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RESEARCH ARTICLE

## Neurodiversity and Communication Ethics: How Images of Autism Trouble Communication Ethics in the Global Age

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'What do the waves mean, son of mine?' says one father of an autistic boy, Jack, as he is filmed on a beach spinning around whilst flapping his hands at the waves of the sea.<sup>1</sup> The YouTube video, with its advocacy of Jack's neurodiversity<sup>2</sup>, arguably troubles or neuro-queers<sup>3</sup> the image within neurotypical human communication and surfaces some important questions for communication ethics in the global-digital or global age.<sup>4</sup>

Human communication and communication ethics are configured through a culture of 'normalcy'<sup>5</sup> which marginalises those with neurodivergent modalities of communication including autistic people.<sup>6</sup> One ethical response to this marginalisation and othering of autistic people is what Nick Walker terms 'neuroqueering'. Walker contends that neuroqueering involves creating artefacts that foreground neurodiversity including showing and using neurodivergent forms of communication which challenges or points to reinterpretations of neurotypical communication and culture. This article asks how and in what ways do digital artefacts, such as videos of and by autistic people made and shared through the affordances of the global age, neuroqueer the cultural history of troubled and troubling images of autistic people? To what extent do these images trouble neurotypical assumptions about the ethics of images and enrich and deepen understanding of communication ethics more broadly?

Building on research that has addressed the ways in which autism is represented in popular culture, in literature and in film<sup>7</sup>, this research examines autistic cultural assemblages<sup>8</sup> afforded by the global age. Empirically, I focus on analysing an assemblage of on-line videos by and about autistic people: self-advocacy YouTube videos made by and with autistic people,

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a campaign video made by the UK's National Autistic Society, and films as 'translations' of a nonverbal autistic world.<sup>9</sup> These, I argue, offer ethical arguments for understanding the sensorial, perceptual, cognitive and communicative diversity of human meaning making including recognising the significance of communication by and with the material world and non-human persons. The article begins by briefly outlining some key terms in relation to the study of autism.

## Neurodiversity and autism

Most people tend to understand autism through an inherited pathology paradigm that underlies historic definitions of autism and which has been central to a genealogy of troubled images of autistic people within popular culture. This article however is positioned within what is termed a neurodiversity paradigm which sees autism as a complex combination of characteristics, not yet fully understood, produced by an assemblage of neurological variations, differently articulated for the individual, that affect cognition, sensory perception, sensory processing and communication. As Nick Walker suggests:

*the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual's subjective experience more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.<sup>10</sup>*

Human neurodiversity, like differences in skin tone or eye colour, Walker argues, is a biological fact. Autism may be understood positively as part of expected human variations that include many kinds of neuro-divergences and that span infinite variations of neurocognitive functioning. In addition, what is known as the 'neurodiversity paradigm' recognises neurodiversity as natural and valuable and argues that the dominant belief that there is only one 'right' way of human neurological functioning is 'a culturally constructed fiction' with concomitant social dynamics that are then manifested in terms of social and economic power inequalities.<sup>11</sup>

Autism within this paradigm is viewed as having a complicated medical, social, *and* cultural and media history. As media theorists Amit Pinchevski and John Durham Peters argue, autism is a complex discursive constellation that includes:

*a domain of research, a genetic predisposition, a cultural trope, a hell for exhausted parents, a body of psychiatric knowledge, a self-declared identity, a small library of memoirs, a hot-bed of pet theories, and a cast of characters including the so-called refrigerator-mothers, Martians and machines.<sup>12</sup>*

Autism is thus an organic condition as well as a social disability that is discursively called forth by a diagnostic label as well as through the troubled images of people on the autism spectrum in popular culture. Pinchevski and Peters also point out that underlying the story of autism in new media is 'a lesson in social epistemology: the ways in which the social itself is discovered and becomes known – through media – by those previously excluded from the social'<sup>13</sup> They rightly remind us that in researching autism and the media it is important to remember the on-going anguish of families and people on the autism spectrum which is often forgotten amidst an increasing 'autism chic' that particularly values the high functioning autistic person over those with more profound differences.<sup>14</sup>

This research, from the perspective of cultural studies and communication ethics, builds on the work of Peters and Pinchevski to highlight how new kinds of mediated digital images of autism in the global age queer images of autism in medical discourse and popular culture and point to the complexity of the ethics of troubled images as well as troubling communication ethics more widely.

