

# HALL OF MIRRORS — SHARDS OF CLARITY

Autism, neuroscience and finding a sense of self

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## Dedication

*Hall of Mirrors – Shards of Clarity* is dedicated with gratitude to Donna Williams, who died recently. Much of what I have learned about autism stems from her selfless dedication to teaching the non-autistic world what it feels like to be on the spectrum. She started me off on a journey that has opened up a different world to the one in which I was born and has also taught me about myself.

## Apology

This book spans forty-five years of work and I have not always been able to catch up with all the people who have shared their lives with mine. Some have died and some moved on. Where this is so, I have altered their personal details beyond recognition. What remains is the essence of our interactions.

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# Foreword

By Professor Kelley Johnson, Professor of Disability, Social Policy Research Centre, UNSW

Our lives are a journey in which we seek constantly to understand each other, reaching out from our subjective worlds constructed through our own unique characteristics and the ways we interpret our lived experience. Sometimes understanding seems to be there, at other times we reach out in vain. In this book Phoebe writes that she aims to ‘construct a story’. But the book is also one person’s journey to try and understand what the world is like for a group of people who have often found it difficult to understand the world in which they live, and who are often not understood by others.

The journey in this book is one of exploration. Phoebe uses her forty years of working with people labelled as being on the autistic spectrum to consider what life is like for them. But more than this she seeks to use new neuroscientific knowledge to help us understand better how this group of people sees the world. In doing this she includes her own personal experiences, her years of work and most importantly the voices of people labelled as being on the autistic spectrum. This is an unusual synthesis and one which provides the reader with an accessible and interesting account which makes a unique contribution to our understanding of each other.

In trying to understand better how people see the world, Phoebe takes the reader on a personal journey into the recent research which is revealing more about how our brains work to create our own unique perceptions and view of the world. This is not an easy road to walk but her interest and passion inform the pages and provide the reader with an accessible account in which the practical implications of the research are clearly stated.

One of the important consequences of this journey into our inner workings is her view that focusing on the behaviour alone of people labelled as being on the autistic spectrum does not help them to live in a more comfortable world, nor does it help those working with them to better understand what they are experiencing. Phoebe emphasises the importance of recognising and responding to the inner world of people, particularly their emotional responses, in order to communicate better and to change the environment so that it comes closer to matching their needs.

While many books now provide accounts of the lives of people labelled as being on the autistic spectrum, they are often written from one particular perspective. This

book is interdisciplinary in its approach. As part of her journey Phoebe draws on history, psychology, neuroscience and personal narratives, bringing them together through her own voice.

As someone who is not a biologist or a neuroscientist but who has worked with people with disabilities for a long time, I was somewhat wary about reading in an area outside my comfort zone. And I wondered as I started the book whether it was going to medicalise people labelled as being on the autistic spectrum. However, while I was challenged by some of the research, I also came to a view that if we are to understand each other we need to ask the question: why do you see the world and other people like this? There is of course no simple answer to this, but ignoring a field of research which suggests some of the reasons for our behaviour and our feelings and emotions denies us the possibility of understanding.

Phoebe's interest and passion and her need to share her knowledge provide us with a vital perspective. The information provided in the book is essential, but perhaps as important is the sharing of those characteristics. When we seek to understand each other we need to bring to the journey those imperatives: the desire to understand and to have the courage to take a journey into worlds we do not know.

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# Chapter 1: Introduction

A week ago, I was driving home across the moors on a thick, gloomy day. As I came round the corner, a shaft of sunlight elbowed aside the clouds and lit up one field, diamond sharp, so brilliant that my whole attention was claimed by it. It felt as if I could count each tussock, every blade of grass and the droplets of water shining on each one. It was a moment of total clarity snatched from the murk.

If one has written as many books as I have on a single subject, there has to be an extremely good reason for embarking on another; something especially fascinating which throws new light on one's focus of interest. This book is a detective enquiry. I am trying to construct a story that marries the avalanche of neurobiological research pouring out from a wide range of professional journals, with approaches being used in care, and at the same time listening to the voices of people with autism. For comparison, since I hope that it will bring more understanding to those of us not on the autistic spectrum, it contains material that is personal – and I am the person I know best.

Currently, in the rush for empirical evidence, burgeoning understanding of underlying processes is not always getting transferred from theory into practice – and on the other hand, researchers are not always pursuing new directions highlighted by the extensive experience of front-line workers. Neither are we listening to what people with autism are telling us.

