A legacy of silence: the intersections of medical sociology and disability studies

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ABSTRACT

Disability remains on the margins of the social sciences. Even where disability is foregrounded as a category of analysis, accounts regularly emerge in silos, with little interdisciplinary dialogue acknowledging the potential intersections and points of convergence. This discord is particularly acute within medical sociology and disability studies, yet there is mostly a legacy of silence about the relationship between the two disciplines. Drawing upon data from a qualitative study with parents of disabled children in the UK, I show the value of meshing ideas and tropes from medical sociology and disability studies to make sense of parents' lived experiences. They described the challenges of living with 'impairment' and a need to readjust expectations. At the same time, parents were keen to not align with a deficit framing of their lives. They talked in affirmative terms about their children as sources of joy and vitality, perceived themselves as 'normal', and described convivial, even unremarkable, interactions in public spaces. Yet, parents encountered difficulties when navigating institutional settings and bureaucratic arrangements, or what was commonly referred to as 'the system'. Their troubles were not located in their children's bodies, but in—as per a disability studies sensibility—cultural and structural systems preventing their capacity to *live well*. I argue that both disability studies and medical sociology offer something to the analysis, thereby recognising the gains of not simply buying into the tradition of one worldview. I conclude by imploring for more concrete conversations between both disciplines.

INTRODUCTION

Disability remains on the margins of the social sciences. Medical sociology is one discipline where analyses of living with disability have been present for a long time. However, these (often canonical) accounts have been critiqued for aligning with a personal tragedy bias which focus only on societal responses to disability (or chronic illness)[1] and the everyday embodied experience of living with such body states (Thomas 2007). This arguably positions disability in a medical model that depicts it as 'an individual failing and a personal tragedy' (Barnes and Mercer 2010, 1). Critiques also centre on the normative positioning of disability by only attending to matters of limitation and impairment, and the alleged passivity of medical sociologists in pursuing scholarship goals rather than committing to assisting disabled people in their battle for equality. The likes of Thomas (2012, 215), instead, plug a 'social oppression' paradigm, which sees living with a disability as being subjugated and at the mercy of structural hostilities. This is a central tenet of disability studies, an interdisciplinary field of both scholarship and activism, that simultaneously seeks to 'quash damaging pathological discourses of disability to offer more sociocultural conceptions' (Liddiard et al. 2019, 1474). It runs counter to dominant hegemonic narratives of disability that 'individualise, pathologise, medicalise, psychologise, essentialise and depoliticise disability' (Goodley et al. 2019, 973). Disability studies, in turn, provides an avenue for liberatory, affirmative and valued configurations rather than assuming pity, calamity and misfortune (Goodley 2014). In response, medical sociologists highlight how such accounts overegg a polar dichotomy between disability studies and medical sociology, exaggerate the espousal of a personal tragedy bias, contribute to a general and oversocialised understanding of disability, and dismiss the realities of living with impairment.

Yet, despite such critiques, there is still a legacy of silence about the relationship between the disciplines. This can be due to a number of reasons: the challenge of defining what disability means; an oft-overlooked association between disability and chronic illness (and, relatedly, the chronically ill not defining themselves *as* disabled) and because disability is not a totalising tag, as made clear in disability scholarship in the Global South (Grech and Soldatic 2016; Ingstad and Whyte 2007). There may also be external factors for this divide, such as disciplinary boundary protection and institutional pressures and requirements. Whatever the reasons, I argue that this divide is futile, produces missed opportunities and risks nourishing silos and insular scholarship.[2]

I begin this article by discussing the existing dialogue between medical sociology and disability studies, and citing recent scholarship that appears to traverse these boundaries, even when not touted as such. From here, I draw upon data from a qualitative interview-based study with parents of disabled children to sketch out the value of meshing ideas and tropes from medical sociology and disability studies to make sense of their lived experiences. Parents described the challenges of living with 'impairment' and a need to readjust expectations. At the same time, parents were keen to avoid aligning with a deficit framing of their lives. They talked in affirmative terms about children as sources of joy and vitality, along with perceiving themselves as 'normal' and describing convivial, even unremarkable, interactions in public spaces. Yet, parents did encounter difficulties when navigating institutional settings and bureaucratic arrangements,

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or what they often referred to as 'the system'. Their troubles, parents argued, were not located in their children's bodies, but in—as per a disability studies sensibility—cultural and structural systems which prevent their capacity to *live well*. I argue that disability studies *and* medical sociology offer something to this analysis.

