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# Constructing Autism: Autistic Adults in Conversation

# Construire l'autisme: conversations entre adultes autistes

Dr. Harriet Cameron
Senior Lecturer in Psychology & Education
School of Education
University of Sheffield
h.cameron@sheffield.ac.uk

Dr. Luke Beardon
Senior Lecturer in Autism
Autism Centre
Sheffield Hallam University
l.beardon@shu.ac.uk

Ms. Sarah Chierico
Expert by Experience

Mr. Mark Etherton
Expert by Experience

Ms. Michelle Hughes
Expert by Experience

Ms. Helen Jones
Expert by Experience

Dr. Ellen Kendall
Wellcome Trust Early Career Fellow and Expert by Experience
Department of Archaeology,
Durham University
e.j.kendall@durham.ac.uk

Mr. Steven Wilks
Expert by Experience

## Abstract

This article attends to the construction of autism during conversations with and between adults diagnosed as autistic in adulthood. Led by a researcher collective of eleven adults belonging to a post-diagnostic support group, and two university-based academics, this paper offers interpretative and theoretical insight into the constructions of autism as neurological difference, identity, and disability, and into the positioning of diagnosis as a route to liberation, resistance and collectivisation. In

exploring the possibility and limitation in these constructions and positions, we draw upon M.Remi Yergeau’s work on neurological queerness (2018). Yergeau’s theorisation offers an exciting view of the defiance that autistic being and queering present to the normative social order; and thus helps to articulate the import of the nuanced experiences and positions the autistic researchers shared as part of this research. We conclude by emphasising the value of autistic-led, participatory qualitative research as momentum for anti-ableist practice and critical scholarship.

## Résumé

Cet article examine la manière dont l’autisme se construit au fil de conversations menées avec et entre des adultes ayant reçu un diagnostic à l’âge adulte. Issu d’un collectif de recherche composé de onze adultes membres d’un groupe de soutien postdiagnostique, en collaboration avec deux universitaires, ce travail propose une analyse interprétative et théorique des façons dont l’autisme est envisagé comme différence neurologique, identité et handicap, ainsi que du rôle du diagnostic en tant que vecteur de libération, de résistance et de collectivisation. Pour explorer les potentialités et les limites de ces constructions et de ces positionnements, nous mobilisons les travaux de M. Remi Yergeau sur la « queerness neurologique » (2018). La théorisation de Yergeau offre une perspective stimulante sur la défiance que l’existence autiste et les pratiques de queering opposent à l’ordre social normatif, contribuant ainsi à éclairer la portée des expériences nuancées et des positionnements exprimés par les chercheuses et chercheurs autistes ayant participé à cette étude. Nous concluons en soulignant l’importance de la recherche qualitative participative menée par des personnes autistes, en tant que moteur de pratiques anticapacitistes et de productions critiques.

### Keywords
Autism; Diagnosis; Ableism; Identity; Participatory Research

### Mots-clés

Autisme; diagnostic; capacitisme; identité; recherche participative.

## Introduction and Literature

This paper is based on a participatory research project (following the framework for inclusive autism research, Chown et al., 2017), and is funded by a British Academy/Leverhulme Small Grant. The purpose of this paper is to share our exploration of how adults diagnosed as autistic in adulthood may make sense of diagnosis (or identity), what this sense-making enables, and how competing and often highly charged stories about what autism diagnosis can mean might be managed. It is aimed at a student, professional and more broadly academic audience. A more accessible presentation of the core findings of this work are also available via our co-produced film, available here. In the production of this paper and our film, we wanted to add to the growing literature and resource that is autistic-team led, and which is voiced by autistic people in the general population as well as by academics. We acknowledge that we do not represent all autistic adults, and that much more work is needed to ensure the inclusion of the voices of autistic people across a broader range of intersections and especially those with greater support requirements (Nair et. al. 2024).

We know from experience there are social risks in 'narrating [our] shit' as autistic people (Yergeau, 2018, p.62). Creating a space where we could share our experiences and thoughts openly was therefore essential. This was possible because of the strong personal connection Beardon had with the post-diagnostic support group prior to this research, and of course because of the co-researchers' connection to one another in connection to this group, and the long hours we all spent together over the course of the project (2018-2023).

The project aims were twofold: firstly, to discuss, and analyse, thoughts, feelings, and experiences around autism and diagnosis in adulthood, and to share these with other adults who were considering a diagnostic journey (see our co-produced animated film, Beardon et al. 2023). The second aim was to explore the ways in which we talked about autism in the conversations: an exploration of how autism, and/or being autistic, was discursively constructed and what these discourses can do. We wanted to think collectively and critically about why these discourses matter, and how they interact with wider assumptions about PNT people and behaviour. The findings discussed in this paper are the outcome of our combined analyses. In the discussion section, we consider the relational contexts in which these discourses are produced; and note how autism as a construct continues to shift. We centre M. Remi Yergeau's work on neurological queerness (2018) to further explore the possibilities and limitations of the discourses constructed for humans more broadly.