Part of the problem is that autism research covers such a wide field. Each branch is publishing in its own particular journals, therefore references to the relevant literature are not necessarily picked up by those who are working at the face of autism. For example, research on pain caused by trigeminal neuralgia, and sometimes overlooked in autism, is mainly to be found in dental journals, since dentists are the first port of call for those with pain in the jaw. Trigeminal neuralgia is characterised by the adult or child chewing and applying pressure with their fingers to relieve acute pain just under and behind the ear lobes.<sup>1</sup>

*'In the midst of a meteoric rise in the rates of autism significant new research into physical symptoms has been done. The challenge is to incorporate this new research into the practice of medicine that historically has stereotyped autism as a purely psychiatric disorder.'*<sup>2</sup>

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- 1 For more information about trigeminal neuralgia see Chapter 2 in Caldwell P (2014) *The Anger Box*. Brighton: Pavilion Publishing & Media Ltd.
  - 2 Kerm JK, Geier D, Sykes L & Geier R (2015) Relevance of neuroinflammation and encephalitis in autism. *Frontiers in Cellular Neuroscience* **9** (128) 519.

As the title suggests, *Hall of Mirrors – Shards of Clarity* refers to two states. It is an exploration triggered by a number of themes which have surfaced and converged during recent work and reading, so it covers a wide canvas. Inevitably it is an idiosyncratic and personal selection – but I hope its somewhat zig-zag hunt for clues may be of interest and assistance to those of us who are involved in shaping care pathways. As before, it builds on the work of others in order to reach some sort of synthesis.

In trying to understand the processes that underlie autism, we have reached a stage that moves beyond behavioural observation to complex neuroscience and neuroanatomy. I have tried to limit the more technical descriptions; where this is not possible I have simplified the language as much as possible. As an author, I am struggling with the interconnectivity of subjects that branch off in multiple directions. It is not easy to find one's way through the thicket of information; there are too many fascinating trails. Some are hard for the non-specialist to understand and some turn out to be dead ends. To start simple I am going to begin with a snapshot from my own childhood.

As a small girl I am taken on a trip to Madame Tussauds, galleries full of waxworks, each immobile on their platforms, groups of the famous and infamous, heroes, celebrities and villains immortalised in wax – but still, in human terms, undemanding and non-threatening as tailor's dummies. All goes well until we move into the 'Hall of Mirrors'.

Suddenly, everything I know as real explodes, my own image, all that I perceived as myself swims and slithers, as if I am being pulled in all directions. What I know of as my self, my physical image, disintegrates: I burst into tears and have to be taken outside to be comforted.

So if a loss of sense of self can have this rather overdramatic effect on a securely attached child, what is it that is so vital about our personal image – and why does a threat to it leave us so intimidated? In this respect, what is the feeling of the aloneness of autism, where does it come from? What is it that leaves those on the spectrum so particularly vulnerable? Are there ways we can make it easier for individuals with autism to be their selves and relate to people other than themselves?

Emerging from my identity crisis, triggered by the Hall of Mirrors, 'shards of clarity', is a phrase used by six-year-old Arran's mother, following a visit to her family to demonstrate how one might use a child's body language to develop emotional engagement (Intensive Interaction). While Arran does not have a diagnosis of autism, there are a number of features of his behaviour (such as

attachment to repetitive behaviour and an apparent difficulty in engaging in personal relationships), that remind one of life on the spectrum.

Arran has a rare genetic mutation. He is registered as having a severe sight impairment, although he does register movement and will stand nose-to-nose with the TV or watch flickering fingers, attempting to draw them closer to his face. After observing an intervention I did with Arran using his sounds and rhythms to communicate with him (Intensive Interaction), his mother said that whereas before, although she had witnessed the effect of using body language to tune into a child, she had not 'got it' but now she saw its potential. She told me later that after I had left she had spent hours sitting on her bed playing with him. For the first time, she and her son had been able to relate to each other. She added that, for Arran, it was as if 'shards of clarity' had come into his world, a world that until now had been making no sense to him.

This is a striking image: fragments of coherence in an environment that presents the brain with sensory chaos, one where swirling pixillated images combine with capricious sounds and overwhelming bodily sensations.

