From pathology to Affirmation: Disability Philosophy in Everyday Life

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ABSTRACT

This paper argues for an affirmative disability philosophy and research methodology. Even after four decades of critical disability studies, much of what we encounter in public spaces - in relation to disability - on a day to day basis remain untouched by this critical scholarship. With reference to composite narratives from two research projects and our own personal entanglements we consider dominant ways in which everyday philosophies of disability threaten to pathologise people with learning disabilities as objects and counter these by offering an alternative affirmative philosophy. We explore disability as affirmation; humane, unbounded, potential. This way of knowing disability should be a regular feature of common parlance and philosophical discourse and requires being informed by disabled people and critical disability studies scholarship. We explore the ways in which inserting disability-as-affirmation into everyday conversations and public life can have significant wider societal impacts through offering a more expansive philosophy of disability.

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1. Introduction

In this paper we join with others exploring how philosophical deliberation can impact on public debate and institutional practices (e.g. Boem & Ratti 2021; Casalini 2020; Kaushik 2022; Montalti 2024). Our philosophical interests reside in an aspiration; to improve the lives of people with learning disabilities[1] *in collaboration* with researchers so-labelled. This is a philosophical *and* methodological paper. We respond to Monteleone's (2024: 4) call for new kinds of philosophical and methodological engagements that shift away from treating people with learning disabilities as objects of study to working with people as members of an intellectual community.

In writing this paper we share a quandary. Sometimes we feel that we exist in two parallel universes. We often feel a clash of cultures between the disability studies research communities that we inhabit with researchers with learning disabilities and the external worlds that we traverse in our day-to-day lives that continue to dehumanise and marginalise people with learning disabilities. When we ponder the external world we are thinking of those daily engagements with others in the street, the supermarket, the restaurant, the park, the countryside, at work, on social media, and sometimes with friends, strangers, in private and public spaces. We are also contemplating contexts that we research including healthcare systems, spaces and encounters. And we are sitting with philosophy. Everyday contexts often feel a lot less welcoming than the spaces created by people with learning disabilities and their allies, friends, comrades and loved ones.

People so-labelled occupy a precarious place in our societies and are routinely excluded from education, work, leisure and community spaces. Furthermore, they endure numerous health inequalities that belittle their human worth. Men with learning disabilities die on average 22 years younger than men in the general population, and women with learning disabilities die on average 26 years younger than people without learning disabilities (White et al. 2021). Forty-nine% of deaths of people with learning disabilities are avoidable compared to 22% of the general population (O'Leary et al. 2018) and nearly half of

[1] The term 'learning disabilities' is used in the UK, with other labels used in different countries ranging from development disabilities, intellectual disabilities and cognitive impairments. We will refrain from offering a mainstream administrative definition of learning disabilities—which would normally refer to issues of competence, intelligence and maladaptive functioning—in response to the wider aims of this paper to contest pathological conceptions of people so-labelled.

people so-labelled live with one other chronic health condition. During the pandemic, people with learning disabilities had more severe COVID-19 infections and higher mortality rates than the general population (Henderson et al. 2020). People with learning disabilities from poor, Black, Asian and minority ethnic groups are more likely to have even poorer health (McMahon et al. 2022, Robertson et al. 2019).

It is against these dire circumstances that we respond; not simply as scholars, researchers or academics but as fellow human beings, as allies, as friends, family members and colleagues. Within critical disability studies and philosophical work on disability, there have been many debates about the place of people with learning disabilities (Aspis 2022, Carlson 2010, Goodley 2001, Kittay 1999, 2016, 2021, Monteleone 2024). While questions are still raised about the presence, place and influence of people with learning disabilities upon critical disability studies – a point we revisit in this paper – we often feel more comfortable with at least the potential of this intellectual community to include, represent and recognise the lives and aspirations of people so labelled, compared with our everyday experiences of disability. The jarring impacts of the world continue to mitigate against the desires and aspirations of people with learning disabilities, their families and research collaborators like ourselves. The world is a disturbing place because disability is often known in particular ways that contrast markedly with the ways in which disability is becoming known in disability studies. While disability scholarship is far from being a place of total agreement, there is at least a sense of possibility and positivity. In contrast, our everyday encounters often disappoint in terms of the kinds of disability knowledge that appear to dominate and be promulgated. This is not to say that the cultural world outside of disability studies is monolithic. Debate and conflict mark all cultural settings. There are some places and spaces where we might find more positive and politicised understandings of disability. What is disappointing to experience in our daily lives is the dominance of particular understandings of disability that we sense and encounter in the world. We oftentimes feel angry, powerless and embittered by the seemingly intractable view that disability is a problem in need of rectification. As people committed to the politics of disability and research collaboration with disabled people's organisations, we find the everyday world to be largely resistant to alternative understandings of disability as being something else other than a problem.

Disability as pathology is a dominant philosophy of contemporary society. And this philosophy has a long historical tale and tail to it. We want to sit

with this historical legacy – disability as pathology – as it relates to the lives of people with learning disabilities and consider how we might respond as research collaborators. In contributing to this special issue we approach the writing of this paper not simply as a piece of scholarly work that sits epistemologically and ontologically with the world, as it relates to disability philosophy and philosophies of disability; we also want to understand how research might work as a collaborative exercise undertake with, alongside and in concert with people with learning disabilities (Aspis 2022). We align ourselves with Carlson (2016, 2021) and Monteleone (2024) who have both made a strident case for the lives of people with learning disabilities being not only worthy of philosophical consideration but also as lives that can expand the very reach, significance and relevance of philosophy. But we want to go further. We desire models of research and practices of philosophy that work in collaboration with researchers with learning disabilities as colleagues, theoretical provocateurs and allies. Only when we work collaboratively can we meaningfully contest pathological versions of disability and open up our academic and everyday lives to more affirmative philosophies and perspectives. Working collaboratively raises questions about how we as researchers and collaborators understand disability and its entanglements which we address in this paper.

