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Outside the ethical parameters: Exclusion and connection for an autistic anthropologist

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Abstract

Is it possible to do an ethnography on ASD (Autism Spectrum Disorder) without consulting a spectrum of autistic people? The limitations structural exclusion of autistic voices place on anthropological knowledges are highlighted in this proudly autistic autoethnography. In analysing the systematic mundane exclusion of autistic people in academia and beyond, alongside the joy felt in neurodivergent connection, 'ethical' exclusion of potential autistic participants is challenged. Embodied more-than-words, following SEN-based recommendations, are expressed through paintings.

Introduction

I was diagnosed with ASD (Autism Spectrum Disorder, henceforth referred to as autism) at 18. I'd reached a point in my life where masking ("the suppression of aspects of self and identity… to avoid stigma associated with negative stereotypes of autistic people" (Miller et al. 2021: 331)) to fit in with neurotypical (for the purposes of this ethnography, neurotypical means non-neurodivergent, where 'neurodivergence' includes neurodevelopmental (Miller 2021: 332) disabilities such as autism or ADHD) peers had had a traumatic effect upon me. This diagnosis brought relief in validating the vast number of ways I did not 'fit in' (Moore et al. 2022: 422), but as with many other autistic people, I quickly fell into grief for the life I 'should' have had (Miller et al. 2021: 333). There was nothing 'wrong' with me, yet I was the one who had to suffer for all the ways in which the neurotypical-dominant society around me could not accept my autistic way of being (Sutton 2021: 677). Hopelessness and burning anger became my mantra, but at some point, I had to accept there was nothing I could do. This would be my life.

https://doi.org/10.15664/eej.v13.i0.2922

'neurotypical-dominant society around me could not accept my autistic way of being'

Two years later, at the beginning of my fieldwork, I aimed to uncover the effects of my masking-induced internal shame. Instead, I found an intricate web of exclusion, in both academic and public spheres, which shamed and silenced autistic ways of being and the people who embodied them. Opening my sensory and emotional self to this amplified ever repressed feeling I had been ignoring since that gradual acceptance years ago. I found the wounds just as raw as before, only now with the knowledge that I would need to bleed them dry to write an ethnography worth the pain. It was in the process of peeling back the scabs that I found the true value of my ethnography: neurodivergent connection as a path to individual and communal healing.

The main section of this ethnography will be split in two halves: analysis of my autistic experience of exclusion in both the wider public world and the academic sphere, and of inclusion in a neurodivergent space. My own artwork is included as depiction of my emotional and sensory states where words fall short, and as an accessibility tool for neurodivergent readers following Sutton's suggestions of a SEN-based (Special Educational Needs) approach to ethnography (Sutton 2021: 685-686).

Exclusion

An autoethnography is not what I wanted to do. I had wanted to do a standard, interview-based ethnography with other autistic students. Unfortunately, I was told that as autism is a protected characteristic as a disability (Equality Act 2010: 5), that project would be outside the ethical parameters. I could not safely and responsibly ask autistic people to participate in my ethnography. I could, however, be involved myself, and so this autoethnography was born. On the surface, this is reasonable and logical - how could I argue against protection for my own neurotype?

Over the course of my fieldwork, I was able to realise that the upset I was feeling as a result was not to do with my inability to carry out that project. It was to do with the reasoning behind the rejection. I was visiting my parents over a short break in my studies, and one conversation with my mum gave me my answer. We had been discussing my therapy, the surface-level aspects, when I mentioned that I took the bus to and from my therapist. She let out a short gasp, a laugh, and made some jest about how she never would have believed it. Right then, I felt all my confidence leave me. I had hated taking the bus before, as it triggered all of my autistic sensitivities in one fell swoop: lights, noise, people, the specific 'rules' of when to say thank you or take your ticket or sit down or press the stop button, an endless string of stressors that I gladly did without. I am proud I no longer find it so intimidating, even though the same environment exists, because now I am confident and loud in my autistic self. I am able to accept and enjoy the reactions I have and the accommodations I need (such as headphones and stimming) in that environment, instead of worrying over how others will see me, or shame of my inability to passively accept such stimuli. My mum did not see that. To her, my autism was not the chaotic, charmingly weird, and deeply considerate part of me that I see it as. It was instead the quietness, the awkwardness, the incapability of a child who does not understand how to be. As my mum, she will always view me as her child, yet her view of my autistic self as incapable and dependent was not purely from our personal relationship. I asked a few people I knew what their perception of autism was, as a way to challenge my own perception, and one answer I received gave me both joy and desperate sadness.

