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Creating In/Disciplined Work in Medical Humanities and Disability Studies[1]

Shaping Disciplines

As with any other critical academic discipline, both Medical Humanities and Disability Studies have histories and trajectories, and knowledge of these can only add to a greater understanding of the critical developments each has made. At the same time, I concur with the editors of *The Edinburgh Companion to the Critical Medical Humanities* that the best way to approach that discipline is not through its history and identity, but rather its imaginary; the various scenes it unfolds (an observation also true for Disability Studies).[2] Even so, it is important to have a sense of how each operates. So, we might want to know some basics: What were the origins of the disciplines and how do they carry these legacies into their current work? Where are their boundaries? What is included and excluded? Who does the work? How does this scholarship overlap with other modes of critical enquiry (both old and new)? What kinds of spaces are made for the work to take place – within the academy, the wider intellectual community, and with the public? What feels important, and what is ephemeral?

One context for these questions might be to note that, relatively speaking, each discipline constitutes a highly specialised community, with a limited audience, and that these are unequal in size. Most people who work on literature and medicine, or the history of medicine (just to select two examples) do not identify as Medical Humanities scholars, and for all its profile, the discipline is undoubtedly niche in wider Humanities approaches to health. Disability Studies is more broadly established, with more scholarship having produced more publications and designated teaching programmes in academic institutions, but it is a subject absent from many universities and some other intellectual

1 This article is an excerpt from my book In/Disciplines. Medical Humanities and Disability Studies, London 2023, published with the kind permission of Bloomsbury Academic, an imprint of Bloomsbury Publishing Plc.

2 Cf. Anne Whitehead and Angela Woods: Introduction, in: Whitehead, Anne and Woods, Angela (eds.): The Edinburgh Companion to the Critical Medical Humanities, Edinburgh 2016, pp. 1–32, here: p. 2.

approaches to disability and healthcare do not engage with its methodologies. In addition, for all that each discipline claims an inter- or multi-disciplinary approach to its subject matter, it can be argued that this is restricted in its reach, selecting some partners but dismissing others. Sometimes, these issues of scale and scope are ignored in discussions about how the disciplines function.

In this essay I want to argue that an idea of *indiscipline* (and specifically *In/Discipline*, a meeting of critical methods and disciplinary formations) offers a provocative and illuminating way to open up both the workings of Medical Humanities and Disability Studies as disciplines, and the connections between the two. I am drawn to it for a number of reasons: First, it allows for an obvious situating within discussions of the disciplinary concerns that necessarily speak of how academic scholarship works in institutional and intellectual spheres; second, it qualifies this location – messes it up – because of its clear suggested unruliness. It places disciplines in recognisable structures but then subjects them to the rule-breaking energy of nonconformity. This is my modest version of Donna Haraway's staying with the trouble, maybe, but, as Haraway has observed, to be in such a situation is not only to be oppositional, not only simply critical. Rather it heralds a positioning that inhabits spaces of both avoidance and adherence. Outlining her ideas of witnessing, Haraway tells us that her witness »is suspicious, implicated, knowing, ignorant, worried, and hopeful«, heir to the »cascading accounts« of configurations that write any topic or subject.[3] It is exactly through this kind of doubtful and/but generative lens that, in my research, I look at the scholarship that marks Disability Studies and Medical Humanities as critical modes.

As my own work on health and disability has developed, I have found that being indisciplined provides the clearest mode for the criticism I hope to write. This is true despite the apparent lack of clarity around the word itself (in English, ›indiscipline‹ is more common that ›undiscipline‹, but ›undisciplined‹ more in usage than ›indisciplined‹). It is important to stress that this adoption of the provisional and contingent does not detract from any desire to shed light on the workings of each discipline and write with clarity, however; it is a matter of how and where to start. From this position, I want to argue, it then becomes possible to attend to the gaps, pauses and vanishing points in both Medical Humanities and Disability Studies and to stress the indiscipline caused in the best work they produce. I want to avoid the insular-

3 Donna Haraway: Modest_Witness@Second_Millennium, FemaleMan©_Meets_OncoMouse™, London and New York 1997, p. 3 and p. 2.

ity and parochial mood that can come with disciplines as they start to settle, whether within a model of disciplinary formation or taken-for-granted critical perspectives. The fact that at this current moment in time parts of academia choose to frame scholarship in medicine, health and disability within certain terms is a passing phase. It will change and develop in years to come. What won't change is the central role that medicine, health and disability have in people's lives and to the social and cultural formations that surround them. I understand it to be the job of both Disability Studies and Medical Humanities to respond to these issues, to be more than words that designate disciplines, subject areas, or the names of postgraduate courses and funding schemes. In fact, I value them precisely because I believe that they can do this. They bring philosophical concepts of selfhood into dialogue with personal experiences of bodily pain, for example, or theorise disabled embodiment as it helps inform systems of social health. To call this inter-, cross- or multi-disciplinary is fine, but only if those words are understood to come as a response to the work that finds formation in and around such headings. I agree with Felicity Callard and Des Fitzgerald's suspicions that these terms, for all that they wish to speak of collaboration and complexity, simply move the space of work out of the disciplinary to a place of ›between‹, ›over‹ or ›lots‹, and that these then perform their own version of stasis, assumed but often unexamined.[4] As ever, methodologies create their own shortcuts.