How autism is understood is changing, and contested (Russell, 2021; Sarrett, 2016). Adults seeking and/ or receiving an autism diagnosis in adulthood have access to proliferating, sometimes contradictory information about autism, with access to an array of discursive resources (Willig, 2008) with which to make sense of themselves, their lives, their strengths and the social barriers they have experienced. Navigating these discourses can be challenging. For example, seeking an autism diagnosis generally necessitates engagement with Global North narratives of neuro-cognitive deficit and abnormality, referred to by Waltz as a 'catastrophic medical model' (2008). Whilst neurodiversity discourse offers an alternative, it can also help to establish a restrictive neuro-essentialism which does not benefit all autistic people equally (Cameron, 2023). Both psychopathology and neurodiversity narratives centre

neurocognitive function and can reinforce an innate binary (normal/abnormal; typical/ divergent), each side defined by the other, each potentially homogenising an 'us' and a 'them' (Runswick-Cole, 2014). The neurodiversity movement, however, is not an entirely unified force with settled terms of reference (Milton, 2023); nor is it completely free from the socially embedded psycho-medical machinery that produces standard diagnostic criteria and (perceived) expert diagnosticians.

Ginny Russell (2021) explores the influence of the neurodiversity movement upon the fifth latest version of the DSM descriptors of autism (APA, 2013), and the broadening of who may land the 'autistic' side of the diagnostic line. Conceptualising autistic/ not autistic as an innate binary or, alternatively, understanding autism as context dependent and thus, as a shifting social construct, both offer particular challenges to the ways in which autistic adults can make sense of themselves in the world. Adults who have come to know they are autistic in this context of heightened awareness, contestation around the meaning of neurodivergence, and marketisation of identity can find themselves in a difficult and frustrating position when trying to make sense of themselves, and others, as they juggle the available discourses (Chapman, 2024). We hoped that by exploring the ways in which we have made sense of diagnosis, diagnostic assessment, identity and neurodiversity, we can offer some helpful insight for other adults on similar diagnostic journeys.

This research offers value to the literature in three key ways: firstly, it explores our conversations as adults after compulsory and/or higher education, rather than centring autistic children and young people (who are more commonly the focus of research). Secondly, the research is autistic-people led. With acknowledgement of those 'not in the room' (Táíwò, 2022; Yergeau, 2018), and of those living in diagnostic

borderlands (Cameron, 2023), we offer an accessible entry point for dialogue around some of the challenges and possibilities of talking about autism and neurodivergence in the global North. Thirdly, we grapple with the apparent dichotomy centred around the concept of 'identity' (Rose & Abi-Rached, 2013) between autism perceived under a homogenous group label and autistic people as a heterogeneous population.

## About the Co-Researchers

'We' (including 'us') - 'we' are the full collective of thirteen researchers; within the participatory model, unless indicated otherwise. Two academic researchers initiated the work: Luke Beardon and Harriet Cameron. Beardon had, and has, a close and long-term relationship with a particular post-diagnostic support group for autistic adults situated in the North West of England and had already had many discussions with individuals in this group about the value of autism identification for adults. Beardon and Cameron approached this group to begin discussions about undertaking a small, collaborative, qualitative project to explore the ways autistic adults experienced diagnostic assessment, and how they constructed the meaning of autism in their given contexts. With the support of members of the given post-diagnostic support group, Cameron and Beardon applied for a BA small grant, and after this was secured, they worked with the 11 members of the support group who were interested in working together on a project. We agreed that we would all be named co-researchers, rather than split into 'participants' and 'researchers' because everyone in the group played a role in deciding on interview questions and format, analysis, construction and presentation of themes, and/or in framing and disseminating the results. Roles

naturally had to be defined (for example interviewer/interviewee) and we acknowledge that each co-researcher brought different skills, experience and expertise with them. We also recognise that Beardon and Cameron, in paid research roles, had more time and resources to undertake this research than the other co-researchers. Those of us interviewed in this study had not been identified as autistic until adulthood, and we might be described in some contexts as high-masking individuals who have expended much energy trying to disguise our neurodivergence, often to great personal detriment (Belcher, 2022).

We are purposefully resisting explicitly naming the neurotype for each author one-by-one because doing so imposes disclosure of autistic identity upon those who do not wish to disclose this, and forces those who have not reached a conclusion about their neurotype into premature categorisation. We acknowledge that this chosen vagueness about who fits which category may be seen as problematic by readers and wish to be open that one author is not at a point where they identify as autistic or as a person of predominant neurotype. The ‘we’ of this paper is considered as an autistic ‘we’ given that twelve of thirteen of us are autistic. Autistic authors are the dominant voice in this work. Eight people in the researcher collective chose to co-author the current paper and we acknowledge the contributions of the five co-researchers who chose to remain unnamed. Cameron and Beardon led on the theoretical exploration offered in the discussion section here and led the final writing up of the current paper with theoretical, analytical and creative insights and inputs from Etherton, Chierico, Hughes, Jones, Kendall, and Wilks.

### *Use of Terms*

We use the words Predominant Neurotype (PNT) - based on the original introduction of PNT (Beardon, 2008) the demographic-led term aims to dilute the more socially charged term neurotypical (with its connotations of nornmal/abnormal). What we particularly enjoyed was that within our research team the very strong PNT was (is) autistic. This contrasts with the fact that the PNT within wider society would statistically be made up of non-autistic individuals.

We draw on ideas of Neuronormativity - the idea that society often assumes that there is a ‘right’ way for the brain to operate and that divergence from that is to be considered problematic or deficient; conversely, the neurodiversity paradigm embraces neurodiversity and rejects the notion of neuronormative value (e.g. Hamilton and Pettyt, 2023).

