

# Delicious Conversations

Reflections on autism, intimacy and communication

Phoebe Caldwell



## Limestone Country

*Fractured by frost, weathered by water's flow,  
ground by the weight of glaciers long ago  
that scratched out runnels, hollowed, bevelled, cleft,  
the scars and scourings of its passing left;  
this is a landscape whittled to the bone –  
a sharp, smooth, flat and craggy land of stone.*

*But in the cracks, deep hidden, often missed  
bloom secret gardens of the barren klist:  
orchids and mountain avens, gentians blue,  
delicate milkwort, cranesbill's burning hue.  
Who in such bleached and arid waste would know  
the sweetest flowers here in earth's wrinkles grow?*

Rosemary Russell



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# About the author

**Phoebe Caldwell** started her career as a biologist. She is now an Intensive Interaction practitioner working mainly with children and adults on the autistic spectrum, many of whom have behavioural distress. Phoebe's methods combine using a person's body language to communicate, with paying attention to those aspects of an individual's environment that are triggering sensory distress. For four years Phoebe was a Rowntree Research Fellow looking at best practice. She teaches management, therapists, parents, teachers, advocates and carers, nationally and internationally, and she has been one of the principal speakers at a BILD annual conference. She is also employed by NHS, social services and community and education services to work with individuals they are finding it difficult to provide a service for. She has published seven books and four training films, and a number of academic papers. In 2010, she was awarded the Times/Sternberg Active Life Award for work on autism and contribution to the community, and in July 2011 Bristol University awarded her an Honorary Doctorate of Science for communication with people with autism.





# Chapter 1

## Introduction

### Autistic and neurotypical: what have we got in common?

This is a book about how we feel, particularly how we experience intimacy, in the form of a series of roving reflections. Set in the somewhat unlikely arena of autism – a condition that is characterised by aloneness, separation and inward focus – it is hardly the place where one might expect to start a journey to experience another mind.<sup>1</sup>

Instead of looking at people on the autistic spectrum as if they exist ‘out there’ on some strange other planet, I want to see what it is that we who are not autistic have in common with our autistic partners; to look at both of us from the point of view of whereabouts we are on the human spectrum, an inclusive attitude rather than one that sees us as separated. What do we share and what can we learn from what we are telling each other?

This train of thought is inspired by an email from a highly intelligent young man with Asperger’s syndrome named Josh, who **has no speech but communicates by typing either in English or in**

<sup>1</sup> Readers who are looking for more detailed information on the use of body language with people on the autistic spectrum will find examples in:

- Caldwell P & Horwood J (2008) *Using Intensive Interaction and Sensory Integration: A handbook for those who support people with severe autistic spectrum disorder*. London: Jessica Kingsley Publishers.
- Caldwell P (2005) *Finding You Finding Me*. London: Jessica Kingsley Publishers.
- Caldwell P & Horwood J (2007) *From Isolation to Intimacy: Making friends without words*. London: Jessica Kingsley Publishers.
- Caldwell P (2012) *Listening with All Our Senses*. Hove: Pavilion Publishing and Media Ltd.

Hebrew. Asked what it is like to experience Intensive Interaction, a way of communicating that uses body language rather than speech, (for example, does he feel it is humiliating or patronising?), his reply is that on the contrary, when his brain stops focusing it gives him the ‘delicious feeling of having a conversation’.<sup>2</sup> What does Josh mean by this?

## Maintaining coherence

Autistic or not, we live in the same world; but it is evident that our interpretation of our sensory experience is different. Whereas those of us who are not autistic can, without difficulty, take in, process and put into context the images we see, the sounds we hear and the feelings we have, the brains of our autistic partners find it difficult to make sense of (and therefore interact with) incoming stimuli, both those that impact from outside the body and those that originate from inside. Sometimes the brain will function normally, placing sensory intake into context, and sometimes it will not. What Josh is telling us is that when he becomes stressed and the processing system in his brain is no longer effective (so his cognitive system is unavailable), if he is offered signals from a source outside himself, such as swinging the head (part of his behavioural repertoire), his brain recognises these easily. He can use this as a point of reference and so maintain some sense of being in touch. On the edge of losing reason this is an alternative channel for maintaining contact with the world outside himself. Rather than being an intrusion into his privacy or experienced as degrading, using Josh’s body language to communicate with him offers him a lifeline.