## (Un) Settling troubled images

To say that an image is troubled is to suggest it troubles the human in us or is troubling, and thus connotes human distress, affliction, difficulty, or need, as well as suggesting human agitation, unrest or disorder. The troubled image, then, may be one that is beset by ethical difficulties in that it depicts distress. A troubled image is not a happy one, or one that is calm, peaceful or at ease. The troubled image is also problematic in terms of what Michael Herzfeld terms 'cultural intimacy'.<sup>15</sup> The image suggests a history, a story, and a tragedy that remains disturbing, with a provenance that includes broken bonds, poor attachment, a lack of security.

Yet, that which is troubling or troubled may also be positive: troubling or troubled waters within Christianity indicates the healing presence of the divine.<sup>16</sup> Hence, the adjective 'troubled' within academic literature within cultural studies has frequently been positively paired with various aspects of human identity to disorder, reveal and bring together seemingly fixed categories or binaries: over the past twenty years there have been book titles that include *Gender Trouble* (Butler) *Race Trouble* (Durheim) *Male Trouble* (Walsh)) and *Identity Trouble* (Elliott).<sup>17</sup>

Images – more than words or sounds – are troubled and troubling in different ways and at different times. Troubled images are gendered: most patriarchal cultures symbolically annihilate crucial parts of the female anatomy such as the clitoris.<sup>18</sup> Religious texts particularly of monotheistic religions have long since forbidden or warned against aniconic images, or images of sentient beings, including God, humans or animals. Thus, Islam gives positive value to nonrepresentational images and patterns. Many indigenous cultures forbid images of human beings because once they die their image may cause contamination in some form between the spirit world and earth world.<sup>19</sup> At the same time, social conventions as to what is troubling will vary across time and space. Hence in the UK, US and Australia the advent of photography led in the 19<sup>th</sup> century practice of 'memento mori' – photographs taken of corpses, including children, often involving the corpse being dressed in their best clothes and propped up in life-like poses with the living.<sup>20</sup>

Historically, the particular medium of the image is ethically significant: in many cultures only certain people are permitted and trained to produce certain art forms.<sup>21</sup> Photography has long had anxieties associated with it: colonial discourse, according to Janet Hoskins, constructed indigenous cultures as troubled by Western photographic practices, contributing to the colonial view that indigenous people see photography as stealing the human being's soul or bodily fluids.<sup>22</sup> Like any 'new' medium digital images produced, saved and circulated through digital technologies and platforms are also constructed as troubling and troubled; yet perhaps it is not that digital images are troubling, but rather that they bring to critical attention the culture of normalcy that remains dominant in the ontology of communicative ethics.

## Ethics and images in the global age

Digital technologies are changing visibility and the visualisation of human beings: this begins with the sonographic imaging of the human foetus inside the female human's body

which is then shared ‘globally’ through social media to friends and family via social media platforms on line.<sup>23</sup> I use ‘global’, a neologism, combining the word global with bit (the smallest contiguous sequence of data) to suggest that we live in an awkwardly disarticulated epoch characterised by unevenly globalised connective digital technologies (infrastructures, devices, software as well as machinic and human practices). The global age, which may be seen to have emerged with connective and mobile media in the late 20<sup>th</sup> and early 21<sup>st</sup> century, is changing human communicative practices and with it the ethical frameworks that arose through and with the communications media of the previous epoch<sup>24</sup>

While images may be broadly understood as energy materialised into forms which may be preserved, copied and adapted, in the global age digitised connective images enable new kinds of affordances in terms of mutability, mobility, and sharing as well as storage, distribution and immersion. Images in the global age become assemblages unevenly mobilised across ‘the global memory field’ that includes local, national and transnational scales and multiple domains (the body, the home, the media, museums, archives, literature, state memorials). An image in the global age is far less discrete than in previous media epochs, attaching to other images more readily to become an element in a changing assemblage which is, at the same time, more easily detached from other images and its provenance. Images as part of a changing assemblage are mobilised and consolidated by agents: an autistic person or person on the autism spectrum, an organisation (the National Autistic Society), a corporation/platform (BBC, YouTube) through the global memory field. The field penetrates the human body (through digital medical imaging, security imaging) traverses the home, work and leisure spaces and extends into the wider universe through astrophysical technologies.

