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Cameron, H. orcid.org/0000-0003-1379-9678 (2023) Runners at the gates: growing around the barriers to diagnosis in autism, ADHD and SpLDs. *Journal of Disability Studies in Education*, 3 (2). pp. 217-241. ISSN 2588-879X

<https://doi.org/10.1163/25888803-bja10023>

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Runners at the Gates: Growing Around the Barriers to Diagnosis in Autism, ADHD and SpLDs

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Abstract

Disability Studies and Educational Psychology tend to construct autism, ADHD and dyslexia as specific, universal neurodevelopmental disorders. A person is thus autistic, or not; dyslexic, or not; has ADHD, or not, in line with the binary logic which also produces modern concepts of neurodivergence and neurotypicality. However, some do not fall neatly either side of the diagnostic line, but land half-in, half out, giving the line an ontological wobble. This paper explores the experiences of adults who consider themselves autistic, dyslexic, or to have ADHD, despite being told that they fall short of a diagnostic threshold, or that assessment is inappropriate or unavailable. It adds to the gathering momentum in Critical Disability Studies which questions the givens of psychopathology and centres 'becoming' rather than static, 'neuro-identity' as core in understanding human experience. The becoming of those living in diagnostic borderlands can be welcomingly disruptive of those arborescent façades constructed in Western edu-psy-disciplines, and increasingly transported around the globe.

Keywords

critical educational psychology – critical disability studies – autism – ADHD – dyslexia – diagnosis – identity – neurodiversity

Introduction

Existing literature critiques the 'nature' of diagnostic categories of neurodevelopmental disorder, and the sometimes contradictory and problematic discourses they invite for describing human being (Beeker et.al.

2021; Timimi & Leo, 2009; Mallet & Runswick-cole, 2012; Mills, 2014; Cameron & Billington, 2015a, 2015b; Collinson & Penketh, 2010; Rose, 2003; Elliot and Grigorenko, 2014; Burman, 2008). There is also a growing literature written by autistic people which, through exploring personal experience, both emphasises the positive and emancipatory aspects of diagnosis (e.g. Bascom, 2012; Beardon & Worton, 2017; Hendrickx & Salter, 2009) and which questions the value of diagnosis (e.g. Gardner, 2011, in Timimi, Gardner and McCabe, 2011, pp.16–27; McCabe, 2011, in Timimi, Gardner and McCabe, 2011, pp.27–33). Furthermore, what can be experienced as a positive in diagnosis (the provision of an explanation, access to resources at school and university, and a release from personal blame for difficulties: Fleischmann & Fleischmann, 2012; Beardon, 2021; Stone & Dekko, 2019; Cameron & Billington, 2015b), may hide a potential for harm (Brinkmann, 2014, 2016; Jutel, 2011; Cameron & Billington, 2015a&b; Sjöberg, 2017; Timimi, 2014). The diagnosis offers the individual a new story through which to make sense of themselves and others, but, Sami Timimi explains,

... I feel labels like ADHD and autism have a life of their own, narrowing people's expectations of the labelled (including the expectations of the person with the label) into a kind of "autistic" (if I can be ironic) tunnel vision and a place where, as far as I can see, it must be difficult at times to feel at ease and accepting of yourself, given that these are definitions of deficit.

TIMIMI, GARDNER & MCCABE, 2011, p.41.

If, as this literature recognises, '[t]he diagnostic moment is simultaneously transformative and contingent' (Jutel, 2011, p.1), what is it like for those who seek such a transformative moment, for those who have carefully researched the given diagnostic category and yearn for its explanatory power, but for whom the experience is denied? This group of people understand their challenges and experiences are similar to those who have been diagnosed; but they are told 'no' – that story is not yours. This may be because diagnostic assessment has been out of reach, or because they have been assessed as not quite meeting the threshold for diagnosis. In the former case, the uncertainty about who you are may persist for a lifetime, and in the latter case, being diagnosed as 'not' (not autistic, not dyslexic, not attention disordered) can be as much 'fraught with symbolism' (Fleischmann, 1999 in Jutel, 2011, p.2) as being diagnosed 'with' (Cameron, 2021). For some participants, it was the school system and actors within which constructed alternative explanations to describe the 'problematic' characteristics (e.g. 'naughtiness', 'inability', 'laziness'). For those whose human

'kind' (Hacking, 2007) is contested, for those who are positioned as difficult to educate, as delusional, as inept, as unable, the gatekeeping of neurodivergent membership changes the possibilities for who those individuals may become.

This research seeks to understand lived experience at the borderlines of diagnosis and also to follow the possibilities for becoming in these borderlands in a life not yet entirely anchored by the 'explanatory power of a fictional concept ...' (Timimi, p.41). Here in this paper, considering autism or dyslexia or ADHD to be 'fictional' concepts is to borrow from Deleuze's ontology (1988, 1995). From this position, the realness of autism, dyslexia and ADHD is produced by the interaction of discourse and materiality at a given time, rather than by an autism, dyslexia and ADHD as essential, universal and timeless truths (Rajchman, 2000). This work has particular relevance to critical disability studies within education, given that 'disordered' learning, communication and behaviour come so reliably into being in educational spaces, from preschool through to higher education. The hope is that this paper adds helpfully to the rising theoretical wave within critical disability studies and education (Goodley et al, 2021).