Trajectories

The relationship between medicine and the Arts is centuries old but Medical Humanities emerged as a distinct discipline in the US from the 1970s onwards as an additional element in the training of doctors and medical professionals. It brought discussions of literature, creative writing, anthropology, ethics and the visual arts in particular to give new perspectives on questions of (among others) patient experience and behaviour, empathy, professional bias, and cultural difference. The subject still functions primarily in this way in the US, with a strong presence in undergraduate and graduate teaching programmes within medical schools. The stress on ›additional‹ is central here, a word that has meant different things at different times. In their early presence in medical

4 Felicity Callard and Des Fitzgerald: Rethinking Interdisciplinarity across the Social Sciences and Neurosciences, Basingstoke 2015, pp. 80–81. As they also put it succinctly: »Interdisciplinarity is a term that everyone invokes and none understands« (ibid., p. 4).

training, the Humanities offered humanist perspectives on clinical processes and opportunities to engage with alternative ways of talking about health. These were not without interest (sometimes significant) but largely peripheral and clearly a secondary set of perspectives.

The discipline has diversified in the last ten years in particular, developing wider interests and more sophisticated ideas of personal, historical, public, and social dimensions of health, and mobilising new critical approaches that address these. Much of this diversity, however, exists with the continuity of the older model. A read through of the website of the University of California San Francisco's comprehensive and influential *Perspectives in Medical Humanities* series showcases books, digital magazines and podcasts that focus on all manner of topics: from poetry and memoir to studies of cancer and climate change, histories of Obstetrics and Gynaecology, and the structures of medical research finance. The Press's mission statement makes clear, however, that the series invites »scholars from the humanities and health care professions to share narratives and analysis on health, healing, and the contexts of our beliefs and practices that impact biomedical inquiry«, an approach recognisable from the discipline's 1970s origins.[5] Similarly, Routledge's book series *Advances in the Medical Humanities* contains multiple titles – on Bioethics, Wellbeing, Palliative Care, Pain, Storytelling and Poetry – almost all of which are connected in same way to Medical Education and person-centred healthcare. It is instructive to note that 2016 saw the publication of both *The Edinburgh Companion to the Critical Medical Humanities*, mentioned above, and Alan Bleakley's *Medical Humanities and Medical Education: How the Medical Humanities can Shape Better Doctor*s, in the Routledge series. It would be different to imagine two more different books with the same central term in their title.

The Introduction to the *Edinburgh Companion* begins with a claim that, as a discipline, Medical Humanities »names a series of intersections, exchanges and entanglements«.[6] In so doing, the volume marked part of a major critical turn that reconfigured the subject not as an additional element or ›critical friend‹ to wider research in medicine and health, but as a seminal part of such approaches. It championed a sustained interdisciplinary inquiry that could not only bring new readings of health moments (of all kinds) but also enact structural change to research environments. What was before just the

5 See ›About Us‹, UCSF Medical Humanities. Available online: ucmedicalhumanitiespress.com/about-us (12.7.2022).

6 Whitehead and Woods: Introduction, p. 2.

presence of other subject areas now became processes of critique, articulated through a variety of theoretical models and directed at the positions and presumptions of biomedical science, clinical practice, and healthcare more generally. The discipline's imaginary has become a force field of approaches to the full range of medical and health effects.

Like Medical Humanities, Disability Studies originated in the 1970s, led by activists in disability-rights movements and others who rejected the idea that disability should be seen predominantly as a medical issue. In place of this, they championed the rights of disabled people and stressed central social concepts – inclusion, equality, accessibility, discrimination – that marked day-to-day disability lives. Initially focused on physical impairment, the movement spread to include those with neurological conditions and learning disabilities and became characterised by a strong commitment to community, advocating affiliation in place of the estranging individualism frequently forced on disabled people within modes of medical assessment and healthcare. The social model of disability, with its the acknowledgement that it is social and environmental factors that disable, and not the difference of the disabled body, took specific institutional forms in the 1980s and remains one of the most powerful critical tools in the discipline.

Disability Studies has also had a critical turn, one (again, like Medical Humanities) marked by the advent of multiple theoretical perspectives and new subject methods. The central status of the social model, rooted in specifics of activism, social policy and law, has lessened, with the discipline broadening into fields of Cultural and Literary Studies, as well as Gender, Queer, and Critical Race Studies. This is not simply a case of scholars from the Humanities coming to a discipline based in the Social Sciences, but also academics within subject areas such as Sociology and Education continuing the engagement with (particularly) Philosophy and Critical Theory that has been part of their analysis of disability experiences for decades. Like Medical Humanities, in the last ten to twelve years Disability Studies has brought a greater multidisciplinary approach to focus on the concept of the ›human‹ that underpins so much thinking about disability and health, and both disciplines criss-cross the promise and problems of contemporary critical topics – such as care, dependency, contested identities, Posthumanism, digital societies – as they affect the lives of disabled people.

