

CHAPTER SEVEN

NOISE, TOYS AND PARENTING BOYS BY SARA KING - GOOD THINGS ABOUT MY EXPERIENCES AS AN AUTISTIC PARENT

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Introduction by Kleio Cossburn

Sara wasn't diagnosed autistic until after her children were born. She describes the social aspects of being a parent as some of the most difficult. An example she gives is attending her children's friends' birthday parties, how much to spend on a gift and the sensory issues of attending a party, such as the noise. This can be an ordeal for some autistic parents. On the other hand, Sara also describes many positives to being an autistic parent.

Sara has found some support from other parents by joining the National Childbirth Trust. She has made friends with other parents who have children around the same age. I would encourage other autistic parents to do this if possible. There are also a few groups on social networking sites for autistic parents where tips and strategies can be shared.

Introduction

I am a mum, with a recent autism diagnosis. I wasn't diagnosed until my mid-forties, and my diagnosis and subsequent increasing understanding of autism has made a lot of sense of many experiences in my life, explaining some of the specific challenges I have had as a parent - now I understand how being autistic I am much better able to anticipate where I may need help or to work a bit differently to get through.

I was fairly late coming to parenting, having thought all through my life that being a parent looked like very hard work and very restricting; it was something that had not appealed to me at all.

I met my (now) husband in my thirties, and that changed everything - I wanted to have a family with him. Becoming a parent helped me to see the autistic traits I have. In the past, I managed my life very carefully to avoid sensory issues, and my social life was carefully orchestrated. It isn't so easy to do this with children, and I began to notice how many times I felt challenged by sensory issues, out-of-step with others socially, and noticed the desire I have to manage and control my environment and routines.

Pregnancy and birth

Once we'd decided that we hoped to start a family, we were devastated to find that it wasn't likely to be a straightforward process for us. This was an emotional and difficult time, and I don't think that I can do justice to the challenges around this in a short article.

We were absolutely delighted upon discovering I was pregnant eventually, a couple of years into our marriage. I duly read extensively about pregnancy, birth and we researched very carefully all the equipment we would need for our new-born.

I sailed through pregnancy and was one of the lucky ones who felt healthy, fit and well all through the pregnancy.

We joined a National Childbirth Trust pre-natal group hoping to make friends locally given that we lived a long way from family and didn't have friends with babies at that time. We happily learnt about natural childbirth, how to prepare for the birth and what music and snacks to take to the hospital. I thought I was incredibly well prepared for what may come.

On the day of my child's arrival, things started fairly calmly with waters breaking, packed bags were grabbed and we travelled to the hospital. This calm start ultimately descended into a frenzied rush on a trolley for an emergency caesarean section with a general anaesthetic, and I am immensely grateful to the hospital staff who kept my baby and me safe and well.

On awakening, I met our baby who I immediately loved with all my heart. I was unwell, though, the procedure had taken its toll. We were taken up to the hospital ward, with around 4 other mums and babies. I hated being in the hospital and felt completely overwhelmed from the experience of having the caesarean, feeling unwell, the sensory issues, the communication with staff and strangers on the ward, and feeling out of my comfort zone in a very public place. I was desperate to leave.

My husband had to go home, leaving me in a noisy, brightly lit, room with loads of strangers.

Midwives, hospital staff and other patients and their visitors came and went, I couldn't get up to care for my baby having had major surgery, and when he cried I had to buzz for the midwife to help me whilst the other (more mobile) new mums tutted and talked about me. The intrusion of midwives trying to help me breast-feed (however kindly they did that), unwanted touch, pain, noise, lights, other people's visitors, other people's babies crying when mine eventually slept had me distraught and frightened.

I couldn't understand the apparent ease and joyful experience that the other mums seemed to be having whilst I was clearly struggling. I left the hospital after only a night, despite recommendations to stay.

If I had known about my diagnosis, what would I have changed? Perhaps I would have had access to a private room as a reasonable adjustment, I may have been able to ask to be pre-warned when medical staff needed to touch me. I may have been able to better prepare for how I might feel, perhaps asked for more information in advance about the specifics of what might happen with each part of the process. I may have had a sensory pack with me with headphones to cut out some of the noise, an eye mask to cut out the lights (which were kept on all night!).

