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The biopolitics of autism at the airport

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Introduction

What happens when autism is claimed in public spaces? What does it give and take away? In this chapter, we explore the “Sunflower Lanyard Scheme” as one example of claiming autism in public spaces. The lanyard system operates in places such as airports to alert fellow passengers and staff that the wearer has the label of disability. The lanyard ‘outs’ the person in relation to autism. Frequently, the scheme is used by people who attract or claim the label of autism. In the airport, security concerns mean that the crush of normalcy weighs heavily on all passengers. The risks associated with failing to observe the tacit and explicit rules associated with airport behaviour might be mitigated by the use of the lanyard. The Sunflower Lanyard Scheme seeks to protect people with ‘invisible disabilities’ from these risks. Wearing the lanyard identifies a passenger as someone in need of ‘help’ but also as someone who may not conform to ‘normal’ social rules. Lanyard wearers are able to use fast-track check-in lanes and go to the front of the passport control queue.

In this chapter we consider the biopolitical work of such schemes in terms of what they give but, at the same time, what they might take away from (all) human beings. We provide a story of lanyard-use in an airport and an account of a conversational exchange between the authors that was provoked by the story. We then pull in a biopolitical reading of the narrative. Often, we argue, biopolitics is drawn upon to make sure of the regulatory effects of discourses. While this is certainly the case, we argue that there is more to biopolitics than regulation; and we unpack the affirmative and excessive effects of biopolitics. This inevitably leads us to consider the biopolitics of not simply autism, but life itself. So, as we contemplate autism, we are contemplating what it means to be human.

An (autism) story

Dan: How was your holiday, KRC? Did you all have a good time?

Katherine (or KRC to her mates): Yeah, good thanks, lovely weather, great food and just nice to spend time together as a family. Ooh, and did I tell you, we used the sunflower lanyard system at the airport for the first time?

Dan: The what?

Katherine: Oh, they've got this system where you go to the special assistance desk, tell them that you are travelling with someone with a hidden disability and they give you a lanyard with sunflowers on it. It means you don't need to queue for check-in and staff are all aware that you might need a bit of extra help or time, you know. Anyway, on the way back there was a massive queue at passport control, and I thought 'Oh no, we can't do that queue' so I just said to one of the staff: 'My son has a lanyard, he's au …'

Dan: You said what?

Katherine: You know, he has a lanyard …

Dan: [mischievously] Come on, let me hear you say it!

Katherine: [with a defiant tone] What?

Dan: You know!

Katherine: [reluctantly] I said 'he's autistic …'

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We are friends and colleagues who have written in the field of critical disability studies for several years. In between conversations about work, you might expect us to talk about our kids (not really kids, all quite grown up, but still kids to us). As the story above illustrates, there is no clear dividing line between conversations about ‘work’ and conversations about ‘family’. A casual question about a holiday and we quickly stumble into yet another conversation about disability theory. Katherine has written elsewhere about her reluctance to engage with diagnostic labels in her (now grown-up) children’s lives (17Runswick-Cole, 2017). She has pondered the meaning of the category of autism and the limits of labelling. And now she reveals, albeit reluctantly, that there, at the end of a queue, she invoked the category of autism to smooth the family’s passage through the airport. In this chapter, we try to unravel the biopolitics of autism embedded within this story and how these discussions are entangled with questions of the human.

Sitpoints

So, we began this chapter with a story set in a very specific location – an airport in the UK – because it ignited another discussion about autism and how these reflections are always entangled with questions of the human. It is fair to say that we are wrestling with the concept of autism, as our interaction reveals. Perhaps the idea of wrestling is too aggressive. It also conjures up images of us in Lycra. Never good. Perhaps, on reflection, we are learning to sit with autism. This latter phrasing of our predicament resonates with a paper written by the critical disability studies and feminist scholar 7Garland-Thomson (2002) in what is now a classic in the field.

Her argument for a *sitpoint theory* of disabled feminism is an intervention into the non-disabled feminist literature that has emphasised – and continues to emphasise –

the importance of standpoint. Clearly, standpoint automatically excludes those feminists who don't do standing and Garland-Thomson is at pains to make this exclusion crystal clear through the deployment of her new term, 'sitpoint', which has in mind people who use a wheelchair. But there is a lot more going on in her argument than simply a need to change the terms of reference.

Instead, what she does so well in her paper is to remind feminist orthodoxies that disabled women have a lot to offer in not only furthering feminist analysis but also couching these insights in new nuanced ways that are demanded by the disabled body. Sitting with ideas, then, is firmly locating oneself in a critical disability studies paradigm. This approach, as we have argued elsewhere, starts with disability but never ends with it (8Goodley, 2013). Disability provides – just as the sitting feminist philosopher embodies – new insights, perspectives and philosophies for thinking about the human condition.