The ethics of troubled images then need to be understood through this 21<sup>st</sup> century context of the global-digital or ‘global’. The global age allows for new generations of data (including image) creation, preservation, sharing, and distributed archiving. Image assemblages have trajectories that continually destabilise legacy binaries – the organic and machinic, the individual and the collective, the private and the public, self and other. Images generated through mechanically produced sound and light waves penetrate the human body, as well as the planet, the atmosphere and wider solar system. Because of this there are ways in which they increasingly confound the conventional distinction within Western epistemology between human and the non-human (persons): media scholar, Joanna Zylińska argues, for example, that photography needs to be understood beyond the conventional human-centric view, since imaging practices no longer always involve human agency and nearly always involve algorithms that shape both the image and how we view it.<sup>25</sup>

Just as images need to be understood within the transformative and transforming context of the global-digital so too do communication ethics.<sup>26</sup> According to Charles Ess, digital media and particularly mobile and social media challenge established ethical ideas relating to privacy and copyright as well as violence and pornography.<sup>27</sup> The combination of the global with the digital is generating multiple cultural variations<sup>28</sup> and thus part of this variation, I argue here, concerns new kinds of challenges to the dominance of neurotypical culture and communication ethics through the generation of neurodiverse images. While the ethics of such images could, arguably, be understood within ethical arguments around cultural inclusion, the autistic assemblage goes further: the neurodiversity paradigm troubles communicative assumptions rooted in a view of human beings as uniform in terms of sensory processing, thinking, acting and communicating.<sup>29</sup> This points to the emergence of ethical practices that queer the dominance of neurotypical communication and thinking and that take us beyond a simplistic ethics of ‘acceptance’ and ‘inclusion’ of ‘people with autism’<sup>30</sup> and contributes to

the emergence of an ethics of communication informed by what Ralph Savarese has termed ‘neurocosmopolitanism’.<sup>31</sup>

## The troubled images of autism

Historically, medical discourse has generated, mobilised and secured powerful images of autistic people that have, in turn, informed images articulated within popular culture. The psychiatrist Leo Kanner in 1943 characterised autism in terms of ‘extreme autistic aloneness’ defined as social detachment, impaired language and the insistence on sameness with things and humans having equivalence. Kanner accompanied this troubled image of the autistic person with the idea that it was the coldness of the parents, especially the mother, whom he claimed, caused the condition.<sup>32</sup> According to Donvan and Zucker, this led to the image of the ‘refrigerator mother’ (never refrigerator father) of autistic children.<sup>33</sup> The psychiatrist Hans Asperger in 1944 simultaneously developed a blueprint of the autistic person as machine-like in referring to autistic children as ‘intelligent automata’.<sup>34</sup> This troubled image was further developed in the 1960s when Bruno Bettelheim characterised an autistic boy called Joey as a ‘mechanical boy’<sup>35</sup> consolidating the image in his subsequent studies *The Informed Heart*<sup>36</sup> and *The Empty Fortress*<sup>37</sup> in which he used the metaphor of a machine to describe autism.

The development of electronic media and early computers in the 1960s also led to these being used as metaphorical images to explain the neurology of autistic people. Thus Bernard Rimland in *Infantile Autism*<sup>38</sup> argued that the autistic brain is one of high fidelity but with a narrow bandwidth. Peter Vermeulin in *Autistic Thinking: This is the Title* uses the metaphor that the autistic brain is like a computer.<sup>39</sup>

Medical discourse was and still is rooted in gender bias equating boys with autism, which was also then conflated with gendered cognitive attributions. This fed into another troubled image by Simon Baron-Cohen and Jessica Hammer in which the different neurology of the autistic brain is characterised as an extreme form of ‘the male brain’<sup>40</sup> which suffers metaphorically from ‘mindblindness’ or not being able to see another’s view point.<sup>41</sup>

The metaphor of ‘blindness’ for autistic people is further mobilised in the work of Peter Vermeulen who argues that ‘high functioning’ autistic people have ‘context blindness’, which explains difficulties in translating one social situation to another, or translating social situations clumsily.<sup>42</sup> ‘Mind-blindness’ from this perspective accounts for differences between human social contexts, which human-centric and neurotypical norms value more highly than the significance of the nonhuman, material and environmental contexts.

