

# Not at a Distance: On Touch, Synaesthesia and Other Ways of Knowing

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*A thousand other things sing to me.*

*John Lee Clark*

*Every possible feeling produces a movement, and that movement is a movement of the entire organism, and of each of its parts.*

*William James*

What if mirror-touch synaesthesia, defined as the experience that ensues when the stimulation of one sensory modality (vision) automatically triggers a perception in a second modality (touch), in the absence of any direct stimulation to this second modality, were not only misnamed, but radically misunderstood? It's not just the nomenclature that I am concerned with here – why a synaesthesia that is said to move between touch and vision isn't called vision-touch synaesthesia like its sisters, sound-taste, colour-grapheme, shape-taste – but the very presupposition that grounds an account of sensation

that can be parsed so cleanly between sense modalities and between the bodies that are said to be the locations of sense. For even if it were called vision-touch synaesthesia, it would still take for granted a whole set of beliefs about both how we perceive and what is considered worthy of being perceived: despite a rare admission that for some the experience of being touched-without-touch occurs through an object,<sup>1</sup> mirror-touch synaesthesia is predominantly a humanist concept. To be touched by that which we see is, in most of the literature, to be touched by the human. This is the question I want to ask here: what is assumed in the presupposition that to be moved is to be moved by the human? And what is assumed when we take vision as the predominant activator of the experience of being touched by the world? Circling around autistic perception and DeafBlindness, I want to ask how neurotypicality as the normative standard for human experience operates in the presuppositions of sense.

### A Thousand Other Things Sing To Me

The dominant neuroscientific literature works with a deficit model of sensation that is neurotypical through and through, most emphatically in its presupposition of a body

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<sup>1</sup> 'It is unclear if MT synaesthesia is specific to viewing a real person, rather than a dummy figure or an object being touched since in their Supplementary material Banissy and Ward discuss some cases of MT synaesthesia also being induced by viewing objects being touched.' Jörg Jewanski, Sean A. Day, and Jamie Ward. 'A Colorful Albino: The First Documented Case of Synaesthesia, by Georg Tobias Ludwig Sachs in 1812.' *Journal of the History of the Neurosciences* 18, no. 3 (2009): 293–303. DOI: <https://doi.org/10.1080/09647040802431946>

schema which acts as the normative ground on which all divergent experience is mapped. In this literature, mirror-touch synaesthesia is chiefly described, as mentioned above, as depending on one body seeing-feeling the touch of another directly on their skin: you touch yourself and I feel it because I see it. In this account, the experience of feeling the other is, paradoxically, considered a deficit: it weakens the body schema. With the feeling of you directly experienced on my body, I lose a bit of what separated me from you. The coming into relation is considered a loss.

The deficit model of sensation begins with the presupposition that senses are fixed and located, working with a pre-constituted body schema whose 'sense of agency,' it is said, is fractured by the increase in sensation. Bodies lose their integrity in the encounter with the touch of the other. This approach, which situates 'sense of agency' as central to what it means to have a body, placing what I have called the intentionality-agency-volition triad ahead of the *agencement* of experience coming into itself to activate a bodying, emphasises that bodies are above all individual, separate envelopes that are in the world but not of it. Bodies are only properly bodies when they can fully distinguish themselves from the world, the implication being always that bodies are separate entities that have dominance over their sensations, and, by extension, over their movements. The deficit model perceives any deviation from this norm to be a lack.

In the context of MTS [mirror-touch synaesthesia], one prediction from this would be that if there were agency-processing deficits these would exacerbate more basic disturbances in bodily awareness. We are

clearly suggesting here that MTS is primarily a ‘disorder’ of ownership, which can have consequences for SoAg [sense of agency] and which in turn can further worsen ownership disturbances.<sup>2</sup>

Bodies that sense too much, bodies that feel the touch of the world and are moved by it, are deficient. When we lack the ability to distinguish our world from the world of others we lose something of what makes us, properly speaking, bodies, and, by extension, human.<sup>3</sup>

Feeling the touch of another body or another object on our body is already a misnomer. It makes too strong a distinction between body and world, a distinction that is everywhere at play in the neuroscientific studies of all forms of synaesthesia, but perhaps even more forcefully so in studies of mirror-touch synaesthesia.

Individuals with mirror-touch synaesthesia (MTS) experience touch on their own bodies when observing another person being touched. Specifically, the images that participants had initially perceived as containing equal quantities of self and other became more likely to be recognised as the self after viewing the other being touched.<sup>4</sup>

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<sup>2</sup> Maria C. Cioffi, James W. Moore and Michael J. Banissy. ‘What Can Mirror-Touch Synaesthesia Tell Us About the Sense of Agency?’. *Frontiers in Human Neuroscience* 8 (2014): 256. DOI: <https://doi.org/10.3389/fnhum.2014.00256>

<sup>3</sup> In Amelia Baggs’s important video *In My Language*, Amelia (formerly Amanda) Baggs demonstrates the degree to which the way she senses and perceives the world excludes her from the category of the human. <https://www.youtube.com/watch?v=JnylM1hI2jc>

<sup>4</sup> Lare Maister, Michael J. Banissy, and Manos Tsakiris. ‘Mirror-Touch Synaesthesia Changes Representations of Self-Identity’. *Neuropsychologia* 51, no. 5 (2013): 802.

Self-identity is the starting point, and it is in the self-identity that the experience of touch is located: ‘These results suggest that observing touch on others not only elicits a conscious experience of touch in MTS, but also elicits a change in the mental representation of the self, blurring self-other boundaries.’<sup>5</sup> There is no mention here of the emergent quality of sensation produced in the world. No attempt is made to explore the ways in which the relational milieu activates this singular composition. Nor is there an effort to explore how the touch that is felt might move beyond the limited concept of ‘simple location’<sup>6</sup> – no questions are asked about how that touch alters the feel of the space, the quality of sensation beyond the actual location of the touch. There is no account of body as process – of bodying. What is assumed is always that we know what constitutes a body – a body, it must always be remembered, that, in its neurotypicality, stands in for the normative standard of whiteness.

Because there is no account of a processual bodying, there is no way to articulate what is activated in the sensation, only what is lost. When bodies are mapped in advance as abstracted from their environment and parsed according to the normative (white) standard, the only conclusion can be that what diverges is a loss – a loss of

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<sup>5</sup> Ibid.

<sup>6</sup> In *Science and the Modern World*, Whitehead writes: ‘to say that a bit of matter has *simple location* means that, in expressing its spatio-temporal relations, it is adequate to state that it is where it is, in a definite finite region of space, and throughout a definite duration of time, apart from any essential references to the relations of that bit of matter to other regions of space and other durations of time.’ (New York: The Free Press, 1925), 58.

the norm. For this is clearly what is at play here, though never addressed as such. In the mirror-touch example, the activation of sense caused by the overlap of sense means individuality (the neurotypical norm) is weakened: in their ‘becoming one’ the one who senses too much loses the very boundary that made it a body. In study after study, the assumption is that the field of relation<sup>7</sup> activated by the touch of the world *reduces* the body schema, placing not only the body at risk, but the whole edifice of representation the neurotypicality upholds. ‘[W]hen MTS individuals view touch on others, it not only elicits a shared tactile experience, but actually alters their body representation.’<sup>8</sup> This altering of the body representation is a deficit because the assumed contours of the body are no longer intact. Without the intactness a body no longer properly feels the distinction between body and world, between self and other.

What if the contours of a body were never intact? In this return to an account of touch ten years after publishing *Politics of Touch*,<sup>9</sup> I hope to do four things: 1) demonstrate that the force of reaching-toward, which is how I defined touch in *Politics of Touch*, troubles the model of ‘sense of agency’ at the heart of accounts of mirror-touch synaesthesia; 2) build on John Lee Clark’s account of dis-tantism as it plays out not only in DeafBlind culture but

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<sup>7</sup> See ‘Toward a Leaky Sense of Self’ in Erin Manning, *Always More Than One: Individuation’s Dance* (Durham: Duke University Press, 2013) for a more detailed account of the relational body.