Methods and Theory

This research brings together Interpretative phenomenological analysis (IPA) (Smith, Flowers & Larkin, 2009) with a Deleuze and Guittarian concept of rhizomatic becoming (1988). The former shaped my approach to interviews with adults living in the diagnostic borderlines of so-called 'specific neurodevelopmental disorders'. I asked participants to talk about their experiences, their feelings about these experiences and about the sense they had, or could make, of these feelings and experiences. An IPA interview, in its hermeneutic ins and outs, is a space where older sense-making can be retold, but also where new sense making and realisation can happen, and where different stories can be purposefully raised up to view past and present experience. A story may be centred or set temporarily aside, to create new possibilities for sense-making. In analysis, I built a sense of the ways in which participants centred desired or degraded identities, and more specifically, a sense of the insecurity in their positioning as a particular kind of person (e.g. as an 'autistic person' or not). Living from this position appeared to be difficult, and pressured, and full of push. Deleuzian ontology, particularly the idea of rhizomatic *becoming* (Deleuze & Guittari, 1988) enabled me to decentre 'identity': to loosen the concepts of identity constructed in initial analysis from their 'moorings' (St. Pierre, 2004, p.293). In other words, an IPA analysis allowed a co-construction

of particular themes centred around experience which felt limited to a consideration of social constructed or interpreted 'being', and the introduction of Deleuze and Guittarian *becoming* enabled a hopeful shift.

Participants

Of the thirteen adult participants, twelve came from across the UK and one from New Zealand. The New Zealander was keen to take part, and given the diagnostic systems and practices are similar in both places, their inclusion did not seem problematic. Table 1 below indicates the participant connections to particular diagnoses. Some participants contacted me to express interest in

TABLE 1 An overview of participants' connections to the relevant diagnoses

Pseudonymised participant	Connection to diagnosis
Hadrian	GP and psychiatrist denied assessment for ADHD .
Elesha	Experienced GP and family/cultural resistance for her desire for assessment for autism for a long period.
Samaria	Experienced institutional resistance to desire for an assessment for ADHD .
Mark	Put off going for an ADHD assessment
Emma	Denied autism assessment by GP
Katherine	Did not meet threshold for autism diagnosis following assessment.
Ben	Waited 30 years for ADHD assessment
Eleanor	Denied assessment for dyspraxia and ADHD by GP.
Xena	Put off going for a dyspraxia assessment after family resistance
Thomas	Did not meet threshold for dyslexia diagnosis
Trevor	Denied diagnosis of ADHD
Damien	ADD diagnosis overturned and replaced with mild learning difficulties
Petra	Did not meet threshold for autism diagnosis following assessment. Denied assessment for ADHD by doctors.

taking part in the research having seen a social media post about the project, whilst others contacted me having heard of the project via word-of-mouth. Each participant was offered the opportunity to reflect upon the analysis of their transcripts and to comment, or to agree, disagree or object. Participant comments were encouraging and no requests for change or omission were made. Ethical approval for the research was given by Manchester Metropolitan University, UK (Ref. ED-1617-049) and confirmed by The University of Sheffield, UK (which became my home institution during the early stages of the research).

I did not ask about participants' ages, sex/gender and race unless they brought these up themselves. This was purposeful. Race, age and sex/gender are considered in the analysis only where participants drew upon these in their stories, or to make sense of their experiences. It is important to note that it was the two participants (Elesha and Samaria), identifying in interview as black and mixed-race respectively, who foregrounded intersections of race and disability. Racialisation is almost certain to have interacted with all participants' experiences, but it is likely that the intersection was less noticed by those racialised as white (Annamma et. al. 2013; Cameron & Greenland, 2019). Gender, similarly, is likely to have been more salient for the female participants given diagnostic descriptors have been constructed around a male norm (e.g. Zener, D). I have used 'he' or 'she' in line with the way participants referred to themselves during interview and have chosen pseudonyms accordingly. None were in full-time education other than Eleanor. Samaria had recently completed her university course.

Interviews

The interviews each included core, and usually very broad, open questions with wording such as 'can you tell me about your journey in connection to [named] diagnosis?'. Follow-up questions pushed for depth: 'what was that like?' 'How did that feel?' and for sensemaking: 'why do you think you felt like that?' 'How do you feel about it, looking back?' and 'why did that matter to you?'. In this way we shift from a description of a moment, of a period, or of a series of events, to the way they were experienced, and to how these experiences can be understood from different positions. The interpretative and constructionist element of this form of phenomenological analysis is critical. The question is of possibility – what *can* this be like within this relational context (Billington et al, 2022; Cameron, 2020)? What sense *can* be made of this? Who *can* I be or become in this? A value of work like this lies in how those experiences and the connected possibilities resonate with other people across contexts and time, rather than in a pretence of traditional generalisability (Smith, 2018).

