

# The ANGER Box



**Sensory turmoil and pain in autism**

**Phoebe Caldwell**



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# Foreword

By Dr Elspeth Bradley

During the past three decades, Dr Phoebe Caldwell has been providing interventions and support to people with autism and learning disabilities (LD) experiencing distress in their lives.

These individuals are invariably described as challenging services or as having challenging or problem behaviours. Phoebe takes an alternative view, noting that ‘most of the individuals I am asked to see are on the autistic spectrum, many of whom are extremely distressed and, seeing the world round them as hostile, sometimes respond to it with outbreaks of violent behaviours’. Phoebe thus resonates with a perspective that essentially places the experience of the individual central to our understanding of why they are doing what they are doing, rather than making interpretations of their behaviour based on our biased non-autism/LD viewpoint.

As part of understanding the experience of people with autism and LD, Phoebe has absorbed herself in biographical narratives of self-advocates with autism (eg. Donna Williams, Temple Grandin and many others). With this appreciation, combined with the courage and willingness to reflect deeply into her own sensory experience, emotional responses, behaviours and thoughts (a pursuit which today would be considered mindfulness practice), Phoebe has been able, using an Intensive Interaction approach, to engage with individuals with autism and LD in distress. Often for the first time, such individuals experience a sense of real belonging in the social world and the behaviours which others have found so difficult fade away. Families and care providers feel empowered to continue this engagement enriching the lives of individuals they support as well as their own. As Phoebe notes in her work with Gabriel, a young man who stopped violently and repeatedly hitting his head against hard surfaces: ‘Real equality is when you are using the same emotional language as each other and you value each other’.

During these same decades I have also been working with people with autism and LD but as a clinical academic LD psychiatrist. I have also been asked to see people referred because of problem or challenging behaviours, the

latter description very much reflecting the outside-in perspective of medical practice and the community at large. I first came across one of Phoebe's books at a conference in London and it immediately caught my attention. Not only was it addressing an issue about which I and my colleagues in LD psychiatry were very familiar – and equally familiar with the feelings of inadequacy in providing some effective intervention – but it was also outlining a very different approach. I was intrigued, but the language and content felt somewhat uncomfortable. For example, the author was describing in simple terms what I had come to appreciate as complex biological phenomena, and she was bold in making connections where I felt more caution was needed. In essence, the author was inviting the reader to engage with an experience outside of their own – in particular with that of individuals with autism and LD – and to recognise the challenge in trying to articulate and share our human experience when there are no words. In later years when I would question Phoebe about this she would typically say, 'Try it out for yourself!' In other words, engage in the behaviour and experience the associated sensations, perceptions and feelings.

While we may recognise that feeling connected to others also occurs in the absence of spoken language – as is evidenced by the mother and the baby engaged in an intimate moment through reciprocal babble, facial communication and other body language – somehow we fail to recognise the existence of an emotional life in people who struggle to communicate whether because of autism or LD. And this is at great cost to them and to those who support them, as emotional regulation embedded in meaningful relationships provides the context within which curiosity, motivation and learning are nurtured and nourished. In the absence of such recognition and validation, distress and problem behaviours arise.

While Phoebe's previous books have focused on interventions in response to particular presentations and symptoms, *The Anger Box* leaps forward, and provides a fascinating and stimulating creative synthesis of emerging neurobiological understanding applied to recurring themes such as sensory sensitivities and distortions, self-injury and pain, that have emerged in her work over the years. In this book we are again reminded of the wealth and depth of Phoebe's experience working with people with autism and LD, as well as her intimate knowledge of the narratives of people with autism. When observing Phoebe at work she is totally present for the individual she is working with and absorbed in their experience while trying to work out what intervention, from their perspective, might be helpful. Her method might be considered practice-based evidence as she tirelessly and gently tests out

hypotheses when engaging with her atypically communicating partner. Her understanding from this absorption is detailed and nuanced and perhaps it is no wonder that she is then able to make what might appear to be stunning leaps, or ‘eureka moments’, as to possible neurobiological underpinnings of the phenomena she is observing clinically. I once asked her how she came to bring certain observations and ideas together and she commented it was not so much bringing things together as things falling into place – like pieces in a jigsaw. I once observed such a eureka moment when Phoebe had occasion to review a poster map (used in medical teaching) of the nerve innervation of different parts of the human body. This followed closely a visit to see a child who would scream for hours and slap her head and face very hard, causing injury. On seeing the poster Phoebe immediately recognised that the pattern of the child’s behaviour (and some others she had seen in the past) matched the pattern of specific nerve innervation of the face and neck. Phoebe, mindful also of the reports by self-advocates with autism describing painful discomfort around the neck and face area which increased when stressed and feeling overwhelmed, started to reflect on whether the trigeminal nerve may be implicated. Subsequent exploration of the families of some of these individuals revealed a tantalising prevalence of trigeminal neuralgia. This intriguing series of observations coming together like pieces of the puzzle is one of many shared in *The Anger Box* and invites our further attention and research.