2. Philosophical resources

To philosophically ground our paper we draw on the work of two radical thinkers: Sylvia Wynter and Rosi Braidotti. To unpack our understanding of pathology we draw on the Black studies scholar Wynter (1992, 2003, 2006, Wynter & McKittrick 2015). Her work provides a unique gauge and deep deconstruction of the normative human category which masquerades as a universal category but is, in actuality, a Eurocentric, white, heterosexist, racist – and we would add ableist – constitution of a particular version of the human. While Wynter's work does not conspicuously engage with disability, it does speak critically and intimately to disability because it demands us to ask; why is it that some people are consistently constituted as the antithesis of what it means to be human?

In drawing on Wynter's work in some of our previous writing (e.g. Goodley et al. 2020; Goodley 2023) it is worth reiterating a point we make there: we are not conflating disability with blackness nor exploiting blackness to read disability. Rather, we are taken by the utility and clarity of Wynter's work

and its relevance to our project; the development of critical and responsive disability philosophies. Hence, when Wynter rails against white racist western bourgeois liberal mono-humanist conceptions of a so-called 'universal' category of the human – that constitutes blackness as a 'wholly other human status' (Wynter & McKittrick 2015: 45) – we pick up on traces of those ubiquitous cultural discourses that also constitute disability as wholly other, unworthy, undesirable and pathological. Ansfield, for example, draws on Wynter's work to explore the ways in which 'black pathology remains fixed and immutable within the dominant mode of subjective understanding' (2015: 126). Racism is promulgated by human subjectivities that are only capable of understanding blackness as the absolute opposite of humanness. And when we fail to overturn and confront these subjectivities – and their dangerously racist epistemologies and ontologies of the human condition – then we risk reproducing this exclusionary humanist hegemony.

The pandemic highlighted the ubiquity of humanism; which values and upholds certain kinds of humans while dismissing others as disposable, expendable, contagious and pathological (Ansfield 2015). As more and more people with learning disabilities were pulled into the spiralling vortex of illness, death and isolation, we were also alerted to the deeply racialised nature of COVID-19. As Phoenix (2022) writes both COVID-19 and the measures taken to arrest it, exacerbated already existing racialised social inequalities. A single account provides one entry point into considering these inequities:

> The news of Kayla Williams, a black woman from Peckham, dying of suspected Covid-19 after being rendered "not a priority" by paramedics on the scene has sat like a stone within me. Apart from being further proof that communities sitting at the intersection of racial and wealth inequality bear the burden of dying from preventable causes disproportionately, her death is symptomatic of a deeper current of structural prioritising of some and de-prioritising of others that predates this crisis. (Misra, 2020: np)

This narrative resonates with our own experiences of the pandemic de-prioritisation of people with learning disabilities. COVID-19 revealed the dangers for people with learning disabilities of humanistic philosophies that deemed people in terms of their value – precious/waste, valuable/disposable and worthy/unworthy – and the rationing of healthcare (see Bartlett et al. 2022). Wynter's work troubles these taken-for-granted notions of the valued

human and demands counter-thought and action. As Misra it, "imagining a different future for humanness does not lie in a new definition but in interrogating what it means to be(come) human – as a process of everlasting evolution, praxis of being, a relational act" (2020, np). Sitting with the work of Wynter's on pathology – and the limits of the contemporary category of the human – brings us to connect with the work of our second radical thinker.

Rosi Braidotti's (2013, 2019a, 2019b, 2020) work is deeply suspicious of humanist man's bounded and exclusionary character and also sceptical of the majority of philosophical work that focuses on what human beings "are ceasing to be" rather than attending to "what we are in the process of becoming" (2019b: 49). Negativity and critique are key elements of philosophical inquiry. Academics are notorious in their pursuit of negative critique. In this paper, we are interested in understanding and critiquing the dominant ways in which disability-as-pathology tends to dominate our social and cultural places. But we also want to celebrate disability's affirmative potential to rethink the human condition and Braidotti's case for philosophical practice which embraces "affirming the possibility of a here and now that would be liveable, that would be sustainable, and affirming, yes, that famous love for the world that one feels so embarrassed in even stating". "Since when", she asks, "are affirmative values an embarrassment? What is happening to us?" (2019a: 479). For Braidotti (2019a: 478) we can find affirmation in what she terms the "alliance of the marginals; These are the queer, post-human missing people that my heart goes out to: women, feminists, LGBTQ+, animals, illegal unregistered migrants, disabled people". We feel energised by this reorientation to disability as a possibility. As Braidotti (2019a: 470) puts it, "the whole point of affirmation consists in inserting the practice of philosophy in such a praxis, so that we can extract from the ruins something that would – will have – triggered the inspiration to go on". It is telling to note how often a philosopher, theorist or empirical researcher has much to say about the failings of the contemporary world without positing affirmative alternatives. Hence, our paper contributes to wider philosophical debates associated with negation and affirmation including cynicism and hope (Allen 2020, Webb 2013).