Whether through asserting agency or a commitment to complicating methodologies then, each discipline asserts the value of reading and championing difference. Medical Humanities wants to bring different critical perspectives to the study of medicine and health, and promote the value of

partnerships beyond professional, healthcare and patient groups; Disability Studies stresses difference as well, working through the positive and generative nature of disability experience to provide theories and models of practice that centre around disability inclusion and the value of disabled lives. Scholars in each recognise that the ongoing complexities of health and disability need critical categories themselves capable of multiplicity. Recognising such a need for difference is one thing, however; practising it is something different altogether.

Thinking Differently

The above emphasis on difference prompts a question: What is the difference of difference? Or maybe it should be: What difference does difference make? Though it is clearly a knotty formation, I have found myself encountering this thought a lot as I have worked on disability especially over the years. I say ›encountering‹, with its slight stress on the provisional, because I suspect now that I have left the question too much at the edge of my mind, possibly not confident that I have skills to properly address its complexity. I use the term disabled difference a lot. ›It is when we use the insight derived from disabled difference…‹ is exactly the (clumsy) start of a sentence I might write. But what exactly do we mean when we talk about physical, disabled, cognitive, neurobehavioral difference? There are easy enough answers of course: A wheelchair experience is different from one that does not involve a wheelchair; seeing and encountering a space through OCD is different to doing the same without having the condition. But, while true, this has come to strike me as a pedantic statement of the position. Pedantry thrives on its presupposition of clarity, but frequently simplifies things in order to do so. The assumption that a wheelchair experience is predominantly oriented around a wheelchair, for example, is a simplification of a complex set of relationships in which the wheelchair itself is only one part. That it is the part that most signals difference should be an argument, not a given.

The academic world of Disability Studies often involves being inside this difference for most of the time. It stresses the complexities and inequities of being made peripheral (others, maybe yourself) while intellectually inhabiting and critically reassessing the very idea of periphery. Indeed, it stresses that it is precisely in learning about, reforming and reclaiming such space that various productive moments (progressive politics, intellectual insight and creativity, to name just some) become possible. Lennard J. Davis' seminal 1995

text *Enforcing Normalcy: Disability, Deafness and the Body* is a classic example of this, identifying the ableist properties of the category of ›normal‹ as it has functioned in the modern period, but also noting that »a society of disabled people can and does easily survive and renders ›normal‹ people outsiders«.[7] Being without allows for the perspective that can critique within, a tactic common in academic methodologies that advocate for social change.

My claim, however, is that at times in Disability Studies the assertion of such difference arguably stops being different and instead becomes a location of assumed knowledge and confident critical superiority. How much is really at stake when an academic professes that disabled difference changes the world? Especially when that academic is almost always implicated in the complex location of the kind of institution which has a problematic relationship with its disabled staff and students (I have not ever known an exception to this). It is not that academics do not realise this, and much excellent work has been produced on what Sharon Snyder and David Mitchell term the often-precarious »cultural locations« of disability, both physical and intellectual; but at the same time the world of Disability Studies can become a space in which to say ›disabled difference‹ is to invoke a go-to statement free from risk, a comforting assertion of progressive liberalism.[8]

This has not always been the case. In the late 1990s, Simi Linton noted how the emergence of Disability Studies worked as a »strategic endeavour«, a corrective to »the constricted, inadequate, and inaccurate conceptualizations of disability that have dominated academic inquiry«.[9] Here, the work was that of interlopers, the proud carriers of freak flags with PhDs and the forthright energy to ask questions about curricula and systemic exclusion in and beyond the academy. To think about the 25 years since is to highlight the complex consequences of the success that (first) Disability Studies and (then) Medical Humanities have achieved as disciplines, especially in the US and UK. The process of bringing into critical focus that which has been misunderstood and excluded, and revising the working methods of older disciplines by suggesting new approaches, is clearly a necessity. Likewise, rethinking research topics and methodologies through diversity and inclusion is essential. But equally, there are dangers that come with such innovation. In terms of new disciplines, innovation can become credentials in showcasing academic relevance, allow-

7 Cf. Lennard J. Davis: Enforcing Normalcy: Disability, Deafness and the Body, London and New York 1995, p. 22.
8 Cf. Sharon L. Snyder and David T. Mitchell: Cultural Locations of Disability, Chicago 2005.
9 Simi Linton: Claiming Disability, New York 1998, p. 2.

ing for the jumping of the queue in seeking resources: jobs, funding, and institutional opportunities more generally. These processes may wear the clothes of difference, may be firmly committed to it, but paradoxically they can often become a new wave of the same.

This is a point about structures, of course. As a scholar in English Studies committed to interdisciplinary work, I still feel that (in my case) creative texts carry the power of critique, but that both critical thinking (theorising, conferences) and institutionalisation (syllabi, curricula, the racial makeup of staff and wider [non]opportunities for career progression) can create a quietude that stifles the emergence of so-called ›new‹ disciplines. The thought that lingers with me is whether, in its continued success, Disability Studies especially might follow a similar trajectory to other disciplines (such as Post-colonial Studies) founded through processes of productive troubling, that we might be in a moment when Linton's agitators become standard equality curriculum-reform memos. And when I say ›we‹ I again acknowledge that I am speaking of myself: someone directly involved in the institutional structures mentioned here.