Such medicalised images inform and are in dialogue with a history of troubled images of autistic people within popular culture. A study of popular images of children with autism in the 1960s and 2000s found that one recurrent image was of the autistic person as an automaton cut off from those around him (rarely her) which was in stark contrast to the narratives of people with autism and their families.<sup>43</sup> Popular culture is dominated by the image of the autistic savant such as Raymond in the film *Rain Man* or the ‘high functioning’ tortured genius WWII codebreaker Alan Turing in the film *The Imitation Game*. As Amit Pinchevski and John Durham Peters note

*The popular image of autism is clearly skewed toward the Aspergers part of the spectrum, neglecting the wide margins of the less glamorous, less functional, and more miserable variants.*<sup>44</sup>

Autistic people within popular culture are often associated with having particular strengths in terms of visual memory and visualisation. Thus in *The Rain Man* (1988) Raymond has a visual memory that means he is able to calculate at a glance how many toothpicks there are in a holder, and memorise all the numbers of the songs on a jukebox. This trope is central to Steve Silberman's observation in, *Neurotribes, The Legacy of Autism and How to Think Smarter About People Who think Differently*:

*All of my top debuggers have Asperger's Syndrome. They can hold hundreds of lines of code in their head as a visual image. They look for flaws in the pattern and that's where the bugs are' (Microsoft Supervisor).<sup>45</sup>*

This association of the autistic mind with visual memory is also something that some autistic people describe in memoirs and autobiographies, as in the work of Temple Grandin:

*So, what is thinking in pictures? It's literally movies in your head. My mind works like Google for images. Now, when I was a young kid I didn't know my thinking was different. I thought everybody thought in pictures. And then when I did my book, "Thinking in Pictures," I start interviewing people about how they think. And I was shocked to find out that my thinking was quite different. Like if I say, "Think about a church steeple" most people get this sort of generalized generic one. Now, maybe that's not true in this room, but it's going to be true in a lot of different places. I see only specific pictures. They flash up into my memory, just like Google for pictures. And in the movie, they've got a great scene in there where the word "shoe" is said, and a whole bunch of '50s and '60s shoes pop into my imagination"<sup>46</sup>*

In an autobiography by the Japanese autistic author Naoki Higashida – the then 13 year old boy – explains that he does not immediately do what he is asked to by a teacher or parent, not because he is 'slow' or being 'naughty' but because he must visualise what he must do first.<sup>47</sup>

Such accounts, however, raise the issue of whether this is the case for every autistic person. Autism is differently articulated within each individual and it may be that the visual is recognised because it resonates within a normative culture that prioritises and values the specular, sight and vision. Olga Bogdashina's recent work on sensory-perceptual issues in autism demonstrates how varied and variable these experiences are for autistic people: she points out that some people may experience the world visually 'in bits'; or they may have acute visual acuity.<sup>48</sup> Her work also points to those autistic people for whom sound or vibration or smell or touch is more critical. What about a neurology that remembers through scents or in textures that in some way may not be translatable within a global binary driven environment that reinforces the visual and the seen as opposed to the haptic, and the unseen world?<sup>49</sup>

At the same time, it is evident that the global age affords people with autism new opportunities in terms of image-led communication through handheld devices and software (tablets, phones, games, mobile apps). Consequently, computers are hailed by some advocates for people with autism as the equivalent of seeing-eye dogs for the blind,<sup>50</sup> and the Internet as the equivalent of Braille.<sup>51</sup> Yet, there is a key difference: most seeing people do not have a seeing-eye dog, but most human beings – even, increasingly, including the poorest on the planet – whether neurologically typical or divergent will have a huge amount of computing power at their finger tips and carried in their pocket or bag in the form of the mobile phone.<sup>52</sup> Neurodivergent people share the same tools as those who are neurotypical and they can also develop content 'artefacts' to queer images developed by and about autistic people in new ways.

## Neuroqueering images of autism

So, what new image assemblages are emerging with digital technologies within the context of an unevenly globalised digital culture? How do these images neuroqueer dominant troubled images of people with autism and wider established media and communication ethics? This section draws empirically on a public campaign by the National Autistic Society in the UK; a Ted Talk by an autistic woman, Rosie King and several films made by and about non-verbal autistic people broadcast on YouTube: *In My Language* by Amanda Baggs and *A Reflection of Aching Joy* by Jason Hagues, the father of Jack, a non-speaking autistic boy. These images neuroqueer communication ethics and the sensory body-self-mind; they unsettle the dominance of vision over sound and suggest the significance of other senses and the material world in culture; they invite us to question 'normalcy'; to consider a wider set of empathies; and to rethink image making and consuming as a collaborative process in which the image is part of a connected assemblage.