3. Methodology

In this paper, we present two composite narratives of two characters: Rosa, a young cisgender woman in her 20s who has learning disabilities, and her father

Phillip, a cisgender man in his mid-50s. A composite narrative approach uses data from several data sources to tell a single story (Willis 2019) and has been adopted as an "opportunity for constructing a detailed understanding of lived experiences" (McElhinney & Kennedy 2022: 220). We also recognise this method as an opportunity to sit with some details of everyday life, human interactions and, dare we say, to provide a snapshot of contemporary culture. In deploying this methodology we revisit an approach adopted by one of us 20 years ago (Goodley et al. 2004). A composite narrative approach to research permits us to draw on two different empirical sources (that we outline below) allowing researchers to "present complex, situated accounts from individuals, rather than breaking data down into categories" (Willis 2019: 471). Short composite narratives can be used as centre pieces for philosophical analysis; contesting an empiricist obsession with the quantity of data which can limit analysis and reflection.

Moreover, composite narratives "confer anonymity, vital when reporting on private deliberations, particularly if interviewees are public figures and can contribute to 'future-forming' research, by presenting findings in ways that are useful and accessible to those outside academia" (Willis 2019: 471). This future forming aspiration fits very much with our hope that this paper resonates with readers in and outside of academia. Our composite narratives boast a methodological rigour because they draw on the aims, research questions, emerging data, fieldwork and methodological conversations emanating from two live research projects and the personal narratives of the authors.

We are also mindful that our telling of particular stories about the lives of people with learning disabilities reflect our own personal biases, political interests and theoretical commitments to the politics of people so-labelled whose health and well-being have been undermined by a host of systemic factors.

Empirical source 1: Live funded research Projects

Funded Project 1[2] aims to qualitatively and philosophically identify principles and practices of empathy, compassion, dignity, kindness and recognition through a co-produced project with researchers with learning disabilities and/or autism, medical clinicians and social scientists. We are working with an

[2] More details can be found here: https://sites.google.com/sheffield.ac.uk/esrchumanising-healthcare/home.

approach to co-production, fieldwork, impact and public engagement that addresses six research objectives:

1. Identify the key priorities and determinants of health of people with learning disabilities and/autism through a literature review of legislation, policy, clinical guidance and datasets
2. Identify key theoretical resources from the medical humanities, disability studies, posthumanities and disability activism to conceptualise Funded Project 1.
3. Implement an investigation of the healthcare experiences of 30 people with learning disabilities and/or autism through 300 days of ethnographic research of the two services and 120 narrative interviews with patients, professionals and families/carers.
4. Analyse the data from our ethnography and narrative interviews through the deployment of our theoretical resources.
5. Identify and share healthcare practices - including referrals, assessments, diagnoses, clinical judgements, investigations, treatments, service management, commissioning, medical training and continued professional development - that are under-pinned by humanising principles of empathy, compassion, dignity, kindness and recognition.
6. Increase public awareness of the healthcare realities and aspirations of people with learning disabilities and/or autism.

For the purposes of this paper, we draw on some emerging findings and methodological narratives from our collaborative research with researchers with learning disabilities, clinical and university researchers. We are interested in developing philosophical and methodological resources that inform how we might find and theorise Funded Project 1 in collaboration with our researchers with learning disabilities.

The other project we draw on is *Funded Project 2*[3]; an international programme of research that brings together disabled researchers and disabled people's organisations to address a particular aim; to centre disability as the driving subject of health research and science. Funded by the Wellcome Trust, this six year programme seeks to redress health research and science's tendency to

[3] More details can be found here: https://www.sheffield.ac.uk/ihuman/disability-matters.

adopt disability as a passive object of intellectual curiosity, empirically investigate disability as a chronic illness or understand disability in terms of impairment or pathology. We hope to cultivate a new cadre of early career researchers across Australia, Canada, India, Singapore and the UK. These country sites capture diverse national/cultural perspectives of disabled people across high/middle income nations across four continents. Seven research phases will each address a research question:

1. How is health research, theory and scholarship transformed by an engagement with critical disability studies?
2. What are the health priorities of disabled people in Australia, Canada, India, Singapore and the United Kingdom?
3. What kinds of research methodologies represent disabled people and their health priorities?
4. How does the presence of disability enable more inclusive health research environments?
5. In what ways can we reimagine representations of disability in health research?
6. How do we build a new generation of disabled and disability-positive health researchers?
7. What transformative knowledge pertaining to equity, diversity and inclusion can be generated through a focus on anti-ableist and anti-disablist practice?

Empirical work will be undertaken concurrently in all five countries in key research sites of universities, disabled people's communities, health research organisations, research funders and spaces of public engagement. Our bold ambitions are to interrogate the assumptions, priorities, methods and applications of different *types* (conceptual, empirical, exploratory, applied and translational) and *fields* of health research (medicine, health sciences, medical humanities, medical sociology and science and technology studies). For this paper we engage with a version of research question 1. how is philosophy and methodology transformed by an engagement with disability. Specifically, we will focus on the lives of people with learning disabilities.

The composite narratives and the characters that we present below are direct products of these two projects. To detail their actual origins to real people and events would lose some of the fictional qualities of these stories and would

undermine our commitment to anonymity that we signed up to when we had our research ethically approved. Suffice to say, we have met people like Rosa and Phillip - and the other characters - in our research encounters across these two projects.

Empirical source 2: Personal entanglements

The second source of data that informs the writing of our composite narratives is more personal; emerging from our everyday lives as people who have varying engagements with the lives of people with learning disabilities. We have various familial, work and research experiences of being in the world with people with learning disabilities. One of us is a mother. Some of us identify as neurodiverse. One of us has had the pleasure of supporting an advocacy group of people with learning disabilities. Another has extensive experience in the care and creative industries populated by people with learning disabilities. We have also written collaboratively with researchers with learning disabilities (Bottomley et al. 2024) and written alone and together (e.g. Goodley 2023). In this paper we want to sit with and critically reflect on our own perspectives as we have come to know the phenomenon of learning disabilities. All of these (and more) experiences have influenced the telling of the two composite stories presented below.