So what is this delightful wordless connection that Josh can use when his cognitive faculties are under stress? How can we use this facility to explore how Josh feels and to recognise the feelings his choice of words engenders in us?

We immediately run into trouble, since talking about feelings can be immensely confusing. For example, autistic or not, there are some areas of experience where we all find that words are inadequate, particularly when it comes to expressing emotional

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<sup>2</sup> Harris J (2012) *Joshua’s Planet* [online]. Available at: [www.joshuasplanet.com](http://www.joshuasplanet.com) (accessed June 2012).

state. We are going to have to start by thinking about what we mean in this context.

## Feeling as sensation, emotion or perception

In the search for appropriate language, confusion starts with the word 'feeling' itself, since we do not always distinguish between the three avenues of 'sensation', 'emotion' and 'perception' – fundamentally different processes haphazardly tossed into the same basket. On top of this, we do not always differentiate between one sensation and another. Take touch for example: because we use the same word for both senses, and because they have no specific and obvious organ such as an eye or an ear, it is easy to confuse the sensation of touch (our diffuse surface sensations) with the sensation of proprioception (the internal messaging system from our muscles and nerves that tells us what we are doing). In many cases they are interlinked and we register the superficial affect of a surface texture to the skin and the reactive pressure applied by our muscles and nerves simultaneously. For example, I fail to differentiate between the smooth sensation of a metal door knob and the exercise of my arm muscles as I open the door; I just don't think about them as separate feelings.

## Using body language to engage attention

Still at school, Martin is a happy young man of 17, that is, the world into which he has withdrawn does not distress him. He rocks and smiles and makes some attempts at speech, usually one syllable. He does not appear to like touch and will flinch if he is touched lightly but will occasionally rub his back and sides hard, and clearly enjoys it when I do likewise for him, applying firm pressure. However, Martin also has a puzzling behaviour: periodically he stretches his arms and hands right down to the ends of his fingers. This over-extension is so strong that the sinews stand out on the backs

of his hands. This behaviour looks unnatural and does not appear to relate to whether he is happy or upset, it happens at any time. I am told it is not related to epilepsy. So how can I understand what is happening here?

I try it out on myself. At 6am I am starting to wake. I do not have to get up at once so I lie back in the half-light between night and morning, floating in penumbral dreams rather than being aware of my body. Time passes and the alarm rings. Before rising, I stretch – my toes upwards, ankles, calves, knees, thighs, chest, shoulders and particularly the joints of the spine – from my toes to the nape of my neck, bringing about sufficient body awareness to launch the transition from the horizontal to upright position. I need to know where I am, to get a clear picture of myself in relation to everything else, to feel my boundaries.

The question is: can this small exploration of my own behaviour cast any light on Martin's extensions? In my case, the sensations I have experienced suggest that my spread-eagled extension mobilises my musculature and helps me return to the daytime world as I define my physical boundaries. So is this what Martin (who appears to be low on proprioceptive stimuli), is periodically doing for himself? Is his apparently bizarre behaviour an adaptation to inadequate perception of proprioceptive stimulus, providing him with a sense of the boundaries of his self, defining his body limits so that he can, perhaps even unconsciously, perceive where he is and by implication what and who he is? Or is it a purely unconscious spasm related to a misfiring in the brain stem? If the latter is true, is it also helping him to know what he is doing when he reaches a state of confusion? Faced with alternatives such as these, we can only tell by responding to an individual's movements or sounds and seeing if this will spark their interest.

Making Martin's movements myself helps me to internalise and align myself with what he is getting out of the action (one that looks odd in my terms), in order to learn what his reality means to him, rather than looking at him from the outside and making judgments based on my own. But, in pursuit of an analogy I need to be careful. Just because my exploration of Martin's spasmodic stretching produces a physical sensation in me, it does not mean that it is necessarily

correct for him. I have to be careful not to project my sensory responses onto Martin.

So is there any point in replicating an individual's actions? Will it lead me to a better understanding of their world and hence to the possibility of developing communication and engagement where there has been none? If I physically take on the rhythms of my conversation partner, will it help me to tune in to them? If so, what will this do for them?