## Images communicating sensory neurodivergence

Digital images of and by autistic people queer communicative norms through valuing and recognising human divergence in sensory perception and cognition. An on-line campaign called 'Too Much Information' by the UK's National Autistic Society uses an autistic actor in a 2 D and a 3D Virtual Reality<sup>53</sup> to queer the neurotypical point of view to that of an autistic child who is experiencing sensory overload whilst on a shopping trip in an indoor shopping mall. The video, available on line, and additionally mobilised by powerful media corporations such as the BBC in the UK, is made from the first-person viewpoint of an eight year old autistic boy who experiences a frightening overload of smells, sounds, bright lights, colours, textures and movements of people and things to the point where his nervous system cannot cope anymore. The boy begins to hyperventilate and then have what is generally termed 'a meltdown'; in that moment the boy and his mother experience critical looks by other shoppers and passers-by. The video ends with him saying 'I am not naughty, I am autistic'. The film has had 6 million views since its release on line by September 2016.<sup>54</sup>

The VR video has been received very positively in terms of how it has been mobilised and the surrounding campaign supported by the BBC. Thus the 'Too Much Information' (TMI) video, which is on UK's National Autistic Campaign website, includes a supplementary 2 D video of a group that includes people with autism and their relatives who express their thoughts and feelings about the TMI campaign. The group is very supportive of the campaign and how it positions the viewer into experiencing what it feels like to have heightened sensory perception and cognition. The latter is something that the enduring image of autistic people as machine like ignores.

Sensory-perceptual neurodivergence is also articulated by Judy Endow, an activist artist and a non-speaking autistic woman. Endow creates art works, that she has put on line depicting the painfulness of the sensory input and overload arising from eye contact. Her on-line artistic works shows the creative advantages of autistic differences in visual acuity and hyper-perception. For example, some of her works include what she terms visual images of 'world tails' which she perceives around things and people. These inform not only her sensory perception but also inform her social interaction since the presence of others disturbs the perfection of the world tails.<sup>55</sup> Endow's work thus turns on its head the idea that sensory overload is wholly negative, rather it shows how it can inform the production of art works which then unsettle our established perceptions of the world and how humans interact.

## Images neuro-queer androcentrism

The second way in which on-line images neuroqueer is in terms of gender, with a growing number of on-line videos by women with autism that challenge the andro-centrism that has long troubled popular cultural images of autistic people. One body of work is by Rosie King who is already known through her work as an autistic child presenting on BBC Children's programmes. Her assemblage of online videos (along with other videos by female autistic people) neuroqueer the dominant image of autism as predominantly associated with men and boys. Rosie King's work along with other that of other women with autism, opens up a new image of the autistic person as female, creative and hugely imaginative unsettling the image of the autistic male maths genius or computer software engineer.

King's video neuroqueers the dominant popular cultural image of autistic people always having great powers of visual memory by showing a different version of this. Her skills are not eidetic, rather, her neurodivergence is in term of a hyper imagination:

*It's like I'm walking in two worlds most of the time. There's the real world, the world that we all share, and there's the world in my mind, and the world in my mind is often so much more real than the real world. Like, it's very easy for me to let my mind loose because I don't try and fit myself into a tiny little box. That's one of the best things about being autistic... , but having also to explain to a teacher on a daily basis that their lesson is inexplicably dull and you are secretly taking refuge in a world inside your head in which you are not in that lesson, that adds to your list of problems. (Laughter) Also, when my imagination takes hold, my body takes on a life of its own.<sup>56</sup>*

In addition, King's images decentre the human eye and eye contact. The viewer watches Rosie, who does not look at viewers or the live audience: yet in so doing the YouTube audience is positioned such that we too do not look each other in the eye rather we look at a human on a small screen sharing communication via an object. Rosie King's video, as with others by autistic people, thus points to the on-line decentred 'eye' rendered through screen based on-line communications in which it is normal and acceptable to communicate with no expected direct eye contact because these are via cameras and screens. Her work, as with others, thus queers the normalcy of the neurotypical person and the value given to eye contact in Western cultures.