## Methods

This is a qualitative research study which sits within an interpretivist paradigm (Schwandt, 1998; Willig, 1999, 2008). As such, we are seeking depth over breadth in terms of data collection and analysis and we do not seek to discover a single objective universal ‘truth’ about late diagnosed autistic adult’s experiences. We recognise that each account, story, and recollection, and each analysis, re-telling and thematic construction, is shaped by and within a complex relational context which it is fundamentally inseparable from. We decided upon a mix of interviews and a focus group, to be undertaking online via zoom video interview. We felt this was the most

inclusive approach, and as covid-19 progressed, it was also the safest approach. Most of us wished to have a one-to-one interview with Beardon, as someone we knew well, and three of us felt that a group conversation would also be valuable. As such, we added one focus group, attended by Beardon as well as three of us as co-researchers from the post-diagnostic adult support group who also took part in an interview.

Interviews were set up online and audio recorded. Each interview or focus group continued for about an hour (and up to 1.5 hours). We agreed on the following questions, with the understanding that we could take breaks as needed, we could decline questions, and we could add questions we would like to ask/ to have been asked as long as we remained respectful.

The following core questions were asked in each interview and focus group:

1. *What does being autistic mean to you?*
2. *What led you to seek an identification of autism in the first instance?*
3. *What (if anything) changed as a result of you getting that autism confirmation?*
4. *What do think is society's perspective of autism/you?*
5. *What needs to change within society to better the lives of autistic people?*
6. *What are the key areas that you think should be researched within the autism field?*

The aim was for a free-flowing conversation, with freedom to diverge, interrupt, wander, and follow up according to interest. This fits the mould of semi-structured interviews, but with more space built in than might normally be expected in interview research of a similar sort. We wanted to provide the opportunity for interviewees to talk about being autistic, their journeys towards identification/ diagnosis, their perception of societal

views and their priorities for change so that we could later explore the ways each of us constructed meanings around autism, and the discourses we used to do this.

## Analysis

We drew upon interpretivist discourse analysis to analyse the transcripts (Willig, 1999, 2008; 2011; Parker, 2004). We examined the available ways of talking about and around autism. Multiple ways of conceptualising autism and autistic experience are available; the 'choice' of which to draw upon can produce quite different 'versions of events and of reality' and can 'do' different things (Willig, 1999, p.2). This version of discourse analysis…

> …*is concerned with the ways in which language constructs objects, subjects and experiences, including subjectivity and a sense of self* (Willig, 1999: p.2).

We considered discourse as part of the collective construction of objects, subjects and experiences, but not the whole story. We recognise discourse as *acted upon* as well as *acting in* an ever emerging relational present. We sought out discourses which counter assumptions of disorder and deficit and asked how discourses 'may constrain or facilitate particular actions and experiences' (Willig, 1999, p,2). We take a positive view of the possibilities of purposeful discursive positioning:

> …*if what we take ourselves and others to be are constructions and not objective descriptions, and if it is human beings who have built these constructions, then it is (at least in principle) possible to re-construct ourselves in ways which might be more facilitating for us*… (Burr, 1998, p.13).

As such, the starting point for the research is hopeful. Agency has been presented in much autism research as something autistic people don't have (Yergeau, 2018), so, here we centre autistic people's agency whilst recognising agency beyond the human (Freely, 2016).

The 'stages' in data analysis numbered below should be understood as relatively loose and flexible: rather than following a fixed method, we follow Ian Parker's concept of discourse analysis as a 'sensitivity to language', rather than a 'series of steps' (Parker, 2004, p.168). Our analysis adhered to standards for extrapolative value, rigour, trustworthiness and reliability appropriate for our chosen approach to interpretivist qualitative research (Ahmed, 2024; Smith, 2019) by ensuring the following: the building of trust and rapport between interviewees and the academic researchers over a prolonged period of time; the systematic analysis of each transcript by two academic researchers, and by the relevant interviewee co-researcher, and through reflexive dialogue, and verification, between these three individuals; and through the creation of 'thick' descriptions (Ahmed, 2024, p.2) of contexts, and choice of focus; the careful documentation of each stage of analysis, mapping and presentation of themes. In interpretivist qualitative research, the bias of researchers is embraced and used as an acknowledged lens through which to view the data. As such, rather than taking steps to minimise or step aside from bias, we perceived bias as useful. As such we do not see our work as generalisable in the traditional sense, but as offering some narrative insight into some autistic adults' diagnostic journeys (Smith, 2018).

1. Each research conversation was audio recorded and transcribed. All transcripts were accessible by Cameron and Beardon; each interviewed co-researcher had access only to the transcript of the interview or discussion they took part in.
2. Cameron and Beardon increased familiarity with each conversation by listening and re-listening to all of the audio recordings, and reading and re-reading all interview transcripts. Etherton, Chierico, Hughes, Jones, Kendall, and Wilks, and the researchers who have chosen to remain anonymous, also received and read their own transcripts.
3. Detailed analytical coding was undertaken first by Cameron and Beardon separately, and then together, transcript by transcript. The core guiding question in this initial coding process was ‘how are *autism* and *being autistic* being constructed here?’. This stage involved staying as close as possible to the language used in the transcript. This is an interpretative process, but nevertheless rigorous and systematic. Rigour here is not understood as a claim to ‘unmediated analysis that can be shown to be correct’ (Parker, 2004, p.161). The text is not considered ‘representative’; it does not contain answers. It is instead viewed here as productive, as acting and acted upon. It is thus not ‘still’ and cannot be ‘correctly’ analysed. Rigour, in this kind of research, indicates care and time taken with each transcript, consistency in approach to analysis, and the purposeful collaboration in production of findings over a period of many months.
4. This analytical focus was followed by an engagement with the questions: ‘How do the people in this conversation position themselves in relation to the discourse they draw upon?’ and ‘What possibilities do the given discourses