In this chapter, then, we seek to ask some very human questions. We have provided you with an exchange between the two of us and the background narrative. Both the story and the interaction are very human encounters. Behind the voicing of ideas, the demands for an answer and the troubled response lie some very affective moments. We did not partake in the conversation in a dispassionate manner. Underlying our chat are deeply held feelings, anxieties, concerns and confusions. Autism, as a phenomenon, is deeply affective. To borrow from another fab feminist 1Ahmed (2004): autism has created a whole host of affect economies. How we come to know autism – like any cultural phenomenon – is through the various circulations of knowledge, economic marketplaces and associated communities of various purveyors of this phenomenon.

People love and hate autism. Autism gives joy and, at other times, is felt as pain. Autism becomes taken up in various communities, from autistic activists to autism specialists, autism professionals, autism practitioners, autism consumers, autism producers and autism researchers. And simply dipping one's toe into this swirling hermeneutic whirlpool we are in danger of being plunged into turbulent waters. Sitting with autism allows us a moment to pause; to consider the kinds of emotions that this phenomenon generates and, by extension, the kinds of affective attachments that it provides. There is no doubt that autism generates feelings of joy, relief and a sense of belonging. The autistic activists represented in this text will convey the potency and potential of autism as a political category and as a pathway into forms of accommodation and inclusion. We know that these affiliations are heartfelt.

But we also know that, for some, autism engenders negative affect. This is especially the case when there is a sense that autism reduces a person to whom it is applied, which has inspired a range of critical approaches to autism, not least in relation to the reclaiming and reconstitution of the very meaning of this phenomenon by activists and their families. We are all more than the categories that are laden on to us. And when one category threatens to dominate a self then that can engender feelings of sadness, anger or disillusionment. Clearly, autism as a phenomenon has cut straight to the emotional hearts of many of us. So, we need to be very careful with others and ourselves when we feel and think about autism.

The biopolitics of autism: a negative reading

We hope that a biopolitical reading of our story may help us to feel and think more carefully about autism. We follow 3Berlant (2006) in understanding biopower as a force which has the power to determine whether something lives or dies; it is a regulatory force which demands that living or dying occur in prescribed ways. Let us introduce Rabinow and Rose's (2006) conception of biopower and relate this to autism:

1. One or more truth discourses about the 'vital' character of living human beings with an array of authorities considered competent to speak that truth (for example, autism as a neurological fact described through neuropsychology)
2. Strategies for intervention upon collective existence in the name of life and health (diagnosis and educational intervention in relation to autistic children)
3. Modes of subjectification, in which individuals work on themselves in the name of individual or collective life or health (autistic people, their families and a panoply of professionals that work around them internalise the category of autism)

This reading of biopower is fairly standard and standardised in social science analyses (especially of a poststructuralist persuasion). The story goes that we come to know life itself through the regulatory workings of biopolitics. Hence, as discourses circle around a phenomenon, they come to constitute that phenomenon. And discourses do not merely emerge as if by magic. They are created and recreated through modes of reproduction tied to powerful institutions, experts, practitioner communities and policy priorities. So, to take one example, autism becomes known through psychological and psychiatric discourses which, in turn, shape the very ways in which autism is known and then understood by people so labelled and those around them. Psychological and psychiatric discourses speak with authority about the vital character of human beings. And various educational, health and social care policies flock to attend to this vitalised phenomenon.

Before long, of course, participants in this biopolitical milieu come to know themselves and others, in part through the vitalist language of autism. And this happens not simply in places that are directly affected by policy – such as hospitals and schools – but also in everyday and mundane encounters; in life itself. We know that ‘on the spectrum’ has become a part of everyday parlance. And we know that autism is a powerful ubiquitous cultural trope found in many parts of the world. This reading of biopolitics is helpful in terms of making sense of how categories of the human come to be constituted, known, tendered, applied and used.

Reading autism as biopolitical also permits us to challenge some of the more naively essentialist readings of autism that often masquerade as common-sense and are documented in various iterations of the *Diagnostic and Statistical Manual for Mental Health Disorders* (American Psychiatric Association, 2013). But, where this reading is problematic is when it creates a wholly regulatory reading of autism: as nothing more than a creation of discourse, authority and subjectification. This is a clinical reading of biopower. There is little here to gain for those who feel the joy of autism’s promise, the contentment in self-identification, the possibilities of access prompted by its appearance in social settings.