Theory

I then leant into theories of *becoming* (Deleuze & Guattari, 1988; Braidotti, 2006; Hacking, 2007) on noticing the ways in which participants pushed against the more available categories of being, and grew, or *became*, around obstacles in surprising and creative ways. Whilst different in their ontological stance, interpretive and rhizomatic positions both ask about relations between people and the world and both reject the essentialist, computational notion of 'mind' that dominates western psychopathology (Rajchman, 2000). Relational being and becoming mean understanding distress, disability, and disorder as woven within and produced by the social-environmental-material tapestry (Nsamenang, 2006), and not as the consequence of an individual mind/brain gone 'wrong'. Where interpretivist, or social constructionist approaches differ from rhizomatic thinking is in their neglect of ontology, or of what Deleuze might call the 'real' (Rajchman, 2001) incorporating the material as well as the discursive. What I have taken from Deleuze and Guattari's work, primarily from their writing on rhizomes (1988), and from others' writing about this writing (e.g. Goodley, 2007; Braidotti, 2006; Rajchman, 2000, 2001; May, 1996) is their ontology. I have borrowed their idea of the dominance in the west of 'tree-like' thinking, with its limiting binary logic; and the value instead of the 'rhizome' as a metaphor for human 'becoming'. The rhizome '... is composed not of units but of dimensions, or rather directions in motion. It has neither beginning nor end, but always a middle (miieu) from which it grows and overflows' (1988, p.21); it is a 'conjunction', and 'and ... and ... and' and as such it does not 'be', in a static sense (1988, p.25). The only thing that 'exists' persistently through time is what Deleuze calls 'difference' (May, 1996); as such there is no 'identity'; only becoming. Doing ontology, therefore, is 'to be able to take up a certain viewpoint toward the world in order to engage in certain ways of living' (May, 1996, p. 294). This concept was useful in recognising that whilst the participants talked about yearning for an autistic identity, for example, or about feeling stuck in a 'just useless' identity, they were busy outgrowing the binary either/or altogether, in part because of their location in the diagnostic borderlines.

Deleuze & Guattari inspired my choice to use the strawberry plant as a metaphor for the ways participants grew before the 'gates' to diagnosis and for the way they came to trouble the neurotypical-neurodivergent binary. Strawberry plants have tree-like and rhizome-like qualities (I risk accusations of misuse of the metaphor, though am encouraged by Rajchman, 2000 on Deleuze's generosity in the face of others' play with his ideas). They grow leaves and flowers from branches off a main stem; they also send out runners. A runner, at first a shoot from a main plant, lands on the earth and makes new roots, and then becomes a new plant. In this aspect it escapes the original

plant, which itself may have escaped another, and is thus different from a tap root. It is an 'and ... and ... and' (Deleuze & Guattari, 1988, p.25). Yet the tree-like aspect of the strawberry plant remains important too, in recognition of the 'western' grooves into which our sense-making, as participants and researcher, most easily fell into and which are imposed upon us as we are 'set straight' (Deleuze & Guattari, 1988, p.14) by education, by psychopathology, and by diagnostic practice (you either *are* or *are not* autistic, dyslexic, proclaims the psychologist, and I get to say!). In analysis here, the rhizomic aspect opened the possibility for constructing themes from participants' experiences which were not bound in a passive *being*, or victimhood, but in agentic *becoming*. As Goodley's presentation of parents of disabled babies as 'rhizomes' (2007) the participants here, '[strawberry] runners at the gates', are likewise making 'lines of flight' (Goodley, 2007, p.14) around, under, between: 'and ... and ... and': hopeful, liberatory, agentic.

Findings Following Interpretative Phenomenological Analysis (IPA)

The key findings below: yearning, despairing, learning, oscillating, and battling/waiting/battling/waiting, should not be seen as chronologically experienced.

One: Yearning

Each of the participants yearned for 1. Acceptance, whether that be by immediate or extended family (especially parents), friends, peers, teachers, workplaces, oneself, or wider society, or by all of these; 2. Understanding and explanation for difficulty, both their own understanding of themselves and others' understanding of them; 3. A positive identity and a feeling of belonging: to feel like a valued, welcome and rightful member of a community, to have an answer to the question 'who am I?' that is graspable and good. Diagnosis was seen as a means to fulfil one or more of the yearnings above, and so diagnosis itself became the overarching object of yearning. For most participants (especially those seeking a diagnosis of autism and ADHD) this yearning was a part of everyday life, and this was hard to bear. There was one participant, Mark, who yearned for an explanation and for understanding, but had come to the opinion that he did not want a diagnosis (or perhaps feared not being given the diagnosis if he tried). And another, Thomas, whose yearning did not seem to have seeped into the everyday, and manifested only as a desire for access to educational resources in specific contexts.

Two: Despairing

Despair grew alongside a feeling of powerlessness in the face of the ignorance, and resistance of individual GPs, psychologists and teachers, and the incomprehensibilities, inconsistencies and snail-like pace of healthcare and educational systems. Participants felt that uninvested, rushed and dismissive professionals had a greater say in who they were allowed to *be* than they did themselves. The sense of unfairness, not being listened to, and the subsequent desperation were an incredibly strong one in most of the interviews, and this appeared to be expressed as a kind of grief. Again, Mark and Thomas are exceptions here. Mark had come to consider self-diagnosis was all he needed or wanted, and his despair was confined to a past before he realised the explanatory potential of self-diagnosis, and Thomas felt frustration, and annoyance, but not despair. The question of why these two stood out in this, I will return to in the discussion section below.

Three: Learning

Although participants often felt like giving up, they universally did not. Whilst what felt like rejection by professionals, family, friends, and/or the system was hurtful and exhausting, and required time to recoup, it appeared to spur action. Participants read popular books, academic literature, made alliances, joined online communities, and rejoined the fray better armed with different knowledges. They used some of this new knowledge to open up conversations with family and friends who had been dismissive or unwilling to consider the participant might be diagnosable. During this process they learnt more about how others saw them, and they also noticed how other people who were behaving in ways considered 'abnormal' (e.g. a someone having a 'meltdown' in the supermarket) were treated. The learning appeared connected to greater compassion for others.