From the point of view of engaging attention, it turns out that the exact trigger for a behaviour is less important than whether or not it is a familiar part of a partner's repertoire (and therefore has significance for their brain if we respond to it). Is this familiarity intriguing enough to re-orientate their focus from involuntary imprisonment in their inner world to engagement with the world outside themselves?

Janice is elderly and presents as being extremely anxious. She chews a towel repetitively and periodically wanders in an agitated manner. When she sits down on a sofa, I sit beside her and follow her jaw movements, exploring the feeling she is giving herself. Realising how rhythmic it is, I tap this rhythm on her knee. Her brain recognises this pattern and she comes out of her withdrawn state and starts to smile and take an interest in what I am doing. (I have shifted her attention from solitary self-stimulation to an activity we are sharing.) Her relaxation is palpable to all the staff present. She lies back and eventually doses off. Her support staff comment that they have not seen her so relaxed before.

So how is using touch to transmit a rhythm that Janice's brain recognises helping us to come into accord with each other?

According to the *New Oxford Dictionary of English*, our 'haptic sense' relates not only to our sense of touch, as in the perception and manipulation of objects using the senses of touch (superficial) but also as in proprioception (internal messages from the nerves and musculature about tension and pressure and movement).<sup>3</sup> Interwoven signals (a sort of global positioning network) help us to

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<sup>3</sup> *The New Oxford Dictionary of English* (1998) Oxford: Oxford University Press.

map our body and give us the sense of where we are in relation to 'other than our body' as well as its physical properties. The same duality applies to the other senses, such as vision.

*'A special sense such as vision is processed at a special place within the body boundary, in this case the eyes. Signals from the outside are thus double. Something you see or hear excites the special sense of sight (or sound) as a non-body signal but it also excites a body signal hailing from the place in the skin where the special signal entered ... When you see or hear, you do not just see or hear: you feel you are seeing something with your eyes or hearing it with your ears.'*<sup>4</sup>

It's not just information about the environment that is being gathered but also information about ourselves: 'what' and additionally 'that' we are, even if knowing about ourselves is not the primary point of focus. External stimuli not only tell us about the outside world but also inform us of our internal state; not just vis-à-vis ourselves but also in relation to the original stimulus. When I tap Janice's knee with a rhythm her brain recognises, it not only draws her attention to an outside source, but also sends her information about her own body. (I shall discuss the critical importance of confirmation later.)

So there is a third consequence to my observation. When I see, hear or feel an object or activity out there, it not only delivers information to me about it and about myself, but it also engenders in me a particular sensation (which may be positive or negative), one that carries its own particular affective charge – my response in relation to what I see, feel or hear. This feeling is specific. If I come across it again, or something like it, I shall revisit it. It and its allies are like provisions sorted, labelled and stored in a larder. If I turn my attention towards its 'flavour', I shall find that it will lift the lid on a whole group of metaphorical tastes stacked on the same shelf.

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4 Damasio AR (1999) *Descartes' Error: Emotion reason and the human brain*. New York: GP Putnam's Sons.

As with touch, what we are looking at is ‘feeling’ as sensory perception, the emergence of ‘cognitions’ or ‘inklings’,<sup>5</sup> some so powerful that they carry us through into qualitative descriptions of emotion: ‘I am very touched by this’, or ‘I’ll be in touch’.

In practice, it is not just touch but all of my sensory experiences, both of the internal and the external world, that carry a definitive affective tag which can be recognised, isolated and revisited. Even the dull ones that may be experienced as boring are a sensory event, one that can be considered and acknowledged. Learning to identify a particular sensation provides me with an alternative navigational system to thinking, arguably a more primitive one, but one with the advantage of allowing access to my subterranean library. This is what Guy Claxton calls the ‘undermind’ – the stuff that is present in my brain but which I am not consciously aware of.<sup>6</sup> For me, the undermind feels as if it has the properties of a no man’s land, somewhere I can send out occasional patrols at night when my conscious brain is quiet.

This affective process appears to connect with the undermind by means of a route that resembles resonance. Something that I am initially aware of externally sparks off related images in my undermind which tune in with the feeling that I derive from my original stimulant. In my case these ‘once-removed’ offspring will normally present as (fleeting) visual images, recognisable as related, but often tantalising in their transience, needing to be grabbed by the heels quickly before they scamper away. Less frequently, messengers deliver a half-heard auditory prompt: ‘Try so and so...’.