“The incapability to socialise.”

It was the perfect response, a precise summary of what I knew I would find. Incapability. Because neurodivergence is identified in terms of difference in behaviour and thought, “deficit-based conceptions of ND conditions” (Sutton 2021: 679) are the norm. For autism, that deficit is heavily associated with the pity-enhancing image of a child (Stevenson et al. 2011: 4). Until May 2019, the NHS’s website page on autism was specifically dedicated to children with autism – the ‘symptoms’ page was split between pre-school and school-age children. Adults had their own page, without mentions of symptoms, and warning that a diagnosis may not even be available to autistic adults within certain areas. The assumption was clear: autism means child. It is a depressing reality that this was not simply a one-time blunder; Stevenson et al. found that “90% of the autistic characters portrayed in the 105 fictional books [they studied] were children” (ibid: 6). A particularly notorious example, Autism Speaks (a charity claiming autism advocacy) created an ad entitled “I Am Autism” (2009).

“I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up you will cry, wondering who will take care of my child after I die?”

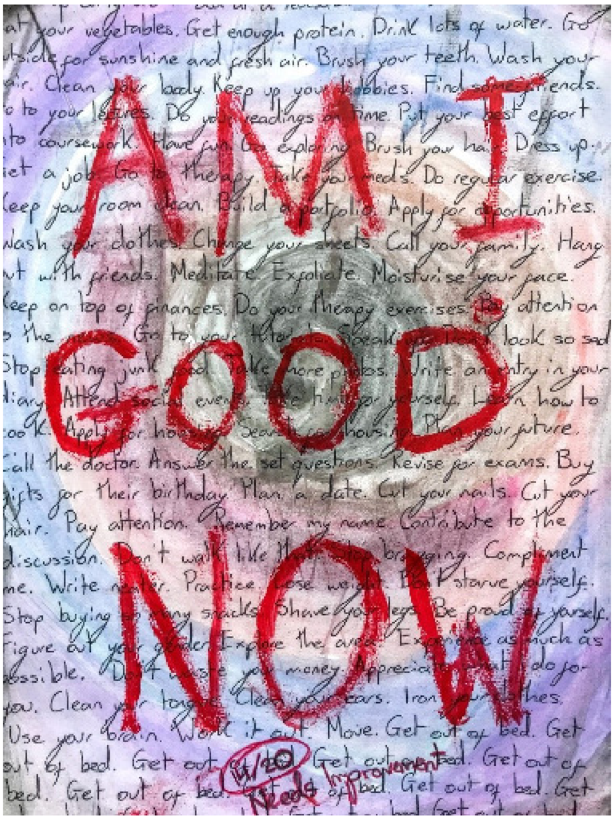
The ad’s ‘uplifting’ response from the parents of autistic children lays out the bare points of what they believe autism is.

“You think because some of our children cannot speak, we cannot hear them? That is autism’s weakness. You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands?”

The autistic children do not get a say in this imaginary argument. Autism Speaks epitomises the belief that children are made incapable of personhood by the ‘terrifying’ autism, and caregivers must fight the autism to recover their child (creating another horrifying implication that the child’s autistic self is not really the child). This is the baseline of what most people are aware of around autism. It is deeply rooted infantilisation – where autistic people are “treated as childlike entities, deserving fewer rights and incurring greater condescension” (Stevenson et al. 2011: 2) – and it is horrifically pervasive.

With this in mind, why is protection via exclusion from ethnographic participation needed? Why is it unethical to have autistic participants discussing their autism? Sutton explores why their argued “neurodiversification of existing research methods” (2021: 678) is needed – ableism. Academic practices are inevitably informed by the society in which they take place, and with the image of autism as childlike, “researchers tend to assume the vulnerability of all [neurodivergent] people”, despite the vast “diversity of the respective experiences” (ibid: 680-681). Therefore, when acknowledging the potential of harm or lack of support in participation for some autistic people, a blanket exclusion is given. Ethnography cannot be neurodivergent because neurodivergent people are not capable of participation. In doing so, “an untold wealth of assets is lost” (Stevenson et al. 2011: 9). What seems to be missed is that neurodivergence is not neuroabsence – the autistic way of being is not lesser than the neurotypical way of being, but simply different, and therefore has valuable divergent experiences and knowledges that neurotypical participants and researchers cannot provide (Mellifont 2023: 876). Instead of "facilitating an inclusive learning and research environment" (Sutton 2021: 682), the entire autistic community and the value they hold is thrown aside – the easiest approach to avoid having to question tradition, and one that passes on all of the effort to the already struggling autistic academics. As Miller, Rees and Pearson put it, "the cost to [the autistic person] is doubly high as they are putting effort into sustaining social cohesion with those who do not put the same effort into understanding them in return" (2021: 335). Due to being denied autistic participants, I had to conduct my ethnography on myself; I had to let my mental health be steadily crushed as every minute of every day became potential ethnographic material, meaning I had to open up my sensitive emotional and sensory self all the time, instead of allowing multiple people to take that burden collectively in a definitively bounded time and space.