I had asked other mums about their birth experience, but there seems to be an unspoken rule that mums don't tell other mums the extent of the nasty parts of the birth experience, they gloss over it – perhaps not to frighten them. As an autistic person who needs detailed information, even if I had felt scared I would rather have known the potential things that could have happened to mentally prepare and gain some feeling of control over the situation.

The early days

Probably unsurprisingly, despite a deep and immediate bond with my baby, I became increasingly anxious and depressed. I managed to do everything that I needed to do to keep the baby fed, cared for and cuddled, but was tired and confused about the new world I found myself in.

I read lots of baby books, attended mother and baby classes and became rather confused by all the bewildering and often completely opposite advice and information available from books, health workers and other parents. Far too late I realised that these were just opinions, and that I could form my own. In all my working life, there'd been a manual or process to follow, the internet to research on, and more senior staff than me to take advice from. I had developed enough experience to make my own judgements at work. I had absolutely no experience to base parenting on and it was rather scary.

I attended mother and baby groups, baby music and movement classes, swimming classes and a whole variety of other activities with the intention of giving my baby and me new experiences, and making new friends in a similar situation. Looking back, I'm amazed at what I and my new-born did – it was all a bit of a blur though, and I felt I was desperately trying to keep up with others and do the “right” thing. I felt increasingly lonely and it became obvious that whilst I chatted with people, other people there made friends and disappeared off afterwards in two's and threes to have coffee and cake while I went home, feeling sad and confused about what I'd done wrong. I was occasionally invited when it was a gang, but didn't seem to manage to connect particularly with anyone to invite further outings.

My NCT group was a lifesaver – they met as a group and seemed accepting of me. I was aware though, that they seemed to be having a lovely time, they mentioned feeling guilty about partners going to work whilst they were off, going to the park and eating cake. I was confused, exhausted, struggling and actually jealous of my husband heading off to work, doing his job, having his routine and being free.

Eventually I was diagnosed with post-natal anxiety, and received support in the form of CBT which helped immensely. Things became a little easier, I got into a pattern. I loved my child so much and I enjoyed watching him develop and learn, and once we got past the baby stage things became easier.

I went back to work part time and once my child had settled in a nursery place I enjoyed what seemed to be a good balance between work and family time.

As time went on, my child started to be invited to toddler birthday parties. Some of the social issues I have started to become even more apparent. I didn't seem to be instinctively able to do what the other parents (mainly mums at that point) seemed to do – what to chat about, how much to spend on the gift, when to intervene and what to do when children are squabbling – I had to watch very carefully to see what was appropriate as I truly had no idea. How to manage social situations between toddlers and older children when one doesn't know the social rules? If your child is absorbed with playing with a train-set do you force them to stop to sing Happy Birthday and watch the birthday child blow out their candles? (I suspect the answer is yes but I wasn't sure and my child screamed the place down as the train was more exciting). I had to watch and learn, and quickly.

Over time, this became a bit easier, however I was never entirely comfortable, and as these people weren't work colleagues, family or close friends, I didn't quite know what they were and

how to act. Were they friends, acquaintances, strangers or some new thing in between? I found it confusing, we were often in people's homes, sometimes they were even in mine - yet I didn't know if they were friends or not! Post diagnosis I understand why that was so hard for me and I understand a bit better how to cope and what to say/not to say in these situations, but it has taken several years of watching and learning and I still don't always get it 'right' from a non-autistic perspective. I realise how much energy it took to mask and how unhelpful that was for my wellbeing. As the children get older, I have to develop new parenting approaches for new and changing situations.

School life

This sort of scenario continued as my child started school. It was further confused by him choosing his own friends – which of course took no account of my thoughts and choices so we had to go with that and had to learn how to manage play-dates, reciprocal visits and the un-written rules of how that all works. Again, everyone else seemed to know what to do. I picked it up eventually by looking to see what some of the socially competent mums did – especially those “in the know” with older children. It was difficult finding a way to navigate through these unclear relationships with whole families!