My intended contribution is twofold. First, I urge for more concrete conversations between scholars of disability studies and medical sociology. This is not an empty and undercooked call for interdisciplinarity, nor is it a platform to indulge in proselytist practices. Rather, my aim is more modest: to recognise the merit of not buying into the tradition of a single worldview and to implore for more conversations between medical sociology and disability studies. Second, I intend to recognise disability as a core topic of interest for social scientists. It often is at the fringes, a niche subject reserved for a cluster of dedicated scholars. Yet its continued relevance to conceptual and empirical debates in the social sciences is clear (eg health, care, kinship, ageing, embodiment, biopolitics, inequality, technology, ethics, diagnosis, stigma, citizenship, etc). Disability remains a marginal and special interest topic, yet it aligns with central and longstanding points of interest within sociology and the humanities—and, thus, deserves (more) theoretical and empirical attention.

I should also clarify two things. First, I do not intend to devalue the vitality of other disciplines that study disability (eg, anthropology, law, policy, geography, literary/cultural studies, history, gerontology, science and technology studies (STS)). Rather, I argue *for* conversations between scholars in different disciplines who take disability seriously as a matter for critical attention. Second, there is a risk of unjustly presenting medical sociology and disability studies as singular, unified disciplines. In disability studies, for example, there is a long history of multidisciplinary contributions, and there are recent calls in critical disability studies (eg, Goodley et al. 2019) to engage with Black and Trans disability studies, crip theory, gender and sexuality studies and STS. I do not aim to undo or displace this work, nor do I intend to craft rough caricatures of disciplines that are united on all matters. Each discipline contains subfields and different theoretical allegiances, methodological curiosities and empirical endeavours; fractures are also both evident and inevitable[3] (although disability studies is unified, I believe, by a social oppression paradigm and promoting the interests of disabled people). Yet, the capacity to draw loosely and lightly upon ideas from each—around living with impairment (medical sociology) and dealing with oppressive structures (disability studies)—is valuable for making sense of my data.

MEDICAL SOCIOLOGY AND DISABILITY STUDIES: A BACKGROUND

The disciplines of medical sociology and disability studies have often passively co-existed, yet sometimes clashed in tense and distant ways. Rarely have they actively engaged with one another or have accounts explicitly discussed this dialogue (or lack of), exceptions being Carol Thomas' corpus (Thomas 2004a, Thomas 2004b, 2007, Thomas 2010, 2012), the work of Shakespeare and Watson (2001,2010), an edited collection by Scambler and Scambler (2010) and a recent article by Mauldin and Brown (2021). Developing the 'social relational' in the social model of disability, inspired by the early *Union of the Physically Impaired Against Segregation* (UPIAS) formulation of a distinctly *social* understanding of disability, Thomas (2004b) argues that disability can be defined as social exclusion on the grounds of impairment. For Thomas, bodily deviation marks social relationships, with people designated as *non-impaired/normal* included and privileged, and people designated as *impaired/abnormal* excluded and disadvantaged. Thomas charges scholars in the heartland of medical sociology with ignoring such ideas as advocated in disability studies. She claims that with its history of structural-functionalist, poststructuralist, conflict theory and interpretative approaches, medical sociology aligns with a 'social deviance paradigm', where disability is understood only in terms of social responses to, and lived experiences of, 'different' bodies (Thomas 2007, 4). This 'medico-centric and disablist' (Thomas 2010, 38) framing of disabled people is bound up with 'impairment effects', the direct unavoidable impacts of impairment on embodied functioning including symptom management, changing bodies and identities, diagnosis and treatment and interactions with healthcare professionals and work institutions (Thomas 2012, 37). For Thomas, this remarkably consistent paradigm in medical sociology focuses upon individual suffering and adaptation, rarely names or analyses sociostructural consequences of disablism and ignores the agency of disabled people. Thomas, then, advocates for foregrounding 'disablism' in social scientific analyses, that is, the 'social imposition of avoidable restrictions on the life activities, aspirations and psychoemotional well-being of people categorised as 'impaired' by those deemed 'normal' (Thomas 2012, 37).

Thomas (2010) argues, though, that this is not to deny impairment effects; disablism and impairment effects are closely intertwined and cannot be fully understood separately. Her disclaimer is that this should be integrated without discounting the governing impact of disablism on people's lives, thereby enabling cross-disciplinary divides to be bridged. Yet, for Thomas (2007, 4), we should predominantly attend to disablism or what she calls a social oppression paradigm, which accounts for how disabled people are subjected to oppressive, unjust practices in daily interactions with institutional and non-institutional actors. Impairment cannot be ignored, but we should not waste time in studying bodily restrictions; "we can say, yes, of course impairment causes some restrictions of activity—but these are not what is of interest in studying and combating disability" (Thomas 2004a, 581). Thomas suggests that medical sociology traditionally has a poor record of recognising this, suggesting that scholars from the field too frequently assume 'a rather mealy-mouthed stance that there is some "social disadvantage" involved for disabled people' (Thomas 2004a, 581). She concludes that if sociology is to retain its relevance and connection to the social landscape, a sociology of disability must abide by a social oppression paradigm.