The sensory experience of each autistic child or adult is different; this is how Iris Johansson describes how it felt for her:

*'It made my body feel like an unmoving piece of meat that often hurt. Then there were dangerous demons and horrible noises that scared the wits out of me. Then I would often scream, bang my head and scream until it quieted. The light was so unpleasant in the ordinary world. Everything changed constantly and my head burned and ached.'*<sup>3</sup>

No wonder a child or adult with autism recoils from a world that physically threatens to overwhelm them and grasps at any stimulus he or she does recognise like iron filings to a magnet.

If we imagine taking the top off our heads and looking inside, we shall see the familiar two halves of the brain. Somewhat like a walnut, they are joined across the middle by a band of fibres called the corpus callosum. Another of the starting points for this particular book arose out of being asked to help find ways to assist a young woman with autism, who also has a diagnosis of damage to this bridge between the two halves of her brain. Trying to unravel what this might mean in terms of behaviour, my attention was drawn to two rather different sources. The first was an astonishing book (and accompanying film) by Jill Bolte Taylor<sup>4</sup>. Jill

3 Johansson I (2012) *A Different Childhood*. Arizona: Inkwell Productions.

4 Bolte Taylor J (2008) *My Stroke of Insight*. London: Hodder & Stoughton.

is a neuro-anatomist. Her research involves post-mortem studies of the brain in relation to mental illness and particularly schizophrenia. At the age of 37, she suffered a severe stroke. Half her brain was flooded with blood – and she literally observed the progress of her stroke with a scientist’s eye while her left hemisphere shut down. She had access to both the ‘inside-out point of view’ of the trauma she was experiencing, as well as a scientist’s observations from the ‘outside-in’. She was able to follow the process of failure in the left brain.

Jill’s contingent outside-in and inside-out experience into left hand/right hand brain functioning is complimented by the research of Michael Gazziniga, a cognitive neuroscientist. Michael and his team and have spent forty years investigating the neural functioning of patients with severe epilepsy who have undergone surgical treatment to sever the corpus callosum, effectively cutting off the two halves of the brain from each other.

Another starting point has been the number of accounts by people on the autistic spectrum who report their experience of blurred boundaries and the loss of a sense of self<sup>5</sup>. In order to describe their different states of sensory experience they use words such as ‘in’ or ‘out’. There are semantic complications to this: while Donna Williams contrasts the chaos she experiences in the outer world with her inner retreat, Iris Johansson uses ‘inside’ and ‘outside’ in the opposite sense throughout her book . For Iris, ‘out’ is when she is lost in her own world (one might think of this in terms of being ‘spaced out’). But for Donna, ‘out’ refers to the world outside her personal inside hideout.

Overall this book is asking what happens to one’s sense of self if one’s brain is receiving a distorted image of the world and its intentions towards oneself, so that much of one’s intake is experienced as hostile, triggering the body’s self-defence system.

*‘Not having a clear sense of my boundaries, what is me and what is not me?  
My personal space feels threatened and invaded.’<sup>6</sup>*

In addition to defensive strategies, such as repetitive behaviours, avoidance, shut down or aggression to self or others to avoid the perceived source of one’s distress, some people on the spectrum will adopt what appear to be different personalities (manifest by different voices) to shield their vulnerability, even a number of these. However, they appear to be bewildered rather than schizophrenic. So what is happening to them? Why do they feel so disembodied?

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5 Caldwell P (2014) *The Anger Box*. Brighton: Pavilion Publishers and Media Ltd.

6 Personal communication with an autistic person.

‘Consciousness’ and ‘sense of self’ are difficult subjects and I do not intend to become embroiled in complex philosophical arguments – but rather to approach them from the point of view of a practitioner, by way of asking what it is that people who have lost any such certainty are telling us about their experience and what does this tell us about our own experience of who we feel we are? Is there anything we can do to support those who are trapped by such a loss?

Finally, I have become increasingly aware of the crucial importance of a subject that I have already written about and that is, autistic or not, the primacy of our need for **confirmation**. What do we understand by confirmation? Why do we need it and what does it do for us? How does it relate to proprioception<sup>7</sup> and anxiety? And to go back to the title, where does confirmation fit into the image of shards of clarity, as used by Arran’s other?

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<sup>7</sup> Proprioception is the sensory feedback from our muscles and joints which tells the brain what the body is doing and where it is in space. We shall be looking at this in detail in Chapter 9.