There may be more than one of these images. If I see X in my conscious mind and X is associated with a certain feeling, my undermind will float up a number of ‘x’s, together with possible ‘y’s and ‘z’s, not necessarily identical but near enough to share at least some sensations with the original. Why bother with this exploration? What is wrong with just a description of X? What does Xx, Xy or Xz give me that I could not locate already by consciously

5 ‘Inklings’ derives from the middle English verb to ‘inkle’, meaning ‘to utter in an undertone’, an ancestry that captures precisely the fleeting nature of these sensory messages (*The New Oxford Dictionary of English* (1998) Oxford: Oxford University Press).

6 Claxton G (1997) *Hare Brain and Tortoise Mind: Why intelligence increases when you think less*. London: Fourth Estate.

bending my thoughts towards it, analysing it through logical progression? One answer seems to be that my awareness of an affective state (and consequent understanding) is expanded. I can tap back into a whole variety of alternative cognitions, which shed light on what may have been a previously intractable situation.

So far, black and white: either I know what I am doing or I feel what I am doing. When I think, I initiate and explore within the limits of my capacity – a conscious process that I feel I am in charge of. The affective process is a skinny dip into the undermind, which I allow to happen, in which I can float and swim in a medium that I am not immediately aware of.

It is this borderline area between ‘conscious recollection’ and the unconscious that is so intriguing. Are thinking and feeling really separate processes? If I cannot think without feeling, can I have a feeling without thinking?

Falling over an obstacle, my chest comes in contact with a heavy sharp object as it hits the ground and I crack a rib. Pain comes, urgent, followed by the almost but not quite contingent thought, ‘My God, this hurts.’ These are two separate apprehensions, the first fast-tracked through the amygdala, the second a cortical assessment of the degree of sensation.

Then there is ‘brain-surfing’, initial attention to a subject followed by emptying the mind, allowing affective connections to get to work, to resonate uncluttered by extraneous matter. We notice an as yet untamed flicker as an idea begins to crystallise but before we have words to express it. Characteristic of such ideas and associations is that they ‘pop up’ – in my case particularly when going to sleep or when waking and before I find words to frame them. Unless one can name these flickers quickly they vanish.

So are these affective thoughts just feelings unframed by words? And is feeling just the substrate for thought – there all the time, whether or not we pay attention to it? I find that during the process of crystallisation (cognitive actualisation) I can either frame the emerging idea in words, or snare it as feeling in metaphor, a vivid picture as yet not formulated in words. Of course, thought and



perception are intricately interwoven and I am constantly using both, crossing and recrossing the boundaries, testing one intuition against the other, checking which of these enticements is relevant and which is not. At least I now have a choice, I am not stuck with the so-called obvious (which can be very misleading).

In order to effect transfer from one layer into the other there are conditions to be met. The first is that an underlying affective match already exists. Have I already met this feeling, or a near-enough match to be recognised as closely related to it? Second, the interface needs to be clear of irrelevant material so that my insight can surface. Finally, I need to be aware that my insight, illuminating as it may appear to me, may be wrong.

As I write this I am aware that while the brain's overall goal of self-actualisation is the same in all of us, the exact point at which any of us lie on the spectrum of affective/thinking differs. I am probably at the extreme end of the affective scale, which works out in practice as a dizzying ride from one perception to another, leapfrogging logic through resonant metaphor, risky but occasionally proving inspirational. I recognise (and sometimes envy) rational processing in others and have had to learn to complement my free-wheeling excursions with analysis. A and B may share the same resonant sensation (qualia) but what is the link and is it really applicable in this instance? What light, if any, does such a 'hop, skip and jump, procedure throw on this present circumstance?

In her excellent and revealing film *Jam Jar*, Donna Williams (who has severe autism) tells us about yet another way that she engaged in her search to make sense of her environment: 'People say there's only one way of thinking but I think there's all sorts of different ways of thinking.'<sup>7</sup> She goes on to tell us that, due to problems with processing speech, she could not always make sounds into words and the words into meaning and put the meaning in context, since they all required interpretation. So she developed what she calls the 'system of sensing', building up a sensory encyclopaedia of sensations for different objects, For example, the table was a 'brown, flat, square, thud thing'. Using such an approach she was able to maintain some sort of connection with her surroundings.