One might read Katherine’s reluctance to identify her son with a label, other than his name, as her struggling with the regulatory framing of her son; that he is nothing more than an outcome, a product, a consequence of the biopolitical autistic machine. Many of us struggle with regulations and rules. And one of the joys of the human condition is our apparent tendency to break the rules. Indeed, the standard use of the biopolitical narrative seems at odds with more resistant tendencies of human beings. This is not to say that we can exist outside of discourse or biopower. Katherine's well documented attempts (17Runswick-Cole, 2017) to sit without autism feel futile; her refusal to name autism does not mean that she can sit without it; even in the refusal to name it there is an engagement with the category. We are both fairly compliant students of Foucault in this regard: we understand the human condition as a condition constituted through the circulating effects of discourse and the subjectifying effects of biopower. But we think there is more room for play, movement and possibility in the biopolitical. And this leads us to a more affirmative reading of the biopolitics of autism.

The biopolitics of autism: an affirmative reading

Autism is a biopolitical category that cannot help but reproduce itself in infinite, ever-changing and ever-morphing ways (9Goodley, 2017). If biopolitics constitutes life itself, then autism's constitution is also tied up with the constitution of life itself. For us, any discussion of the category of autism must engage with the simultaneous study of the category of the human. To consider the biopolitics of autism in isolation from a discussion of the biopolitics of the human would be, for us, a mistake, and a dangerous one at that. To distinguish autism from humanity is not only a separatist and disabling act but also ignores the assertion that life itself is always biopolitical (16Rose, 2001). That is to say, how we come to be or become human is always constituted through the generative effects of the workings of biopower.

So, just as autism is diagnosed, it releases a tidal wave of biopolitical possibilities. This reading of biopolitics is in keeping with more affirmative readings which emphasise the generative excesses of biopolitics. Key thinkers here include 10Hardt and Negri (2000) whose ideas around their concept of Empire sought to understand some of the possibilities that emerge from the globalisation of biopolitics. Their work attends to the biopolitical excesses that are produced through globalisation, economic expansion of late capitalism, rapid developments in digital communication and big data and the resultant impact of this globalised biopower (or Empire) on the subjectivities of global citizens.

Autism is in demand (12Mallett and Runswick-Cole, 2012; 142017). A host of products, interventions and training and education services branded as ‘autism-specific’ are available for consumption; there is a multimillion-pound autism industry, which many of us, including contributors to this volume, are critical of, while at the same time being beneficiaries of the commodification of autism simply by writing this chapter (12Mallett and Runswick-Cole, 2012).

In the story at the airport, autism is also in demand, not as a commodity, but as a category which makes it possible for requests to be made of the airport staff. As we’ve seen before, the category of autism has a hyper-functionality in the context of an airport removing the need to queue at passport control, taking away at least one aspect of the more general inaccessibility of airports (13Mallett and Runswick-Cole, 2016). Once the category is offered, and, in this story, confirmed by the presence of the lanyard, the airport staff remove the barrier and accompany the family to the front of the queue. By offering the diagnosis, Katherine expects the staff to perform differently. As 6Ebben (2020) argues, this type of information exchange is not driven by commodification but by performativity.

Our story is but one example of the biopolitical excesses of autism. There is a pre-existing shorthand set of rules and expectations, collections of already known instructions associated with responding to people with autism. And yet, while the airport staff must perform the role of (literal and metaphorical) barrier removers, one family member must wear the lanyard, and while some people may wear the lanyard with pride and experience the relief it delivers, in this story, Katherine feels constrained by biopower as the force which requires her to perform gratitude, with a faint whiff of embarrassment, as they are ushered past the queue of jet-lagged, grumpy travellers. All eyes are upon the family and silently questioning why *that* family is now at the front of the queue. Here, again, the biopolitics of autism gives with one hand (promoting reasonable adjustment) and takes with the other (introducing a particular kind of known difference). Even in the affirmative excesses of the biopolitical constitution of autism (missing the queues) there are also the negative undertones (found in the stares of the strangers).

And when we turn to the information about the origins and purpose of the lanyard to be found on the Hidden Disabilities web page, we find these biopolitical tensions written through the explanatory text:

> The Hidden Disabilities Sunflower Lanyard originated in 2016 when London Gatwick Airport asked "How can we recognise that one of our passengers may have a non-obvious disability?" The answer was to create a lanyard with a simple sunflower design on a green background. It was intended to be a subtle but visible sign enabling airport staff to recognise that the wearer (or someone with them) may require some extra help, time or assistance when moving through the airport.
>
> (Hidden Disabilities, no date)