Medical sociologists (loosely conceived) have responded to such critiques. Disability studies—driven by a oppression paradigm—can overlook certain people (eg, people with learning disabilities; older disabled people) and can present an oversocialised and monolithic account of living with disability. Moreover, accusations of complicity with a personal tragedy/deviance bias is perceived by some scholars as unfair, simple and exaggerated (Charmaz 2010; Williams 2010b). Charmaz (2010) refutes the charge that micro (interpretative) analyses in medical sociology exclusively tell stories of tragedy, citing incidents of individuals recounting positive tales of appreciation, compassion, courage, transformation and interdependence. Similarly, Shakespeare and Watson (2010) suggest that the polar dichotomy established between disability studies and medical sociology by some scholars is 'overdrawn and unjust to the world of medical sociology'. In addition, they suggest that impairment is significant and, so, we must not misrepresent how activities and identities are disrupted and fractured by this. The separation of impairment

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from disability implies that the former is unproblematic and, so, endorsement of the social oppression paradigm is the only viable option. While disabled people are often oppressed (eg, economically), this might not be the case for everyone, impairment still plays a crucial role in shaping people's lives and assuming a barrier-free utopia is unrealistic (Bury 2010; Shakespeare and Watson 2001; Shakespeare and Watson 2010)[4]. Finally, there is an issue in disability studies of simply 'lumping together' people living with diverse forms of impairment, since this overlooks key differences and homogenises a medley of disabled people's experiences (Shakespeare and Watson 2010, 60).

Instead, Shakespeare and Watson (2001) argue for a sociology of disability which accepts that disabled people are 'disabled both by social barriers and by their bodies', a complicated interplay between impairment and excluding environments (Shakespeare 2005). Indeed, in their separate studies, they found that impairment effects and oppressive practices are involved in the process of disablement; looking exclusively at oppression, they argue, would not present 'a clear picture of disabled people's experiences' (Shakespeare and Watson 2010, 72). Impairment and disability are not dichotomous, but rather 'describe different places on a continuum, or different aspects of a single experience' (Shakespeare and Watson 2001, 22). Disability, then, for Shakespeare and Watson, is a 'complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision' (Shakespeare and Watson 2001, 22). They argue that by bringing together the commitment of disability studies with the empirical thrust of the chronic illness/medical sociology perspective, we can offer an engaged sociology of disability that goes beyond the (limited) social model to take a more nuanced approach to disability. This involves placing inequality, powerlessness and structure at the centre of analysis.

THE INTERSECTIONS OF MEDICAL SOCIOLOGY AND DISABILITY STUDIES

Scambler and Scambler (2010) provide an example of how this should be done. In their research with individuals who have Batten disease, Scambler and Newton (2010, 102) claim that the lifeworlds of families cannot be understood solely through 'the biological, social or psychological impacts of the disease process'. They argue for a more complex theoretical framework, yet in tandem draw upon the traditionally fought dichotomy between impairment and disability to claim that while oppression is recognised in their participants' worlds, it is secondary to the biological effects of the condition. This arguably demonstrates why canonical concepts in medical sociology—biographical disruption (Bury 1982), loss of self (Charmaz 1983), enacted and felt stigma (Scambler and Hopkins 1986), illness narratives (Frank 1995) and narrative reconstruction (Williams 1984)—have stood the test of time (Scambler and Scambler 2010, 1).

Nonetheless, a small section of social scientists have identified the value of meshing tropes and thrusts of medical sociology and disability studies. For example, Williams (2010b, 219) prompts sociologists studying chronic illness/disability to use a range of theoretical perspectives that link individual experiences to 'biopolitical agendas in the global age'. Williams (2010a) analyses the functional relationships between chronic illness/disability, labour markets and the impact of 'economic progress' and 'public policy' on people in postindustrial regions. His approach links microperspectives/macroperspectives to grasp how disability is categorised and regulated in order to govern access to welfare entitlements. Moreover, Scambler (2004,2018) and Charmaz (2020) reconsider Erving Goffman's concept of stigma to show how neoliberal policies and practices affect people's experiences of stigma and exclusion, thus calling for analyses that join 'structural arrangements with subjective experience' (Charmaz 2020, 24). Relatedly, McLaughlin's study with young people living with disability, participants talk of 'independence' as a core life-goal, reflecting political imperatives to be self-sufficient as welfare services and resources are depleted (McLaughlin 2017). Moreover, their agency in remaking their bodies in consultation *with* healthcare professionals suggests resistance to stories *only* of stigma and exclusion. By considering 'the wider structures informing everyday experiences of stigma' (McLaughlin 2017, 245), we can see how *impairment* and *disabling conditions* intersect in meaningful ways.