appear to open up or to close down for the person in their stories and experiences?’ Beardon and Cameron spent between 1 and 2 hours discussing their individual analysis, the similarities and differences between their codes and notes and the possible reasons for these differences. Each annotated transcript was shared with the relevant interviewed co-researcher via google docs. The interviewee added their own analytical notes, questions, and comments and engaged with a back and forth dialogue within the google document with Cameron and Beardon and sometimes through additional meetings and emails, thinking through similarities and differences in analytical notes, until we agreed on the discourses, ideas and themes speakers had drawn upon. These were pulled across into a separate thematic map, uncoupled from the name of the coresearcher being interviewed, so that they might be shared with the whole team.

5. To preserve the anonymity of team members, Cameron and Beardon aggregated the themes presented in the individual maps into one‘master’ map with three detailed tables. No information was lost here - it was rather differently arranged to mask connections to individual interviews. The master map (1: constructions and experiences of being autistic’, 2. ‘Experiences around diagnosis’ and 3. ‘Key challenges and hopes’) were brought to the whole team to discuss and organise, and through a combination of live Google documents, video meetings, and emails. To meet the access requirements of some co-researchers, the data were also presented in a table. Over a period of roughly eighteen months, which included some Covid-19-related delays, we agreed on the core themes. The

aggregated analytical maps, notes and tables are archived in the University of Sheffield data repository here.

## Findings: Autism as…? Three Constructions of Autism Produced in The Conversations

We use gender-neutral pseudonyms for interviewees, with ages left unlisted, to avoid identification in connection to extracts within specific interviews. All of the interviewed co-researchers were diagnosed as autistic in adulthood; seven are female and four are male. Whilst we did not record the specific ages of co-researchers, we range from early adulthood to late middle age to post-UK standard retirement age. Given we are mostly white, and mostly British, we have not added this explicit information to each pseudonym below, again to avoid identification. Interviewees: Fern, Dom, Ruby, Alex, Sammy, Shaz, Sal, Vic, Max, Lor, Romily.

Focus group speakers: Robyn, Jem, Mo (with Luke facilitating. Focus group members were also interviewed but are given a second pseudonym here to protect anonymity).

### *1.1. Autism as neurological difference: a neurotype: 'it's okay to be neurodiverse. That's ok!' (Fern)*

The language of neurodiversity was highly valued by all of us . We used this language to construct autism as difference, rather than disorder. We are not neuroscientists, and

recognise our understanding of neurological functioning is limited - but we find the concept of being 'wired' differently to most other people to be a useful one. When we talked about neurological differences we included, as we perceive them, differences in processing information, differences in sensory experiences, and differences in processing and communicating. Whilst language of autism as 'deficit' did appear in interviews, it was usually countered shortly afterwards, recognised as problematic, and resisted. Whilst identifying as neurodivergent is now commonplace in the UK and Global North at the time of writing, it is important to recognise the relatively recent popular usage of this discourse, and to recognise the power it has to resituate and reframe common understandings of 'neurodevelopmental disorders' and overlapping medicalised constructs. In addition, the recently developed concept of autistic epistemology and the hypothesising that much of mainstream 'knowledge' around autism constitutes misplaced or misinformation should still be taken into account (Beardon, 2025).

We foregrounded 'neurotype' in the conversations by making use of computer or machine metaphors for the brain with reference to differences in wiring, operating systems, or types of processor. For example,

> *I like the analogy that the brain is wired differently because that makes most sense to me (*Dom).
>
> *It's my entire sort of neurological operating system* (Ruby).

We also used other metaphors to present difference, rather than disorder; for example, being a cuckoo in the nest or a square peg being forced into a round hole.

Construction of autism as a neurological difference helped us to reject the idea that one can always observe autism from the outside, or through observation of behaviour. We roundly rejected ideas of 'high' or 'low' functioning labels.

## *1.2 Autism as identity: 'It's who I am' (Sammy)*

All of us constructed autism as an intrinsic part of the self. We did not see autism as an add on, but as fundamental to who we are. When we spoke about autism in the research conversations we all did so in a way which constructed autism as core to our personhood. We draw upon Jim Sinclair's writing here, and agree that autism is

> … *is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence.* (Sinclaire, 1993/2012)

Identifying as autistic in the conversations usually meant connecting to the unique, the strength-based, and the joyful, as well as acknowledging that these were nuanced and often paired with challenges. The point of formal diagnosis was pivotal for a number of us in that it permitted more open identification with a positive vision of autism. For some this openness was tentative – and only with oneself: *I'm not "out of the closet"* (Lor), and for some only with certain trusted others. Whether or not speakers share their self-knowledge directly, understanding autism as a way-of-being connected with confidence, acceptance, and self-understanding.

> *It defines how I see the world and how I experience things* (Ruby).

> *I am quite proud of the person I am* (on realising neurodivergent identity - Fern).