<sup>8</sup> Maister, Banissy and Tsakiris. ‘Mirror-Touch Synaesthesia’, 802.

<sup>9</sup> Erin Manning. *Politics of Touch: Sense, Movement, Sovereignty* (Minneapolis: Minnesota University Press, 2007).

more broadly in the neurotypical worldview; 3) consider the ways in which accounts of mirror-touch synaesthesia as well as synaesthesia more broadly support a deficit model of sensation that is deeply neurotypical; 4) explore how ProTactile, a movement for language-in-the-making and DeafBlind experience, remaps the spacetime of sensation away from the categorical limitations that come with the imposition of sensory regimes that privilege the body-world separation.

The word on the breeze, and through the floor

*Liz Ball*

‘The TV is off, but I can still hear (and feel on my skin) the current of electricity powering all that equipment,’ writes Aspiegrl on her blog ‘Autism and Angels.’<sup>10</sup> Hearing what moves infrasensorially through her surroundings, being moved and changed by the field of relation, makes it impossible for Aspiegrl to hold onto the neurotypical imposition of body-world separation. Already considered at a deficit by her autistic difference, by the standard of neuroscientific work on synaesthesia, she is doubly pathologised, her divergent sensory processing further evidence of her faulty ‘sense of agency’. She suffers from a disturbance of sense perception that will, most likely, be considered as a disadvantage in learning environments: she will be taught, if not through the violent practices of ABA (Applied Behaviour Analysis),<sup>11</sup> then through the

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<sup>10</sup> Autism and Angels, <https://aspiegrl.wordpress.com>.

<sup>11</sup> For an important critique of ABA, see Melanie Yergeau, *Authoring Autism: On Rhetoric and Neurological Queerness* (Durham: Duke

ubiquitous behavioural codes that are systemic in our education systems to direct her perception so as to sense less fully, thereby attempting to craft a less porous body. But this will not actually make her sense less. It will simply make more violently apparent that a sensing body in movement is a deficient body. She will learn that in order to pass she will have to background the feel of electricity on her skin. She will have to act as though she is in control of her surroundings. She will pretend that she has agency over what moves her. She will be told in a thousand ways that value resides in subtracting from the welter of experience. She will learn that the standard of neurotypical life is one of sense-poverty. She will be considered properly treated if she can ‘pay’ attention, attention no longer dancing at the pace of the more-than.

What if we were to turn the sensory model on its head and ask what it is that keeps so many feeling so little?

Synaesthesia is usually defined as an overlapping or cross-mapping of the senses. In the most widely studied cases of synaesthetes – colour-sound and colour-grapheme – great emphasis is placed on mnemonic systems, focusing on the modality of parsing from the more-than synaesthesia is said to facilitate. Synaesthetes are acclaimed for their unusual abilities: autistic Daniel Tammet,<sup>12</sup> for instance,

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University Press, 2017). See also Laura Smith Donohoe’s ‘Regarding Applied Behavioral Analysis Therapy’ in <https://laurensmithdonohoe.com/2018/08/11/regarding-applied-behavioral-analysis-aba-therapy/> as well as Anthony Easton, whose articles include ‘Why do Autism Specialists want to Stamp out Autistic Traits’ in <https://www.theglobeandmail.com/opinion/why-do-autism-specialists-want-to-stamp-out-autistic-traits/article28441771/>

<sup>12</sup> <http://www.danieltammet.net>

is celebrated for being able to visualise pi to a previously unimaginable degree (22,514 digits), while others inspire wonder by being able to retrace their past to a remarkable degree thanks to a colour-grapheme synaesthesia that enables them to see any day of the week as far back as they want to go.<sup>13</sup> These stories – and there are many of them – are fascinating, and the abilities are remarkable, but they only touch synaesthesia at its limit. In addition, they foreground a model of value that is deeply neurotypical: they emphasise not the qualitative complexity of their sensual fields but what can be culled from those relational fields, and thereby quantified. And, insofar as they include autistics such as Daniel Tammet, they replay the well-worn narrative of autistic savantism, reminding us at every turn that while these abilities may be extraordinary, displaying ‘high functioning’ traits, they do not tend to carry over into other ‘lower functioning’ realms of autistic experience. In addition, not only does the narrative of savantism cleave autistics by singling out, for value-added, those who have particular gifts that can be studied, it also provides an ideal opportunity to reinforce the narrative of deficiency among those who do not share these mnemonic talents, keeping autistics in their place as deficiently sub-human.

This approach to diversity as divergence from a neurotypical norm is all over the writing on Tammet. Described as a ‘high functioning autistic savant,’ his sensitivity to the world is bracketed by functioning labels that only serve to

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<sup>13</sup> Lix Buxton. ‘Experience: I See Words as Colours’, *The Guardian*, 19 August 2016, <https://www.theguardian.com/lifeandstyle/2016/aug/19/experience-i-see-words-as-colours>

reinstall neurotypical norms. For instance, when describing the ways in which he functions outside his mnemonic synaesthetic abilities, he is said to be unimaginative because ‘he tends to take things literally’.<sup>14</sup> The claim is as simplistic as it is widespread in the world of autism: to take things literally is to not be able to hear the undertones of communication that veer it toward subtexts, and thereby not really being able to communicate at all. As autistic Melanie Yergeau argues with rhetorical flourish, this kind of claim to non-communication is well known.

Autistics are multiply bound to non-rhetoricity. In many respects, the idea of an autistic culture is often rendered as the cute or pathological machinations of autistic people who lack insight into the horrors of their arhetorical circuitry. [...] Autistic culture — and its flirtatious bristling against rhetorical norms — is a queering of rhetoric’s conditions.<sup>15</sup>

No inquiry is made by the psychologist Simon Baron-Cohen (see fn. 16, p.158) as to how the excess of sense coursing through Tammet’s every thought and movement creates a radically different engagement with the world. No effort is made to understand how the queering of expression in his hypersensorial universe shifts the conditions of sense. If there is indeed a tendency in some autistics toward literality, what is it that cannot easily be parsed from communication? What nuance is

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<sup>14</sup> Ralph Savarese. ‘Reading Fiction with Temple Grandin: Yes, people with autism can understand literature’, *Salon*, 2 September 2018 <https://www.salon.com/2018/09/02/reading-fiction-with-temple-grandin-yes-autistic-people-can-understand-literature/>

<sup>15</sup> Melanie Yergeau. *Authoring Autism*, 42.

reverberating in the field of experience that distracts from the process that would facilitate a neurotypical selection we call irony, or sarcasm? Is it that human communication itself stands out less than other activities in the wash of perception, as a result of which some of its layers of sense are easily missed in the dance of attention? Or that those layers of sense that neurotypicals find so central to communication are less interesting, in the moment, than neurotypicals assume they are? Because there is no question, ever, that autistics are incapable of feeling nuance and, where apt (often in reference to neurotypicals), of using sarcasm.

The obsession with emphasising the ‘low functioning’ tendencies in neurodiversity, even in cases of autistic savantism, serves to maintain the deficit model of sensation with respect to synaesthesia. If we know that Tammet, despite his extraordinary synaesthetic capacities, ‘doesn’t notice if someone is upset,’ it will be easy to argue that the touch of another on his body decreases his capacity to truly be human. If we read that Tammet ‘commits frequent faux pas,’ is ‘asocial’ and ‘avoids social situations and finds parties confusing,’ we are reinforced in our belief that there is no neurodiverse sociality. If what is foregrounded is that he is ‘obsessed,’ that ‘he has strict routines,’ what we learn is that no matter how sensitive he is, there is no real latitude in his capacities. And if we read that he ‘showed severe tantrums at change of routine as a child,’ that he ‘showed head-banging in his cot,’ and ‘sat with fingers in his ears in primary school and with his eyes tight shut,’ we become convinced in our assessment that no matter how extraordinary his reciting of pi, he

has nothing on us, we neurotypicals. For Tammet is nothing more than an arhetorical unimaginative mind-blind less-than-human incapable of truly being aware (of us), detached, distanced, apart, 'in a world of his own'.<sup>16</sup>

Or, we recognise that all of this is less about Tammet than about the presuppositions that accompany the imposition of the neurotypical norm on all experience. Turning our attention away from the neurotypical norm, we note that with hypersensoriality comes a sensitivity so powerful that it activates the field of relation in ways sometimes impossible to hold. Bodies collapse under the strain. We learn that what the literature calls tantrums are the undoing, in this collapse, of any boundary between self and world, a body succumbing to the pain of having to hold at bay the forces that shape experience. And we learn to recognise the violence in the account, an account that polices the body-world boundary in order to maintain the well-worn habit of enforcing (white) dominance.

