just one of countless opening lines to conversations my husband David and I began having when Ch3 (assigned female at birth, pronouns she/they, born in 2006) turned two. She wouldn't answer us, respond very much or turn her head when called. Yet at other times she would be giggly, engaging and curious, and appeared to hear perfectly.

That spring, we decided to visit friends in Atlanta in the United States, and coming through the airport were stuck on a shuttle train with very high-pitched white noise. Ch3 put her hands to her ears and began to scream. The screaming went on way after the noise had stopped, and even when the screaming stopped her hands remained on her ears.

Over the coming weeks, Ch3 would hold her hands to her ears on and off all day. If there was a loud bang, the extractor fan buzzing, the kettle boiling, and eventually even the low hum of the fridge – hands to ears in clear discomfort. She certainly didn't have a hearing problem! Venturing out became tricky as we were potty training, and if we visited a public toilet the sound of someone using the hand-dryer would have her running from the cubicle mid-flow. The world through Ch3's eyes suddenly looked fraught with danger, and she experienced fearful reactions to everything around her.

Ch3 was also a bit quirky. We love quirky in our house, so we celebrated her desire to wear every outfit off one shoulder; we delighted in her obsession to do up and undo buttons (although this was not so good with those of complete strangers); and

we thought it adorable when she referred to herself in the third person.

The noise issue was a problem, though, so I decided to take her to see our local health visitor. This lady had been in the profession for many years and was about to retire. Ch3, in her usual off-the-shoulder attire, took one look at the health visitor's cardigan and began a quest to undo and do up her buttons. The Health Visitor observed Ch3 for about five minutes and said, "I think she may be autistic." Ch3 was referred for an autism assessment.

This was a key moment where things could have gone one of two ways. Had that health visitor not been so knowledgeable and attentive, Ch3 would have started nursery with everyone none the wiser about what was going on. Starting the diagnostic process later could have been very detrimental to Ch3's experience of school and her young mental health. I am forever grateful for that health visitor's expertise and professionalism in pushing for the assessment. In fact, it gave me great delight years later when I became the president of the Community Practitioners and Health Visitors Union (CPHVA), to be able to give something back.

While waiting for the assessment, David and I began to read about autism and alarm bells began ringing for Ch3's older sibling, Ch2. Ch2 was then seven years old. Those early memories of them lining up toys and only eating certain foods that must not touch each other came flooding back. At school they were terrified of black and white photographs, or anything old. They were outstanding at art and dance and all things creative. They found it hard to navigate school, friendships were complicated,

they were bullied, and they felt teachers didn't like them. Years later, Ch2 would describe this as "feeling like an alien".

Ch2 hit their school grades, though, and ticked all the right boxes for "school normal". We were told they were "fine", yet every school day was a living hell.

Neither of these children identifies as female any more, but I do want to take a moment to talk about the fact that autism in girls or those assigned female at birth often doesn't get picked up. There are many shades of autism, but one undisputable fact is that girls often fly under the radar. The child may be very outgoing, sociable, make eye contact or have an outstanding vocabulary, but beneath the surface could be struggling to understand or comprehend the world around them. They may have overwhelming sensory issues and a rigid, very concrete way of understanding what is being said. This social communication issue may leave the child feeling as if they are in a war zone at school, with teachers shouting, demands not understood and therefore felt as threatening, and threats of detention or punishment. Friendships are confusing, baffling, bewildering, and painful. Feelings of not fitting in and an alarming, ever-growing sense of failure eventually lead to self-hatred. Daily meltdowns at home lead to school refusal, and eventually result in complete shutdown and/or mental breakdown. By the age of nine, our beautiful Ch2 was asking to die, and unfortunately it was only at this point that we were taken seriously. Maybe this was autism but not as we knew it?

But why should this be the case? The simplest reason is that until recently it was believed that autism was a male condition, and most of the research had been done on males, or those assigned