<sup>7</sup> Williams D (1995) *Jam Jar*. Film. Fresh Film in association with Channel 4, UK.

Nevertheless, in a world that, in her words, demanded that she lived through interpretation, the struggle to do so was extremely stressful and created a war in her head from which it was easier to retreat into her inner world.

While one might object that such a system of sensing excludes the possibility of generalisation, Donna tells us that she managed without interpretation, it was redundant to her. (In this context it is interesting that even partners with extreme autism can manage to generalise if such a generalisation takes place in the context of, what is for them, meaningful sensory experience and not in the realm of cognitive interpretation. ‘I know that you will answer me if I flick my string, how about if I bang the sink?’ It would seem that the process of generalisation itself is not the problem so much as the mode in which it is being organised and expressed.)

In this inner world of autism, the brain is able to focus by concentrating on a single (or limited number) of physical sensations that become hardwired in through endless repetition, becoming so familiar that they succeed in bypassing the processing system. What the observer witnesses is a repetitive behaviour that reflects a conversation between the brain and body which is intelligible to their autistic partner and helps them to avoid sensory overload and stress, to ‘hang on in’. The brain sends messages to the body that tells it to initiate a sound or movement. This sends feedback to the brain which it recognises, an input that in the swirling chaos provides a point of reference and allows it to stay on track. Now at least there is something in the person’s environment that makes sense and helps them maintain coherence. Tito Rajarshi Mukhopadhyay speaks about how the reflections of shadows and flapping his hands by a mirror made him feel secure. He knew what to expect from them.<sup>8</sup> Understanding the world through physical sensation is quite a different process from analysis through cognition – or through the matching resonance of affective and intuitive twinges.

Donna Williams’ work illuminates not only the world of autism but also our own processes and the way that we struggle with what we have. Recent research suggests that the brain may even have its

8 Mukhopadhyay TR (2008) *How Can I Talk if My Lips Don’t Move? Inside my autistic mind*. New York: Arcade Publishing.

own refuse collection system in the form of daydreaming (which is distinct from dreaming in sleep). Far from being an idle process to be actively discouraged ('Stop daydreaming child and attend!'), this mode of brain activity is a default mechanism which it reverts to when not actually engaged in thinking. It can be envisaged as a kind of auditing, 'where the default network, a cluster of regions arching through the midline of the brain from back to front', talks to the hippocampus (the memory store), selecting those memories that are important enough to catalogue and store, and discarding the rest so that the brain does not become overloaded. So important is this apparent resting process that when the brain is engaged in this way it uses far more energy than when it is in thinking mode – and even more than the beating heart.<sup>9</sup> There is also evidence of this tidying activity during early sleep.

In direct contrast to daydreaming (low on attention but high on metabolic requirement), meditation is highly focused and low on energy demands. Laying aside whether its primary intention is spiritual or secular, the world stills for the person practising. One of the side-effects of meditation is that attention to emptying the mind of its business unblocks the channels of process. The interface between the conscious and undermind becomes more and more porous: buried but resonant material is more easily accessed, identified, compared and expanded. For me, the tree of possibilities flowers and my practice is enriched.

Still prowling around in the maze of 'feeling', we come to emotion, a term which, as Damasio points out, is frequently restricted to self-orientated concern.<sup>10</sup> What is clear is that we often find it difficult to handle the surges of passion that are part of our makeup.

Steering clear of purple prose, words mutate, changing nuance if not absolute meaning. Nowadays 'emotional' is a term that carries a whole baggage of projection: oceans of teddy bears and flowers wrapped in plastic. In his fascinating book on the Japanese concept of *Wabi-Sabi*, a metaphysical attitude that draws attention to the states of imperfection and transience, Leonard Koren suggests that

9 Raichle M, MacLeod AM, Snyder AZ, Powers WJ, Gusnard DA & Shulman G (2001) A default mode of brain functioning. *Proceedings of the National Academy of Sciences of the United States of America* **98** 676–682.

10 Damasio AR (2000) *The Feeling of What Happens*. London: William Heinemann, p56.

we are losing direct contact with how we feel. He writes that the expression of our passions:

*'is being progressively ironed out in an accelerating trend towards the uniform digitilisation of all sensory experience, wherein an electronic "reader" stands between experience and observation, and all manifestation is encoded identically'.<sup>11</sup>*

We are in danger of losing our capacity to bare our feelings.