The violence is not only in enforcing this separation by demonising those bodies that collapse under the strain of overstimulation, but in openly recognising as valuable only those who can be reflected in the mirror of neurotypicality. Baron-Cohen writes:

With age, DT [Daniel Tammet] has developed more of an idea of how to behave and how he seems to others, raising the possibility that mindreading skills are not completely absent but are simply delayed. It helped when, at the age of 13, his mother was able to

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<sup>16</sup> Simon Baron-Cohen et al. 'Savant Memory in a Man with Colour Form-Number Synaesthesia and Asperger Syndrome'. *Journal of Consciousness Studies* 14, nos. 9–10 (2007): 237–51

give him some feedback and tell him to look at others' eyes and not at his own feet. This suggests that in individuals on the autistic spectrum, for whom such social insight and consciousness of others' minds does not develop naturally at the right point in development, learning to consciously attend to key parts of the environment (faces, eyes, expressions) may help.<sup>17</sup>

The criteria for inclusion into humanity are always neurotypical. That Tammet prefers not to have eye-contact has absolutely no bearing on what he sees or feels. It is Baron-Cohen and all those who adopt neurotypical standards for body schemas, those who insist that eye contact has anything to do with a regard for the other, who are here displaying their narrow-mindedness, if not mind-blindness. As those of us who do not feel pain when looking others in the eye know, there is nothing easier than to pretend presence through eye contact while being altogether elsewhere. Eye contact is a practiced mechanism for allowing the human to feel that we are at the centre of experience, nothing more.

Daniel Tammet functions just fine. He is neither 'high functioning' as a savant nor 'low functioning' in the rest of his life. Functioning labels, as anyone in the movement for neurodiversity will emphasise, say nothing at all except that neurotypicals are obsessed with categories that keep their way of knowing at the forefront.<sup>18</sup> To function, according to these labels, means to deploy movement,

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<sup>17</sup> Simon Baron-Cohen et al. 'Savant Memory'.

<sup>18</sup> For an excellent piece on functioning labels in autism see <https://ollibeian.com/problems-functioning-labels/>

expression, sensation in ways that ‘pass’ for neurotypical: to take on a posture that does not announce too forcefully the sensory processing challenges that come with overstimulation; to be able to meet requirements for independence imposed by a belief in individualism before all; to be able to perform competence in ways that do not endanger the body schema of those for whom the template of neurotypicality has become second nature.

Study after study links autism and synaesthesia. Indeed, this view has become so widespread that even Simon Baron-Cohen, who for decades kept his research on autism and synaesthesia separate, recently decided to bridge them:

I have studied both autism and synaesthesia for over 25 years and I had assumed that one had nothing to do with the other. These findings will re-focus research to examine common factors that drive brain development in these traditionally very separate conditions. An example is the mechanism ‘apoptosis,’ the natural pruning that occurs in early development, where we are programmed to lose many of our infant neural connections. In both autism and synaesthesia apoptosis may not occur at the same rate, so that these connections are retained beyond infancy.<sup>19</sup>

In this research, rather than asking how ‘apoptosis’ might challenge his theory of ‘mind-blindness’ – the condition of not being able to read ‘the mind’ of another mentioned above in relation to Tammet as ‘mindreading’ – by demonstrating that the hypersensorial tendency in autism that is likely in part due to ‘apoptosis’ results in them

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<sup>19</sup> <http://www.cam.ac.uk/research/news/synaesthesia-is-more-common-in-autism>

being *more* in contact with the world and not less, Baron-Cohen takes it upon himself not only to reemphasise the concept of mind-blindness but to counter other studies that suggest that those with mirror-touch synaesthesia may be more attuned to the world than those without. A recent article, entitled ‘Mirror-Touch Synaesthesia is Not Associated with Heightened Empathy, and Can Occur with Autism,’ he and his co-writers (Robson and Allison) make their position abundantly clear.<sup>20</sup>

When Baron-Cohen speaks of empathy, he is referring to the Empathy Quotient, a measure for empathy he developed with Sally Wheelwright. Empathy, for Baron-Cohen and Wheelwright, Wikipedia explains is ‘a combination of the ability to feel an appropriate emotion in response to another’s emotion and the ability to understand the other’s emotion.’<sup>21</sup> All of this is of course associated with theory of mind, ‘the ability to attribute mental states – beliefs, intents, desires, pretending, knowledge etc. – to oneself and others and to understand that others have beliefs, desires, intentions, and perspectives that are different from one’s own.’<sup>22</sup>

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<sup>20</sup> Simon Baron-Cohen et al. ‘Mirror-Touch Synaesthesia is Not Associated with Heightened Empathy, and Can Occur with Autism.’ PLoS ONE 11(8) (2016): e0160543. DOI: <https://doi.org/10.1371/journal.pone.0160543>.

<sup>21</sup> [https://en.wikipedia.org/wiki/Empathy\\_quotient](https://en.wikipedia.org/wiki/Empathy_quotient). Note also that the Empathy Quotient suggests that connection to humans over animals is a sign of empathy. As with Theory of Mind, Baron-Cohen seems incapable of imagining the force of relation outside a Humanist paradigm. <https://psychology-tools.com/empathy-quotient/>

<sup>22</sup> [https://en.wikipedia.org/wiki/Theory\\_of\\_mind](https://en.wikipedia.org/wiki/Theory_of_mind). For more on autism and theory of mind, see Melanie Yergeau, *Authoring Autism*. I have also written about it in ‘The Ethics of Language in the Making,’ in *Always More Than One* and in ‘Coming Alive in a World of Texture,’ in Erin Manning and Brian Massumi, *Thought in the Act*:

To be empathetic is to be able to parse from the world that which most closely conforms to what we already recognise as having value. It is to carry forward a power relation that acknowledges similarity and responds benevolently to it. I feel you because your feeling corresponds to what I already recognise as feeling. Empathy, the feeling-in of an interiority that recognises itself in the other, thereby creating a measure of the self-same, must be seen not only as a profoundly humanist marker of self-recognition, but as the neurotypical marker par excellence of exclusion of all that cannot be recognised as self. It is this assumption that feeling is internal to the body that allows Baron-Cohen et al to assume that autistics are mind-blind and, by extension, have no empathy. For when Baron-Cohen says that autistics cannot ‘understand that others have beliefs, desires, intentions and perspectives that are different from one’s own,’ what he seems unable to comprehend is that the definition excludes those modes of feeling proper to the neurodiverse. The concept of empathy simply cannot recognise experience expanded from the normative interiority of a neurotypical body-schema. When Baron-Cohen et al write that ‘individuals with MT [motor-touch synaesthesia] have a *reduced* aptitude for social situations,’<sup>23</sup> this is always in reference to the ‘in-feeling’ of empathy. A neurotypical viewpoint cannot recognise neurodiverse

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*Passages in the Ecology of Experience* (Minneapolis: University of Minnesota Press, 2014). For a nuanced account of empathy reading neuroscientific studies in relation to a project of reading with autistics, see also Ralph Savarese, *See It Feelingly: Classic Novels, Autistic Readers and the Schooling of a No-Good English Professor* (Durham: Duke University Press, 2018).

<sup>23</sup> Baron-Cohen et al. ‘Mirror-Touch Synaesthesia.’

sociality precisely because it is always feeling-in, led by a model of interiority that presumes that feeling is only what a body contains, not what a body does in the worlding. There is no feeling-with in this account.