4. Methodological rigour in writing composite narratives

Composite narratives blur traditional distinctions between theory, method and analysis. Whereas traditional empiricist approaches separate theoretical orientations from the methodologies adopted, the empirical data produced and the analytical work that is done to that data, our writing of composite narratives collapses these distinctions. Indeed, our composite narratives are constituted as much by our philosophical aspirations as they are by the data saturation that comes about when one brings together our two empirical resources. We agree with Johnston et al. (2023: 108) who argue:

> Composite narratives can be constructed using multiple participant accounts, representing their experiences while also capturing the properties and categories of qualitative research findings. The ability of composite narratives to represent the multiple facets of theory construction through a singular narrative point-of-view is unique and provides a concise and credible method to present research findings.

As mentioned, we know people like Rosa and her Dad because these familiar characters often appear in our empirical sources. We also feel and think we know the kinds of disability philosophies that gather around folk like Rosa and Phillip. We have collated qualitative field notes of healthcare and public contexts that have found their way into these two narratives. We have endured our own painful experiences of disability discrimination in our own families and amongst our friends and collaborators. Our two narratives are as fresh and new as they are as old as the well-worn tales that we have become familiar to us in our personal, familial and professional lives. When composite narratives work then they are culturally responsive to the collective experiences of people (Porter & Byrd 2023).

For example, we have had the displeasure of coming across many similar experiences to Phillip's in the first story. His experiences as a father build on narratives told to us by parents of young adults with learning disabilities. We have had the pleasure of working with researchers with learning disabilities that remind us of Rosa. And she reminds us too of the researchers that continue to influence how we go about our work. Rosa's intellectual contribution in rethinking humanising forms of healthcare draws directly on our engagements with co-production research with advocacy-based organisations run by people with learning disabilities. In some ways, we present Rosa as an ideal type – the subversive activist-researcher with learning disabilities – and she embodies many brilliant research collaborators, friends and family members that have pulled us with them as they contest and challenge disabling barriers in their lives.

5. Analysis

Writing these two composite narratives invites us to explore two philosophies of disability: disability as pathology and disability as affirmation. These two distinct philosophies are prominent tropes in our research and everyday lives: where we try to counter the former and promote the latter. We are mindful of the blurring of method and analysis; and the composite narrative's qualities to blur these artificial boundaries between data and findings.

Disability as pathology

We start with a sadly familiar story that says much about the ways in which particular philosophies of disability as pathology populate the lives of people with learning disabilities and their loved ones.

6. That time when Rosa's dad nearly forgot to buy bread

Phillip was sure he'd finished his very rushed grocery shop in his local supermarket. He greets the man at the checkout:
"Morning love".
Just as he starts to unload his trolley, he remembers.
"Shit, the bread".
Phillip reloads the trolley and moves with what he thinks is the grace of a Premier league footballer – but is more like the clumsy coordination of an ageing Rugby prop – and bounds towards the bakery counter.
As he rounds a corner and makes his way down the tinned items aisle he notices a familiar face - Claire - a key support worker of his daughter Rosa. At first Phillip thinks Claire has recognised him but no; Claire is deeply involved in a conspiratorial chat with another middle aged person; a slight woman with short curly hair.
Claire: "You'll never guess what *one of mine* did".
Friend/colleague: "Go on".
Claire: "Well she had her typical meltdown in the local cafe. No diet coke you see".
Friend/colleague: "Oh God!" [accompanied by a knowing look].
Claire: "*They* can be such hard work".
Phillip feels something drop in his stomach.
Should he say anything? They still have not noticed his presence.
Phillip makes a break for it, hurrying past, to pick up the soda bread. He remembers that only last week Claire had informed him that Rosa had had 'a moment' when they'd been out together during one of Rosa's days off from her job with the advocacy organisation.
Back to the checkout.
The sinking feeling gets deeper and deeper.

We find Phillip's centrality as a father to be important in thinking about disability philosophies of everyday life to be crucial as families and especially parents are deeply implicated in the lives of people with learning disabilities (Hastings et al. 2020). Parent-activists and parent-researchers have called upon

disability studies research and scholars to acknowledge the complex ways in which parents are entangled in the stigma, objectification and disablism of their children (Douglas et al. 2021; Kittay 2009; Ryan & Runswick-Cole 2008; Runswick-Cole & Ryan, 2019). Kittay's writing as a mother and philosopher has been incredibly influential in pulling the lives of people with learning disabilities into the very centre of philosophical analysis; while also admonishing those philosophers who treat people so-labelled as objects of curiosity and examples of diminished humanity.

In our narrative we find Claire and her colleague objectifying Rosa. And while it might be tempting to attack these characters for the ideas that they hold, their fictional quality encourages us to think more readily about the discourses, epistemes and knowledge systems that make us who we are as people and dominate the ways in which contemporary culture makes sense of learning disability. We are influenced here by the work of Langness and Levine (1986) whose edited collection highlights a simple though profound point; the very phenomenon of learning disability provides an entry point into a consideration of the dominant ways in which cultures know learning disability. Too often learning disability is known in terms of a homogeneous category that troubles normative conceptions of humanity. Problems require a response – a solution – and this hegemonic conceptualisation of disability pervades many cultural understandings (Mitchell & Snyder 1997, 2006, 2015). And these hegemonic Eurocentric conceptions of the human – humanist models of the human being – over-represent themselves as the human being of our contemporary and historical times. Able-bodied-and-mindedness is a core element of the humanist human. One knock-on effect of this narrowing of humanity – indeed one mode by which this narrow conception retains its power – is through the constitution of some as 'absolute others. Hence, disabled people are cons 'out there' (Wynter 2003: 282) – as 'them' rather than 'us'. Rosa is one of 'them' that Claire can speak of with her friend.