Losing touch with our own feelings, we vicariously hunt down and share the desolation of strangers. When a microphone is thrust in their face, victims and their neighbours say, 'It feels very emotional' and we are caught up in the second-hand flow of their desolation, but without the responsibility that comes from owning it. So I will mainly use the term, 'affect' rather than 'emotion' to express how we feel.

## Second-person engagement

A side-effect of our withdrawal is that some people, even professionals, find affect so difficult to handle in their own lives that they feel uncomfortable with any discussion of feeling, excluding it from permissible interaction. Allied to this is the problem of how to encode affect, no matter how moving the interaction appears. So the practitioner may feel manoeuvred into evaluating joy by getting out their ruler to measure proximity.

This is clearly absurd and leads to the suspicion that in our desire for scientific detachment we have been led into an intellectual cul-de-sac, in particular we are confusing the cerebral and affective processes – how we think with how we feel. In her groundbreaking book *How Infants Know Minds*, Vasu Reddy distinguishes three different ways of engaging with other minds. The first-person approach knows other minds as an extension of self. The third-person approach is detached, and views them through observation. The core of her book

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11 Koren L (1994) *Wabi-Sabi for Artists, Designers, Poets and Philosophers*. Berkeley, CA: Stone Bridge Press.

is an alternative, the second-person response approach, ‘where others are experienced as others in direct emotional engagement’. She points towards the difference between being the subject of a smile from a friend and observing a smile directed at another person: in the former case, being its subject is experienced as ‘phenomenally different’ and calls for an affective response.<sup>12</sup>

## Should practitioners engage with feelings?

Working towards establishing communication with people who have little or no speech, the question is still occasionally raised as to whether or not it is part of my role as practitioner to engage with affect. However obliquely, one school of thought suggests that such work should be confined to analyses of what we see happening, rather than trying to understand our partner’s feelings. The implication is that involvement with (and interpretation of) affect is unscientific. But this suggestion raises the whole question of the role of the practitioner. Is it legitimate for them to align with and interpret their therapeutic partner’s feelings or should they confine themselves to observation and recording data? Critically, in order to improve our understanding, how can I pin down something as nebulous as my assessment of my partner’s feeling, define it accurately and pass it on to you, so that you receive an accurate evaluation of our affective interaction? To put it another way: how can I help you to taste its flavour?

## Do people with autism have feelings?

Because we find it difficult to read the body language and hence the affective state of those on the autistic spectrum, (since it does not necessarily correspond with ours), it is often assumed that they do not feel emotions. Therese Jolliffe, who has severe autism, warns us that it is not true to suggest that people with autism lack

<sup>12</sup> Reddy V (2008) *How Infants Know Minds*. Cambridge, MA: Harvard University Press.

feelings. She says: 'We do love people and feel lonely',<sup>13</sup> but they have problems with the feedback they get from their bodies. Temple Grandin describes emotion as being totally overwhelming, 'like a tidal wave'.<sup>14</sup> In the introduction to his book, *Look Me in the Eye: My life with Asperger's*, John Elder Robison (who is on the Asperger's end of the autistic spectrum) writes: 'Above all, I hope this book demonstrates once and for all that however robotic we Aspergians might seem, we do have deep emotions.'<sup>15</sup>

## The difficulties inherent in transmission of feeling

So what can I hope to know about my partner's affective state? And do my speculations add to our understanding? In a personal sense, just as it is difficult for you to know what I mean when I do not make it exactly clear in what sense I am using the term 'feeling', so it can also be extremely hard to find language that accurately transmits to you what it is that I am actually feeling, and to be sure we are talking about the same thing. One person's feeling may be another's black hole. On the other hand, in talking about valuing the quiddity (essence) of another human being, what we now intuit about communication suggests that it is not enough to observe and record the actions of our partners without also considering how they feel. An autistic man tells us that he likes it when people tune into him.<sup>16</sup> So while it may not be possible for us to record affective relationship 'uncontaminated' by our own responses, just because it is difficult it does not mean that it is not worth trying.