My first son starting school coincided with my second son being born. I was healthy and well through my pregnancy again. Second time round I had a better idea of what to expect and had a planned caesarean - although I was in complete denial about this and didn't tell even my mum or my sister the date until a few days before, and just tried to pretend it wasn't going to happen. I was more confident about my ability to meet the needs of a baby and put much less pressure on myself to join in with social mum and baby activities. We did do a few favourite things like music groups which my new son really enjoyed. We had contacts through school and the NCT group who had siblings the same age as my second child, and it was much easier and very pleasant to meet up with people we already knew rather than start again to try and make new friendships.

Road to diagnosis

Around this time, I noticed a few children in my new world of school and families that I suspected were autistic. I didn't know much about the subject at that time, but these children seemed very clear examples of what I did know, and I saw a bit of cross over with my own children's behaviours. I became very interested in the subject and started reading extensively about it, although I wasn't sure why I was so interested. Eventually I came across a list of female traits and it was like reading about myself. I showed my husband, who agreed, and discovered a couple of online tests which also seemed to indicate that I was autistic. After further reading and dwelling on this for some months, I eventually went to have an assessment. This wasn't a full diagnosis, but at that point a sort of half-way house – I was a bit nervous at that point about it to commit to a full diagnosis (my biggest fear being that something would go wrong and my children would be taken away. I know this sounds extreme but it really was something I was terribly concerned about). This assessment confirmed my suspicions.

I eventually felt the need for a full diagnosis to avoid all doubt. I saw a different specialist for this as the previous consultant didn't offer the full diagnostic service, and she confirmed my diagnosis. Since that point, I have been through a process of reflection and re-framing which has made so much sense of my life, my experiences and also my parenting – the brilliant bits and the not so good bits. It's been particularly helpful to read experiences from other parents– those

accounts are rare but increasing. Individuals are being diagnosed as adults, sometimes after their own child receives a diagnosis, which I hope will increase the body of information available.

The difficult parts of parenting

Parenting can be a challenging experience for anybody for all sorts of reasons. It generally means a huge change to all areas of one's life, and can mean lack of sleep and resulting lack of energy, noise, lack of time, dealing with differing family views on parenting, mealtimes and social interactions with other families and organisations such as school.

I found it difficult for a variety of the reasons I've mentioned above. There are some specific difficulties though that I believe are directly related to being autistic.

Infertility

This is a traumatic situation for many people. I found the lack of control and inability to plan and manage this particularly difficult. The extensive research I carried out to understand the situation, find solutions, and try to reduce my anxiety by trying to gain some control led to this becoming a new special interest for me. The additional appointments, physical examinations and the requirement to communicate with specialists on a very emotive and personal subject felt invasive and humiliating. Managing the social discussions about starting a family with other people was another area that added extra layers to the already challenging area of social communication.

Sensory

For me, the sensory impact is probably the most difficult part of everyday parenting. The noise, and even physical movement around me can be distracting and cause over-load. Children, their toys, their activities and their friends can be noisy and generate lots of movement and other issues such as bright lights.

Imagine trying to get two very physical children out of the door to leave for school. Even during the short time it takes to leave the hallway to go through the front door there is talking, sometimes arguing, the thump, rustle and sight of coats and bags being flung, the noise of zips, they jump up and down, ask questions, hug me and each other, prod each other, scream and squeal. Needless to say, I have often left the house without outside shoes or another vital item.

Dealing with opposite sensory needs of my children – one child seems to be sensory avoidant, one seems to be sensory seeking. This is not easy to manage in the same household and I have my own sensory triggers to factor in too which compounds the effect.

Food and mealtimes can be tricky. There are many things I won't eat including meat and fish and I cannot abide certain strong smells such as fish cooking. The sight of meat can make me feel ill. I have phases where I will eat the same meal every day for a month or two, then change to a different food preference. Trying to find a meal we can all eat is challenging, we often have different things from each other at mealtimes.

My husband and children eat meat and fish although my children also have strong sensory issues and preferences. We have found ways to accommodate this. I don't cook anything that I can't cope with, my husband cooks meat and fish for the children, we often eat vegetarian meals together. If he wants to cook fish, he does it when I'm out, and makes sure that the house is ventilated before I come back!