## Neuroqueering verbal communication

Films by non-verbal or non-speaking autistic people offer a third powerful challenge to established communication norms. A film by Amanda Baggs, a non-verbal autistic person, not only shows something of her inner world, but also radically unsettles normative ethics and neurotypical assumptions and values about the meaning of images, the value given to verbal communication, as well as what it means to communicate, how to communicate and about what it is one as a human communicates.<sup>57</sup> 'In my Language' (2006) shows Amanda Baggs in continual dialogue with her material environment through body, gesture, vibration and sounds such as tapping and humming. She then communicates with the YouTube audience through typed words on screen:

*The first part of the video was in my native language. When I talk about this being in my language people assume this means that each part of the video must have a particular symbolic message within it designed for the human mind to interpret. But my language is not about*



*designing words or even visual symbols for people to interpret. It is about being in a constant conversation with every aspect of my environment. Reacting physically to all aspects of my surroundings. In this part of the video the water doesn't symbolize anything. I am just interacting with the water, as the water interacts with me.*<sup>58</sup>

Her work troubles the image within Western culture as a symbolic referent queering the indexicality and symbolic meaning of the language of images. Her language points to thought processes and sensorial experiences which value dialogical communication with the non-human environment. This suggests the development of a communication ethics informed more deeply by the insights of new materialism that decentre human beings as well as much older ideas within indigenous cultures that recognise how the world human beings have made as well as the natural world continually communicates with us. Bagg's work suggests that a communication ethics that only recognises the written and spoken language that human beings are capable of is in fact limited and narrow: it supports instead ethical ideas that give value to a much broader understanding of what it means to communicate including the ways in which the environment is in conversation with each human being and us with it. The image then through this video is reframed as always in a sense troubled or rather troubling since it technically and socially structures into irrelevance so much that is also present in the world.<sup>59</sup>

The video made by Amanda Baggs is echoed by a short, beautiful film by Jason Hague – *A Reflection of Aching Joy*.<sup>60</sup> The Facebook version of the video went 'global' and within 4 days had 1 million views.<sup>61</sup> The film shows an autistic non-speaking boy called Jack. He is on a beach communicating with the waves as Jason Hague his father recites his poem:

What do the waves mean, son of mine?  
I watch you flap your hands  
In sines and in cosines,  
Over shapes and colors sending shocks of sheer delight.  
We've tried to flap them with you,  
But the magic eludes us,  
Our experience excludes us,  
From the poems of your palms  
And the fables of your fingertips.<sup>62</sup>

The video positions Jason the father and the viewer as excluded from something magical – another realm of the world and meaning that Jack but not the neurotypical person can access. The video unsettles the imaginary that the internet and new technologies are like braille to the blind to the person with autism. Instead, Jason Hague's work queers the idea of language itself and questions the assumption that autistic people should be given a voice, asking 'I knew I had the power to give Jack a voice. But would that be right? Would that be (dare I ask of a children's bedtime story) ethical?' Further on, having filmed his son by the sea, humming and waving his hands in continual communication with the waves and wind, Jason Hague says:

*Autism is not a disease. It is, for better or for worse, a part of who Jack is. But is it all of who he is? Would the removal of symptoms constitute a fundamental change in personhood? And if so, doesn't that get us right back where we started before the awareness campaigns began? Wouldn't it mean we are once again defining our beloved children by the things they cannot do?*<sup>63</sup>

Hague's film is very thoughtfully produced, although, arguably, there is still the significant ethical issue of informed consent since his son is unable to this.

While consent to make and publicly share a video made with good intent and with such care is perhaps less worrying, the issue of consent acutely troubles another genre of on-line videos of autistic people. These are videos made by parents of an autistic children and uploaded to YouTube that seek to share with a neurotypical public the severity of the life of an autistic child in their care. Such videos bear witness to children having meltdowns, hurting themselves, being restrained and having seizures. Perhaps, there are arguably a number of justifications that could be given by parents for filming and uploading videos of their child in this way. They document the private and personal challenges for autistic people and their families; they enable the neurotypical and ignorant to witness the usually unseen anguish and grind of everyday family life with an autistic person; they provide new kinds of evidence for carers to advocate for resources for the autistic person, perhaps assisting in what is an on-going struggle of accessing support and resources from educational, health and social services.