Four: Oscillating

Most of the participants oscillated between relative confidence in self-diagnosis (especially after periods of active learning about the diagnostic category), and feeling like a fraud. The power that professionals had in proclaiming the 'truth' of a participants' diagnosis was strongly felt, and despite trying to resist it, it was hard for most to be confident in their self-diagnosis all of the time. This was hardest for those who had been diagnosed as 'not' (not dyslexic, not autistic etc) and had become less pronounced for those who had eventually received a formal diagnosis. Participants also oscillated between feelings of pride in being a person with a diagnosis, and feeling shame in this. However, the shame in being a person with particular challenges without the desired diagnosis appeared to be greater. Participants also yo-yoed between the feeling 'I can do

this' and 'I can't do this anymore'. The journeys for most of the participants had been and continued to be emotionally exhausting.

Five: Battling, Waiting, Battling, Waiting

Some participants had been through assessment and been diagnosed 'not' and were either seeking reassessment or had decided to consider the assessment inaccurate in its conclusion; some were stuck in the system, waiting for referrals having been 'fobbed off', or having been placed on very long waiting lists; and some had eventually received their desired diagnosis. Mark had decided not to pursue formal diagnosis at all. But on the whole, participants had had to battle individuals and systems repeatedly, and had experienced very long waits in between or during these battles. Diagnostic assessments are high stakes affairs, especially if one feels one's identity is to be damaged or affirmed in the outcome. Thus waiting in this context is hard: like holding your breath. It also requires one to place trust in systems and individual professionals whom have sometimes shown themselves not to be trustworthy. For some participants this appeared to be traumatic.

Discussion: Runners at the Gates

This section uses the metaphor of a strawberry plant to frame the ways in which the participants' yearning, despairing, learning, oscillating, battling and waiting discussed above catalysed the growth of new 'lines of flight', new

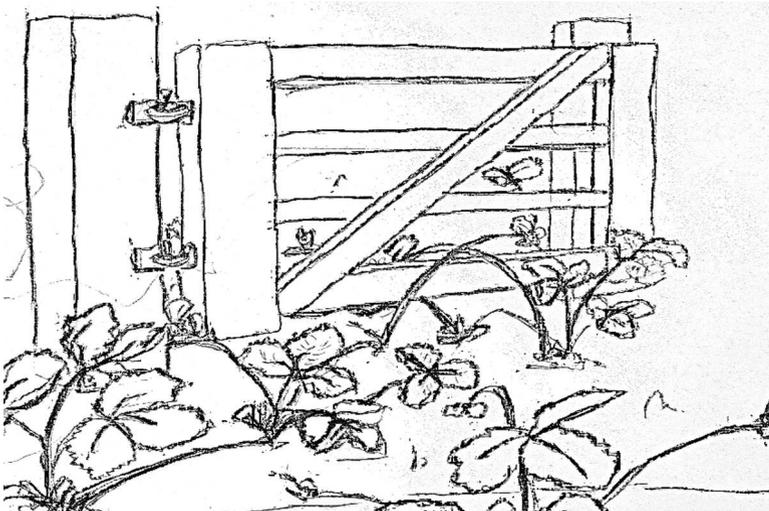


FIGURE 1 Sketch of strawberry runners arriving at and breaching a gate.

'runners' seeking fresh ground and different possibilities for becoming. The strawberry plant with multiple 'runners' is chosen to represent both the binary, tree-like expectations and categories offered by relevant social systems, as well as the rhizomoid possibilities of escape from those binaries. The strawberry plant, as the participants, meets the closed gates to desired diagnosis and imagined identity, but ultimately, the gate cannot contain the runners' hopeful protrusions (Fig. 1). Each runner seeks new ground from which to escape the original plant, bound as it is on its spot one side of the gate. The two themed sections forming the discussion are as follows: 'arriving at the gates to diagnosis' and 'sending out runners: back, under, over, around and between; growing off the beaten track'.

Arriving at the Gates to Diagnosis

Gates to Assessment: 'You Don't Have It!! ...' '... for God's Sake, You're Just Nuts!'

The gates for the participants of this study were various, and were met at different times and spaces. Primary and secondary schools, universities, families, workplaces and other social spaces (the systems, structures, ideologies and individuals within) were presented both as spaces where the feeling something was 'wrong' grew and spaces which themselves constituted the closed gates. Rhizomatically speaking, these gates may first be seen as catalysing 'knots' blocking new growth.

Firstly, participants became 'problems':

I was identified as a problem at school, they just didn't know what it was.

HADRIAN

I used to go to [school] discos and sit in the corner while all my friends went off and snogged people, I used to sit in the corner and be there still and silent for the entire disco.

BEN

I thought just, there's something wrong with me, I just thought: this is my personality I have lots of little bits not correct..

PETRA – on not making friends from school onwards

The categorisation of the problem for the participants here was tightly controlled at home and in education: access to names like 'autism', 'dyslexia', 'ADHD', and 'dyspraxia' were heavily guarded. Access to other names such as 'trouble-maker', 'clumsy', 'hopeless', 'slow', 'insane or in-pain', 'aggressive' 'lazy',

'disorganised', 'odd', 'a bit rubbish', 'no stickability', 'crazy', 'just nuts', 'a non-achiever', 'a disappointment', 'a bitch', 'awkward', 'on drugs' and 'a potential career criminal' were freely offered. Participants came to understand that from their roots up, either the essence of their character or an aspect of their innate cognitive ability was problematic, disordered, undesirable, or flawed. Being 'normal' was not possible.