Even if we do decide that it is legitimate to be working with our partner's feelings, they are not easy to describe and pass on to a third party in such a way that transmits the same meaning for both of us or that offers us an absolute standard. As we search for acceptable language we have to bear in mind that the sensory experience of people with autism is completely different to ours and that we shall be led badly astray if we assume it is the same.

13 Jolliffe T, Lansdown R & Robinson C (1992) Autism: a personal account. *Communication* 26 (3) 12–19.

14 *A is for Autism* (1992) Film. Fine Take Productions with Channel 4.

15 Robison JE (2008) *Look Me in the Eye: My life with Asperger's*. New York: Ebury Press.

16 O'Brian A (undated) Personal communication with the author.

## Using metaphor to transmit the essence of a feeling

Sometimes the only way to capture the essence of sensory experience is to engage with an image that has common resonance for both of us, through the language of simile and metaphor. If what my partner feels sparks off an image in me, it may also resonate for you. Trained as a scientist, I am well aware of the danger that coming at a subject through such a subjective approach lays it open to the use of figurative and emotive language. But in snatching a passing metaphor, can I hitch a ride on it and see how far it will take me? Can I cadge a lift home; bring it to internal presence so that I see the feeling from inside and from here can convey it to you?

If it is powerful enough, a relevant image will transform a description into a sensation. A striking example is offered to us by an able child on the autistic spectrum. His general progress at school is good but he is struggling with French. He tells his mother that he has problems with this particular classroom: 'It's like being in a car-compact'. This eloquent description of the sensory difficulties he experiences (a claustrophobic sensation of life-threatening pressure due to the phenomenon of lack of permanence, whereby dimensions can expand or shrink without warning) hits the affective target squarely – bulls eye. Instead of struggling with details, I now know what this feels like. The image the child offers of the sensation he has experienced literally triggers a sensory response; it 'feels in me'.

Despite the idea that people with autism lack the ability to think flexibly, they can be extremely good at giving us insights into the sensations they experience. Like the child who tells me that light touch feels like 'a whole load of spiders trying to crawl out of my skin'. All of her skin sensors are firing at once. Looking at the powerful feeling this initiates in me, I suspect the picture presented is so vivid that it is activating a sensory motor pattern in my brain – just as I experience a slight shiver when offered the more familiar description of 'a goose walking over my grave', as the cold 'slap-slap' of webbed feet imprints the marrow of my bones.

Metaphors offer a two-way process in the development of understanding. I align myself with the empathetic images of others,

tuning myself in to their experience, able to resonate with their perceptions. I offer you my sensory experience in a package that I hope will give you an internal model, one that strikes a chord in you. This is the way we learn about each other, not just as objects that can be assessed but as living realities to whom we can relate. The hope is that this exploratory approach may lead us to open up new perspectives.

## Accounts from people on the spectrum

The question that still needs to be answered is whether, in this sensitive territory of relationship, an attitude of intuitive (and sometimes imaginative) process can take us any further in the shared journey with our partner (as subject), than that of an expert who has an agenda to impart to their student (as a ‘sometimes-unable-to-co-operate’ object).

Is it legitimate to place my feelings alongside the supposed feelings of my partner, and what are the limitations of reading personal experience into body language? How can we build in checks to circumscribe any wilder flights of fancy? In order to be of value, we need to harness multiple sources for any discussion on the affective state of our partners, testing one against the other. Together, do they build a coherent picture?

First, we now have the considerable literature placed at our disposal by people with autism themselves in the form of memoirs, film, video and audiotape. Particularly useful is the Channel 4 film *Jam Jar* where, among other insights, Donna Williams discusses how she processes her sensory intake.<sup>17</sup> Accounts from Gunilla Gerland, Therese Jolliffe, Temple Grandin, Lindsey Weekes, Kamran Nazeer, John Elder Robison (a brilliant man with Asperger’s syndrome), and the remarkable Tito Rajarshi Mukhopadhyay with his poems and stories, can help us to understand how it feels to experience autism.

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<sup>17</sup> Williams D (1995) *Jam Jar*. Film. Fresh Film in association with Channel 4, UK..