Sympathy – what things do when they shape each other – is a threat to neurotypicality precisely because it challenges the centrality of empathy as in-feeling. Turning to the force of a shaping, sympathy extends care toward the world, highlighting the world's own concern for experience unfolding. When Baron-Cohen et al insist that autistics fail to demonstrate empathy, what they are actually insisting is that we retain empathy as the baseline for experience in order to maintain the account of interiority that keeps body and world separate. This of course includes the Karolinska Directed Emotional Faces Test and the presupposition of identification that comes with it. To be empathetic is to be able to parse human expression according to the normative framework of expressivity. Despite the general knowledge that faces can contort to represent states required of them (much like the bestowing of eye-contact to pacify an interlocutor), despite the widely held experience that we can demonstrate interest we don't share by moving our facial muscles in ways that are normatively recognised, face-tests such as the Karolinska Directed Emotional Faces Test remain the marker for adhesion to humanity by way of a model of empathy that will always exclude those who cannot be recognised and embraced as self-same.

Empathy is a white concept. It requires an identificatory frame that can be mapped onto the other. It requires the extraction from experience of all that does not conform

to the choreography of human-human interaction. To be empathetic according to these standards is to be capable of cutting out the feltness of the world activating a body beyond its-(white)self. There is no inability-to-feel relation in neurodiverse sociality: indeed, in the sympathetic force of worlding, a folding-in and through the world is at its height. All is felt-with. The problem for neurotypicality is that feeling-with cannot be contained within the limited category of an Empathy Quotient. Leaky, the sympathetic encounter with what things do when they shape each other, takes over. This synaesthetic feeling-with cannot be measured precisely because it cannot be located in a body precontained. It is of the world. Its feeling-with shapes the conditions of experience in the very same gesture that it shapes a body. Neurodiverse sociality might be described as a sensitivity to this shaping, a commitment to how the shaping orients, unmoors, disturbs any idea of a body as self-enclosed. Neurodiverse sociality lives in and through the force of the shaping, a shaping so deeply alive with the world that it continuously activates new fields of resonance at the edging-into-existence of body-worldings. The force of these body-worldings what explodes when a body collapses under the weight of neurotypicality.<sup>24</sup>

Simon Baron-Cohen deserves no more of our time. I turn to his work only because it is prevalent in the field

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<sup>24</sup> Many autistics have written important pieces on the consequences of the deficit model, among them Melanie Yergeau in her recent book *Authoring Autism* (2018), David J. Savarese, 'Passive Plants'. *The Iowa Review* 47(1) (2017) <https://iowareview.org/from-the-issue/volume-47-issue-1---spring-2017/passive-plants>, and Tito Mukhopadhyay in *The Mind Tree: A Miraculous Child Breaks the Silence of Autism* (New York: Riverhead Books, 2007).

and therefore affects both the literature on autism and on synaesthesia. To address the claims he makes, and then to move away from him, it is necessary to underscore the following: 1) all models of relation that begin with a preconstituted body schema and make human interaction the only marker for empathy are deeply erroneous. These are models of interaction, not relation.<sup>25</sup> 2) empathy is a humanist construct that privileges a human-centred account of importance that is always organised around preexisting norms. These norms are based on neurotypicality, which also means whiteness, male-centredness, gender normativity and able-bodiedness. 3) synaesthesia is never going to be a condition that can be adequately studied with an experimental method that begins with a neurotypical body schema. This is the case not only because the quantifications of sense that are the results of such studies are only the tip of the iceberg, but because all sensation occurs in complex overlaps. 4) sensing is not limited to sense-presentation. All sensing is amodal and amodal sensation can only be mapped, if it can be mapped, topologically. To address synaesthesia, new modes of expression will continuously have to be invented. With them will come new modes of knowing. 5) autism tends to express itself not as a lack of feeling as Baron-Cohen argues, but as an overfeeling, as a feeling-with-the-world of such intensity that it is difficult to

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<sup>25</sup> For an important account of the difference between interaction and relation, see Brian Massumi, 'The Thinking-Feeling of What Happens.' *Inflexions: A Journal for Research-Creation* 1 (2008) [http://inflexions.org/n1\\_The-Thinking-Feeling-of-What-Happens-by-Brian-Massumi.pdf](http://inflexions.org/n1_The-Thinking-Feeling-of-What-Happens-by-Brian-Massumi.pdf)

parse into the quotient scientists like Baron-Cohen use to measure humanity. I have defined this tendency of suprasensation or overfeeling as autistic perception, emphasizing that it exists on a continuum of neurodiversity but expresses itself most intensely in classical autism. As I have argued elsewhere, this intensity of feeling is relational to the core. It is alive with the more-than. We all stand to learn from a modality of feeling that is so ecstatically more-than human.

### What Things Do When They Shape Each Other

All things living and dead cry out to me  
 when I touch them. The dog, gasping for air,  
 is drowning in ecstasy, its neck shouting  
 Dig in, dig in. Slam me, slam me,  
 demands one door while another asks to remain  
 open. My wife again asks me  
 how did I know just where and how  
 to caress her. I can be too eager to listen:  
 The scar here on my thumb is a gift  
 from a cracked bowl that begged to be broken.

John Lee Clark *Clamor*<sup>26</sup>

John Lee Clark, to my knowledge, has never been tested for synaesthesia. How could he be, when the neurotypical assumption around the sensing body automatically discounts a DeafBlind person from mirror-touch synaesthesia, or any other kind. What would there be to measure? Indeed, the neurotypical view of DeafBlindness suggests

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<sup>26</sup> John Lee Clark. 'Metatactile Knowledge'. <https://johnleeclark.tumblr.com/post/130321809778/metatactile-knowledge>

that there really is no life to be experienced without the senses of vision and hearing: ‘The loss of both sight and hearing constitutes one of the severest disabilities known to human beings. Essentially, it deprives an individual of the two primary senses through which we acquire awareness of and information about the world around us, and it drastically limits effective communication and freedom of movement, which are necessary for full and active participation in society.’<sup>27</sup>

And yet. What about the synaesthesia so clearly felt in these lines? What of the strength of feeling-felt?

All things living and dead cry out to me  
 when I touch them. The dog, gasping for air,  
 is drowning in ecstasy, its neck shouting  
 Dig in, dig in. Slam me, slam me,  
 demands one door while another asks to remain  
 open. My wife again asks me  
 how did I know just where and how  
 to caress her. I can be too eager to listen:  
 The scar here on my thumb is a gift  
 from a cracked bowl that begged to be broken.

These words of Clark’s are reminiscent of autistic Tito Mukhopadhyay’s account of the mining tragedy in Raleigh County, West Virginia in 2010. Mukhopadhyay writes:

It’s true that when I think of the situation, there may be empathy. But my empathy would probably be towards the flashlight batteries of those trapped coal miners if there happens to be a selection on my part. Or my empathy would perhaps be toward the trapped air around those coal miners. There would

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<sup>27</sup> John Lee Clark. ‘Distantism’. <https://johnleeclark.tumblr.com>.

be me watching through the eyes of the flashlight cell the utter hopelessness of those unfortunate miners as my last chemicals struggled to glow the faint bulb so that I didn't leave them dying in darkness. As the air around them, I would try to find a way to let myself squeeze every bit of oxygen I have to allow the doomed to breathe, for I am responsible for their doom. And while I found myself trapped, I would smell the burning rice being cooked with neglect in an earthen pot.<sup>28</sup>

For Clark, the touch carries a proximity that is also felt in Mukhopadhyay, though in Mukhopadhyay's case, the strong sensorial feeling-with is carried across senses in ways that more clearly make apparent what Brian Massumi would call a relational, or virtual body, a body of 'pure variability' activated in the sensing.<sup>29</sup> With Clark, the same force of relation is felt, but to register, the actual proximity of touch is added to the mix. That said, there is also in Clark's poem the sense of the activation of an emergent relation, a feeling-with that exceeds the actuality of the hands-on of touch. As with Mukhopadhyay, there is a sense of a more-than that accompanies the actual body, composing with the sensation that moves through that body.