At the same time, it can be simple to characterise agitation and the championing of difference as straightforward forms of an uninterrogated critical force for good. It is common to end an academic event or argument with a call for more radical thinking, as if that was something agreed and understood as opposed to an admission that this is an incredibly difficult process or fanciful wish. Radical agitation can be as closed and blinkered as the causes it seeks to oppose, another version of the same. In today's social media saturated world, where a Tweet can make anyone a pariah, disability itself is one of the subjects that nudges close to the you-cannot-say-that third rail of self-appointed progressivism that marks academic and public social discourse, with its firm sense of what constitutes justice and demand for appropriate experiential expertise when approaching the topic. Outrage is pervasive on such platforms, and prejudice against disabled people common, but this does not mean that the disability-positive version of such commentary should be excused its no-exceptions intolerance. There is a lot of claiming around as to who can and cannot speak on what topic and while there are countless vital and progressive arguments that have been possible through claims articulated in this way, particularly by those who lack access to more mainstream media outlets, it is clear that numerous debates are in fact typified by the shared intolerance of the antagonists. Entitlement takes many forms and those who want to propound difference can easily end up enacting the same.

There are any number of examples in academic discourse where difference can become same then. But there are more important and complex manifestations of disability/same continuities. For many disabled people, many activities – studying, getting a job, having a partner, starting a family – are part of the fabric of all sorts of lives. Equally, many disabilities can be understood as a same: those with congenital conditions have never known lives without the body they have. Here, we can see that Linton's assertion of the right to claim is not only a claim to the status of being disabled and the power of that difference; it is also another format of claiming sameness, that which is unique in the everyday and mundane, the ordinary stuff of life.

This kind of disability same is everywhere, but a complexity, even a tautology, kicks in here. It is precisely a demand for ›same‹ in disability encounters that underpins ableism. In this formation, same is active in repressing disability meaning in that it enacts a retreat from difference to ignorance and intolerance. Here then is a challenge for disability scholarship's use of difference, one where the very idea begins to creak under the pressure of the work it is doing. As the above anecdote demonstrates, disabled difference folds into and around, but does not necessarily replicate, how any body and mind might work in the world. Collapsing disability into a wider idea of ›bodily difference‹ is a dangerous relativism that misunderstands how power works. But at the same time, there is an interweaving of difference/same through disabled and non-disabled experience, the naming of which can only help in expressions of disability recognition and justice. Lennard J. Davis speaks to this in his collection of essays *Bending Over Backwards*, where he asserts in the title of the book's Introduction that »People With Disability: They are You«, an argument about same he develops with reference to an increasingly ageing global population for which disability will become a fact of life. At the same time, Davis embraces disability as an unstable »difficult position« (a term in his book's subtitle) precisely because of the difference it produces. Such ›difficulty‹, he asserts, could provide both a new ethics of the body and an identity position that can be a link between others (he mentions race, gender and sexual orientation) in a fully multicultural patterning. This is, Davis acknowledges, highly ambitious, but is nevertheless an example of what he believes that a critical mobilisation of disabled difference could do.[10]

Michele Friedner is even more explicit about the interconnections between different and same in her study *Valuing Deaf Worlds in Urban India*, which

10 Lennard J. Davis: Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions, New York 2002, pp. 13–14 and pp. 22–23.

analyses deaf communities in Bangalore. Friedner notes that a common greeting between deaf people in the city is »deaf deaf same«, a phrase that means »I am deaf, you are deaf, we are the same«. »Deaf deaf same«, she notes, is »a common sentiment and statement in Bangalore's deaf worlds, and it is a way of expressing deaf similitude or a shared language of being in the world based on common sensorial experience, use of sign language, and an awareness that structural barriers exist for deaf people«. A feeling of »deaf deaf same«, she continues, interacts with deaf people's circulation through space and locations to produce what she terms »deaf turns«. At the same time, Friedner develops an idea of »deaf development« that is geared towards a drive for social equality, something that »will result in deaf people's becoming equal to normal people–though it will not result in their becoming the same«.[11] Difference and same are held in a complex interrelationship here, one where the concepts of development and turn mark movements in how each operates (I especially like the suggestion of turning towards/away/between different and same). And crucially the idea is disability led, in that »deaf deaf same« is the origin (Friedner employs it at the very start of the book) of the development that reaches out for equality, and therefore justice. This careful charting of the interweaving of difference and same gives a depth of meaning to each as well as the relationship between the two.

We can learn much from these examples then, and avoid falling into the flat uselessness of saying that all bodies are the same because they are different in some way, or that our ›common humanity‹ means we are all the same despite what are obviously vast differences in experiencing the world. We can learn to respect the particularities of disability and ill health without pushing (or pulling) these so far away that they become fearful or exotic. They can be recognizable, from within and without, even as they weave within and without together.