> *I am just in that really early stage of, yeah, coming to terms with a different way of looking at me* (Sammy).
>
> *…being different is fine, and this is an identity* (Alex).

Autism as identity appeared as a useful way to name the strengths connected to being autistic. Strengths named included high levels of empathy, being very caring, critical thinking, a love and care for animals, a strong sense of fairness, standing up for injustice, having high standards, attention to detail, and honesty and directness in communication. Our common use of 'we' here also helped to construct a group identity, e.g. *We are so analytical* (Romily).

## *1.3 Autism as a socially created disability: 'I think society views autistic people as broken…' (Alex)*

Much of our experience in connection to autism in these conversations involved talking about trauma, distress, frustration, loneliness, self-criticism and anxiety; but these aspects of being autistic were almost always tied to the environment, rather than constructed as intrinsic to our autistic neurotype. In other words, the disabling was a consequence of environments (and associated social norms) not designed for us to thrive, indeed sometimes not even for us to survive. We defined socially constructed disability after Vivien Burr's (1998) theory of social constructionism. In other words, the assumption that we are innately disordered or broken is incorrect - these are '*not objective descriptions'* (we repeat from Burr, 1998, p.13).

Being bullied, criticised, ostracized, dehumanised, treated as unacceptable, all pushed us into learning how to mask, to hide, and how to please others. Although this

enabled survival in certain contexts, masking came with its own disabling consequences: longer term exhaustion and sometimes poor mental health, as well as shorter term 'social hangovers'.

> *One learns what is unacceptable. I learned to be quiet, not make a fuss, and just be….and put up and shut up, nothing that drew attention or made them ashamed. And it's learned behaviour from a very, very early age and you just carry it through (Fern).*

Framing the downsides as environmentally contingent also enabled us to acknowledge of autism as a fluid construct; that is – its meaning can change depending on the environment and on how you feel:

> *It definitely depends on what environment you're in and what you're doing in that environment how much it affects you and what it means. So like in my work it's great because it's like a gift, it's so helpful, but then like interacting with my family sometimes it's a bit of a nightmare because I can't do what they all want to do – or I just end up exhausted (*Robyn).
>
> *Well it's the environment isn't it, I think that's really clear, and it's also trying to live in the 21st century with all the demands that the 21st century brings with it. And I do question whether some of us would have been diagnosed like 50 years ago because the world wasn't set up in a way that really showed up our difficulties to the extent it does now (Sammy).*

## Findings Section 2: What do These Discourses *Do*

### *2.1 They liberate: 'It's like starting again as the person you were always meant to be' (Jem)*

Combined, the three constructions of autism produced in the conversations and discussed above offered liberation for us. It is notable that the societally dominant discourse of disorder was largely absent in our conversations. Given the master narrative of autism has been one of cognitive disorder behavioural abnormality and tragedy it is positive that we were able to use alternative discursive resources to shake off those discourses of deficit. The joy and freedom we felt in being autistic was clear. Embracing autism appeared particularly connected to the fact that all of us came to realise we were autistic later on in adult life after years of being as pathologically deficient in at least some part of our every-day lives.

Below are a couple of examples of freedom of action we shared:

> [On hearing a loud fire alarm test] *I put like just one finger in my ear and they were all laughing. It was like 'you've got two ears, do you not need to put it in two ears?' And I was like 'well no, for some reason one ear is enough', … whereas I think a couple of years ago I would have just been like gritting my teeth and I wouldn't have tried to let on to people that the noise or whatever was….I was finding it hard. So I think I've kind of become, well not more autistic but more like I'll let more things out than holding it in* (Shaz).
>
> *Another thing being autistic gives me permission to do is sit there stroking my [pet amphibian] while we're talking because it's keeping me calm* (Ruby).

Autism diagnoses also gave us permission not to feel ashamed about who we are but to be proud; no longer having to beat ourselves up for being different, no longer always having to hide or conform.

> *[understanding autism as neurotype] gives me permission to design a life that is going to work for me going forwards rather than continuing to live on the edge of chronic fatigue and emotional exhaustion the whole time.....This is about me understanding myself so that I can be kind to myself.* (Sammy)

## *2.2. They resist: 'change the shape of the goddamn hole!' (Dom)*

Resistance in these conversations appears as a follow-on from relative liberation. Freer from the misconception that they are inherently wrong in shape, square pegs may cease squeezing themselves into round holes and call, as Dom does, to 'change the shape of the goddamn hole!'

Trusting one's own judgement is hard when you have been told for much of your life that you are probably wrong in your interpretations.

> *The problem, it's like you don't trust your perception because everyone tells you you're wrong all the time, like 'it's not that loud' or 'oh you can't possibly be that tired', 'you're wrong'* (Robyn).

Drawing upon the discourses of autism presented here, we were able to resist the idea that our own sense of things was incorrect. For example, on no longer judging oneself negatively through others' eyes, Sal explained 'I can now brush it off'. With the formal

diagnostic assessment, that 'bit of paper', Dom can more directly resist negative assumptions: 'I then become the authority, I'm the author of my own life' (Dom).

Being able to draw upon discourses of autism as difference, as positive, and as identity, allows autistic people to stand up for themselves more confidently. Robyn explained,

> *Now I've got my diagnosis I would absolutely say 'this is not acceptable, when I say no I mean no, I mean absolutely no, I don't mean I don't like this and I want you to do it anyway'* (Robyn - on having people sing happy birthday to her publically).