Critical disability studies writers and disabled activists have highlighted and contested the dangerous and common ways in which disability is socio-culturally constituted as pathological (Oliver 1990, 1996). Disability as pathology remains a common story re/told within our everyday lives; as exemplified by our first composite narrative piece. But what of philosophy? Do these same pathological stories of disability populate the work of philosophers? While we are not stating that the discipline of philosophy actively promotes negative discourses

of learning disabilities, like any academic discipline philosophy is always in danger of reproducing ableist ideologies that assume the human being at the heart of theory, research and teaching as "very much a male of the species: it is a he" (Braidotti 2013: 24). The human being centred in many humanities, social science and medical disciplines is assumed to be "white, European, handsome and able-bodied" (ibid, p. 24), 'an ideal of bodily perfection' (Braidotti 2013: 13), "implicitly assumed to be masculine, white, urbanised, speaking a standard language, heterosexually inscribed in a reproductive unit and a full citizen of a recognised polity" (Braidotti 2013: 65), "a rational animal endowed with language" (Braidotti 2013: 141).

Moreover, following Carlson (2016, 2021) and Monteleone (2024), the subject of philosophy (and the philosopher themselves) tends to over-emphasise those human beings who are cognitively capable, autonomous and self-sufficient. This ableist constitution of the human subject of philosophy sits in stark contrast to the pathological depiction of the person with learning disabilities. We worry that our supermarket chat might well be replayed in the context of the philosophy department because universities inculcate an understanding of disability that "abstracts people from their environments as well as from other people' to the extent that 'it remains difficult to locate any version of what disability might be other than lack of function" (Titchkosky 2020: 205). To state that disability is but one element of humanity seems, at the very least, to be trite. What rational person would not think of disabled people as human beings? The problem with rational thought, of course, is that it is imbued with ableist ideology, hegemony and dominant cultural imaginaries that render the non-disabled person the gatekeeper of humanity. Here the person with learning disabilities figures as a kind of "honorary member" whose inclusion into the category "human" hinges on the mercy of the non-disabled hegemony. Disability as pathology fundamentally overwrites the humanities of people with learning disabilities.

Disability as affirmation

We now turn to our second composite narrative. In presenting this story we are thinking with Braidotti's ideas of affirmation; "what the world needs now is heavy doses of counter-negativity in the mode of affirmation" (2019a: 464). This impulse deeply resonates with the aspirations and desires of people with learning disabilities and their families. In the first story Rosa was conspicuous

by her absence. In this second narrative she is, we are happy to report, front and centre.

7. That time when Rosa found out that she could actually act

Rosa is running late for the face-to-face workshop. The tram had been delayed and when she eventually squeezed herself onto the carriage she found it overburdened with commuters. Eventually, she gets off at her stop and follows her google maps directions to the venue: a broken down but still rather stately hotel. Making her way through the entrance she is greeted by Bojana and Nikita; the researchers on the project that she and her advocacy organisation are collaborating with. Hellos and hugs are exchanged and the three make their way to the conference room which is already full to bursting with old and new friends from the four advocacy organisations, clinical and university researchers: all collaborators on the research project.

This collective had set itself a challenging task: to answer the question "What makes for a humanising healthcare practitioner?". Today builds on a number of online workshops and meetings in which the different researchers have discussed, debated and disagreed on what they considered to be the best kind of healthcare. Later on, the best part of the day; the afternoon's role play. The aim? To create a play of a bad healthcare experience followed by a performance of a good healthcare moment.

One of the advocacy supporters asks for volunteers to take on different characters; a patient, their Dad and a General Practitioner. An appointment room is mocked up. Two chairs facing a table. Rosa puts herself forward to play the role of Dad. It was a simple choice. He always has her back whenever they visit the doctors. The play starts. Patient and Dad enter the GP's office. "Morning love", Rosa's Dad exclaims.

Disability as affirmation constitutes a philosophical turning point. It signifies a conversation starter that considers disability as the driving subject of human inquiry – not simply in research and scholarship – but also in relation to how we might better encounter the world. This approach is incubated by the aspirations of the *Funded Project 2* programme – which urges us to work with disability as a resource from the very outset of our scholarship – and is furthered by the *Funded Project 1* project; specifically our co-production work with researchers with learning disabilities. To start from the premise that disability offers us affirmative opportunities for reimaging our shared humanities is to sit

with the promise of disability. Disability as affirmation also creates a space to think more readily, practically and deeply about a philosophy of affirmation. Whereas disability is often pathologised by a humanist register that misrecognises disability as less than human, an affirmative turn asks us to sit with the potential, possibility and joy of disability (Braidotti 2019a, 2019b). This is a philosophical position with a very different orientation to disability.

Rosa has her own experiences to draw upon to offer her reading of a Funded Project 1 practitioner. Indeed, as a researcher with learning disabilities she brings with her personal and professional experiences that significantly augment her understanding of the intentions of the role play.