A notion of difference/same and the ways they are expressed in both the experiences of lives lived in health and disability and the new academic disciplines that have come to coalesce around them are, I want to argue, major elements in how we might think about the relationship between Medical Humanities and Disability Studies. They speak to and of the multiple poles/not poles, dualisms/not dualisms that shift and oppose, complement and contradict, inform and challenge our efforts to make sense of what these essential labels – medicine, disability, health – mean when we come to speak

11 Michelle Friedner: Valuing Deaf Worlds in Urban India, New Brunswick, NJ 2015, p. 3.

and write them. In the light of this, my arguments here about the workings of the two disciplines are attempts to specify methods and offer interventions, knowing that these lie over the missing words of each related topic, the indisciplined and palimpsestic presences that inform understanding but also always suggest possible erasure, helpful signposts and challenging shadows. Aiming to provoke in this context involves finding fluid intersections even while admitting that these might also be powerful oppositions: and wanting to do justice to both in their full manifestations.

Critically, there is nothing new in observing that dualities have unstable poles and work as continuums as much as contraries; it is a mode that drives theoretical framing and works to recognise nuance and sophistication. But to assert an indisciplined approach to disability and medical contexts of difference/same is to engage with a different critical process, one that is not only a critical paradigm but addresses vital and sensitive elements of health, agency and personhood. After all, there is significant space between a health condition designated as clearly ›different‹ to the majority of the population and a health status figured as the same as, or consistent with, that majority. With disability, this is equally acute: Here, difference is an essential category for multiple reasons, whether in terms of self-image and agency, (non-)acceptance by others, or access to benefits and allowances. For health and wider state bureaucracies, if a disabled person is deemed to be the same as others, their very status in society can be called into question. Equally, public perception of such a person is unlikely to register their disability experience. Here, to be the same is not to be disabled.

It is an act of indiscipline, then, to argue for a greater interweaving of difference and same. It is a provocation to assert that ill health should not always be understood to be a medical outlier, or that disability is not difference. I want to argue for the specific forms this takes when the topics are not only medicine and disability, but also Medical Humanities and Disability Studies. Most stories of health lives and their contexts never come near academic disciplines, but the latter claim a stake to discuss the former and uses complex critical tools that make this happen. To argue for disability same is to confront some of the politics of identity positioning Disability Studies holds dear; to do something similar with health is to contest one of the very premises of treatment. But, I would claim, ways that health services treat difference are themselves frequently problematic; and academic study of disability is (surprisingly) often less open and tolerant than might be expected.

Following these trajectories in my own work has led me to a series of indisciplined encounters that produce new provocations: On the complexities

of claiming; the critical power of cynicism and anger; the prevalence of sneering condescension; the limitations of theory; the structures of listening; and the shortcomings of what might appear to be critical acuity and disciplinary success. To take one of these as an example: listening. Especially in the critical communities in which I find myself, listening presumes the value of a process that extends from the assessment of any given situation or experience to the delivery of what that assessment means. Listening – to a patient or a disabled person – is a good, a foundational element in Medical Humanities and Disability Studies scholarship. Yet frequently such an assessment is inattentive to exactly how structures obfuscate the very idea of such ›delivery‹ and here listening can become a gesture, an act that does not move on from its initial, well-intentioned, formation. I am as pleased as anyone who lives with or cares about disability that we talk more about it in the (UK) culture in which I live, that there are more disabled people on television and children's books and that as a result we, as societies and cultures, reach out, listen and try to understand disabled lives. Equally, I welcome any initiative to talk more, and better, about mental health (especially as someone who teaches young people). And yet, the systems of the worlds in which many of us reside continue to disempower those whose bodies or minds signal alternative ways of being in or experiencing the world. Demands to be a certain kind of individual, to move at a certain pace and produce in certain kinds of ways, are as pervasive as ever and to fall ill, have or acquire a disability is to be placed outside of what are incredibly powerful and seemingly unstoppable narratives of personal and communal worth. What spaces are there for those who face a future in which acceptance appears to be welcomed but who are excluded by structures? At times, this feels more insidious than blatant ignorance because it creates what appears to be an attitude of care. Often, cruelly, it can begin with listening.

The offer of the same then, of inclusion, understanding, and welcoming, masks what in fact is frequently an ongoing stress on the kind of difference that is intolerant, that excludes and (at worst) actively punishes. Individuals might be championed, but categories and populations are allowed to fall away. In social and political contexts, these latter remain under-resourced, with care budgets and community services always high on any list of austerity cuts. Likewise the presence of (for example) mental ill-health as a subject of agreed social concern does not translate into meaningful support for those whose health is so affected. What, put bluntly, can Medical Humanities and Disability Studies do about this? Do they, indeed, want to work with these subjects in mind? Maybe to even ask this is to misunderstand the trajectories

of their disciplinary concerns as they are manifest in those who work under their umbrellas. It would be cruel to find that the disciplines themselves are examples of the welcoming/exclusion dyad.