We also resisted negative discourse and positioning for other autistic people, not just for ourselves. Access to discourses of difference, diversity, and the social model of disability enabled direct and cutting critique of the practice of Applied Behavioural Analysis, its normalising aims, and its theoretical assumptions. Knowing that autistic people are '[n]ot just defective neurotypicals' (Ruby), means that they do not need 'fixing', and they don't need to be made the same as others:

> *...all the ABA stuff, you know: 'make them indistinguishable from their peers',' spend all this money', 'get this cure'. And it's like oh, they don't really need a cure, they need someone to understand and remove the barriers so that they can thrive* (Max).

## *2.3 They collectivise: 'it is important that you do know there is a tribe like you, too' (Alex)*

Being able to resist negative assumptions about what it means to be an autistic person was more powerful when we could talk about 'us' rather than just 'me'. Being part of a particular population who share similar strengths and struggles and having the language to name that group and their common strengths and struggles enabled us to have a sense of social belonging. Although there was always care to recognise autistic people are not all the same, the things-in-common conversations constructed a sense of collective identity and shared autistic culture, which in turn, spurred further passion for collective self-advocacy. This kind of political collectivisation is, of course, not new, and not surprising. However, it is perhaps formed belatedly in the autistic community, whose characterisation for decades was dominated by an autism-as-tragedy model, historically promulgated by organisations such as Autism Speaks (e.g. Saunders, 2018).

We recognised our minoritised status as a population, for example by noting parallels with the Black Lives Matter movement (BLM, 2024), and with feminism. We built identities from their own experiences, or those of family members, and then linked to autistic people everywhere:

> *I go further; I go wider; I stop thinking about me. Me? I'm sorted. I'm trying to look what else I can do so the others will find out, you know?* (Romily).

## Discussion: Disruption, Invention, Invitation

### *Storying autism for ourselves*

*'…autistic stories are, at root, queer stories.'*

*(Yergeau, 2018. p.18)*

In this discussion we consider how the findings above may be read as an open invitation to enact creative, anti-ableist social disruption. We draw upon M.Remi Yergeau’s (2018) ideas of neuroqueering as compliance and/or non-compliance with neurotypical ways of being (see also, Walker, 2021.p.168). We use their neuroqueer theory, amongst the work of other recent writers such as Robert Chapman (2023) to navigate any homogenising ‘Us and Them’ tendencies (Runswick-Cole, 2014) within the interviews, to explore our queering and reclaiming of the clinical diagnosis, and to make visible the transformative potential of the shared stories for anyone. We also problematize the marketization of autism and neurodivergence, and recognise alongside Yergeau (2018), which autistic voices are heard and which are not.

## Queering the Clinical: Reclaiming the Moment and the Meaning of Diagnostic Assessment

*[I]sn’t every statement on autism a statement about its diagnostic criteria?*

(Yergeau, 2018. P. 20)

A surface reading of the discussions we had about diagnosis might lead us to the disappointing conclusion that diagnostic assessment necessarily serves to reinforce the medical and deficit model of autism (Nadesan, 2005). This is because diagnosis is made via application of the deficit-based diagnostic criteria for autism written into diagnostic manuals like the Diagnostic and Statistical Manual of Mental Disorders (DSM5) (APA, 2013). It also, arguably, reinforces the status and power of the qualified professional assessor and, with that, it legitimises the discipline of psychology, its application, its scienticity, and truth claims. The existence of a professional hierarchy

and set of institutional rules, assumptions and relations enable the assessor to name the mind of others, confirmed with a written report: 'that bit of paper' (Sal). Further, assessment is entangled with a capitalist economic and political system which benefits from human classification and hierarchisation. In short, a lot is going on in the event and space of a diagnostic assessment (Hayes et al. 2022). We could leave it at this, and despair at the pathologisation we must endure to open the door to resources and identity: however, Yergeau helps us to move past this knot.

Although the formal diagnostic apparatus does not recognise its narrative condition (McGrath, 2017), autistic people can and do. Reclaiming and restorying the meaning of diagnosis is part of what Yergeau (2018) might consider a part of queering the clinical: we have diverted the script – we decide which bits are useful and which language we can discard. We show in the findings (1.1) that we prioritise the language of neurodiversity and neurotype in our research discussions, and (1.2) we emphasise our joyful, active, desiring of autistic identity, and discourse. We also show (2.3) above how our self-description and action can act as resistance to normative demands. This kind of discursive work challenges the foundations and ableist regulatory intentions upon, and for which, diagnostic manuals and systems were built (Gaines, 1992). Autism as a 'disorder' was supposed to mark out and regulate certain people seen as less-than-human, to 'manage' those unpredictable, 'unruly', 'misbehaving', 'asocial' minds and bodies. This dehumanising starting point feeds a narrative of autism as an epidemic of 'doom' and 'crisis' (Yergeau, 2018, p.11) . Autism was not supposed to be desired. In desiring autism and autism identities, autistic people are breaking through the inherent cracks in the diagnostic apparatus to reclaim the territory in unintended ways (Skott-Myhre & Taylor, 2011).

