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MEDIA REVIEW: On the “Puzzle of Autism” and the Incompleteness of Autism Awareness

Autism has had a longstanding association with the figure of the puzzle. In much the same way that, for example, the pink ribbon has symbolically come to represent breast cancer awareness, or the red ribbon to represent AIDS awareness, the puzzle piece has been adopted as the icon of autism awareness. The puzzle piece brands a great many contemporary advocacy organizations worldwide and it is commonly used to mark “autism awareness” on car bumpers and websites, necklaces and key chains, shopping bags and posters, golf balls, cufflinks, champagne glasses and so many other likely and unlikely objects and places. If to tell the story of our awareness of otherness is a necessary (and, even, desirable) function of living with others – and I believe that it is – it also becomes necessary to understand our awareness stories as functions of power: to attend to the ways in which such stories are producing and governing ourselves and others.

In her book, *Queer Phenomenology*, Sara Ahmed (2006) writes: “to be oriented is to be turned toward certain objects, those that help us to find our way” (p. 1). In relation to discourses of autism awareness, the figure of the puzzle is one such object. In the pages that follow, I work through *how* the figure of the puzzle not only marks “autism awareness,” but also orients our collective “awareness” of something called “autism.” I attend, too, to the inherent uncertainty of the task of awareness. Of what are we aware, as we become aware of autism? How is the figure of the puzzle orienting “us” – those of us who identify (or are identified) as autistic and those of us who identify (or are identified) as non-autistic – in relation to autism? How is this object, following Ahmed, helping us to “find our way” in relation to autism?

The “Puzzle of Autism”

I now turn toward this so-called “autism puzzle,” trace its jagged contours, and attend to the ways in which it is working to shape our awareness of and relationships with autism. I ask: “How are we in touch with this ubiquitous figure of the autism puzzle?” Perhaps we might begin to think through this question by considering how we are in touch with puzzles in general.

Consider the example of a traditional jigsaw puzzle. Jigsaw puzzles are composed of pieces of a whole. They are made up of parts that, if put together in a predetermined way, (re) create an originary, whole picture. Imagine, for a moment, an unsolved puzzle. In this scene, the puzzle pieces are scattered; they lay this way and that. In short, the isolated

pieces are without any apparent order – a chaotic cacophony of colour and shape. Dominant understandings of puzzles suggest that the reasonable thing to do with this cacophony is to order it. When faced with a puzzle, we solve it – or at least try to. In this way, puzzles are connected to a sense of possibility. The puzzle's possibility – its promise – is that it *can* be solved by logically uncovering and piecing together the pieces, thus revealing some underlying, sensible and originary order.

With the jigsaw puzzle, possibility is inaugurated by the image on the box. This image recalls the promise that the unpredictable and uncertain disorder of the individual pieces can certainly be brought together and arranged into a sensible, orderly whole. Individual pieces are brought into proximity by the puzzle solver and they are locked into place. The puzzle solving process is governed by a collection of "rules" and, in order to reasonably solve the puzzle, the puzzle solver must abide by these rules. Such rules dictate that proximity must be achieved through fitting the pieces together, by orienting the pieces in particular ways and by connecting them in a predetermined order. And, there is a "right" fit and a "wrong" fit. For a jigsaw puzzle to be complete, the pieces must be tessellated, that is to say, the pieces must come together in such a way that there are neither overlaps, nor gaps. Through the act of putting together the puzzle, isolated pieces, thus, are transformed; the puzzle that is solved is no longer a puzzle at all, but a picture. An old image is made anew. So the story goes.

As I mentioned earlier, dominant enactments of advocacy work often draw on commonsense understandings of the jigsaw puzzle as metaphor for the character of "autism." In her essay, "Perspectives on a Puzzle Piece" (1988), Helen Green Allison – a founding member of the UK advocacy organization, the National Autistic Society (NAS) – argues that the puzzle piece is effective in that it tells us something about autism; it tells us that people with autism are disabled by a puzzling condition which serves to isolate them from typical human contact. As a result, people with autism do not fit in.

This same meaning of the metaphor of the puzzle was made particularly explicit when, in honor of World Autism Awareness Day

(WAAD) in 2009, celebrity artist Yoko Ono was commissioned by the US-based advocacy organization, Autism Speaks, to create a seven-foot-tall puzzle art piece – entitled *PROMISE*.

Ono's puzzle – which depicts a blue sky with white clouds – is comprised of 67 pieces which, according to Ono, symbolize the 67 million people worldwide affected by autism (Autism Speaks, 2009). The pieces were broken apart and individually auctioned off to raise funds for (predominantly biomedical) autism research, but only with the promise that when the cure for autism is found, all the pieces would be reassembled once again for a single day. Said Ono in an interview on the Today Show: "[the puzzle mural] is still imperfect and we're going to solve the mystery of autism and then we put it back there so that the sky will be complete again" (Bell, 2009).