Yet, although such documentary videos might show how challenging life can be for a person with autism and their family, often times the films I viewed are made with the deliberate intent of shaming, disciplining and humiliating young people with autism. Autistic self-advocates such as Fablebird on a forum called *The Wrong Planet* (written by people with autism) points out:

*autistic people cannot control themselves during a meltdown, and therefore consenting to being filmed is ludicrous. We can't consent. You're just humiliating us by showing the world us at our most vulnerable. We didn't even choose to have a meltdown in the first place; we aren't tantrumming toddlers doing it on purpose. You're taking advantage of us--you're pity-mongering. Classic ableism.*<sup>64</sup>

Such videos point to the question of whether such images of autistic people unsettle the idea of the image itself within the concept of visual culture disrupting the usually taken for granted socio-cultural dimensions of what Hal Foster has termed 'visuality'.<sup>65</sup> Visuality as Karin Becker and Paul Frosh argue depends on 'a discursively ordered ecology of corporal sensing agencies: our sight, hearing, touch, taste, smell, proprioception and vestibular senses are given meaning through and by a framework of neurotypical normalcy'.<sup>66</sup> As Asko Lemuskallio suggests, visual studies and the analysis of images is biased towards those with average eyesight which neglects differences in seeing<sup>67</sup> as well as diversity in visual processing. Such videos produce a sense of semantic visual friction in the slippage between the visual medium and neurotypical visuality: the hidden assumption of normalcy underpinning communicative ethics is queered through the contradiction of sharing images of an autistic person without consent. In the ethical chasm, perhaps, if we are feeling optimistic, we might argue that there are then the seeds for growth of a neurodiverse communicative ecology.

## The autistic assemblage: concluding remarks

This article argues that on-line assemblages of images of and by autistic people neuroqueer, in a number of ways, the genealogy of images of autism and trouble communication ethics in important ways. First, on-line images by and of autistic people allow for more heterogenous assemblage of stories/images, as well as new insights that decentre the dominance of neurotypical cultures. Videos by women with autism, for example, unsettle androcentric bias. Self-advocacy videos enabled through digital technologies such as Amythst Schaber's *Ask an Autistic* YouTube channel<sup>68</sup> contributes to the self-awareness and self-development of neurodivergent people enabling the sense of a connected community for people with autism. Along with this, projects such as Exeter University's Mobile App 'Brain in Hand' for autistic

people enable greater independence for people with autism, as well as a wider network of support for families.<sup>69</sup>

However, this analysis of images of and by autistic people in the global age also point to evident vulnerabilities for autistic people and their families. Images of autistic people can become over determined: brain scans and MRI imaging penetrates the body/brain turning the person inside out, resulting in a colonisation of the neurodivergent human with new kinds typologies and ‘cures’. Virtual reality 3 D imaging/first person videos might be said to conflate images with autistic reality, suggesting – wrongly – that the varied autistic experience is ‘knowable’ through images and new technology. Further, the videos examined here do not eliminate the on-going inequality between those who are defined as ‘High Functioning Autistic’ people, largely those who are verbal or speaking and those without access to neurotypical written and spoken languages.<sup>70</sup>

There is also, as noted, the question of consent for autistic children filmed by parents. And, at the same time, there is the danger that the apparent confidence of some self-advocacy videos by high functioning autistic children and adults reinforces the erroneous idea that somehow ‘we are all a bit autistic’ or ‘on the spectrum’ because such videos can obscure as much as they reveal about the daily challenges, loneliness, pain and discrimination against autistic people and their families.

Nonetheless, assemblages produced by non-speaking autistic people such as Amanda Baggs positively trouble or neuroqueer the ethics of the image in the global age. Baggs’s work challenges the ‘normative ideal’ of speech-centred communication and highlights the frictions of visuality. She reminds us that all images are in fact troubled: they unsettle our being in the world because they too are a translation of what it is that they do not show. Amanda Baggs conversations with her environment, with the air, water and objects around her point to the ethical significance of the human-made material world, as well as the non-human material environment of the earth. Such assemblages value forms of communication that amplify and celebrate a diverse perceptual range of ‘sensoralities’ beyond the visual and sight moving communication ethics towards what Ralph Savarese terms neurocosmopolitanism.<sup>71</sup> Focussing on the ethics of images of autistic people also resonates with the insights of new materialism and with non-Western perspectives within communication and cultural studies. The autistic assemblage points to wider struggles such as those by indigenous people to gain recognition for the voices, songs and memories of the natural environment including mountains, rivers and trees.<sup>72</sup>

The global age mobilises new kinds of images of people with autism, to neuroqueer images of autism as a biological, social and political identity and enriches and gives value to aspects of communication ethics in troubling ways. Images of and by autistic people challenge what we know, what we can know and how we know it: they show how language and knowing are both framed by and yet escape the image as a continual conversation, as an interchange of hitherto hidden dimensions involving an acuity of vibrant ‘sensoralities’ beyond the word, beyond the image, beyond ourselves.