A shared gate for Elesha and Samaria in educational contexts was an unbearable, unjust set of institutional and social rules which constructed them as badly behaved, rebellious, anti-social, odd, over-confident, inadequate and problematic. Both Samaria and Elesha, as black or mixed race girls and then young women, had to manage the whiteness of school spaces, where they met racist constructions of black girls as inferior and disruptive (Phoenix, 2009). This racism intersected with the marginalisation these two participants experienced in connection to differences in learning and communication in comparison to the 'norm'. Later Elesha and Samaria would respectively self-identify as autistic and as experiencing ADHD, but in school they were named as naughty, aggressive, rude ('I was rude as hell' – Elesha), and hard to handle. Samaria explained:

My mum ended up being told [by the school] she had two troubled teenagers [referring also to Samaria's sister] and all this, but I never thought we were that bad, and I think we were just misunderstood.

Whilst in early adulthood, whilst at University, Samaria found a supportive GP who suggested ADHD assessment, it was a University mental health support worker who refused to write a letter of support for the assessment, angrily dismissing the possibility of ADHD. In the meantime, NHS assessment waiting lists in themselves were a barrier. Samaria was told by the GP that she needed to write an exaggerated account of her distress: 'you have to make it sound urgent, like you're really not coping'; and after writing such a letter faced the disdain of the earlier mentioned mental health support worker who would not support the account.

Individual teachers, family members, friends, support staff, GPs, psychologists and psychiatrists often appeared as gates or gatekeepers in the participants' stories. These individuals were frequently described as being angry, exasperated, and incredulous at the participants' identification with a given diagnostic category. Below Emma describes her GP's reaction after Emma asked her again if she could be referred for an autism assessment (capitals indicate Emma's oral emphasis, three dots indicates speech which has been omitted for clarity):

... she [the GP] got angry with me ... She got REALLY angry, she said EMMA! I am TELLING YOU. ... she said EMMA I'M TELLING YOU I have patients with autism all the time and you DO NOT HAVE IT, and I said but you don't know me, you don't know me at home. When I come to you, I'm fitting in with society ... and she said, DON'T be so RIDICULOUS. ... and she said, JUST how you're speaking to me NOW, you HAVEN'T GOT AUTISM.

Trevor was initially blocked by a psychiatrist in his request for an ADHD assessment because the doctor considered he was 'doing fine' and therefore did not require one. As it had been for Emma, the practitioner had no idea how difficult life had been for Trevor, yet made a judgment on the spot:

I really found the psychiatrist hard to deal with, she was very, almost contemptuous, to say well ... you don't have any significant issues, this isn't holding you back in life, you're doing fine, so why are you here?

The situation was similar for Eleanor when seeking a dyspraxia assessment:

the GP tried to, you know, sort of well, brush me off really, with the fact that I've got this far in my life, you know, why did I want a [dyspraxia] diagnosis?

For Emma, Trevor, Elesha, Hadrian, Damien ... professionals judged the challenges faced to be due to mental ill-health and instead diagnosed depression, and prescribed anti-depressants or beta-blockers. Here is Elesha, followed by Emma:

it's so difficult because my doctor's only diagnosed me with anxiety and depression, but with my history of things, I know that it's more than that as well, and they just wanted to fob me off with pills ...
[the GP said] 'well first of all, let's get you on these anti-depressants' and I was saying 'I don't need anti-depressants, that's not what, I don't, please stop throwing tablets at me'

Being 'fobbed off' with pills was a common description of treatment by GPs by participants in this research. Some felt that the GP's hadn't properly informed them of side effects of the medication, and felt that offering pills was a way of ignoring potential autism or ADHD. For Hadrian, on the other hand, not having a diagnosis of ADHD prevented his GP from prescribing him the pills he felt he

needed. After her GP refused to consider ADHD as a possibility, Eleanor has not returned to ask again as she feels she will only meet further resistance – but her sense of yearning remains. For Petra, her difficulties were put down to a pre-existing medical diagnosis. It was considered for her that one label was sufficient.

Individuals with power as gatekeepers within the British NHS (and the equivalent in New Zealand), whether supportive of these participants or actively resistant, worked within systems which participants variously described as inconsistent, inadequately resourced, dogmatic, prone to administrative errors, slow, bogged down by clashing agendas and poor communication both between and within departments and with patients (issues reflected in the literature, e.g. Hayes et. al. 2022). For example, one of the multiple times Hadrian was denied an ADHD assessment was reportedly because his particular region demanded a pre-existing childhood diagnosis as a condition for adult assessment.

For Elesha, Eleanor, Samaria, Xena, Emma, and Katherine, the resistance from family to finding a formal name to explain their experiences sometimes led to despair. For Elesha, wariness of (white) professionals, and community-centred worries about the shame of being labelled as psychologically ‘disordered’ coincided to produce multiple gates in her quest for an autism diagnosis. She explained:

We take on this thing, as black people, like you have to kind of bear what’s given to you ... you don’t talk about it, you just kind of carry it, and you deal with it by yourself, or deal with it with god.

it’s either you’re classed as something spiritually is wrong with you, or you are just going a bit mad, and there’s no kind of happy in-between

For most of the women in this research, one or both parents, or other close family members were simply dismissive, and did not want to engage in a discussion about autism and ADHD. This encourages self-doubt and oscillation in confidence around self-diagnosis:

there were a lot of times when I asked my mum to take me to the doctors cos I knew something wasn’t quite right, but she never really listened to those.

ELESHA

they go ‘NO YOU’RE NO’T. You Haven’t got autism, for GOD’S SAKE, you’re JUST NUTS’

EMMA on her family’s reaction

They knew there was something wrong with me ... basically they saw me as perhaps, lazy I was lazy or I had no stickability..um, those were the kinds of labels that were pretty much, or they were, it wasn't it wasn't overt, it was covertly sort of ...: I was covertly deemed as being a bit lazy, a bit hopeless, a bit you know, just rubbish, basically

XENA on her family's reaction to the suggestion of dyspraxia

You get a lot of um, oh "oh NOW you you don't SEEM autistic, Noo, oh EVERYBODY's like that, um, you know it's just a matter of confidence." And that, that hurts.