In reflecting upon (2.1) the experience of liberation through diagnosis, we should also acknowledge that attending an assessment can be a scary prospect. As Jem explained 'when I got assessed I was just....I was just so sure this was what it was and I said 'what if they say no?'. If a qualified assessor proclaims that you are not autistic it can feel terrible. Worse than it might have been with no assessment, before the negative diagnosis was given (Cameron, 2021; Cameron, 2023). This is a significant issue, not only because there is plenty of evidence that women and girls, and anyone else not fitting the standardized white-male autistic presentation may be not be diagnosed (Hendrickx, 2015), but also because lines drawn between human types are fuzzy, shifting, and loaded with social meaning (McGrath, 2017). Those informed by the diagnostic assessor that they are not autistic may be experiencing as much or more distress and marginalisation as those diagnosed *as* autistic, yet without the diagnosis, they are locked-out, so to speak, both from a desired and liberating narrative through which to story themselves, and denied access to educational, or occupational resources (Cameron, 2023). One conclusion we draw from our work is that self-diagnosis can and should be on offer to people who see their own story as one of neurodivergence; and at the same time, the shifting of diagnostic boundaries to include more people is welcomed. This way, the liberation we experienced can be extended to others who follow a less formal route to identifying as autistic.

Feelings of liberation upon diagnosis may be diminished when autism is solely defined in deficit-terms. If taken as the whole truth of autism, a rigid story of deficit may engender a subsequent narrowing of expectations (Timimi, Gardner & McCabe, 2011). Mo touches on this issue in the conversations when she considers the possibility she has grown positively in ways she wouldn't otherwise have done had she been

diagnosed as autistic earlier in life. Her comment echoes ideas in the literature of diagnosis as 'a closure in an otherwise open becoming.' (Sjöberg, 2017,p.612). Fixed neuro-identities could mean certain bodies are 'over-coded' which in turn restricts what one imagines may be possible for those bodies (Freely, 2016, p.871). However, in our storying of autism, any potential narrowing for us has been countered through a reconstruction and broadening of what autism means: autistic people are taking charge of what autism 'is' after using formal diagnostic criteria and diagnosis as one useful launching point. For us , the diagnosis has been largely experienced as unpinning, opening of becoming, and not closure. However, we recognise this is a nuanced discussion and that our experience is not universal. We also consider that the issue of narrowing raised above is most powerful when autism is constructed as deficit, and less so when reauthored by autistic people, as it is here.

## Managing Capitalist Capture of Neurodiversity Discourse and Rejecting 'Functionality' Labels

> [Capitalism holds that] *regardless of degree, low-functioning and high-functioning bodies are effectually non-functioning bodies, are bodies inhospitable for workplaces, are bodies in need of vocational, occupational, and behavioural interventions, all means and manner of treatment that works in service of crafting independent persons capable of producing and labouring.*

Yergeau, 2018, p.50

> *The posthuman predicament is … framed by the opportunistic commodification of all that lives, which…is the political economy of advanced capitalism.*
>
> Broderick & Roscigno (2021)

> *I think everything is going to be a double-edged sword*
>
> (Dom)

Here, we reflect further on the findings which explore our collective resistance (2.2 & 2.3) to the normative categories and expectations shaped by the marketisation of human values according to a hyper narrow 'norm'. The money-making industry formed around 'special education needs', neurodivergence generally, and autism specifically, is well acknowledged in the literature (Mills, 2014; Tomlinson, 2012; Mallett et.al. 2012; Runswick-Cole & Mallett, 2016; Milton & Moon, 2012; Broderick & Roscigno, 2021; McGuire, 2016, Chapman, 2023). Autism, according to Mallett and Runswick-Cole, (p.65) 'has become a commodity; it is produced, exchanged, traded and consumed.' . Commodification is made possible through the bundling together of many different people, with different behaviours and experiences into one 'type'; as soon as this type is recognised as an 'identifiable category' it may be commodified (Mallett & Runswick-Cole, 2016, p.69). Schools and private companies profit both 'from the dominant cultural metaphors about autism and the interventionist narratives they sustain' (Broderick & Roscigno, 2021,p. 77). Whilst much of the literature focuses upon the financial incentives built into the provision of interventions (such as ABA), there is also recognition of the commodification of autistic *identity* (Broderick & Roscigno, 2021).

We agree that the marketisation of autism and autistic people is a problem, and one we are acutely aware of as autistic people navigating education, work and social life. The use of functionality labelling, for example, has been 'horrifically useful' Yergeau (2018, p.50) for subjugating autistic people; we agree with Yergeau that 'functionality' is the story from which 'clinicians draw when they wish to refute the desires or claims to identity of those whom they study.' (p.50). Using functionality labels like this not only keeps us in boxes according to how 'productive' or worthy we are perceived to be, but it can also be used to silence us. Yergeau explains that, according to this logic, 'autistics have too much autism and not enough autism' to be able to speak reliably about autism (2018, p.51).

Capitalism gains from the division of humans, often through psychologised labels, into hierarchies of productivity and value. Within the spectrum of autistic identity, greater value may be afforded within the neoliberal marketplace to people who are identified as 'high functioning' (Bagatell, 2007) a term we reject, and one that is rejected by many in the autistic community (Beardon, 2021). Categorisation according to perceived degree of functioning reflects what Robert Chapman (2023) calls the ''new cognitive hierarchies of capitalism' (p.40); these hierarchies, Chapman (2023) argues, are both a product and a tool of a capitalist marketplace that 'traps each of us' no matter how near or far we are from the neuro-norm. Given that autistic 'identity' was discursively constructed as key to freedom (2.1), resistance (2.3) and collectivity (2.2) in this research, one emerging question is how identity can be celebrated without necessarily feeding the capitalist desire to sell our identities, resistance, and creativity back to us?