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## Notes

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7. Stuart Murray, *Representing Autism, Culture Narrative Fascination*. Liverpool: Liverpool University Press. 2008; See also Mark Osteen (ed) *Autism and Representation*. London: Routledge, 2009.
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47. Naoki Higashida - *The Reason I Jump: one boy's voice from the silence of autism* 2013. For other people who are autistic the reason they may not respond immediately is to piece together fragmented or disordered perceptions through the other (ie no visual) senses. See Olga Bogdashina *Sensory Perceptual Issues in Autism and Asperger Syndrome: Different Sensory Experiences – Different Perceptual Worlds*. Jessica Kingsley Publishers. 2016



48. Olga Bogdashina *Sensory Perceptual Issues in Autism and Asperger Syndrome: Different Sensory Experiences – Different Perceptual Worlds*. Jessica Kingsley Publishers. 2016
49. Research on sensory processing also suggests how our seven senses, auditory, tactile, vestibular (sense of movement and gravitational information), visual, proprioception (Sense of body position, force, speed, control), olfactory and gustatory may not only vary within individuals on the autistic spectrum but that these can vary according to a range of other contingencies such as time of day and the environment. For a brief overview of research in this area see Roseanne C Schaaf and Lucy Jane Miller. 'Occupational Therapy Using a Sensory Approach for Children with Developmental Disabilities. *Developmental Disabilities Review*. Vol. 11. Issue 2 pp. 143-148. 2005.
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52. Amit Pinchevski and John Durham Peters, Op Cit. p.12)
53. Too Much Information Campaign Video. Autism 3 D Virtual Reality Video: <https://www.autism.org.uk/vr>
54. 2 D version of Too Much Information Campaign Video. UK National Autistic Society < [https://youtu.be/Lr4\\_dOorquQ](https://youtu.be/Lr4_dOorquQ). There are a number of videos available as part of this overall campaign which are changed regularly. There are other first person accounts which also show sensory overload in this way. See for example, "Carly's Café" : Carly Fleischman <<https://www.youtube.com/watch?v=KmDGvquzn2k>>
55. Judy Endow <<https://ollibean.com/eye-contact-autistic-dissociation-one-example>>
56. Rosie King 'How autism freed me to be myself' <[https://www.ted.com/talks/rosie\\_king\\_how\\_autism\\_freed\\_me\\_to\\_be\\_myself](https://www.ted.com/talks/rosie_king_how_autism_freed_me_to_be_myself)>. There are a number of related videos of Rosie King including one from when she was a child and one as she moves to University.
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58. Amanda Baggs 'In My Own Language' <<https://www.youtube.com/watch?v=Jny1M1h12jc>>.
59. The cultural theorist Eviatar Zerubavel *Hidden in Plain Sight: The Social Structure of Irrelevance* Oxford: University of Oxford. 2014. suggests that people with autism have an attentional style, a different way of processing information which highlights that what we see, give meaning to and attention is a matter of convention.
60. Jason Hague 'A Reflection of Aching Joy'. <[https://www.youtube.com/watch?v=-sY1o\\_Q3g3w](https://www.youtube.com/watch?v=-sY1o_Q3g3w)>
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62. Ibid
63. Ibid
64. Fablebird. The Wrong Planet. Parents Filming Meltdowns.. 30 Jan 2015, 3:58 pm <<https://wrongplanet.net/forums/viewtopic.php?t=275598>>
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68. Amythyst Schaber Ask an Autistic #1 - What is Stimming? <<https://www.youtube.com/watch?v=WexCWZPJE6A&t=24s>>
69. See Braininhand <http://braininhand.co.uk/>. This is an app using a traffic light support system for people with autism developed by the University of Exeter, UK.
70. Pinchevski and Peters. Op Cit.
71. Savarese. Op Cit.
72. A Maori tribe the Whanganhui in New Zealand after 140 years of struggle won non-human rights for the Te Awa Tupua River which means that it must be treated as a living entity with its own legal identity that includes corresponding rights, duties and liabilities of a person. Eleanor Ainge Roy 'New Zealand River Granted Same Legal Rights as a Human Being'. <<https://www.theguardian.com/world/2017/mar/16/new-zealand-river-granted-same-legal-rights-as-human-being>>