Indisciplined Lives

In my own research on disability and health memoir and life writing, I have tried to follow the consequences of thinking about indisciplined and provocative difference/same through the ideas I discuss above. As my thoughts about listening might suggest, my suspicion of individualism and humanism means that I do not read life writing because it is the product of singular viewpoints, but rather because it is structural and enacts the *naming of a world*. In my view, the best life stories do not claim to supply a veracity of individual experience but work through the recognition of systems and sly mechanics of fabrication and editing, often taking the individual self out of truth and breaking down its centrality as the agent of worth. If this sounds counterintuitive, then I would note that it is not only an assertion I might make: It is there in the content and indeed the very titles of some of the best books that discuss disability and ill-health. Lauren Slater's self-styled »metaphorical memoir« *Lying* is, she tells the reader, »a slippery, playful, impish, exasperating text, shaped, if it could be, like a question mark«,[12] while Bassey Ikpi's collection of essays on her experience of being Bipolar, *I'm Telling the Truth, but I'm Lying*, captures the same logic. The titular tension here includes not only Ikpi's disjointed immersion into mental ill-health, but also the inherent contradiction in any claim that writing of such an experience offers a truth-telling clarity. As she says, »Lying is how I survive this […] I lie to control the narrative«. What she terms »parceling truth« is the survival mechanism that lets her »walk though this world vacillating between existing and not existing«.[13]

In the memoir of her depression, *Willow Weep for Me*, published in 1998, Meri Nana-Ama Danquah makes precisely this point about world naming when she observes the ways in which Black women are subject to specific structural stigmas in relation to mental health:

> Stereotypes and clichés about mental illness are as pervasive as thought about race. I have noticed that the mental illness that affects white men is often characterized, if not glamorized, as a sign of genius, a burden of cerebral superiority, artistic

12 Lauren Slater: Lying: A Metaphorical Memoir, New York and London 2001, p. 221.
13 Bassey Ikpi: I'm Telling the Truth but I'm Lying, New York 2019, p. 49.

> eccentricity – as if their depression is somehow heroic. White women who suffer from mental illness are depicted as idle, spoiled, or just plain hysterical. Black men are demonized and pathologized. Black women with psychological problems are certainly not seen as geniuses; we are generally not labelled ›hysterical‹ or ›eccentric‹ or even ›pathological‹. When a black woman suffers from a mental disorder, the overwhelming opinion is that she is weak. And weakness in black women is intolerable.[14]

Facing her own illness, Danquah saw structure everywhere. No part of her depression escaped the fact she was Black. Even the central metaphors given to medical illness' manifestations–»A black hole; an enveloping darkness; a dismal existence through which no light shines; the black dog«–became markers of race. »But«, she adds »what does darkness mean to me, a woman who has spent her life surrounded by it? The darkness of my skin; the darkness of my friends and family«. For Danquah, »Depression offers layers, textures, noises« but it is not constituted through blackness: »It is loud and dizzying, inviting the tenors and screeching sopranos of thought, unrelenting sadness, and the sense of impending doom. Depression is all of these things to me– but darkness, it is not«. Later in her memoir she writes: »I despise the way blackness, in the English language, symbolizes death and negativity. Because I believe that the absorption of these connotations contributes to self-hate, I avoid them at all cost«.[15] Compare this to one of the most famous memoirs of depression, novelist William Styron's *Darkness Visible* (written in 1990, just a few years before *Willow Weep for Me*) which charts a journey from darkness into light, from »hell's black depths« to the »shining world« of health.[16]

Stryon's book is firmly focused on an idea of self, detailing the terror that comes when it is lost, and the power of the individual to reclaim it. Danquah complicates all this: she tells her readers that »Many names and skins have been shed in order for me to evolve into the person I now am«.[17] Born Mildred Nana-Ama Boakyewaa Brobby in Ghana, and called Nana-Ama as a child, she became Mildred Brobby after moving to the US. »In the face of people who were not part of the culture that I had come to know as my own«, she writes, »my public name and, ultimately, my public persona became Mildred, the English name I was given at birth [...] It hung strangely on my bones, but it was what was given to me so I took it and absorbed

14 Meri Nana-Ama Danquah: Willow Weep for Me: A Black Woman's Journey Through Depression, New York and London 1998, p. 20.
15 Ibid., p. 22 and p. 182.
16 William Styron: Darkness Visible, London 2004, p. 84.
17 Danquah: Willow Weep For Me, p. 103.

all that it was until even my flesh became redolent of its ugliness«.[18] But Mildred transformed into Mary when Danquah was still a child, because »I convinced myself that only a plain, simple ›American‹ name could provide me with what I wanted most desperately: the luxury of slipping into a void of invisibility«.[19] As a student, Danquah changed her name again when Mary felt unsatisfactory: »I didn't want to be bland and anonymous anymore. I wanted to be myself–whatever that was. I toyed with the name, exchanging letters here and there, until I arrived at Meri. When I looked at the name Meri Danquah, something inside clicked. I felt as if I already owned it«. Reworking her first name and taking her mother's maiden name, after twenty years Danquah found a name that »wasn't a persona. It was me, who I had been all along«.[20]