This is also a story of research production – specifically co-production – which signals a different kind of philosophical engagement; "a shift away from treating people labelled with intellectual disabilities as objects of study to treating them as members of an intellectual community" (Monteleone 2024: 4). We propose that our second composite narrative captures what Monteleone (2024: 12) terms "doing Philosophy Differently [...]. We need to create new ways of doing philosophy. We cannot just try to fit disabled people into nondisabled ways of doing things". Indeed, we are struck by Rosa's entanglements with other researchers with and without learning disabilities. "We", as Braidotti (2019a: 53) writes, "the dwellers of this planet at this point in time – are interconnected, but also internally fractured. Class, race, gender and sexual orientations, age and able-bodiedness continue to function as significant markers in framing and policing access to normal 'humanity'". Rosa addresses internal fractures by offering a moment of interconnection and an opportunity to rethink how we might re-theorise *Funded Project 1* in ways that are responsive to collective practice. *Funded Project 2* posits the idea that many research methods – and intellectual approaches - continue to marginalise disabled people; treating them only as objects of research. The push across much social and human sciences for co-production offers one opportunity for redressing negating pathological understandings of disability. Identifying, promoting and enhancing modes of research co-production feeds into Oliver's (1990) desire for emancipatory disability research: where the very act of research is not only disrupted by the presence of disability but research is reconvened as a practice through which disabled people might flourish. This brings us back specifically to the desire of *Funded Project 1* to position our co-researchers as research managers, social theorists, methodological provocateurs, analysts and impact experts who, through their

research expertise and expertise-by-experience, will encourage us to think critically and productively about healthcare (Nind 2014; Goodley et al, 2019). The composite character captures, in part, the contributions of our advocacy-based organisation partners on *Funded Project 1* who are paid daily consultancy rates as key research partners to offer leadership, audit and accountability. Rosa's performance in the second narrative provides a narrative entry point for understanding in practice how researchers with learning disabilities can and should dictate and inform new disability philosophies; in this case in relation to affirmative philosophies and practices of healthcare.

8. Conclusion

Philosophies of disability – and disability philosophies – have a huge role to play in reimagining our everyday lives. We are firmly of the opinion that disability philosophies should engage with the wider public (Littman 2014, Esser 2023). It is therefore incumbent on all of us engaged in the practices of philosophy and social theory to ensure that our ideas travel beyond the narrow confines of the academic space; to truly impact on our places of work. We would assert that disability is as good a subject as any to initiate deep reflections on the cultural practices of our everyday lives: itself an urgent and much needed form of philosophical inquiry. We conclude this paper outlining ways in which affirmative disability philosophies and methodologies can have significant reach in and outside of our academic contexts.

(I) *It is incumbent on all of us to recognise the philosophical knowledge of researchers with learning disabilities.* Just as Rosa demonstrates in our second story, people with learning disabilities do have "epistemic resources to make sense of their experiences, but that those resources have not been acknowledged or valued by those in positions of power" (Monteleone 2024: 7). Philosophers and researchers need to challenge the stubborn conceptualisation of disabled people as objects of curiosity and recognise disability as authority.

(II) *We should use philosophical critique to affirm action and reimagine the role of philosophers of disability.* As Braidotti (2019a: 466-467) claims, "The task of critique is to actually make something happen in the world, creating assemblages and planes of encounter with other transversal subjectivities, injecting counter-codes in a system that is over-coded by the axioms of capitalism". One of these axioms is cognitive capitalism – the constitution and exploi-

tation of cognitive labour – that creates people with learning disabilities as necessary collateral damage (see Carlson 2010). Following Braidotti again, "the whole point of affirmation consists in inserting the practice of philosophy in such a praxis, so that we can extract from the ruins something that would–will have–triggered the inspiration to go on" (2019: 470).

(III) *We might centre storytelling as a core element of affirmative philosophical inquiry.* Affirmative research has encouraged more creative modes of representation and kinds of methods (Jeffrey & Thorpe 2024). Storytelling remains a mode of telling, a form of representation and a social practice through which to not only evidence old and new disability philosophies but as a performative method for putting philosophy into action. Our second narrative captures Rosa's power in reconceptualising a healthcare encounter.

(IV) *We must contest academic ableism within philosophy and the wider university.* A key aspect of our work involves engaging in practices, community building and intellectual endeavour that depathologise the university (Goodley 2024). When disability rocks up in a disciplinary space, research environment or university place of learning as an opportunity to do things differently; a conversation starter in relation to questions of equality, diversity and inclusion; a resource from which to reconsider how things are done together and a productively disruptive phenomenon to limiting, narrow and orthodox practices then we might find ways of working together that are philosophical and pragmatically helpful.

(V) *Philosophies of disability and disability philosophies must redress their exclusion of philosophers with learning disabilities.* While we respect the work of disabled theorists and philosophers, as well as those philosophers with familial and personal experiences of disability, we note the absence of people with learning disabilities in our academic communities, publications and spaces. This is where methodology is so important; to create opportunities for debate, conversation and inclusion which bring to the fore some of our fellow human beings who are too often marginalised, dehumanised and segregated away from the mainstream centres of thought and theory.

(VI) *We must embrace what Allan (2020) terms "productive forms of interruption" that disability brings to philosophy and social theory.* An interruption creates an opportunity. And in this opportunity is a moment to stop, to reflect, to consider and perhaps reconsider what we are doing. Philosophy should impact on public debate and institutional practices (Casalini 2020, Boem & Ratti 2021, Kaushik 2022, Montalti 2024). But philosophy should be open to

self-critique and reflexivity; to revisit how it goes about its business. Finally, any philosophical inquiry must be mindful that people with learning disabilities endure systemic health inequalities that belittle their human worth. We share a responsibility to research and contest these inequalities and work hard not to reproduce inequalities through the very act of research and scholarship.

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REFERENCES

Ansfield, B. (2015). Still Submerged: The Uninhabitability of Urban Redevelopment. In K. McKittrick (Ed.), *Sylvia Wynter: On Being Human as Praxis* (pp. 124–141). Duke University Press.