A touch is here foregrounded, I want to suggest, that is synaesthetic, felt-across and with. Synaesthetic because

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<sup>28</sup> Ralph Savarese. 'More Than a Thing to Ignore: An Interview with Tito Rajarshi Mukhopadhyay'. *Disability Studies Quarterly* 30, no.1 (2010) DOI: <https://doi.org/10.18061/dsq.v30i1.1056>

<sup>29</sup> Brian Massumi. 'The Art of the Relational Body: From Mirror-Touch to the Virtual Body'. In *Mirror-Touch: Thresholds of Empathy With Art*, ed. Daria Martin (Oxford: Oxford University Press, 2017), 201–202.

it carries the more-than of sense. If synaesthesia is the making-felt of experience as emergent across a field of relation that is itself infrasensing, and what is activated in both Clark and Mukhopadhyay's words is the feeling-with of experience itself, these are synaesthetic experiences. This may be no surprise in relation to Mukhopadhyay, who has written extensively about his synaesthesia.<sup>30</sup> But it might be a surprise to consider that someone who can neither see nor hear sees-hears with the world's touching.

Listen again: 'All things living and dead cry out to me / when I touch them,' writes Clark. A hearing in a touch. 'My wife again asks me / how did I know just where and how / to caress her.' A seeing in a touch. And even more than that. A feeling toward a seeing-hearing touch, a knowing with the world in the relation. A virtual body felt and activated. In Massumi's words: 'Every "single" sense experience is the envelopment in a dominant mode of appearance of an "infinitesimal" (virtual) continuation of other-sense experiences. Every perception is a composition of the full spectrum of experience, "practically" appearing as if it were disparate and disconnected from the continuum.'<sup>31</sup> Synaesthesia is this experience intensified.

In 'The Art of the Relational Body: From Mirror-Touch to the Virtual Body,' Massumi writes: 'Synaesthetes do not add a deviation from the normal path of development.

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<sup>30</sup> See Tito Mukhopadhyay. *How Can I Talk If My Lips Don't Move: Inside My Autistic Mind* (New York: Arcade Publishing, 2011). There are several passages in this book that expand on Mukhopadhyay's synaesthesia, including the description of a woman's voice 'that tasted like a tamarind pickle' (p.110) and a man's voice that 'transformed into a long apple green and yellow strings' (p. 200).

<sup>31</sup> Brian Massumi. 'The Art of the Relational Body', 195.

They just prune the same developmental path less fully.<sup>32</sup> To understand this process philosophical approach to sensation, it is necessary to begin with the fullness of experience and to see modes of narrowing or subtraction – such as consciousness – for what they are. Consciousness, as Alfred North Whitehead states, is the ‘acme of emphasis.’<sup>33</sup> It is the reduction from the welter of potential of what can be named, organised, categorised. But it never comes completely denuded. With all consciousness comes the tremor of what evades it, of what exceeds it. This is what I call the more-than. Synaesthesia is the more-than of sense, which is already always in excess of what can be quantified experimentally or otherwise.

The feeling-with of the world is never experienced consciously in all of its fullness. A certain parsing – or pruning, in Massumi’s terms – is always necessary in order to subtract from the welter and distinguish one sensation or perception from another. This is not detrimental to experience: experience grows from the cuts that propel it in new directions. To parse is absolutely necessary. The question is, as Massumi also asks, what kind of parsing is at stake? And under what conditions? Massumi speaks in this context of ‘artful perception.’ ‘If a perception is a composition, there is an artfulness to it.’<sup>34</sup> When Mukhopadhyay writes ‘I may select a fraction of the environment – say, “that shadow of a chair” or “that door hinge over there” – and grow my opinions and ideas around it’ he is creating artful

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<sup>32</sup> Brian Massumi. ‘The Art of the Relational Body’, 194.

<sup>33</sup> Alfred N. Whitehead. *Adventures of Ideas* (New York: Free Press, 1967), 182.

<sup>34</sup> Brian Massumi. ‘The Art of the Relational Body’, 196.

conditions for perceptual experience. The 'artful' here suggests not that Mukhopadhyay makes an artwork of perception, but that he composes with the wealth of potential in perception as he experiences it in order to extract its most lively expression. This is artfulness: the effects created through a moving-with of experience that alters the conditions of existence. Mukhopadhyay explains: 'This creates a defense system for my over-stimulated visual sense organ. Maybe poetry happens to grow around these things.' By finding artful modes of subtraction, he creates the conditions for expression, which in his case, means poetic writing. How might non-synaesthetes parse more artfully?

In Clark's *Clamor*, we also hear artfulness. 'I can be too eager to listen: The scar here on my thumb is a gift from a cracked bowl that begged to be broken.' A feeling-with the world is everywhere present, not as a frustration, but as a gift that brings to expression new ways of knowing. Cracked bowls feel their way into the urgency of a touch.

The touching evoked here is of two tonalities. It is both the touching of the hands-on feeling of the world, and the incipient touch the world calls forth. It is both the being in the world of feeling, and the feeling-with of the world emerging. In Mukhopadhyay we hear this through the personification of the oxygen, a personification which is not a making-human of the oxygen, but a more-than-human becoming-oxygen. What is heard here is the molecules struggling to counter their disappearance, the effects of this disappearance on the environment, and on those who most need it, the humans. All at once, each level of experience overlaps, the incipiency of one

affecting the coming-into-actualisation of the other. If mirror-touch synaesthesia, or sight-touch synaesthesia, is about feeling-with, these are two examples of it, it seems to me, neither of which directly require either touch or vision.

Why call it mirror-touch synaesthesia, then? With Brian Massumi, I would agree that the nomenclature is deeply misleading. Building on research on mirror neurons – neurons that fire when an action is observed –<sup>35</sup> the problem with mirror-touch synaesthesia is that it seems incapable of imagining a world that begins with a feeling-with, a world that begins in the relational middle, in the virtual body. As such, it carries the same implied bias of much work on mirror neurons, ‘that our perception is fundamentally a passive reception of an image constituting a private representation of the world, which, under normal conditions, is then cognitively corrected to purify it of illusions of perspective and other unthinking errors.’<sup>36</sup> In addition, the assumption that we ever perceive along single sensory routes is deeply erroneous:

What normally pass for mono-sense experiences are, in fact, cross-modal fusions presented in a dominant sense. For example, to see the shape and texture of the object is to perceive, in vision, its potential feel in the hand. To feel that potential touch is to see the potential kinaesthetic experience of walking towards

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<sup>35</sup> A more complete definition is as follows: ‘A mirror neuron is a neuron that fires both when an animal acts and when the animal observes the same action performed by another. Thus, the neuron “mirrors” the behaviour of the other, as though the observer were itself acting.’ [https://en.wikipedia.org/wiki/Mirror\\_neuron](https://en.wikipedia.org/wiki/Mirror_neuron).

<sup>36</sup> Brian Massumi. ‘The Art of the Relational Body’, 192.

the object. [...] It is well known that object vision cannot develop without movement. [...] Every 'single' sense experience is the envelopment in a dominant mode of appearance of an 'infinitesimal' (virtual) continuation of other-sense experiences. Every perception is a composition of the full spectrum of experience, 'practically' appearing as if it were disparate and disconnected from the continuum.<sup>37</sup>

Senses are felt on a continuum in an amodal register. The world is felt across registers of sensation that bathe our bodies in complexity, a co-composition of world-bodying that changes the environment and the bodies composed by it at every turn.

John Lee Clark proposes the concept of distantism to counter the tendencies at the heart of these assumptions. Distantism, defined by Clark as the tendency to privilege mediation over direct perception, is what allows the neurotypical worldview to dominate, what allows the body to be parsed from its environment, and what enables a worldview that DeafBlind experience – to speak of just one discounted form of experience – is no experience at all. Whether we are speaking of the necessity to frame our academic knowledge based on objective data, or whether as DeafBlind people our engagement with the world is considered by others to be impossible without the mediation of a sighted intervenor, or whether we are expected to diminish our experience of the world as autistics by limiting our sensory experiences in order to 'pass,' or whether our black, brown or indigenous bodies are expected to be less threatening by moving to rhythms (including

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<sup>37</sup> Ibid., 194.

rhythms of thought) neurotypical (and the list goes on), we are engaging in distantism.

