

# Flourishing across the Spectrum

The handbook on raising a child with autism



Bebe Boyse

# Section One

## What are we talking about?



***“Write to be understood.  
Speak to be heard.  
Read to grow”***

Lawrence Clark Powell

## What is autism?

You will hear terms such as autistic, Asperger's, spectrum disorders, high functioning autism, atypical autism and so on. These are all one and the same thing, and the now commonly used term is autism spectrum.

Autism spectrum is very different to ADHD (attention deficit hyperactivity disorder) and so not to be confused. Please note that a child might have autism spectrum *and* ADHD, or autism spectrum *and* any other difficulty or disorder.

As mentioned, how one child experiences autism spectrum will be very different from another. However, there are three main areas of difficulty in autism spectrum:

1. communication and social interaction
2. behaviour
3. sensory experience.

The definition that I use is:

***Someone with differences in neurological processing that can affect their sensory experiences, their communication and social interaction, and their behaviour.***

***(Bebe Boyse, 2014)***

The condition, therefore, is about how the brain processes information which affects how the child experiences the world around them and how they then respond to that.

You may be asking what causes autism spectrum? The research is ongoing but to date scientists have determined that there are a number of genes that can contribute to autism. For some families they will find that autism spectrum runs in the family and for others it might be a one off

malformed gene. The ongoing debate is around what causes the malformation of genes, and that is where you will read about vaccinations and other factors causing autism.

This handbook does not dwell on the how and why but focuses on the delights and challenges of parenting, with hints and tips to get through the day to day obstacles that you will face.

On a personal note I really surprised myself in terms of the beliefs, hopes, wishes and expectations I had about being a parent. I had always thought of myself as someone who was very laid back, but I found that I departed from this in having a baby.

Where did these expectations come from? Glossy magazines? Films? Books? TV? Family? All of the above, or just some?

I don't know, but I had them and they have all been challenged over the last 21 years.

Having learnt many lessons, I now very clearly take the view:

***Take each day as it comes. Do your best to work with the challenges that are presented on that day. They will all be different. Resolve to enjoy the ride.***

I have on many occasions been lulled into a false sense of security that I can anticipate what will happen, and I have been proven wrong so many times.

In my view being a parent of a child with autism requires four key things:

- 1. Being open-minded***
- 2. Being flexible and responsive***

## **Summary of first indicators**

- **When a parent stands back and looks at the WHOLE picture there are usually some common early indicators of autism spectrum.**
- **These can be (but are not exclusive to): feeding issues, sleeplessness, inconsolable crying, gastrointestinal problems etc.**
- **Suspend your understanding and belief of what is normal.**
- **Try alternatives to establish what the issue might be.**
- **Be kind to yourself; ensure you get sleep, healthy food and a rest whenever you can.**
- **See the beauty in the small things.**

## What is being communicated through behaviour?

***'There is something in everything.'***

By this I mean:

**1. If a child screams and reacts violently when touched, then there is a reason for this.**

They might have super sensitivity to touch or they may experience pain in a different way.

A baby might demonstrate this, as James did, by:

- pulling away from cuddles
- clawing at your face
- screaming through any bath time
- resisting being dressed, including having nappies put on
- screaming at the beach
- refusing to play with paint or in a sand pit (any messy play is a no go)
- screaming at meal times
- refusing to put their hands on the floor etc.

Here are some things that worked for James and me. With the cuddles, if I let James initiate the first touch he seemed more comfortable to have sustained physical contact.

When James had to be held and was clearly unhappy about it then his favourite blanket was wrapped round him. Plus I always kept his finger nails short! My mum did get a broken nose once when James was wrapped in his blanket but he threw his head backwards and collided with her nose... ouch! Watch out for that one. We quickly learnt which clothes were the preferred items. We tried all sorts of play including painting and playing in the sand pit. But if these were distressing to James we just didn't do them again.

It is important to be open-minded and flexible about what you do and when you do it, and be responsive if things are not going well.

**2. If a child will not touch or play with certain toys then there is a reason for this.**

It is likely to be a sensory sensitivity such as sound or touch. A toy that we think makes a fun noise could be heard very differently by a child with autism. The volume may be different as well as the pitch. I certainly found that he always preferred the toys that made no noise such as toy cars and tractors.

**3. If a child is unable to sleep through the night, then there is a reason for this.**

James would cry for hours and the only calming situation was being outside at night looking up at the starry sky. I can understand James' fear or rejection of certain things due to touch or hearing, but to this day I do not understand what woke him from a sleep and kept him

## **First contact with professionals**

Your child may have a formal diagnosis of autism spectrum or they may not. Regardless, you will come into contact with a range of professionals throughout the years, from doctors to school teachers. These situations will require you to explain the unique nature of your child's needs. Always remember that you are the expert on your child.

If you find that you and your child are being referred for a more detailed assessment there are a few things you need to be alert to.

1. You are the parent and you know your child best of all. Stay in control. If you think that something sounds wrong or uncomfortable, trust your instinct and challenge it.
2. If you want the help of the medical profession, they will be able to do their job more effectively with the most specific information that you can give them. They will never know your child as well as you do.
3. Small and seemingly inconsequential information can be very important to professionals. Be as detailed as possible about patterns of behaviour.
4. They will use jargon and they won't be aware, in most cases, that they are doing it. Be confident, ask them what they mean and ask for explanations of any unfamiliar terms used (there will be a lot!).
- 5.

## How do these apply to children with autism?

Don't make any distinction. Assessors work with every child over a year to determine whether they meet, exceed or do not yet meet each standard. There are four areas of gathering information:

- From parents
- From the child
- From other relevant adults
- From observations

Parents are critical in this process; therefore I have identified particular areas that you may want to consider for discussion with your child's first teacher.

If a child does not yet meet a particular standard, this is called an 'emerging' ability. This is a great term to use with teachers and other professionals.

**Listening and attention:** This is interesting because very often a child with autism will be listening but the person or people around them may not be aware of this. Usually we identify that someone is listening when they look at us and give non-verbal cues such as a nod of the head or a laugh etc. For a lot of children with autism they find eye contact very difficult and therefore it might be perceived that they are not listening. In fact the reverse is true, in that in order to listen the child has

to block out other stimuli such as what they can see and therefore have to look away in order to be able to hear.

## Holidays

I persevered with holidays for around ten years. I was hopeful that the more I subjected James to holidays the easier it would become.

***‘The first sign of insanity is to keep doing the same thing and hoping for a different result!’***

My perseverance was just false hope, as the reality was that there would be 358 full days between each holiday.

That is 358 days of a set comfortable routine for James.

358 days of James knowing what to expect.

358 days of being in an environment that is safe and secure.

For me to think that James would get used to a seven day blip on the landscape was deluded. The destination is unknown, requires a significant journey, the weather is different, the people are different, the food is different, the activities during the day are different. How could this cause anything other than stress?

The light dawned on me in 2004 and that was the last holiday we had.

Other children who experience autism might be perfectly ok with holidays. It is just that it didn't work for James. I think if there had been one place that we went to on holiday then the experience might have been different, but hindsight is a wonderful thing.