This book will, I think, excite and inspire and be helpful to a broad range of readers including those with autism and their families and other care providers providing support, members of the multidisciplinary teams supporting individuals in distress, and those interested in behavioural neurobiology or researching the mind and the brain, especially as this applies to autism and LD.

While others might be contemplating retirement, Phoebe says she keeps working ‘because it is possible to bring calm into their lives and to teach others to do so’.

*The Anger Box* is a welcome addition to understanding the distress experienced by people with autism and LD and in helping all of us bring calm into their lives.

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# Who is this book for?

There has recently been a shift away from considering autism from the point of view of its presentation and symptoms, towards an increasing exploration and understanding of sensory issues underpinning the condition and its physiological and neurobiological roots<sup>1</sup>. The central theme of this book differs from previous ones I have written on autism in that its focus is on the one hand the experience of physical pain and emotional distress and trauma consequent to developmental deficits and sensory distortions – and on the other, the responses of society to resulting behavioural outcomes. What I have tried to do is to marry theory and practice, placing new ways of looking at the autistic spectrum alongside extensive experience of engaging with children and adults on the spectrum.

*The Anger Box* is a book of ideas spanning a wide field of research. Some of it is speculative. I hope it will be interesting for professionals who, because of the volume of research pouring out of their journals, can get corralled inside their own disciplines – but I have tried to write it in such a way that it will be readable to parents and those who have a general interest in autism. I hope that it will also be of interest to some of my autistic friends. When we add new pieces to a jigsaw, we begin to make out new patterns.

I have followed the custom of altering names, except where individuals and families have decided to use their own, on the grounds that their contribution is important and they or their parents do not wish to conceal their identity, a choice with which I sympathise. I value their contributions and I am pleased to attribute them to those to whom they belong. Where relevant, I have revisited some interventions previously published – but much of the practice described is new. However, books like this are not just the work of their author. We build on each other's work. So I want to pay tribute to all the people who have generously talked to me about their

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1 Caminha RC & Lampreia C (2012) Findings on sensory deficits in autism: implications for understanding the disorder. *Psychology and Neuroscience* 5 (2) 31–237.

autism, as well as those who have given me so many ideas and so much help. Particularly it is for William, for his ideas and drawings of the Anger Box and Good Box – and for Chris and Amy – and for Elspeth Bradley, Nicole Whitman, Jemma Swales, Janet Gurney, Michelle O’Neill, Damian Milton, Philippine Sowerby and many, many others who have fed me with information and laid the foundations for my thoughts.

Thank you also to Holly for technical help. Finally, the development of this practice could not have happened without 30 or so years of continuing support in a variety of ways from the Norah Fry Research Institute, Bristol University.

# Chapter one: The Anger Box

## William

William is drawing his anger box, the shape of a cornflakes packet. In place of the iconic cockerel, a face snarls from the front, squinting with rage. As he draws, he explains in quite a detached way how it lives in his chest, and that when he is getting upset the top opens and the anger flows out, up into his head and down his arms, into his elbows and on down into his wrists and knuckles and his fingertips. (A clever child, William is six and these are the actual words he uses to describe his body parts.)

He says that once the box is open, he can't stop it. His hand stiffens as he demonstrates the progress of the pain, wiping one arm with the other hand, almost in horror, as if he was trying to obliterate it.

William's description of the actual sensations involved when he loses control are in fact very similar to those described by both Donna Williams<sup>2</sup> and Gunilla Gerland<sup>3</sup>, although they locate the starting point in the nape of the neck. In particular, all three describe sensations that radiate out from a central point into the arms and elbows and so on down. Donna describes how they, 'spread to every fibre of my body like cracks in an earthquake', with the sensations spreading down to her feet. 'My eyes frantically look for meaning, my head seems to explode.'

The purpose of this book, *The Anger Box*, is to ask a number of questions about autism. I do not have all the answers, but I hope that it will lead us to reflect on the autistic spectrum in ways that are helpful. I make no apology for the fact that it will have to cover some familiar ground in order to reach a little further into the paradoxes and discontinuities that are part of the

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<sup>2</sup> Williams D (1994) *Somebody Somewhere*. Toronto: Doubleday (p99). (See Appendix 1.)