For Clark, distantism promotes the impossibility of a DeafBlind feeling-with the world. In this limit-case of distantism, a lived experience of feeling-felt is denied. Clark writes: ‘Researching our community’s history, I see that we have always been tactile. But hearing and sighted people have always attempted to keep our tactilehoods in check. We’ve always been denied access to some of the most basic human rights. What should we call this force of suppression? I propose to call it distantism.’<sup>38</sup>

There is no distantism in the relational body. That is to say, distantism is not a quality of bodying: bodying is never parsable from the world with which it co-composes. ‘If one brings one’s perception to the edge of release and inhabits the resurgent complexity, has one acted upon experience—or released oneself to be acted upon by it?’<sup>39</sup> Perception on the edge is always already with the world in its unfolding. This withness, as mentioned above, can never be articulated in its fullness, but the feeling of it remains with us nonetheless. It is this feeling that moves in the lines of Clark and Mukhopadhyay’s poetry, in the rhythm of the more-than-saying their feeling-with makes felt. Distantism is not how we perceive, it is how perception is imposed on us. It is how it is framed by Empathy Quotient tests. It is how it is made intelligible by baseline beliefs about the homogeneity of experience neurotypically parsed.

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<sup>38</sup> John Lee Clark. ‘Distantism’ <https://johnleeclark.tumblr.com>

<sup>39</sup> Brian Massumi. ‘The Art of the Relational Body’, 196.

This has spacetime effects. In his piece ‘My Dream House: Some Thoughts on a DeafBlind Space,’ Clark writes:

Now I’m going to discuss something very particular and perhaps difficult for non-DeafBlind people to fully grasp, so bear with me as I try to explain it. You know the saying ‘Out of sight, out of mind’? Well, for DeafBlind people everything that’s out of sight remains in the mind’s eye. We can relate to what Gauguin once said: ‘I shut my eyes in order to see.’ This is why DeafBlind vision is often better than eyesight—we know where everything is and see them through walls, through doors, through drawer doors, through anything in front or under or below them. They aren’t hidden. The bad news is that we also see, or imagine that we see, everything that’s behind the walls, under the fridge, inside the gap between the floor and the bottom of the cabinet under the sink.<sup>40</sup>

DeafBlind vision is topological. It is not restrained to the imposition of Cartesian perspective. Perception moves with the world, creating a lively image of its composition and altering that image, while retaining its complexity, through coming into contact with it. This account of DeafBlind spacetime is analogous to the account of the body-world continuum being put forward here. Bodies are not limited to their envelopes – they are extensive, moving-with the world in its transformation. Think of how the oxygen moves in Mukhopadhyay’s account. There too, space is topological. To move with the world

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<sup>40</sup> John Lee Clark. My Dream House: Some Thoughts on a DeafBlind Space, <http://visionlossresources.org/blog/dbsm/my-dream-house-some-thoughts-on-a-deafblind-space>

is to have bodied, and to have bodied is to have worlded. The world grows in the bodying.<sup>41</sup>

Qualities of experience overlap. There is no distance. Everything has an effect. Everything makes a difference. A body is this quality of multisense overlap in incipient contact with an infinity of sense potentials. These sense potentials are not located in a discrete sense, or in an object. They cannot be distilled to an ear or an eye, and cannot be located in a table or a marigold. They are always between, amodal, operating as thresholds of sensation that carry intensities themselves carried in the feeling. Following Lucy Blackman (see fn.64, p. 187), and her emphasis on the verb ‘carrying’ as a way of reminding ourselves that everything is always in movement, we might speak of feelings carrying the edge of consciousness, feelings not fully subtracted, not fully known-as-such, but nonetheless active and transformative, their effects lively, the bodying recomposed in the relation.

Massumi writes: ‘A determinate experiential form origami-ifies into relief when an actual movement cuts its patterning and orientation into the vibratory intensity of the virtual body, drawing out a determinate stand-out

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<sup>41</sup> For a very interesting account of Deaf space with a particular focus on the dorsal, see Robert Sirvage’s TEDx talk at Gallaudet entitled ‘An Insight from DeafSpace’ <https://www.youtube.com/watch?v=EPTrOO6EYCY>. In this video presentation, he described the relational movement of signing Deaf couples walking together to demonstrate that their communication includes an attention to the incipient movement all around them. This is more than simple protection (watching someone’s space and making sure they are safe). This is included in the communication itself. It is at the heart of the ethos of Deaf communication.

expression of the potential it enfolds.’<sup>42</sup> The virtual body is the topological shape feeling takes when it moves with the world. ‘The closest geometrical approximation to the hyperorder of the virtual body is not the extensive grid defined by the Cartesian coordinates. It is topological. Topology is the geometry of continuous deformation.’<sup>43</sup>

Bodying, always topological, is regularly projected onto Cartesian coordinates, the Cartesian coordinates in turn back-gridded onto it. If they weren’t, Clark wouldn’t need a Dream House and it wouldn’t be necessary to continuously emphasise how the body is not limited to the form it most visibly takes. To give the body the shape of an outline is to impose distantism on the body. Having done that, the further imposition of Cartesian coordinates on the geometries in which we live and move is an easy second operation. If we are a limited spacetime, a bounded envelope, if we are already coordinated by a template that organises us, why wouldn’t we create architectures that support that very kind of body schema? And in that architecture, in those worlds, wouldn’t it make sense that we should restrict our sensing to the coordinates it privileges? Of course, no architecture is fully capable of organising a body, but as Clark emphasises, when you are DeafBlind, it can come close to negotiating for you the measure of your movement experience.

Clark’s Dream House and Mukhopadhyay’s account of the near-oxygenless mine remind us that the only people who take Cartesian coordinates and neurotypical

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<sup>42</sup> Brian Massumi. ‘The Art of the Relational Body’, 201.

<sup>43</sup> *Ibid.*, 202.

limitations for granted are those who most easily fit in the category where the senses are nicely pruned and existence is organised according to preimposed restrictions. I am not saying that DeafBlind folks are neurodiverse in the sense of neurologically divergent. Some may well be, but I wouldn't want to generalise across a heterogeneous population. What I am saying is that their lived experience of topological spacetime and the effects it has on their bodying make them squarely non-neurotypical. It is time, perhaps, to think of another term that carries the force of the non-neurotypical without including the 'neuro' as the marker of its difference. Because even autistics, who are most definitely neurodivergent, are diverse in an infinity of ways that expand from the neurological. This is why I use the adjective neurodiverse – to remind us that we need a concept for a diversity within diversity that isn't measured by the standard of typicality. A diversity in diversity is one that senses fully and differentially, that lives and participates in a world still defining itself according to measures not yet in place. It includes populations historically excluded from the matrix of the human: neurodiverse life, DeafBlind life, black life, indigenous life, feminist life, trans life. It includes modes of life-living that exceed the human, that feel the more-than human world not as other but as with.

In the mid 2000s, a group of DeafBlind activists began to invent and share a mode of communication that would allow them to take back control of their own complex fields of sensation and to collectively invent new ones. The hope, as Clark articulates it, was to be able to move

from a distantist engagement with touch to a metatactile one. He writes:

[A] response I often get when I interact with people [is] [h]ow did I know that their shoulder needed a massage, or that they were hungry or sad, or a spot on their arm was itchy? The owners of pets I meet are also amazed. Almost immediately I've found their pets' sweet spots. 'That's right! She loves that. But how did you know?' I wasn't conscious of it. It was natural. So natural, in fact, that I didn't have a name for it, this skill that goes beyond just feeling texture, heft, shape, and temperature. I'd like to call it metatactile knowledge.<sup>44</sup>

This 'skill that goes beyond just feeling texture, heft, shape, and temperature' sounds a lot like the feeling-with Mukhopadhyay describes as the feeling-being of oxygen in the miners' space.<sup>45</sup> The becoming-oxygen of the more-than-human is the way Mukhopadhyay enters into the touching of the environment. It is how he feels-with the texture, heft, shape and temperature of that singular ecology.