Social and community

Having a family means that I have to cope with a much wider social world than I was previously exposed to, and doing that on behalf of and with a child with you can be difficult. Experiences now include children's parties, friendships, activities with other families, regular communication with school and other organisations.

There are some elements of school life that I struggle with. Parents' evenings are tricky for me. The timeslots allocated are too short, lots of verbal information is provided very quickly, usually in a noisy school hall with loud bells and a feeling of urgency which is very distracting. I often come away not remember what I've been told, apart from any information such as test scores that have been given in writing.

Other families have different styles of parenting, different methods of rules and discipline, different priorities, manners – all of these things impact hugely when you have a family. There are two sides to this – firstly it helps to give context to the things we do has a family by comparing and contrasting, it also provides ideas for improvement and I often find I copy good practice when I see something that works well, and it's often a very good lead in to a discussion with our children if others do things differently. Conversely, it can be difficult when your child's friend has a completely different family rule that you perhaps disagree with – how do you manage the social relationships to discuss what happens when your child is at their home?! Navigating and refereeing arguments between our two children can be very difficult too.

Lots of the parents seem very social and often arrange meals out and other group activities, including Parent Teacher Association (PTA) events for fundraising. The expectation to join in is a pressure and I find it stressful. Conversely, it can be upsetting and hurtful to not be invited (even if I don't want to go!). I try to help with PTA events in a way I can cope with, for example I volunteer for preparation jobs I can do at home on my own. I find the social element of these activities too complicated to cope with as they are usually in groups; I cope with social activities much better on a one-to-one basis.

I have had periods of depression following social experiences that have gone wrong. There is no way to run and hide from someone involved in school when you have to be there every day. I have found that what starts as a small social mistake can make me anxious which then leads to feeling vulnerable and noticing further errors, spiralling into a very depressed state. Sometimes I think about moving our family to a lighthouse and home-schooling. For my children's sake, I have to find a way succeed at these things and cannot just avoid (which would be my natural preference!) – the cost is not to me it is to my children and that is just not acceptable to me.

Lack of control

Loss of control of my environment is difficult. I have others in my family with different needs and choices and I need to respect that. I didn't realise, pre-children, how much of my life was pre-planned and organised. Having children can mean that plans change, they may not want to do what we adults would like to do, they can get ill, they have their own activities. My energy is used on caring for them, managing their school life, activities, and their social lives. I work too, and study. There is very little time or energy left to follow my own interests. We have chosen the family life we have and I am happy with that, however having children is all-consuming!

I miss having my own personal time and space, either to just re-charge or to follow my own personal interests. Interruptions to that can be challenging and I cannot multi-task.

I also have a tendency towards perfectionism. I accept that it is impossible to "do" perfect parenting. Realising that I will occasionally get things wrong is difficult.

Managing the different parenting approaches and style my husband I and have is challenging and it is important that we reflect on this and ensure we have a consistent approach, whilst still retaining our individual strengths. My tendency is to want to do things my way, and I have to make sure that I don't allow this to undermine our family unit.

Once I've learnt to do something, I tend to want to do things the same way in the future. This isn't always appropriate when parenting - what has worked with a first child, won't necessarily work with a second or subsequent child! My children are very different, and we often need to change how we do things to accommodate that.

My general approach to some social problems, prior to having children, might have been to hide and avoid things and people. I no longer have that choice, as the relationships are ongoing and not always mine! I also find it difficult to mask to cope with social issues when it's long term – it's much harder to keep up an illusion of social competence over a period of years.

Good things about Autism and parenting for me

I am great at routine. It's often said that many children thrive with some structure, and I have been very good at providing routine, clear information about what we're doing and why. Although I get things wrong sometimes, I think very carefully about what I'm doing as a mum and my husband and I work closely as a team to parent as effectively as we can.

I'm a good planner. The children are my priority and I've been very lucky that I've been able to change my working pattern to make sure that either myself or my husband are available for school runs, plays, shows and other activities. – I realise that this isn't always possible for families so I am very thankful for it.

I'm great at research. I have actively researched many areas of parenting, and have tried to be the best mum I can. This includes researching things that my children are interested in, and providing them with a wide variety of experiences and information. I'm interested in what they're studying and love to hear about their work and homework too.