Drawing on the puzzle as metaphor, both Green Allison's and Ono's enactments of advocacy suggest that autism is a puzzling "condition" that is locatable in the bodies and minds of certain individuals. Autistic bodies, it is remarked, are "handicapped" by the puzzling condition of autism, and because of this, these bodies are "isolated," "broken apart," and do not "fit in" to everyday "normal human contact." These examples tell us that what is puzzling about autism is that crucial pieces of its presumed whole are missing or unknown. We do not have all of the pieces of the puzzle of autism – the story of what autism is remains an "imperfect" one. And, indeed, without all of the pieces, it is impossible to put together (and thus to have) the whole "completeness" of autism. As Ono's art piece reminds us (and as per our dominant orientation to puzzles) the reasonable thing to do with a puzzle is to find the missing pieces, to search and re-search, to "solve the mystery" (Bell, 2009) – to find a cure. The solution to autism's so-called dis-order is conceived of as the revelation of more pieces of (typically, biomedically-oriented) information – more accurate brain scans, more precise genetic tests, more case studies – and to connect this information in such a way that gives order to the so-called (autism spectrum) dis-order. The autistic body, itself, is therefore always and already conceived of as inherently dis-ordered, unpredictable, and unknown.

Still, even as the autistic body is framed as "dis-ordered" and "unknown," it is simultaneously,

framed as *order-able*, and, essentially, *knowable*. The puzzle is drawn upon in relation to autism only insofar as the puzzle is interpreted as a problem that requires a solution. Moreover, the figure of the puzzle makes a “solution” appear as both desirable and attainable. The partiality, and so the uncertainty, of the “autism puzzle” is recognized only with an implicit understanding that knowledge about autism can be made certain with enough sleuthing – the progressive and objective unveiling of the elusive, but nonetheless existent, whole and static “truth” of autism. In this context, what is puzzling about autism is read in a particular way, namely, as a biological problem or puzzle that ought to – and can – be solved, or in familiar biomedical terms, “cured.”

Recall that once a jigsaw puzzle is solved, it ceases to be a puzzle; it is instead transformed into a picture. The common sentiments of hope and possibility that have come to be associated with the metaphor of the “autism puzzle” – sentiments symbolized by the image of the open blue sky of possibility from the Ono mural – represent the hope and “PROMISE” that the puzzle might not always remain as such. Put differently, the puzzle metaphor comes to represent the hope that what is puzzling about autism might be solved, what is uncertain may be made certain, what is partial might be made whole; it comes to represent the hopeful possibility that the disorderly body of “autism” might be modified, rehabilitated, and the orderly and expected body of “non-autism” – the metaphorical “picture on the box” – might be recreated, or as is now commonly articulated in autism advocacy discourse, “recovered.”

This orientation to puzzles and people implies that autistic difference (that is to say, autism *as autism* and not as, say, autism on the way to non-autism) is neither valued nor valuable in our collective life and even works to produce and sustain conceptions of autistic difference as non-viable. Yet, as many autistic activists and advocates have articulated, autism is more than merely a puzzle needing to be solved. Consider, for example, the autistic self-advocacy slogan, “I am not a puzzle, I am a person” (Svoboda, 2009). Such disruptive articulations invite us to contemplate what is puzzling about autism and autism awareness and to make these things matter differently.

The Value of Insoluble Puzzles

The question remains: “In the absence of the possibility for its solution, what is the value of a puzzle?” Rather than drawing upon the puzzle as a metaphor that objectifies individuals or an individual condition, or provides a story of a body-gone-wrong, I am suggesting that we make use of the notion of the puzzle as a social action. Likewise, rather than drawing upon the metaphor of the puzzle as a way to understand autism strictly as an individual biomedical condition, we might also understand autism as a *social condition that puzzles, provokes, and questions*.

What new possibilities might this re-orientation allow for? If the figure of the puzzle typically is read as marking the possibility of certainty, can it not be transgressively re-oriented as a symbol for the possibility of uncertainty? In this act of re-orientation, perhaps we might re-conceive mystery and uncertainty as essential parts of human difference, and therefore as valuable and even as something to desire. For the remainder of this paper, I will explore how “we” (all) might begin to re-orient to the puzzle – *the puzzle as a puzzle* – not as some-thing that is in need of solving, but as an *event* that can remind us of the uncertainty of our relatedness, and our awarenesses; an event that is, and must be, insoluble.

As a way to begin to glean this, I would like to tell a story. This story is a memory and, as such, I am engaged in an ever-partial process of remembering. And so, this story is, inevitably, about (my) incomplete awareness. I was a young child, maybe eight or nine years old, my younger brother was upset, crying. We were playing together in the sand and then, unexpectedly...tears. I remember putting my hand on my brother’s arm, having been taught that that is how “we all” show and express love, that is how we comfort, soothe, and make better. I remember him responding to my seemingly ordinary touch by swiftly recoiling his arm, shouting at me, jolting me out of the ordinary.