Dissent, of one kind or another, may be amongst the possible answers – this may take many different forms, including 'disidentification' – a rejection of the categories on offer by health and education industries; it may also mean embracing of neuro-identity as a means of resisting some normative discourse and intervention (Broderick & Roscigno, 2021). It may also mean an opening out of autistic identity to embrace all self-identification, and eschew the professional diagnostic industry (Cameron, 2023, Russell, 2021). The self-naming is key here: 'To be named autistic is to be assumed subordinate. To name oneself autistic – to name oneself anything – is an expression of agency.' (McGrath, 2017 p.186).

## We Know We Are Not Just our Neurons: Beyond Neuroessentialism, Beyond 'Us' and 'Them'

Nikolas Rose has explored the growing tendency in western discourse to present human beings as dictated by our neurological wiring (Rose, 2003). We acknowledge the concerns of an overly neuroessentialist perspective (Botha, M., & Gillespie-Lynch, K., 2022), and we also know very well that being autistic is an embodied and relational experience. It is not just our minds which challenge normative orthodoxy. As Yergeau (2018) writes, autistic bodies, 'not only defy social order' but can also 'fail to acknowledge social order's very existence.' (p.27)

Nick Walker (with Raymaker, 2021; 2022), an autistic scholar writing in the field of critical autism studies, offers a number of novel ways of talking about autism which preserve the joy and liberation in neurological difference, whilst guarding against neuroessentialism. Her ideas of 'neurofluidity', 'neuroqueerness', and

'neurocosmopolitanism' (Walker & Raymaker 2021, p.9; 2022, 20:34) conjure, respectively, freedom from the rigidity of immutable neuro-categories, embracing challenges to ideas of normality, and celebration in the 'genius of diversity' (Walker, 2022, 20:34) within the human community. We conceptualise neuro-identity as a useful tool, rather than an essentialist commitment. In other words, we understand autistic identity as always moving (2018, p.136), within a network of relations, rather than fixed in place for all time (St.Pierre, 2004).

We recognise that conceptualising an 'us' (neurodivergent) and a 'them' (neurotypical or allistic) can be divisive and homogenising (Runswick-Cole, 2014). Beardon's (2021) conception of 'predominant neurotype' is one we draw upon as one alternative. The possible existence of multiple neurotypes shifts the division between 'normal/not normal' to a multitude. Chapman's (2023) writing against a focus on 'us' and 'them' is also of value here: he writes,

> *...it is not the neurotypical who oppresses the neurodivergent, but capitalist domination that, in a certain sense, creates and harms both neurotypicals and neurodivergents, albeit in slightly different ways depending on any given individual's proximity to the norm.' (p.48)*

What may appear as a valued or devalued neurotype in one era or context may not be noticed in another (Walker, 2021; Russell, 2021). As Beardon notes, it is 'autism *plus the environment* that equals outcome' [our italics] (Beardon, 2017). The relational and temporal nature of autism and neurotypicality is obscured by a Euro and North American-centric discourse which roots itself in the brain-centred, rational scientific search for the truth of human being [McGrath, 2017; Rose & Abi-Rached, 2013). 'Neurodiversity studies' arguably remains largely a narrow paradigm of the Global North

and one which under-attends to the intersectional (Nair et al. 2024). Western concepts of essentialist neuro-identity do not engender identical possibilities for people of majority-world, indigenous, or minoritised populations and offer a very limited concept of what it means to be human in certain contexts (Douglass, 2023). However, we argue, as others have done, in favour of embracing neurodiversity approaches as multiple, inclusive, and heterogeneous (Dwyer, 2022), context-dependent (Beardon, 2017), often discomforting (Jackson-Perry & Rosqvist, 2024), and always ‘in dynamic flux’ (Stenner et al. 2025).

## Conclusions: Invention and Invitation

*Autism is ‘inventional’ not lack or loss but ‘ever becoming’*

(Yergeau, 2018, p.181)

Being autistic offers creative, inventive and defiant ways of being human. Whilst not everyone is autistic, everyone can join in the questioning and queering of restrictive, exclusive social norms. An autistic culture, as part of a neurodivergent and neuroqueer culture, ‘extends beyond the mereness of autism and embraces a plurality of queer/crip experiences, personas, and performances.’ (Yergeau, 2018, p.67). Non-compliance and a-compliance with normative rules on timeliness, body movements, communication, sociality, sensory experience, emotional expression, whilst embodying the ‘clock defying and unruly’ (Yergeau, 2018, p.65), are ways of moving in the world, and everyone is invited. Capitalist attempts to box autism up for market sale is continually being undone by autistic people’s resistance to being boxed. Indeed, we

consider that being autistic ‘constitutes a direct challenge to the codes and functional differentiations of postmodern capital’ altogether (Skott-Myhre and taylor, 2011).

Panic around the meaning of autism can be polarising, with fears on one hand of an ‘autism epidemic’ or an ‘autpocalypse’ (Yergeau, 2018, p.34), and refutation of the existence of (some) autistic people on the other (p.138). Autism as deficit, as neurological difference, as social construction, or as contingent and relational each offer up or close down possibilities for action and becoming. We hope that our work will act as a support to adults who are currently storying themselves as autistic in such polarising conversations.

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