KATHERINE on workplace peers reactions

The gendered assumptions around autism (Hendrickx, 2015) were noted by women in this study, and were recognised as a barrier to diagnosis and understanding across contexts.

Gates to Diagnosis: 'Not Enough for the Tick Box' and Missing Jigsaw Pieces

A number of participants (Katherine, Thomas, Trevor, and Petra) underwent diagnostic assessment but did not meet the given threshold for diagnosis; whilst Damien was diagnosed with ADD, a diagnosis he didn't feel was correct, and which was later retracted.

I just got [a diagnosis of] dyspraxia, and I was told, I was so close for dyslexia, but not [close enough] and if you've got one [one other diagnosis], that will do.

THOMAS

They don't think that I have it, they said I had spectrums of it, and traces, but, not enough to produce like a full diagnosis [of ADHD and/or autism].

PETRA

[The assessment for autism] was all over in ... an hour and a half, and [the assessor] talked about the very classical male traits and eventually she said um I had some every strong traits, but I didn't have enough of them ... She said she compared it to a jigsaw, and she said whilst I had a lot of the pieces, I didn't have the four corners.

KATHERINE

what [the psychiatrist] said exactly was ... that I had [had] childhood attention deficit disorder, and that had resulted in learnt behaviours that I'd carried forward as an adult, that I [should be able] to unlearn

TREVOR – denied a diagnosis of current/ adult ADHD following assessment

I just didn't feel [the ADD diagnosis] was appropriate, um, I I yeah, I felt in my gut almost, in my heart that it didn't really feel right and I didn't know why what the reason was, it just didn't really it just didn't really sit well with who I thought I was as a person

DAMIEN – who identifies as dyslexic, not as someone with ADD

For those participants who were diagnosed as 'not' dyslexic, autistic or as not having ADHD, it was harder to claim a belonging under their desired category. Other than for Thomas, being told they did not meet the diagnostic criteria for the given diagnosis was extremely distressing, and in some ways, worse than if they had continued with the uncertainty felt prior to assessment when the possibility of future diagnosis remained (Cameron, 2021). As Katherine said 'it is worse than not knowing at all'. Petra explained that the experience of being told she had 'traces' of autism or ADHD 'but not enough' did not match at all with the difficulties she faced in everyday life. 'Traces' suggests something had passed through Petra, leaving a trail behind. This odd image reinforces the idea of autism and ADHD as a discernible 'thing' within, an appendage (Sinclair, 2012); but in this case, a 'thing' which only passed through. Petra now sometimes explains to others that she 'has 'traces of autism'; even though she feels she is actually autistic. The idea of a 'little bit' of autism can be offensive to autistic people (Beardon, 2021), which thrusts people in Petra's position into a difficult space: one which proclaims that you either are autistic or you are not; 'traces' are not possible here – back to the binary. This can be distressing, as other people are unlikely to understand that Petra's 'traces of autism' is not the same as another person's flippant and dismissive, 'I am a little bit autistic, too'. However these spaces of denial to the object ones yearning are arguably part of what stimulated the growth, new 'runners', or lines of flight to new ways of framing and understanding who they might become (see theme two).

Thomas's diagnosis as 'not' dyslexic appeared more as a source of annoyance than as a cause of distress more broadly. Thomas had hoped to have access to specific educational resources and supports (Cameron et al, 2019); however many of these he was able to access because of his prior diagnosis with dyspraxia. Thomas did not seem to desire a dyslexia label as a means to belonging, and, unlike the other participants, did not appear to consider dyslexia or dyspraxia to be essential parts of his being.

A Note on Fear, Stigma, and Time

Whilst the most prominent gates to assessment or diagnosis were those described above, it is worth noting the hands of fear, stigma and time also holding the gates closed. The fear of ‘what if I am not?’ loomed large for some participants. Katherine explained:

I'm frightened, I'm frightened now of going again and still being told “you're not autistic ENOUGH!” hahahaha. [That's] a terrible thing to say to somebody.

And here is Hadrian describing the moments just before he received his positive diagnosis after a very long wait:

I was genuinely petrified that [a diagnosis of no ADHD] was going to happen. I was petrified. It was going to be like that first time I went to see the doctor, and they'd say to me, you're kidding yourself on, you're looking for an excuse for the fact that you are too lazy to live life well ... and it was actually the fear was so high, that when she did say that I had ADHD, again, I started crying ... just because the level of relief I felt was so high.

This account is reflective of the degree of investment many have in the diagnosis. It can have a profound personal meaning. Without the diagnosis, the person can inhabit a limbo in which it feels to them that their moral character, their value, their integrity, and even their humanity is up for question. For Xena, the disappointment her father felt in her fed her desire to have a diagnosis so he would change his opinion about her and love her. She explained:

I didn't have any love, because he just thought I was rubbish ... [so] a diagnosis would be good, because I could say “dad you know, look, I've got THIS,” whether it is dyspraxia, or it's, you know, adhd or or whatever, at least then you can signpost them to somewhere where they can read and just think that it's not just a figment of my imagination.

Hadrian explains that, if he had received the answer that he did not have ADHD, then he would have seen his differences and struggles ...

... ‘not [as existing] because of the fact that I am wired differently, but because of the fact that I ... am a failure because I couldn't make myself do the things that other people could do; not because I wasn't able to do them, but because I was too lazy ... without being able to see into

somebody else's head, how could I make the assumption that they hadn't tried harder?'