Name changes such as these are not unusual in immigrant families. They often signal issues of race, ethnicity or nationality and how these are adjusted following a move to societies unsettled by difference (hence Danquah's reference to skins and the internalised ugliness produced by systemic racism). But, as she makes clear in the discussion of her name, Danquah associates this with her depression and the ways in which it created a disassociation of selfhood – the ›void of invisibility‹ – that affected both mind and body. In her book, she mentions the name changes near the start of a section entitled ›Ghosts at the Edge of a Swamp‹, which details a return to the neighbourhood in which she grew up. Ghosts, and especially haunting oneself, occur frequently in women's memoirs about their health; for Danquah they are manifestations of the »uncertainty and self-hatred« she experienced on her arrival in the US, experiences that she links explicitly to her depression.[21]

Danquah's testimony is another example of the difference of difference (here, the way in which the structural dynamics of understanding mental illness are so often exclusionary of specific experiences) but also difference as same (the way that illness is, for Danquah, always framed within the endlessly repeating tropes of stereotypes about being Black; racism means that her difference is nothing like Styron's). It is the figuration of her depression that speaks to and informs the realities of her Blackness, and vice versa, and this then spills out into the world she names in her memoir. When she reads in a newspaper that a significant number of Black people suffer from depression, she immediately counters: ›But why wouldn't there be?‹, continuing:

18 Ibid., pp. 103–104.
19 Ibid., p. 108.
20 Ibid., p. 130.
21 Ibid., p. 104.

> Depressive disorders do not discriminate along color lines, people do. People determine what is publically acceptable and what is not, who may behave in what way at which time and under which circumstances; and these social mores spill into our private lives, into the images we create. White people take prescription drugs with gentle, melodic names; they go to therapy once or twice a week in nice, paneled offices. Black people take illicit drugs with names as harsh as the streets on which they are bought. We build churches and sing songs that tell us to »Go Tell It on the Mountain.« Either that or we march. Left, right, left, from city to city, for justice and for peace. We are the walking wounded. And we suffer alone because we don't know that there are others like us.[22]

The social mores that spill into private lives are a stark signpost to the structures that create and sustain mental ill-health. Recognising this helps explain how Styron (and others like him) can present their depression in terms of a humanist selfhood precisely because of the social space and capital he accrues as a privileged (and here, white) novelist. Because she is Black, Danquah is denied such security and community. The ghosts of her depression are interwoven with those built into her experiences of race.

In looking at work such as Danquah's, I find what I see as the fault lines and test limits of Medical Humanities and Disability Studies' status as disciplinary approaches, where the inevitable interweaving of life and health becomes a topic of critical enquiry. Such interweaving provokes an obvious question: why should we keep health and disability separate in ways that, as terms, Medical Humanities and Disability Studies clearly indicate? One answer is that, of course, this does not happen and that recognition of the overlappings of race, class, sexuality, gender, embodiment and others takes place all the time in intersectional work. But the disciplines' titles aren't meaningless, and their differing priorities and distinctions they create aren't simply products of academic legacies and institutional flag-waving. Disciplinary differences themselves become constitutive of how health and disability become understood in the social imaginary. They funnel into media, for example, whether through journalism or the siren status of social media, and they inform political opinions. Medical Humanities and Disability Studies scholars are vehemently opposed to any allegations that their work is in any way part of an ivory-tower-research-for-its-own-sake paradigm (activism and teaching are prime examples of engaged commitment). Well, fine. But if this is the case, we have to be attuned to how the critical parameters of our engaged

22 Ibid., p. 184.

work might inform debates surrounding health in ways that might actually be counterproductive.

Writing like Danquah's helps me make sense of this. Because they are Black, writers such as Danquah and Ikpi provide complex interrogations of stigma not found in other life stories of mental ill-health. They invoke communal understandings of health and as such are practitioners of the kinds of indisciplined world naming I discuss above. The fact that both are women has also been a vital guide to my own work. As might be expected, there is a considerable amount of life writing by men that discusses ill-health, but (as with Styron) it is often shaped by the power of the personal, a centrality that clusters around the individual expressed (obviously) in terms of patriarchal entitlement in one form or another. In my research I have read much of this but – put bluntly – do not find it useful in putting forward the arguments about Medical Humanities and Disability Studies that I found to be the most vital to address. I have come to realise that the reason for this is simple: Women's stories provide the best ways to analyse the disciplines because they are the most complex. They give the best critical insight into topics like disability/same and they do so with the kinds of indisciplined reasoning that signifies the most provocative (and therefore the most useful) modes of health telling.