Only later, many years later, did he articulate that certain kinds of touches, particularly unanticipated ones, are physically uncomfortable, painful even. Only later, many years later, did I re-member the story of my trying to comfort him, and reshaped the memory with new awareness. When I touched my brother’s arm,

I suppose I was expecting him to feel what I would feel – the comforting touch of someone who cared. I acted on the supposition of a cohesive "we." As "I" made contact with "you," I suppose I was expecting our "fit" to be smooth – no gaps, no overlaps. Something, however, failed to get across in our interaction.

In this memory there is an invitation to be puzzled. The story's gaps and incongruencies, its "then-ess" and its now-ness, its him-ness and its my-ness, its insoluble puzzles, invite me to begin to address, more broadly, moments and methods of contact on the basis of that which fails to get across. To return to the metaphor of the puzzle, there is no escaping those cracks, those gaps that hold the pieces in place. And, even while some "fits" might be smooth and comfortable, others might unexpectedly contort us, change our shape, and shift our orientation. The disruption caused by disability's (autism's) unexpected and, sometimes even uncomfortable, relation interrupts and, thus, questions the assumed wholeness and completeness of any "we."

And, insofar as autism interrupts and questions the assumed certainty of how "I" connect with "you," it provides a unique occasion to theorize this "we," to work with and through our awarenesses of others in our research, our work, our relationships and, of course, our performances of advocacy. How am I, as a disability studies researcher, connected to and encountering others? How am I being touched by others? How am I returning this touch? How are we reading, writing, speaking the other – how are we narrating a "we"?

Puzzling Our Awarenesses of Autism

For the many and varied participants in ongoing conversations about autism and autism awareness, the question of how "we" relate to, and are aware of each other – how we make contact with one another is a critical one; members of autism and autistic communities are as disparate as we are unified. The question of our awareness is a puzzling one. This is all too evident when we consider the vast and variegated array of physical, sensory, cognitive and mental impairments that are put in touch with one another under a rubric of "autism"; when

we consider how discourses of autism awareness encompass people who identify as autistic, people who are identified as autistic, as well as (autistic and non-autistic) medical professionals, community workers, service providers, parents and family members and more; when we consider how systems of ableism come into contact with autistic bodies that already have been touched by other (and perhaps multiple) systems of oppression; when we consider the ways in which autism provokes complex and even contradictory embodied feelings of comfort and discomfort, pride and shame (Chandler 2010) and so on. Within this complex sociopolitical space, we – all of us – are making sense of this thing called "autism" that is many and shifting and endowing it with particular and sometimes conflicting meanings. Autism "awareness," then, is no simple task.

Our awareness of autism then, is always puzzling; it must be. And, in this interruption, there exists an invitation. Thinking through the puzzles we face as we articulate a "we" – puzzling our awarenesses – can open up new spaces where "we" might critically engage with questions of difference and uneven power relations within autism awareness discourse and autism advocacy more broadly. Puzzling our awarenesses might open up space for those engaged in the project of raising autism awareness to critically engage questions of power and privilege within discourses of autism and autism advocacy, questions that might very well challenge the persistent and problematic use of the puzzle piece symbol as a way of metaphorizing autism as nothing more than a puzzle in need of solving, a problem in need of solution.

Endings and Beginnings

Autism disrupts the way "we" typically make contact and, in doing so, presents us (all of us) with an opportunity to re-imagine the ways we come into contact with an other – to look without necessarily making eye contact, to touch with a tentativeness and an awareness of the inherent risk in making contact with sensitive surfaces, to research with an awareness of our partiality and incompleteness: a place to begin.

I promised at the outset that this article would end and begin with a puzzle. However, unlike the traditional jigsaw puzzle and unlike the so-

called “puzzle of autism,” the theoretical/methodological puzzle I am suggesting in this article is neither complete, nor on its way to completion. It is, as Walt Whitman describes, “the puzzle of puzzles, the puzzle of being” (Whitman, 2001, p. 25). It is not a recognizable product of myriad pieces arranged carefully together in particular ways. It is not an elegantly patterned realization of a prior or expected image. In fact, its pieces come from many different puzzles, offering fragmentary glimpses of multiple images. The puzzle I imagine will always have pieces missing and the pieces that are before us are unexpectedly arranged. There are gaps and spaces of distinctive sizes and shapes. Some pieces are face down, and some have fallen atop others, obscuring them from view entirely.

The jagged fragments that interlock do not always fit together in the ways we might typically anticipate. Some of the pieces are upside-down and disoriented, some come together smoothly and easily. Irrespective of the particularities of their arrangements, the pieces of this puzzle are always in-touch with one another, though sometimes the contact that is made cannot be described as a physical nearness. Some pieces fit so closely that the gap that separates them is almost imperceptible. It is not unlike the colorful moebius strip puzzle, claimed as a symbol of the neurodiversity movement [see the Autism Self-Advocacy Network (ASAN, 2012)]. The pieces of this puzzle often come together in novel and unanticipated ways. This puzzle’s possibility lies not in being able to reproduce the image on a box, but in the uncertainty of what new figures might be generated from these surprise encounters, and what new awarenesses might be gleaned. And, to be sure, the puzzle I imagine is not finished...

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