It could be said that this is a simple mistake, over-precautions unintentionally causing harm. To claim the cautious approach, however, the autistic people already in academia must be protected and accommodated too. This is not the case. As an autistic student, I spend most of my time burnt out and exhausted – physically and mentally – due to the additional challenges of an academic environment built solely for my neurotypical peers. When I attend a lecture, I must sit and concentrate in a room of bright lights, prepared for a potential social situation (sitting between two friends, the lecturer enforcing discussion, etc), unable to stim as this would break the attention and annoy students around me, and using twice as much of my normal concentration in order to understand the lecturer's speech, given my autistic auditory processing difficulties. I cannot miss a lecture if I do not have the energy to manage this overwhelming experience, as they may not be available online meaning I may miss vital information. Lectures happen up to three times per day, and after I must still have enough energy to mask (a deeply exhausting endeavour (ibid: 331)) through social events, look after my health and environment, and carry out set coursework and additional readings. Tutorials are worse – I briefly unmasked during my fieldwork in a tutorial, opening myself up to taking in more sensory input than usual, and immediately found the awareness physically painful.



'spend most of my time burnt out and exhausted'

All of these issues are immediately obvious to anyone with an awareness of common autistic sensory sensitivities. The fact that they exist, and that the only way I may have a hope of arranging accommodation is to make public something so private and personal, displays how little protection is in place for the real active autistic people in academics. To place the effort of making the academic environment comfortable on the autistic people themselves by forcing them to arrange their own accommodation, and then claiming protection of autistic people by placing blanket exclusion of participation in academic research is a clear display of laziness. It is easier to keep to tradition, passively accepting the "stigma that silences" (Mellifont 2023: 880).

Inclusion

The toll of my fieldwork became too much. I went to the one person who I could trust to help me figure out what to do with the Pandora's box I had opened – my therapist. I had become too aware of how my masking had prevented "a real connection" with most people I knew and loved (Miller et al. 2021: 334), yet I had enough experience of harm from others due to unmasking that taking the mask away became a frightening concept. Not only that, at some point, masking becomes instinctual – it is hard to separate what is 'me' and what is my 'mask' (ibid). As ever, my therapist had the perfect simple solution – unmask around those I already trust to not cause the harm I was afraid of. Unlike my experience in my tutorial, I could allow myself my full emotional and sensory range without pain, and, should all go well, gain an experience of trust and connection with those I had been hiding from for so long.

'masking had prevented "a real connection"'

I decided to hold a casual gathering where I lived – a space I had curated for my own sensory comfort – giving a shorter explanation when inviting and then a full explanation on my friends' arrival of what I intended to do. Their quick acceptance of the concept was reassuring. Even so, I found my heart beating faster than usual, my cheeks flushing with heat as I prepared to reveal the most vulnerable parts of my autistic expression. It was not only fear of humiliation that affected me, but fear of abandonment also. Should any of my friends find my autistic self too 'weird', they could consciously or unconsciously draw away from me. Even worse, should any react negatively, I would instantly lose any building trust I held for them. Either way, I could lose a relationship I held close to my heart. The effects of my lifelong experiences of exclusion ran deep, despite my constant self-reassurance that, if such a thing did happen, that relationship would not be a healthy one for my autistic self.