<sup>3</sup> Gerland G (1996) *A Real Person*. London: Souvenir Press (p56). (See Appendix 1.)

autistic condition. To save repeating previous books too much, readers not familiar with the ‘insider’s’ point of view of autism will find the information they need in **Appendix 1: An inside out approach**.

Central to autism is that the brain finds it difficult to process too much incoming information and goes into sensory overload, a bottleneck where unprocessed images and sounds and sensations clog the brain systems. This situation arises not only as a result of both hyper and hypo-sensitivities to any one of the senses (including the internal sensations that arise from emotional overload) but also because the brain is unable to prioritise and filter out unnecessary stimuli. So, for example, someone on the spectrum may be hypersensitive to sounds, hearing noises like the hum of machines or electricity in the walls. Visually they may see detail rather than getting a whole picture. The exact nature of sensory sensitivity varies from individual to individual.

‘My brain is like dial-up modem. If you feed it too much data it crashes.’<sup>4</sup>

Under pressure, the brain casts around for a coherent pattern, something that it recognises in order to prevent being tipped into what is described variously as tantrums, losing it, kicking off, meltdown, fragmentation or, more accurately, ‘the autonomic storm’. First it looks for some way of reducing sensory inputs that are so distressing it by shifting its point of focus. If this fails, the brain tips into self-defence mode, which shows up in a number of different ways but are usually specific to a particular individual.

Among other aspects of the autistic condition, I want to look at what it is that determines exactly how the body tries to fend off the confusion that results from sensory overload. Why do some take refuge in repetitive behaviour and others run away? Why do some people with autism shut down completely, while others apparently ‘blow their fuses’? And why do some hit themselves and others attack those close to them? What is happening inside the individual that determines how they respond to what they may perceive as life-threatening?

These are important questions if we are to escape the straightjacket of viewing autism in the light of behaviours that are the outcome of its effects rather than its causes.

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<sup>4</sup> WeirdGirlCyndi (2007) *Sensory Overload Simulation* [online]. Available at: [www.youtube.com/watch?v=BPDTUotHe0](http://www.youtube.com/watch?v=BPDTUotHe0) (accessed January 2014).

As a practitioner, my first contact with caregivers is usually in the form of an enquiry as to how staff can cope with a particular behaviour, because behaviour is uppermost in their minds. The query, ‘What do we do about John?’ takes precedence over the question of why John is attacking people, self-injuring, getting stuck in awkward positions, unable to continue with a task or simply hiding.

Before addressing how we can contain him I shall be asking *why* he behaves so strangely? What is going on in his mind? Is there anything we can do to help reduce the obvious distress that he is clearly experiencing?

## Alister in meltdown

Nearly a year ago, I worked with an eight-year-old boy, Alister<sup>5</sup>. Alister, who has ASD, is deeply distressed, lying on the floor in the school foyer, kicking out, bellowing and periodically shouting, ‘No, no, no’. Four staff are standing around him but he is resisting all his teacher’s patient efforts to persuade him to stand up and come to his class. I suggest they move back and, standing out of reach of his flailing limbs, I use his non-verbal language to engage his attention. Each time he bellows I answer him empathetically, but my voice is softer and lower than his. After a minute or so he quite suddenly takes off his shoe, slams it on the floor and looks at me defiantly. This is good news in a way, since up until now he has appeared to be completely disconnected. Refusing to be drawn into a custodial role of trying to put his shoe back on, I turn to his shoe and, using one of his sounds, empathise with its solitary plight.

Alister looks extremely surprised, picks up the shoe and puts it on again immediately, but in doing so, he folds in the back of it on his heel so that it is uncomfortable. Using a curved finger to make an accompanying gesture, I speak to him for the first time, saying, ‘Shall I make it comfy for you?’ He promptly sticks out his foot for me to do so. He then resumes his bellowing but it is more muted. I continue to answer each time. After a few more sounds, he suddenly gets up, places his hand in his teacher’s, abruptly says ‘sorry’, and walks back to his classroom. Normally his distressed periods last for up to an hour. This whole episode was over in five minutes. (However, the tone of his apology is interesting: both his teacher and I notice independently that the word sounds detached from himself, empty, as if he is aware that this is a ‘noise’ appropriate to the occasion but is unaware of its affective content. He does not sound as if he feels it.)

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5 Caldwell P (2012) *Delicious Conversations*. Brighton: Pavilion Publishing.

On the face of it, we have a child having a tantrum. However, if we start to unpick what is happening, a rather different picture emerges.