I'm interested in all sorts of things, and try to share that love of learning with my family.

My children are both currently on the pathway for autism assessment. I'm not sure what the outcome will be, but I believe that they both have sensory issues at the very least. I'm lucky that I can understand how the world might feel for them and hope to provide support and understanding.

I prepare well for change and large events. I moved around a lot as a child. When we moved house, I very carefully thought through the impact of that on my child (who was a toddler at that point) especially given that he struggles with change and is very visual. He went to nursery on moving day, whilst we moved, and I thought it would be extremely confusing to leave one home in the morning, and come back to a different one the end of the day. Instead, I got him to pack one box of his special favourite toys and personal belongings and explained we needed to move them. After nursery, we went back to the (then empty, apart from his box) flat, we said goodbye to our old home, and he moved his box from our old house to the new. I'm sure many parents would do this – mine didn't think to, though, and as a child that struggled with change moving was difficult.

I have had the unexpected and un-looked for benefit of making some very close friends through my sons' friendships and the "school gate". Despite the challenges I clearly have had, several parents have been especially kind. We have found common ground and I am sure that these special and caring people will be friends for a long time.

My children have many interests and talents between them. Our family has been introduced to a whole range of different experiences and activities which I hadn't anticipated. This has given all of us lots of pleasure, shared time together and opportunities to bond. They have some lovely friends, and it's been a joy and a privilege to have seen these friendships develop over the years.

Things that have helped me

Having a diagnosis has helped me have an explanation of challenges I have faced, together with a way to anticipate what might impact on me, and a way to explain those challenges to others, including my very supportive and understanding husband.

We have to work as a team, I do the bits I'm best at, he does the bits he's best at (or the bits I can't cope with, regardless of whether he's best at them!). We plan carefully so that I don't get overloaded. I used to wonder why the "nice" things, like family holidays, used to leave me stressed and exhausted. I understand the concept of social over-load and my need for time alone, and we try to build quiet time in to help.

Planning and structuring our family time seems helpful, we take trips and plan outings when travel and crowds are likely to be minimal, and we try to be realistic about what I can cope with.

We make sure that the children have lots of physical activity as this seems to help them with regulating their emotions, gives structure, and improves their general health in addition to offering social opportunities. They are then able to focus on other activities, such as homework, afterwards. If they are calm and peaceful, then that also helps me!

I now use noise cancelling headphones when I need them, and am confident enough to explain them away if asked ("I can't cope with too much noise" is the simple explanation given to curious people!).

If I'm overloaded, I ask for quiet and help, and I manage my diary very carefully, making sure that after busy work events or social events there is some quiet time for recovery.

We encourage the children to explain how they're feeling, if they are able, and to ask for help and understanding.

In an ideal world, what else would be helpful?

- People in services to have a good understanding about autism and how it can impact. (Midwives, GP's, school staff, etc.). This will improve the support available. Some supports (a quiet environment, time to process, active listening, for example) are fairly easy to provide once people understand
- Greater awareness in the wider community of neurodiversity, Access to family training. Workshops and case studies for modelling of parenting skills, especially managing social scenarios with children
- Peer sharing – perhaps other autistic people have tips and techniques on family life for them could share with others
- Additional resources to help children to understand their other autistic family members (bearing in mind that individuals in the wider family may also be autistic and there needs to be reciprocal understanding).

Summary

My children have brought so much to my life. There is a deep joy in seeing one's children flourish and develop. To have a connection and close family bond is amazing. I've had to confront and learn how to cope with many new situations and experiences that in the past I would have avoided – this has been rewarding and fulfilling (and frustrating and exhausting); I'm learning and changing. I've made some very good friends who have been kind, understanding and inspiring. I may not have come into contact with these individuals if I hadn't had children.

There are some things that I cannot change about me, or my environment. I hope that I can develop tools to get by, and I hope that my family will learn to accept difference and develop the skills to support themselves and others, and to realise that it's ok to ask for help. I hope that they will grow up to be kind, healthy and fulfilled, and embrace all of the opportunities open to them.