Conclusion: Disciplines Again

As a discipline, Medical Humanities is successful in many ways because it functions as a broad network of connected approaches across and through multiple subjects. It is through a synthesis of these, one imagined as much as actually theorised, that it lays claim to a critical power. In so doing, it self-consciously aspires to greater sophistication and has moved from deterministic models of instruction and listening (teaching doctors and consulting patients) to critical modes of entanglement and discipline crossing that ultimately are acts of complex reading. Disability Studies builds sophistication into highly complex theoretical frames that host critical projects of advocacy and interrogations of social and cultural activities; it is wary of structures that discriminate and committed to the project of championing disabled presence and forms of knowing the world. In contrast, Medical Humanities still positions itself so as to carry the authority of the category of ›Medicine‹ (even as it critiques it) and, as a result, inevitably operates with some of the legitimacy the word accrues – I find this to especially be true at an institutional level. Through the use of a complex grid of enquiry it seeks to organise better,

to challenge, and provide improved critical insight into how medicine and health work. Disability Studies is more interrogative of structures and the rethinking of space and time, more committed to activity and organised change. Because of its history as a subject that argues for the need to use the arts in health and to respect the personal voices in patients, Medical Humanities still works through processes of enlightenment, an unveiling that demands more complexity as it asserts its place at the health and medicine table. In the ways in which Medical Humanities pushes to be more than a critical friend to clinical/academic conceptions of health, more than a recourse to humanist modes of understanding experience, for example, or a flat model of therapy, it has successfully argued – especially at levels of theory – for a need for interweaving, uncertainly and greater sophistication in seeing what health is. But arguably it does so through the addition of perspectives, even as its most critically complex. Disability Studies more fully names a recognisable and critical world, even in its sometimes contradictory and exasperated forms.

At the same time, Medical Humanities aims for greater critical inclusivity and can push back against many of the uninterrogated assertions made by Disability Studies and the assumptions inherent in its affirmative modes of counter narratives. I have long found the argument that the ›medical model‹ of minds and bodies underpins misunderstanding of disabled bodies and minds to be frustrating (and this is even if such a model is not seen as that practised by medical specialists but rather a public understanding of this practice). Do processes of medicine cause such problems because of their structures? Of course (think of the incredibly reductive nature of pain scales). Do they do so through recourse to an overarching and coherent model that guides this? Clearly not. Critical Disability thinking grounded in such a viewpoint can simplify the complexities of medicine and the arguments and tensions between different approaches to health and treatment: Health system officials insisting on discharging a patient from hospital, for example, set against rehabilitation experts who know that the person requires additional care; or a surgeon deeming an operation a success, when other doctors know complications are inevitable and will have to deal with patient and family confusion about the future. I once heard a psychiatrist lament wearily that they felt the idea of a medical model was a construction by social scientists (especially) and cultural theorists that licensed dismissive straw man arguments about medical practice, and I confess sympathy for that view. Disability Studies sometimes does the same with ›clinical‹ and ›biological‹ science (I have been guilty of the former). If critical work on disability can demand rightly that subtlety and nuance are essential to understanding

its multiple manifestations, it is hardly reciprocal to resort to attacks on something called ›science‹ as a way of doing this.

In part, this problem arises because Disability Studies, understood here in its systemic disciplinary formations, is not always good at being inclusive. Scholars in the separate subject areas that contribute to research on disability believe rightly that their work is often vital in addressing issues that affect the lives of disabled people. Working to reduce prejudice, institutional exclusion and systemic discrimination, or understanding cultural narratives, questions of representation and issues of gender (just to give some examples) is enough to take up the most of any working day and there is not necessarily a need (or a desire) to attend to alternative ways of approaching disability experience. Many who work predominantly in Social Studies harbour suspicion towards the theoretical frameworks of Cultural Studies methods, while Critical Disability Studies may aim to build community, and so reaches out to engage with the thinking of others – gender/queer/race – because an alignment of methods can open new doors, but the results can be mixed. At its best, these processes are energising, bringing rich discoveries to ongoing work. But they can be dismissive of research located in specific disciplinary approaches and also produce a lazy intersectionality that lines up critical approaches without thought and actually collapses the specificity of each. Similarly, a commitment to provocative engagement can assume that counter narratives to ableism are de facto good simply by existing in opposition. I often feel that the tendency of Critical Disability scholars to claim the moral high ground through an assertion of wide-ranging inclusion to be something that needs investigation and revision, because it all too often simplifies complexities of disability lives. I find more tolerance in Medical Humanities approaches to critical methods, possibly because the subject acknowledges that it does not have the same kind of foundational core subject (the disabled person, for example) as other disciplines. It knows that it needs to know more.

In much disability theory, assumptions are made about what disabled people are or what they want and even if these come within a language of inclusion that suggests variety, they can be remarkably inflexible. The sometime-stereotyping of the disabled person or consensus about what disability is and how it functions evident in much disability scholarship can be off-putting, especially when the desire is to champion the diversity of disabled lives. The settled agreement that sometimes results can easily become self-righteous. A consensus needs troubling if it becomes in danger of telling people how to think and what to do.

I am aware that I have possibly been drawn into the position of choosing sides in the ways that I have structured the above, but I hope that it can be seen to be more than this. Putting different elements of the two disciplines in conversation and opposition is not about deciding that one is superior to the other; rather it admits that, like all critical approaches, they have strengths and weaknesses. I am an optimist, and as such I see them as provocative possibilities, ways of making interventions in the critical work that both Medical Humanities and Disability Studies undertake and therefore ways of better understanding medicine, health and disability across the wide range of their manifestations.

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