A modality that moves beyond but includes the hands-on gesture of touch, metatactile knowledge is the act of reaching-toward experience, allowing all co-composing bodily senses – including the kinaesthetic, the proprioceptive, the vestibular – to connect to the incipencies of

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<sup>44</sup> John Lee Clark. 'Metatactile Knowledge'. <https://johnleeclark.tumblr.com/post/130321809778/metatactile-knowledge>

<sup>45</sup> This is also a responsibility-before, a modality of touch I discussed more thoroughly in *Politics of Touch*. Touch, in this way of living, is the emergent quality of the relation as it unfolds. This is different from a responsibility-for, which still suggests a hierarchy of interaction. I discuss this more at length in 'Waltzing the Limit,' in *Always More Than One*.

a welling environment. Encouraging the welling environment to 'grow around him,' as Mukhopadhyay might say, enables the necessary parsing while facilitating the richest possible experience of sensation, or feeling-with. I say feeling-with to foreground the Whiteheadian notion of feeling which also does its work without cognition and cannot be reduced to a human experience. 'Consciousness presupposes experience, and not experience consciousness'.<sup>46</sup> In a philosophy of pure feeling (as opposed to one of pure reason), the world is alive with feeling, and it is this feeling that moves through us, creating the lures that orient our experience.

When Clark speaks of the bowl asking to be touched he is resisting giving touch a primarily human inflection. To sense for him is to feel-with in the Whiteheadian manner, to be in experience, affected by it. This is metatactile sensing, to connect to the quality of an encounter as much as to the actual shape of the surface with which one comes into contact, to feel *with* the encounter, coming into contact with the complexity of relations the encounter calls forth.

Clark suggests that metatactile knowledge is a 'protactile' mode of touch. The ProTactile movement celebrates the metatactile: it honours all kinds of tactility, including, I would hazard, the shaping of experience through the force of the relational, or virtual body. Foregrounding the importance for communication of a direct perception of relation, ProTactile encourages DeafBlind people and anyone who communicates with them to engage

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<sup>46</sup> Alfred N. Whitehead. *Process and Reality* (New York: Macmillan, 1985), 53.

in continuous physical touch. This continued contact, they argue, allows them to finally become autonomous in their communication by being more attuned to the nuances of the nonlinguistic aspects of communication. Bringing out the full potential of TASL [Tactile American Sign Language], and allowing, as becomes necessary, for TASL to depart from the habits of VASL [Visual American Sign Language], which remains the mother tongue of many in the DeafBlind community, ProTactile is as much a linguistic as a cultural movement. Claiming experience according to their own complex registers of sense, ProTactile teachers and students emphasise that it's high time for the DeafBlind to be teaching the DeafBlind.<sup>47</sup> As Christine Roschaert describes it, ProTactile 'broadens the spectrum of communication of the Deafblind outside of the standard Tactile with (American or any other international) Sign Language and several other manual methods.'<sup>48</sup>

ProTactile does not limit itself to a set of preexisting coordinates. It is not a system of gestures or touches. It is not a grid that can be used generally across myriad situations: 'we want to emphasize that PT is not a set list of symbols with associated meanings, like "touch signals"', Jelica Nuccio, the founder of ProTactile explains. ProTactile is a linguistic-cultural paradigm, and an ethos. 'ProTactile

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<sup>47</sup> John Lee Clark writes: 'There are distantist modes of touch and there are protactile modes of touch. A distantist cannot truly teach or empower our children to live and learn as tactile people. Yet the field of education of DeafBlind children has never included us as teachers. Why is that?' <https://johnleeclark.tumblr.com>

<sup>48</sup> Christine Roschaert. Tactile the World (blog), <https://tactiletheworld.wordpress.com>, 2013.

philosophy is not just about “accessing” communication; it affects all areas of life, including DeafBlind culture, politics, empowerment and language.<sup>49</sup> Based on the strong belief, also prevalent in the Deaf community, that separating language and culture is an impossibility, ProTactile brings into action tendencies of listening and speaking that best address the singularity of DeafBlind experience. A mode of encounter grown from within the culture, ProTactile is a call for the DeafBlind community to reject distantism and embrace the incipency of feeling of a touch that reaches toward experience in the making.

Jelica Nuccio and AJ Granda describe the ethos of ProTactile this way: “The purpose of ProTactile philosophy is to support DeafBlind culture, language, interpersonal relationships, [and] politics.”<sup>50</sup> While touch has always played an important role in DeafBlind culture, and much communication already moves through touch,<sup>51</sup> the modality of touch foregrounded through intervenors tends toward distantism: “We can see in the record how distantism set in, and how hearing and sighted people wanted things to look right. It didn’t look good when we went around “groping in the dark.” It didn’t look good for

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<sup>49</sup> Jelica Nuccio and A.J. Granda. Welcome to Protactile: The Deaf-Blind Way (vlog #5). [protactile.org](http://protactile.org), March 2016.

<sup>50</sup> Ibid.

<sup>51</sup> For an account of ProTactile from an ethnographic perspective, see Terra Edwards, ‘Bridging the Gap Between DeafBlind Minds: Interactional and Social Foundations of Intention Attribution in the Seattle DeafBlind Community’, *Frontiers in Psychology* 6 (2017) DOI: <https://doi.org/10.3389/fpsyg.2015.01497>. On Touch Signals, Haptic Communication and Back Channeling, see <https://nationaldb.org/library/page/2588>. See also <https://www.facebook.com/ntfdbi/posts/841440079290709>

us to cluster together and have too much fun. Education meant we had to sit behind a desk.<sup>52</sup> With the intervenor, the practice is to create a communicational model that mediates touch. Touch is necessary, it is understood, but only at certain stages of the (mediated) encounter. ‘But when we go exploring or when we just exist, sighted and hearing people rush in to intervene. Can they help us? Please don’t touch. They will be happy to describe it to us. They will guide us. No, they will get it for us. It’s much easier that way. Hello! My name is Katie and I’m your Intervenor!’<sup>53</sup>

For someone outside the DeafBlind community who cannot understand sign language, a proTactile video provides little to no information-as-content. I cannot understand the details of what is being said. What I can perceive, however, is the force of relation: bodies are actively listening and composing together. The conversation has a shape, and that shape feels dynamic. A vitality affect is felt in the watching. Communication has clearly taken on an emergent quality, activating the virtual body of sensation in the encounter.

Vitality affects, as described by Daniel Stern, are emergent attunements felt in the relation. Stern speaks of an overlap of movement, time, force, space and intention/directionality as being at the heart of all vitality affects, or what he also calls vitality ‘forms.’<sup>54</sup> These five elements

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<sup>52</sup> John Lee Clark. <https://johnleeclark.tumblr.com>

<sup>53</sup> Ibid.

<sup>54</sup> Daniel N. Stern. *Forms of Vitality: Exploring Dynamic Experience in Psychology, the Arts, Psychotherapy, and Development* (Oxford: Oxford University Press, 2010), 4.

must not be seen to work in isolation. Together they form a Gestalt, and that Gestalt has affective tone. Describing vitality affects, Stern speaks of:

the force, speed, and flow of a gesture; the timing and stress of a spoken phrase or even a word; the way one breaks into a smile or the time course of decomposing the smile; the manner of shifting position in a chair; the time course of lifting the eyebrows when interested and the duration of their lift; the shift and flight of a gaze; and the rush or tumble of thoughts. These are examples of the dynamic forms and dynamic experiences of everyday life. The scale is small, but that is where we live, and it makes up the matrix of experiencing other people and feeling their vitality.<sup>55</sup>

Vitality affects are:

the felt experience of force – in movement – with a temporal contour, and a sense of aliveness, of going somewhere. They do not belong to any particular content. They are more form than content. They concern the ‘How,’ the manner, and the style, not the ‘What’ or the ‘Why.’<sup>56</sup>

ProTactile is a recognition that DeafBlind communication carries its own singular vitality affect, and that this needs to be valued. One aspect of this singularity is the emphasis on movement. Without sight and hearing to facilitate connection to the world, DeafBlind people have to connect more deeply to their kinesthetic and vestibular senses. They do this by doing what we all do: they move.