The power of the psychologist or psychiatrist as judge in this context is immense, and alongside the personal investment in the outcome, this makes the undertaking an assessment the more terrifying.

The passing of long stretches of time without assessment or care from the system exacerbated anxiety and harmed participants' mental health. The longer the wait, the more professionals put down growing anxiety and anger to mental ill-health, and the more anti-depressants were prescribed. Meanwhile, assessors are bound by the same binary logic, institutional pressures and service-users stories, desires and distress (Hayes et al. 2022). However, as I explore in the second theme, this often unbearable position as neither one 'thing' nor another pushed out new growth to challenge the binaries on offer.

*Sending Out Runners: Back, Under, Over, Around and between;
Growing Off the Beaten Track*

Despite feelings of despair, and sometimes feeling as though there was nothing they could do, none of the participants in this study appeared as passive objects in the stories they presented. Just as the strawberry plant sends out runners, the participants grew around the barriers presented in creative ways to create new possibilities for themselves. They pushed back against the power of professionals and systems, and grew in the no-mans-land between binary diagnostic categories. They became simultaneously autistic and not autistic, dyslexic and not dyslexic, or persons with and without ADHD, oscillating, never still. The *becoming* happening in this neither/nor space did not appear to be one of victimhood. It pushed growth in new directions, off the beaten path.

Becoming a Force for Change

There was a mismatch between the statements around loss of hope in the interviews, and the actions participants described taking in order to grow around the challenges they were presented with. For example, although Elesha explained 'all I can do is really wait [for the diagnosis] ... literally that is the only choice I have', her description of her actions and determination contradicted this. Elesha read extensively, and rooted her learning in histories and cultures of the Black British community; metaphorically speaking, she sent out runners into new ground to help make sense of her situation and to find possibilities for becoming beyond the constraints of the health and education systems. Her learning through research and conversations with others appeared to strengthen her resolve to change things for her community. She talked to

people about the intersections of race and autism, and the challenges around diagnosis, because she was experiencing those challenges herself.

I think that those conversations SHOULD be had ... um, because I think you'd find that there's a lot of people that are going through the same things, but either never had anyone to talk to about it, or never actually knew what it was that was happening with them

I feel like it's [difficulties with diagnosis and recognition of autism in the black community] even more a reason to speak on these issues and to speak on the fact that there are a lot, particularly young women, they get overlooked for mental health difficulties and for learning difficulties as well.

Whilst Elesha was probably the most active in this regard, purposeful reflection, resistance and re-storying were present in the other participants' experiences, too. In other words, the lack of diagnosis pressed participants to think deeply about the potential meaning of diagnosis and non-diagnosis in their everyday social contexts, and to rewrite the story they had been presented with. It also led them to support others who were going through similar struggles whether or not their struggles were connected to a label of neurodevelopmental disorder. Eleanor, as another example, felt that learning about dyspraxia and ADHD and dyscalculia (even though she was denied assessment for these) had made her ...

much more self aware, um and aware of other people's ... aware of all of our differences, and ... I feel very strongly about sort of promoting awareness of neurodiversity amongst my peers, you know. I'm sure they get sick of me banging on about it, but I think that every day if I can change the way that someone understands the way that other people behave, even if it's just some one who serves you in a shop, or something like that you know, it's so easy to make negative comments about people, but actually if we start to understand where they're coming from they are maybe not bad or mean or rude or ... or any of these things, then that's a really good thing, so for me it's about engendering understanding.

The difference between the motivation to understand other people appeared to be general, and not just about people who were diagnosed, and perhaps this general acceptance of others is sought partly because one cannot know for sure who is autistic or dyspraxic, etc, and who is not. Thus, there is a focus on

accepting and celebrating different behaviours and ways-of-being in the world regardless of diagnostic status.

Self-Diagnosis, Disrupting Institutional Power, and Growing between Categories

Resistance was apparent in all participants' reflections. Most participants looked for acceptance via diagnosis, found this denied, but would then reflect and reassess and at least some of the time found they could say 'no'. This 'no' might be directed at a GP, a psychiatrist, a sibling, a parent, a colleague, a teacher or a system. Through their own research and self-diagnosis, and connection to the neurodiversity movement online, participants could access a story which helped to explain the challenges they had faced in their lives, and they found that, sometimes, they could claim this story without the permission, via diagnosis, of a professional. Below Emma uses a discourse of autism (masking) and modulates how she connects to diagnosis ('presenting' as an autistic person, rather than 'being' an autistic person).

When I'm indoors [at home] I am not going to say I am very autistic because I don't know, but, I very much present as an autistic person and when I go outside I am the world's best masker

Emma described feeling similarly to a gay person who has yet to 'come out'. Whilst she says 'I couldn't possibly come out and say "I've got autism" if I haven't had a diagnosis' she manages self-diagnosis obliquely, and is able to be open about her self-diagnosis with her partner and children (some of whom have been formally diagnosed as autistic). She describes being part of her own little autistic community at home. Katherine achieves something similar in her account. Whilst she describes the feeling of rejection following a diagnosis as 'not' autistic:

Here we go again. I've had so many diagnoses, and here was a, I still hadn't found one that fitted. Um and then, I felt very frustrated and angry and then, really just, sad. Sad that I felt locked out again, rejected, not accepted into THIS group, either

... she describes a reclaiming of the diagnosis in subsequent years:

I've gone on in the last 7 years to read a lot more about autism in women, and there is absolutely no doubt in my mind that I AM, well I say that, until I get a diagnosis, I can't be sure, which annoys me because, I mean,

why should it be down to somebody else? you know, I'm the one who's living with it, but anyway. I am absolutely autistic, I KNOW I am.