My worries proved to be unfounded. Not only was my stimming, random noises, unsuppressed reactions to positive and negative stimuli, and long-winded dives into areas of special interests taken in stride, but actively supported and encouraged. One friend, unprompted, collected a plastic tub of fidget toys to encourage easier and more satisfying stimming. Later in the evening, when asked if any difference had been noticed in my behaviour, the only response was that I had seemed more 'open' and 'comfortable'. These were incredibly validating experiences: the autistic expressions I had always hidden were not shameful, but a valued part of myself that others actively encouraged. The 'problem' of my former exclusion had created a false sense of personal fault (Moore et al. 2022: 435), but my struggles to find friendship and connection had nothing to do with myself. It had only to do with the external world, and the different social communication styles to mine those I interacted with used (Miller et al. 2021: 334). With people who were able and willing to communicate in my autistic communication style, I could find comfort, joy, and connection.

This connection was further enhanced by a distinct sense of unspoken solidarity and kinship through common experience. I was not the only one to use the fidget toys. As time went on, more and more of the gathered group picked up and made use of them, until eventually the whole room was fidgeting as they talked. I was in no way singled out – this autistic expression became communal, a shared moment of sensory joy. In a brief lapse in conversation, the noises of clicking, snapping, popping, and whirring became a new language, communicating a simultaneous individual and shared contentment. An activity which is often, in wider society, considered abnormal and disruptive was subverted into normality and became an expression of respectful connection. I was able to settle into the relief the fidgeting gave me, without the ingrained shame, and steadily I was forgetting I had previously found embarrassment in the activity at all. I later discovered the same hope-inducing concept described by Miller.

> *"Research has suggested that a feeling of community belongingness not only provides a sense of kinship but can also mitigate the effects of internalized stigma."* (Miller 2021: 335)

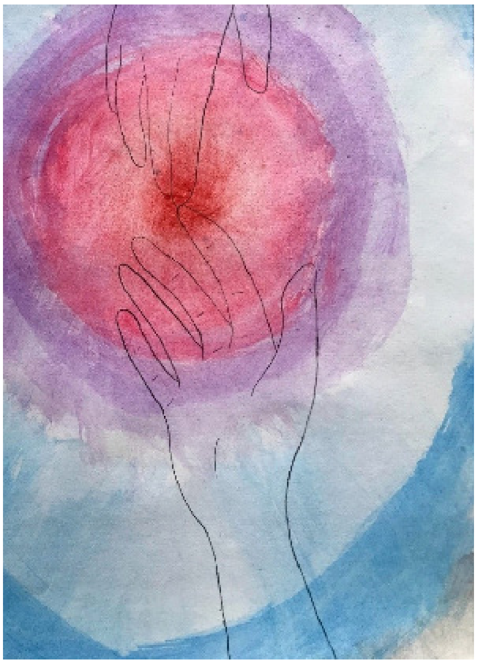
The community belonging of this particular experience went beyond sympathetic communication. When discussing the evening with one participant later, they said they enjoyed having people around who "understand the things [they] do on a fundamental level". The communal experiences we shared were not fleeting or bounded in one evening, but a continuation of a communal experience of autistic-like being – diverting yet joining together at the most vulnerable points. Those shared memories, though sometimes drastically spatially and temporally separate, create an unspoken sense of belonging. The fascination and joy with which those in the room made use of the fidget toys speaks to a deeply buried part of the autistic self that was denied those pleasures. A conversation late into the night on how 'accepted' we would be in past centuries is the blissful imagination of people who believe they have no hope achieving such acceptance in the present day, as a consequence of the popularised rejection they have experienced before.

'diverging yet joining together'

In a space where deeply impactful experiences are communal, there is support and safety in bringing out those experiences and attempting to understand and heal from them. By finding a community in which autism is not just accepted but embodied, I was able to find comfort and joy in my autistic expressions that were otherwise deemed shameful and so find pride in my true autistic self. Not only this, but my moment of healing created a space for others to share in, autistic or non-autistic, exploring the possibility of a life without exclusion.

CONCLUSION

Exclusion of the autistic way of being is a complex reality. What is often "ignorance born of marginal exposure" (Stevenson et al. 2011: 10) can spiral into horrifically harmful action – the effects of being forced to mask alone can lead to suicidal feelings (Miller et al. 2021: 331). Academia is not exempt from this. Misplaced 'protection' and a difficulty creating safe accommodation for autistic academics leads to an "absence of [neurodivergent] ethnographers, anthropologists, and anthropologies" (Sutton 2021: 679). However, should the scales of advocacy and accommodations be tipped in the right direction, we may find a growing sense of autistic community belonging which can work to heal the scars of past exclusion and build towards a future where neurodivergence is valued and normalised.



'heal the scars of past exclusion'

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