Allan, J. (2020). Disability Studies and Interdisciplinarity: Interregnum or Productive Interruption? In L. Ware (Ed.), *Critical Readings in Interdisciplinary Disability Studies. Critical Studies of Education*, vol 12. Springer. https://doi.org/10.1007/978-3-030-35309-4_1.

Allen, A. (2020). *Cynicism*. The MIT Press.

Aspis, S. (2022). Why are Disabled People with Learning Difficulties Being Prevented from Leading Campaigns, Projects and Initiatives? *Disability & Society*, *37*(1), 154–159.

Bartlett, T. et al. (2022). Surviving through Story: Experiences of People with Learning Disabilities in the COVID-19 Pandemic 2020-2021. *British Journal of Learning Disabilities*, *50*(2), 270–286. doi: 10.1111/bld.12463.

Boem, F. & E. Ratti (2021). Science and Politics in a Time of Pandemic: Some Epistemological and Political Lessons from the Italian Story. *Humana.Mente*, *14*(40), 89–124.

Bottomley, M. *et al.* (2024) 'Co-producing ethics guidelines together with people with learning disabilities'. British Journal of Learning disabilities.

Braidotti, R. (2013). *The Posthuman*. Polity.

Braidotti, R. (2019a). Affirmative Ethics and Generative Life. *Deleuze and Guattari Studies*, *13*(4), 463–481. doi: 10.3366/dlgs.2019.0373.

Braidotti, R. (2019b). 'A Theoretical Framework for the Critical Posthumanities'., *Theory, culture & society*, *36*(6), 31–61. doi: 10.1177/0263276418771486.

Braidotti, R. (2020). "We" Are In This Together, But We Are Not One and the Same. *Journal of bioethical inquiry*, *17*(4), 465–469. doi: 10.1007/s11673-020-10017-8.

Casalini, B. (2020). Care and Injustice. *International Journal of Care and Caring*, *4*(1), 59–73. doi:https://doi.org/10.1332/239788219X15730452949174.

Carlson, L. (2010). *The Faces of Intellectual Disability: Philosophical Reflections*. Indiana University Press.

Carlson, L. (2016). Feminist Approaches to Cognitive Disability. *Philosophy Compass*, *11*(10): 541–53.

Carlson, L. (2021). Why Does Intellectual Disability Matter to Philosophy: Toward a Transformative Pedagogy. *Philosophical Inquiry in Education*, *23*(2): 72–82.

Cooper, S., G. McLean, B. Guthrie, A. McConnachie, S. Mercer, F. Sullivan, & J. Morrison (2015). Multiple Physical and Mental Health Comorbidity in Adults with Intellectual Disabilities: Population-Based Cross-Sectional Analysis. *BMC Primary Care, 16*(110). doi: 10.1186/s12875-015-0329-3.

Douglas P., K. Runswick-Cole, S. Ryan & P. Fogg (2021). Mad Mothering. *Journal of Literary & Cultural Disability Studies*, *15*(1), 39-56.

Esser, A. M. (2023). Philosophy Today: Public philosophy – Do we need it? *Deutsche Zeitschrift für Philosophie*, *71*(1), 119–121. doi: 10.1515/dzph-2023-0008.

Goodley, D. (2001) 'Learning Difficulties', the Social Model of Disability and Impairment: Challenging epistemologies, *Disability & Society*, *16*(2), 207–231.

Goodley, D.*, R. Lawthom, K. Liddiard, & K. Runswick-Cole (2020). The Desire for New Humanisms, *Journal of Disability Studies in Education*, *1*(1-2), 125–144.

Goodley, D. (2023). Being Human As Praxis: For People With Learning Disabilities. *Subjectivity, 30*, 167–184.

Goodley, D. (2024) Depathologising the university, *Pedagogy, Culture & Society*, DOI: 10.1080/14681366.2024.2316007.

Goodley, D., R. Lawthom, P. Clough, M. Moore (2004). *Researching Life Stories: Method, Theory and Analyses in a Biographical Age.* Routledge Falmer Press.

Goodley, D., R. Lawthom, K. Liddiard, & K. Runswick-Cole (2019) Provocations for Critical Disability Studies, *Disability & Society, 34*(6), 972–997.

Hastings R. P., V. Totsika, N. K. Hayden *et* al (2020). 1000 Families Study, A UK Multiwave Cohort Investigating The Well-Being Of Families Of Children With Intellectual Disabilities: Cohort Profile. *BMJ Open*, 10:e032919. doi: 10.1136/bmjopen-2019-032919.

Henderson, A., M. Fleming, S. Cooper, J. P. Pell, C. Melville, D. F. Mackay, C. Hatton, D. Kinnear. (2022). COVID-19 Infection And Outcomes in A Population-Based Cohort of 17203 Adults with Intellectual Disabilities Compared with The General Population. *Journal of Epidemiology and Community Health, 76*(6), 550–555. doi: 10.1136/jech-2021-218192.

Jeffrey, A. & H. Thorpe (2024). Relational Ethics of Care in Pandemic Research: Vulnerabilities, Intimacies, and Becoming Together-Apart, *Qualitative Inquiry*, *30*(1), 101–113. doi: 10.1177/10778004231163497.

Johnston, O., H. Wildy, H. & J. Shand (2023). 'Student Voices That Resonate – Constructing Composite Narratives That Represent Students' Classroom Experiences.', *Qualitative Research*, *23*(1), 108–124. doi: 10.1177/14687941211016158.

Kaushik, R. (2022). The Passivity of Institution in Merleau-Ponty: Pandemic Thinking. *Humana.Mente*, *15*(41), 177–194.