Talking to Alister's parents, they explain that they have felt that it will help him to fit in to society if he is good mannered and to this end they have laid emphasis on certain patterns of behaviour. For example, he has been encouraged to hold open the door and let others through before going through himself. He has taken this on board and it has become part of his routine.

On this particular day, Alister comes in to school at a time which would normally be quiet – but today there is an alteration in the timetable and he is met by a large number of children leaving the school at an unusual time and is swept aside. He finds himself in a severe predicament: on the one hand he has in his brain the message he has learned telling him that he must hold open the door – and on the other, the message that he cannot fulfil this requirement.

These contradictory messages place an overwhelming strain on his processing system: his brain becomes a battleground, tipping him into a painful autonomic storm that sweeps aside his ability to behave in the ways that he knows are expected of him.

Alister is now at the mercy of an unregulated sympathetic nervous maelstrom with all its attendant physical distress. Desperate to emerge, he shouts, 'no, no, no', and lashes out at anyone who comes near or speaks to him since proximity and speech only increase his sensory overload, processing difficulties and attendant physical and psychological distress. At this point I intervene and use the technique known as Intensive Interaction. Intensive Interaction bypasses speech and works instead with body language, recognising and responding not just to what the individual is doing but also to the way they are doing it – and what this tells us about their internal affective state; how they feel. Contact is made using familiar signals, ones that are part of their personal repertoire or 'vocabulary', which do not add to the difficulties the brain has in processing incoming signals. The most effective way to use it is not simply to 'copy' but to respond in a way that is based on their sound or movement or rhythm but with slight differences. Imitation will get attention but the 'alteration' will intrigue the brain sufficiently to shift attention outwards onto the source outside itself. (Musicians have a name for this – 'call and response' – where a phrase is delivered by one musician and the response from another is basically the

same, but slightly altered.) The effect has been described as like being thrown a life-belt in a stormy sea.

First of all, I simply insert a contingent response to each of Alister's utterances. These capture his attention, shifting his brain's focus outward, away from his inner sensory despair. He becomes aware of something in his environment that he recognises and that his brain can latch on to. But his body is still flooded with adrenalin, and his first contact with me is angry and defiant. He is taken completely by surprise when my response – which he recognises because it is part of his own body language – continues to be one of empathy, but this time for his displaced shoe: slamming it on the floor is his way of representing to me how and possibly where he feels himself to be. He immediately replaces it. We are in contact with each other and he is no longer trapped in his inner conflict. Now I can talk to him but I use gesture to support my speech. Re-orientated, he is able to return to class.

From the point of view of practice, it is the element of surprise in this intervention that is critical in re-orientating his attention from his inner world to connecting with the world outside. By the time I insert the surprise factor (empathy with the shoe), we are sufficiently tuned in to each other for his brain to anticipate a familiar response from me to each of his utterances. At this critical point, however, what he gets from me is a response sufficiently related to avoid breaking continuity, but strange enough to jolt him out of his internal conflict. He stands up and is ready to go back to his class.

Alister is clearly a child who is extremely anxious to please his parents and to do what they ask of him. The difficulty arises when circumstances prevent his fulfilling their expectations. Speaking to Alister's parents, I suggested that he might be less anxious – and consequently less likely to become sensorily overloaded – if they eased up on insisting on his conforming to particular patterns of behaviour. A couple of months later his mother tells me that, following this advice, he is much more relaxed.

Two themes emerge from this account. The most obvious is the approach used to defuse a critical situation – Intensive Interaction.

But rather than laying the emphasis on how to cope with disturbed behaviour, the second theme, the one that is the focus of this book, recognises the need to examine instead the *context of behaviour* if we are to hope to understand it – and possibly find ways of assisting the individual out of their distress. Because what we are still calling 'challenging

behaviour' in people with autism is a response to sensory overload that should more properly be thought of as 'distressed behaviour'. And distressed though it may be (and distressing to observe), under the circumstances it must be considered understandable.

However, Intensive Interaction is not just about crisis management, but is also widely used to tune into and engage with people with whom it is difficult to communicate (see **Appendix 2: Intensive Interaction**).

Not for nothing is autism described as a spectrum, and the variation in presentation refers not only to the severity of autistic features but also to the way the child responds to sensory distress. While William and Alister react to stress with outbursts that culminate in aggression, some children (and adults) immerse themselves in repetitive behaviour, some remove themselves from the source (as they rightly or wrongly perceive it) by hiding their eyes or running away, some self-harm while others shut down or freeze. The common denominator is that these different behaviours are attempts by the individual to defend themselves against what are perceived and experienced by them as life-threatening assaults: in sensorily overloading them we have triggered the body's self-defence system. Quite why this manifests in so many different behavioural ways is more difficult to understand.