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<sup>55</sup> Ibid., 6.

<sup>56</sup> Ibid., 8.

In a description of ProTactile communication in process, Clark emphasises the role movement plays. In *Where I Stand*, he writes:

As a DeafBlind person, standing for me is almost never about being still or in one place. Waiting for a bus, I would move without realizing it. My way of standing by moving around gives me more information about where I am. I'm taking in the scene, being present in the world, and prodding things a bit, exploring. And when two DeafBlind people talk to each other while standing, they always move around so that, after a while, they're standing where the other person was. Later on, they'd be back to their former positions, having circled around each other. This phenomenon is the result of each person shifting to the left to listen to the other person tactilely in a more comfortable way, hand following hand at a certain angle. I would always find myself emerging from an engrossing conversation standing in a different place.<sup>57</sup>

Movement gives experience shape. Speaking about the primacy of movement in experience, Stern writes:

[D]ynamic changes [...] occur constantly. Our respirations rise and fall over a cycle that repeats every three or four seconds. Our bodies are in almost constant motion: we move our mouth, twitch, touch our face, make small adjustments in head position and orientation, alter our facial expression, shift the direction of our gaze, adjust the muscular tone of our body position, whether standing, sitting, or lying (if awake). These processes go on even when not visible

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<sup>57</sup> John Lee Clark. *Where I Stand: On the Signing Community and My DeafBlind Experience* (Minneapolis: Handtype Press, 2014) Kindle Edition. Loc. 116-120.

from the outside. Gestures and larger acts unfold in time. They change fluidly once an act has started. We can be conscious of any of this, or it can remain in peripheral awareness. In addition, with every movement there is proprioception, conscious or not.<sup>58</sup>

How to well the chaos? ‘How do we not implode into the intensity, lost in the infinite virtual folds of potential experience?’, Massumi asks. His answer: ‘through movement. Every movement makes a cut—it brings certain elements of experience into relief, origamiing the continuum on the fly.’<sup>59</sup> Movement is primary: it is through movement that incipient sensation catches the world’s tendencies and moves into them, altering them in the passage.

Making movement primary by itself shatters distantism, for distantism requires position. It requires pre-choreographed placeholders that have already been given value, that have already been signalled as worthy of attention. This is why distantism is so central to the template of neurotypicality: it allows the value of experience to be mapped in advance. And this is why neurodiverse experience is so threatening: because it makes felt what would otherwise remain backgrounded, and gives it value, thereby reinventing the very concept of value. New ways of living proliferate, and with them come new ways of knowing.

Movement is everywhere in the literature on ProTactile, itself called a movement. For too long, DeafBlind communication tended to be watered down to the most

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<sup>58</sup> Daniel N. Stern. *Forms of Vitality*, 9.

<sup>59</sup> Brian Massumi. ‘The Art of the Relational Body’, 199.

atrophied of communicational models: third party interpretation. Not only was this slow, it lost the quality of the vitality affect of the communicational swarm in the stagnancy of the ordered back-and-forth. Little could be shared in the making. This mode of communication was closer to reporting than conversation. With ProTactile comes a liveliness in communication that allows the vitality affect of the conversation to be felt by all. This results in ‘a true sense of empowerment’ (Granda).<sup>60</sup> As Nuccio says: ‘Deafhood<sup>61</sup> involves so many things – ASL, culture, who you are, your identity – that is exactly what PT is.’<sup>62</sup> This is not to say that facilitators are never necessary: ‘I am not saying that we don’t need sighted assistants. After all, we do live in a distantist society, and we should avail ourselves of distance-information readers. However, the way our SSP services are performed can be smothering. That’s why a key concern of the Protactile movement is autonomy.’<sup>63</sup> When intervenors become ProTactile, they shift from mediators to facilitators, facilitators here understood in the sense given to them by autistics such as

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<sup>60</sup> Jelica Nuccio and A.J. Granda. Welcome to Protactile, 2016.

<sup>61</sup> On the Deafhood foundation website ([www.deafhood.org](http://www.deafhood.org)), Deafhood is defined in the following way: Deafhood ‘is a way of gathering together and framing what we already know of Deaf culture, life, politics, etc. The framing process itself reveals ways in which we can move ‘beyond’ present Deaf cultural limitations resulting from the colonialism of Sign Language Peoples (SLP).’ The concept was developed by Paddy Ladd in 1993.

<sup>62</sup> Jelica Nuccio and aj granda. Welcome to Protactile: The DeafBlind Way (vlog #3). [protactile.org](http://protactile.org), March 2016.

<sup>63</sup> John Lee Clark <https://johnleeclark.tumblr.com>

Lucy Blackman,<sup>64</sup> who emphasises that communication is relational at its core. Facilitation is important in all life situations, not to mediate experience but to co-compose techniques that move beyond the insistence, in our neo-liberal economy, on individuality-above-all. Metatactility, after all, is a collective action, an aliveness with the world that acknowledges the interpenetrating registers of experience.

Metatactile modes of touching put the dynamic shape back into DeafBlind communication: they make the vitality of the exchange felt to all who participate. This shape is continuously composing itself, as is the case in all communication. Reinventing what it might mean to communicate is key to this practice, and this includes communication with the more-than, engagement with what else the world carries, and what else a body-world relation can be.

There is much to learn from ProTactile's engagement with touch as an ethos that troubles distantism. The neurotypical template moves at the pace of distantism, opting for mediation at every turn. Working with a pre-existing matrix, it organises, categorises, prioritises, grids, excludes. Justifying forms of knowledge acquisition, modes of self-presentation, moral categories, it shapes the contours of education. It also organises the vocabulary of sensation, of perception, of experience. When Suzi Guimond writes – 'the world of deaf-blindness is far from a dead one. The world is constantly full of vibrations and smells

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<sup>64</sup> See Lucy Blackman, *Carrying Autism, Feeling Language* (Self-published, 2013).

and changes in temperature and air pressure. Many people seem to believe that without ears and eyes, the world becomes unmoving and still, but this couldn't be farther from the truth' – she is speaking about a value-system predicated on neurotypical understandings of sensation. She is underscoring the ways in which the categorising of experience in advance through neurotypical codes limits our capacity to imagine experience beyond the spatiality of distantism. Organising bodies by limiting the wealth of sensation fosters a systematic account of experience that supports the kind of classification that marks many of us as less-than human and keeps us from receiving (or inventing) the opportunities we need to thrive.

ProTactile *immediates* experience.<sup>65</sup> Moving-with experience in the making, the intervenor-as-mediator no longer has a role to play. Experience is lived, from the edges in. 'The formative relation of co-implication in the same event is the changing ground of experience. If the virtual body can be said to represent anything, it is this relationality of the life of the body' (Massumi 2017: 204). ProTactile is a reaching-toward the world that makes felt how the world is already poised to meet the encounter, the relational body of communication alive with the force of the touch that will give it dynamic shape. For what occurs in the encounter of emergent communication can never be reduced to two enclosed, pre-constituted selves, one active, one passive. Nor is the encounter only human. Or only interactive. 'Society is not companionship or

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<sup>65</sup> For a sustained encounter with the concept of immediation, see Erin Manning et al. series *Immediations* (Open Humanities Press).

friendly association with others; it's companionship or friendly association without others, in the absence of the other, in the exhaustion of relational individuality, in consent not to be a single being'. The 'consent not to be a single being', in Édouard Glissant's resonant words (in Moten 2016),<sup>66</sup> is a call to a synaesthesia that honours the more-than of sense that includes the force of metatactility and vibrates with worlds verging toward consciousness. Not distantist, but not proximitist either. In the field of minor sociality where relational bodies compose with the force of the incipiency of a touching beyond touch, ProTactile proposes a reaching-toward that touches experience in the making.

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<sup>66</sup> Fred Moten. Bobby Lee's Hands. Organise Your Own (blog), 5 December 2016. <https://organizemyourown.wordpress.com>

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