Kittay, E. F. (1999). *Love's Labour: Essays on Women, Equality and Dependency*. Routledge.

Langness, L. L., & H. G. Levine (Eds.) (1986). *Culture and Retardation*. D. Reidel Publishing Company.

Littman, G. (2014). Writing Philosophy for the Public is a Moral Obligation. *Essays in Philosophy*, *15*(1), 103–116. doi: 10.7710/1526-0569.1492.

McElhinney, Z., & C. Kennedy (2022). Enhancing the Collective, Protecting the Personal: The Valuable Role Of Composite Narratives In Medical Education Research. *Perspectives on Medical Education*, *11*, 220–227.

McMahon, M., C. Hatton, C. Hardy, N. J. Preston (2022). The Relationship Between Subjective Socioeconomic Status And Health In Adults With And Without Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*, *35*(6), 1390-1402. https://doi.org/10.1111/jar.13028.

Misra, A. (2020). Humanity's Catastrophe: Following Sylvia Wynter in the Age of Coronavirus. *Critical Legal Thinking*, https://criticallegalthinking.com/2020/04/10/de-prioritising-humanity/.

Mitchell, D. & S. Snyder (Eds.) (1997). *The Body and Physical Difference. Discourse of Disability*. Verso.

Mitchell, D. & S Snyder (2006). Narrative Prosthesis and The Materiality of Metaphor. In L. Davis. (Ed). *The Disability Studies Reader. Second Edition*. Routledge.

Mitchell, D. & S. Snyder (2015). *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*. University Michigan Press.

Montalti, C. (2024). The Body, the Earth. The Participation of Disabled People in the Environmental Discourse. *Journal of Ecohumanism*, *3*(1), 31–43. https://doi.org/10.33182/joe.v3i1.3071

Monteleone, R. (2024) Complexity as Epistemic Oppression: Writing People with Intellectual Disabilities Back into Philosophical Conversations. *Hypatia*, 1–14. doi: 10.1017/hyp.2023.85.

Nind, M. (2014). *What Is Inclusive Research?* Bloomsbury.

Oliver, M. (1990). *The Politics of Disablement*. Macmillan.

Oliver, M. (1996). *Understanding Disability: From Theory to Practice*. Macmillan.

O'Leary, L., S. Cooper, & L. Hughes-McCormack (2018). Early Death and Causes of Death of People with Intellectual Disabilities: A Systematic Review. *Journal of Applied Research in Intellectual Disabilities, 31*(3), 325–342. https://doi.org/10.1111/jar.12417.

Phoenix, A. (2022). (Re)inspiring Narratives of Resistance: COVID-19, Racisms and Narratives of Hope. *Social sciences (Basel)*, *11*(10):470. doi: 10.3390/socsci11100470.

Porter, C. J. & J. A. Byrd (2023). Juxtaposing #BlackGirlMagic as "Empowering and Problematic:" Composite Narratives of Black Women in College. *Journal of Diversity in Higher Dducation*, *16*(3), 273–283. doi: 10.1037/dhe0000338.

Robertson, J., R. Raghavan, E. Emerson, S. Baines, & C. Hatton (2019). What Do We Know About the HJealth and Health Care of People with Intellectual Disabilities from Minority Ethnic Groups in the United Kingdom? A systematic review. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1310–1334. https://doi.org/10.1111/jar.12630.

Ryan, S. & Runswick-Cole, K. (2008) Repositioning mothers: mothers, disabled children and disability studies. Disability & Society, 23(3), 199-210.

Runswick-Cole, K. and Ryan, S. (2019) 'Liminal still? Unmothering disabled children', *Disability & society*, 34(7-8), pp. 1125–1139. doi:10.1080/09687599.2019.1602509

Titchkosky, T. (2020). The Bureaucratic Making of Disability. *New Formations: A Journal of Culture/Theory/Politics*, *100*, 198–208.

White, A., R. Sheehan, J. Ding, C. Roberts, N. Magill, R. Keagan-Bull, B. Carter, M. Ruane, X. Xiang, U. Chauhan, I. Tuffrey-Wijne, & A. Strydom (2021). *LeDeR Annual Report: Learning from Lives and Deaths – People with A Learning Disability and Autistic People. Autism and Learning Disability Partnership*. King's College London, https://www.kcl.ac.uk/ioppn/assets/fans-dept/leder-main-report-hyperlinked.pdf.

Webb, D. (2013). Pedagogies of Hope. *Studies in Philosophy and Education*, *32*(4), 397–414. doi: 10.1007/s11217-012-9336-1.

Willis, R. (2019). The Use of Composite Narratives to Present Interview Findings. *Qualitative Research, 19*(4), 471–480.

Wynter, S. & K. McKittrick (2015). Unparalleled Catastrophe for Our Species? Or, To Give Humanness A Different Future: Conversation. In K. McKittrick (Ed.), *Sylvia Wynter: On Being Human as Praxis* (pp. 9–89). Duke University Press.

Wynter, S. (1992). No Humans Involved: An Open Letter to My Colleagues. *Voices of the African Diaspora*, *8*(2), 13–16.

Wynter, S. (2003). Unsettling the Coloniality of Being/Power/Truth/Freedom: Towards the Human, after Man, its Overrepresentation – An Argument. *The New Centennial Review*, *3*(3), 257–337.

Wynter, S. (2006). On How We Mistook The Map For Our Territory, And Re-Imprisoned Ourselves In Our Unbearable Wrongness Of Being, Of Désêtre. In L. R. Gordon & J. A. Gordon (Eds.), *Not Only The Master's Tools: African-American Studies In Theory And Practice*. Paradigm Publishers.