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The question ‘How can we recognise that one of our passengers may have a non-obvious disability?’ reveals the desire of staff at the airport to ‘know’ who does and, by implication, who does not, have ‘a non-obvious disability’. This, of course, begs several questions, not least, what ‘an obvious disability’ might look like? And why do staff need to know a person’s impairment status before help is offered? After all, staff could offer assistance to anyone who seems to require it. And yet biopolitics demands that we establish the ‘truth discourse’ about a disabled person before help is offered – does the person *really have* autism understood as a neurological fact described through neuropsychology (and fit with the culturally dominant ways in which autism comes to be known)? Only then can the intervention, or ‘the help’, be offered and individuals, and in this case the family, must gratefully subject themselves to the help offered to a lanyard wearer and put up with the gaze of the other passengers (for their own good and for the good of those around them). The lanyard removes the discomfort expressed by the airport staff who are not sure whether the passenger has a hidden disability, but the price for this reassurance, as we’ve seen, comes at a cost to the lanyard wearer who must work on themselves to perform disability in ways that can be ‘known’ to the staff at the airport. The queues are avoided, but so is any wider thought or engagement as to how these spaces can be made more accessible for all passengers.

The website goes on to explain the origins of the sunflower motif; it was chosen to suggest “happiness, positivity and strength” (Hidden Disabilities, no date) but this affirmative framing is undermined by the description of the lanyard as allowing a person “to be subtly visible when they need to be” (Hidden Disabilities, no date). Having a hidden disability is not, then, a matter of pride; it is something only to be “visible” *when necessary*, in other words, when it is necessary to satisfy the airport staff's need to know who has (and who does not have) a hidden disability and is legitimately in need of help.

Despite her well-rehearsed resistance to labelling, Katherine offered the category of autism in exchange for the benefits of the sunflower lanyard. She knew the risks of engaging with the discourse, but she also knew the risks of not doing so. The airport is a place where the crush of normalcy (5Davis, 1995) is keenly felt by all travellers. As we queue up at security, many of us feel cowed by the need to behave 'normally', not to attract attention to ourselves and to stick closely to the social conventions of the airport in an unfamiliar and busy environment. Many of us find the experience of travel – and the space of the airport – to be an overwhelming experience. Dan is typically known to check on his passport at least 17 times even before he has got to the departure gate! A failure to perform normalcy at the airport carries risks – being questioned, subjected to further searches or being stopped from boarding a fight. These risks are heightened for anyone who does not know, or struggles to follow, the rules.

And here is the conflictual position that Katherine grapples with – of being in use of autism's biopolitical framing while also being simultaneously negatively affected by its potential to other her son and her family. Hence, to read biopolitics is not to seek an either/or – a binarisation – of the phenomenon, but to consider the parallel play of positive and negative affective consequences that are constituted as soon as the biopolitics of autism are enacted.

This holding of tensions and a non-binarised contemplation of biopolitics is commensurate with an affirmative ethics, analysis and politics articulated by 4Braidotti (2018). She argues for a form of awareness that attends to the *actual* "both what we are and what we are ceasing to be", and the *virtual* "that is to say, what we are capable of becoming" (32). The actual, in our story, refers to the use of the lanyard, the walk past the queues and the stares from the bystanders. The virtual is the conversation between Katherine and Dan; Katherine's reluctance to know her son *as autism*, the desire to seek other ways of being and becoming and Dan's questions about the excesses of autism: what does a biopolitics of autism give and take away? No one escapes biopolitics. A life without biopolitics is not a life at all. But in the debate about biopolitics of autism we query the kinds of life we want to value and the troubles of the kinds of life that are valued and devalued through biopolitics. Braidotti (2018: 34) writes "we are ontologically oriented towards the affirmation of our innermost freedom – the freedom to become all we are capable of, all our bodies can take" (34). In asserting this she is not denying the realities of biopolitics. What Braidotti is demanding us to consider are the kinds of freedoms we are desiring to create with one another in the world.

We want to consider, then, the constraints and the possibilities that are offered by a biopolitics of autism (especially those associated with dominant bio-psychological constructions of the phenomenon). But we are also raising questions about life itself. There is more to Katherine's son than a lanyard and, equally, there is more to autism than easy social scripts. One of the gifts of autism is that it raises more general questions about life itself and therefore, by extensions, questions about the human condition. Autism is but one actual and virtual intervention into a wider inquiry about the human condition.

Autism gives and takes away. Autism offers and holds back. And the human condition is always in the midst of this interplay between the actual and the virtual. What we are and what we might become. Our sense of being and possible becomings. Our knowledge of our past and our present. Holidays end. Flights arrive. Lanyards are taken off. Conversations are never-ending. And this sense of the endless becomings – in this case, as we contemplate autism and then human – should be kept in mind. We are always, endlessly, infinitely constituted, shaped, reconstituted, reshaped in the biopolitics of life itself. And this dynamism which we effortlessly apply to the human condition should also be applied to any contemplation of autism.

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