Trevor's experience echoes Emma's. At first accepting the doctor's dismissive reaction, and ...

it wasn't until I started picking up the books again and thought, you know what, that it it's just not working, I need to go back and explain the circumstances again and see if there is an alternative diagnosis, or [something else] or ... or has thinking changed, or was that guy talking drive? ...

After sufficient research, Trevor self-diagnosed with confidence:

Oh I Oh I I KNOW I am, [I mean] there's no doubt about it.

And after a time, Trevor began to feel he did not want or need to have a formal diagnosis – the space in between was one where he felt more secure, especially in the workplace. Thomas, similarly, managed to *sort of* identify with dyslexia even though he couldn't bring himself to do this entirely. The result is settling into a contradictory – 'I am but I am not':

I definitely feel an imposter with dyslexia. I count myself in it, but I know I'm not.

Eleanor appeared also to openly label herself with AD(H)D or dyspraxia in certain contexts, despite not having a formal diagnosis and being denied assessment by the GP. She found it useful to laugh and say 'it's because I have ADD):

It [telling friends she is dyspraxic or has AD(H)D] HAS made a difference ... you know, I don't have to feel embarrassed anymore, whereas I used to feel VERY embarrassed

Interestingly, too, the lack of a formal diagnosis potentially allowed these participants to distance themselves from the medicalised and stigmatised language of deficit and disorder and to connect more flexibly to different constructions of the given diagnostic category (sending runners around the gate), or even situate themselves between a range of different categories (multiple runners either side of the gate). Petra, for example, saw a benefit

in not being labelled as having 'special educational needs' at school because of the stigma she perceived to be connected to that term. Xena most strongly identified with a dyspraxia diagnosis but without being diagnosed she felt she could freely shift that identification to ADHD or to autism when that made most sense. For Ben, learning about the ADHD category was a conversation starter that led him to feel included in the neurodiverse community – but the lack of a formal diagnosis, he felt, enabled him to 'pick and choose' which aspects to connect to. Recognising positive differences in styles of communication with friends (e.g. through music); recognising strengths (e.g. greater creativity); allowing oneself to stray from the 'norm' (e.g. recognising and then enjoying ones hyper-focus); making sense of family relationships using a lens of ADHD; and specifically seeking out friends within the autistic community and finding affinity there, were all examples of how participants took on some of the affirming discourses around neurodiversity without necessarily having to take on an accompanying self-diagnosis as 'disordered'.

Mark felt that identifying sometimes as 'neuroatypical' and sometimes as 'neurotypical' (or somewhere in between) gave him a useful flexibility and humility. The former identification meant he had permission to 'go off on a tangent' and to celebrate having 'four ideas before breakfast' when that was helpful, and the latter identification helped him to focus upon commonalities with colleagues and friends, and to take shared responsibility for difficulties in relations with others. He felt that most people think they are not 'normal' and the value of placing people in the 'normal' or 'not normal' camp was limited. Mark, at this point in his journey, no longer wanted a definitive answer about his neurotype from a doctor. In embracing this in-between Mark was also saying 'no' to hegemony of the binary. He was sending his runner away from the gate entirely.

Conclusions

This paper has focused upon the voices of an often ignored group of people (both in practice and in the research literature) who find themselves on the borderlines of diagnosis. In doing so it highlights a far broader set of concerns around identity, becoming and belonging as a human in this period of global neoliberalism. In a world where humans seem increasingly likely to describe themselves, or be described by others, using binary neuro-centred discourse, the troubling of the seemingly natural divisions is important. I have discussed the ways in which he having or not having of a particular diagnosis interacts in complex ways with individuals' sense of themselves over time. Those

denied and/or awaiting diagnosis or assessment find closed certain direct paths to resources, support, self-understanding, desired identities, and social acceptance. However, this research indicates that those denied do not sit and shrivel at the closed gates: they read, question, resist, and reconceptualise and in doing so they grow around (over, under, between) the barriers they meet. In such growing they push against the presented binaries: dyslexic/not dyslexic (just slow at reading), autistic/not autistic (just 'weird'), attention disordered/not attention disordered (just badly behaved). In this analysis, their active self-reconstruction offers a collective resistance to the existence of the binary altogether (Goodley, 2007). For some of the participants, a calm was found in the diagnostic no-mans-land, which in itself begins to disable the 'us' and 'them' divisions that discourse around 'neurodivergence' arguably engenders (Runswick-Cole, 2014). In being denied what is perceivable as a stable identity the knots in the rhizome are perhaps loosened, or to go with my own chosen metaphor, multiple new plants (becomings) are possible. Here I echo Sjöberg (2017): '[t]he individual diagnosis works as a closure in an otherwise open becoming.' (p.612)

This conclusion should not be seen as a dismissal of the very real exhaustion, despair and distress many of the participants described. In no way is this paper suggesting that it is simply a 'good thing' for people to be denied entry into a diagnostic category. In fact, I would argue for an opening up of categories, particularly within educational contexts where people seem initially to become 'problems' and where labelling can crystallise. In other words, I call for a more substantial embrace of self-identification; a system which relies less upon psychometrics and medicalised diagnoses and more upon listening and acting upon individuals' requirements in given contexts whatever their relation to a named category. Notwithstanding this, the collective efforts of people such as those in this study fuzzy diagnostic lines in a way which I argue here is meaningful, liberatory and welcomingly disruptive.

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