Second, there are conversations with autistic people themselves. ‘Listening’ to what Joshua Harris tells us on his website, we can understand that when his brain processing system is becoming confused, using his body language to get in touch with him (Intensive Interaction) ‘feels like having a delicious conversation’.<sup>18</sup> In a world where his sensory distress is triggering his body’s self-defence system, it helps him to maintain coherence. At the other end of the emotive scale is an unnamed man, fixated on leaves, distraught because the mower has run through a pile of them and cut them up. His coherence is destroyed and he exclaims: ‘They are killing my friends, they are killing all my friends.’ It is not necessary to be deeply intuitive to sense the feelings that prompt observations such as these, running through the complete spectrum of affect, from delight to desolation.

Third, there are quite a surprising number of people on the autistic spectrum who, if one listens to the way they speak, are apparently splitting their personalities into ‘good’ person and ‘bad’ person, an unconscious strategy that is explored in Chapter 10. In this case our partner’s feelings are expressed through completely differently sounding voices – one cheerful and the other (sometimes) savage – as they struggle to come to terms with the negative responses they have received and the images they have of themselves. Socially acceptable attitudes grapple with suppressed feelings. Acknowledge the darkness, either verbally or through body language, and we meet a third voice, centred and breathing relief. Someone has understood how they really feel. Since our sense of who we are is largely derived from our sensory picture of ourselves, confirmation of our partner’s negative self gives them permission to be who they really feel they are, a position from which they are normally divorced since they are barred from feeling and expressing their ‘bad bits’.

## Reading our partner’s behaviour

So far we have been concerned with the expressions of people who have speech. What about those who do not?

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<sup>18</sup> Harris J (2012) *Joshua’s Planet* [online]. Available at: [www.joshuasplanet.com](http://www.joshuasplanet.com) (accessed June 2012).

Intensive Interaction is an approach to communication that focuses on the body language our partner displays. In one of many discussions we have had about the use of body language to interact, Michelle O'Neill suggested:

*'I also think of it as affective attunement, listening to the quality of my partner's body language so that I can respond to how they feel.'*<sup>19</sup>

Those who care daily for non-verbal people with autism are usually quite good at judging whether they are having a 'good day' or a 'bad day'. This is a skill that depends on reading body language, how people are making their movements and sounds, and one which improves as we learn that people's body language is the voice of their affect. But 'good' or 'bad' days represent gross affect, amounting to an expression of mood rather than a response to the brain's running commentary on events as they happen, any small incident of which may register as threat. In people with autism, where the autonomic nervous system is on red alert, the threshold for setting off the body's self-defence system is at floor level.<sup>20</sup> Maybe I smile at you. If you are experiencing emotional overload, instead of getting a nice warm feeling – 'this woman likes me' – your body may implode under pressure from the tidal wave of sensation that is the autonomic storm in all its sensory violence. So by way of counterchecks and constraints, working with people whose behaviour is often labelled as severely challenging and whose stress levels are extremely high, if my interpretation is faulty, my partner will run away or I shall get thumped. Both responses leave little room for doubt as to how my partner feels.

For example, I have been asked by a consultant psychiatrist to see if I can find ways of engaging the attention of a young man with severe autism who is living at home. His behaviour is so disturbed that it is no longer possible to find people who are willing to work with him. Using his sounds and movements, we are able to communicate and are getting along fine; he is smiling and eager to engage. I allow myself to be lulled by his contentment into responding and moving into one of his initiatives, touching his hand when he is not looking.

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19 O'Neill M (date unknown) Personal communication with the author.

20 The autonomic nervous system regulates systems that are not under conscious control, for example, breathing, heartbeat, sweating and the digestive system.

He immediately lashes out. In my enthusiasm for our interaction, I have overlooked the fact that his brain cannot manage stimuli that are unexpected. (If he loses touch with what is happening it triggers his self-defence system. He feels as though he is being attacked and responds accordingly.) I have let my feeling of pleasure at our engagement override his urgent need to know what is happening. Lesson learned. We can now proceed on the basis of his sensory experience rather than mine.<sup>21</sup>

If our partner is disturbed, we may not have time to sit back and think. Danger sharpens the wits and under these circumstances intuition and analysis need to be contingent. Go with the flow but watch your navigational instruments. Fortunately, this complex sounding process is not nearly as difficult as it sounds, since it appears that our brains are equipped to do it naturally.

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21 Caldwell P (2006) *Finding You Finding Me*. London: Jessica Kingsley Publishers.