Such scholars acknowledge the potential for new dialogue and resolutions of difference, where impairment effects are discussed *alongside* macro-level structures that impact on systems and lifeworlds alike (Scambler and Scambler 2010). Extending such olive branches are still a rare occurrence, although other work offers hope—even where the relationship between both medical sociology and disability studies is not explicitly cited or examined. For example, Mauldin (2016) draws upon ideas from both disciplines, together with science and technology studies (STS), to examine the social consequences of cochlear implants for healthcare professionals and parents of deaf children. Mauldin captures how neuroscientific claims about neuro-plasticity, deafness and language are deployed to encourage compliance with medical technology. Moreover, White (2019) explores the everyday experiences of people living with irritable bowel syndrome (IBS) as a taboo and taken-for-granted illness. As well as telling stories of resourcefulness and resilience, rather than only of disruption and stigma, White shows how people with IBS are frequently denied access to public toilets on account of the condition's *invisibility* equating to *illegitimacy*. Public spaces became sites of struggle; the socio-spatial exclusion of disabled people is a common observation in disability studies. Finally, Harper (2019) discusses the past, present and future lives of people with Leber hereditary optic neuropathy (an inherited form of vision loss). Harper's research is clearly located in classic medical sociology theory, yet she claims that whilst her participants recovered some sense of 'ordinariness' or 'normality', they also encountered both attitudinal (eg, stigma, unwanted attention) and architectural (eg, inaccessible transport) barriers.

Such contributions recognise that a meaningful dialogue between medical sociology and disability studies can occur and that common ground is evident. My study with parents of children with Down's syndrome (DS) makes a similar contribution. The testimony of parents is valuable for understanding the value of meshing medical sociology and disability studies, given their intimate knowledge of *impairment effects* together with being privy to, and at the forefront of, navigating environments central to the *social oppression* of them and their children. I will now briefly outline my project.

THE RESEARCH

This article draws upon a study undertaken between July 2018 and May 2019. It involved three modes of data collection: (1) interviews with 22 parents of children with Down's syndrome (DS); (2) an ethnography of a large congress for people with DS, families and allies such as advocates, professionals and researchers; (3) analysis of textual matter (eg, newspapers). I draw only on interview data here.

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Interviewees were recruited via gatekeepers who were part of personal networks and charity organisations. The eligibility criteria were that participants were parents of a child with DS and lived within a 2-hour drive. Information sheets and consent forms were distributed via email and social media. Gatekeepers provided me with contact details of people interested in participating, although some participants contacted me directly via social media/email. Participants were invited to take part in a face-to-face interview in a place of their choosing. Two interviews were completed by phone for convenience purposes. Twenty of the participants were in a relationship (10 couples) and interviewed together. Both parents (mothers) interviewed individually were married, but their respective partners were unable to participate. The parents were aged 35–70 years and children were aged 1–15 years. Parents were mixed with respect to their backgrounds, educational history and employment status. Interviews lasted between 1 and 2 hours. I informed participants that they can withdraw and/or stop the audio-recorder at any moment, and avoid answering certain questions. They were told that their information would be kept confidential and safe, and I would attempt to ensure their anonymity is preserved (pseudonyms are provided here).

I recognise how talking exclusively with parents (and not children with DS) can work to silence the voices, and neglect the (possibly competing) perceptions, of disabled people. The methodology, arguably, reflects the common position of medical sociologists rather than scholars in disability studies—and, ostensibly, does not meet the participatory imperative of 'nothing about us, without us' (a slogan resonating with the history and underlying principles of the disability rights movement). This is a limitation of my project. However, this is not to discount the perceptions and experiences of parents. These are vital to obtain, not least as parents—particularly mothers (Runswick-Cole and Ryan 2019)—are on the frontline of navigating attitudinal, material and structural inequalities. My argument is that we should speak to parents as key stakeholders (although not exclusively) and that interviews, in spite of its flaws and complications (eg, Blakely and Moles 2017), provide an appropriate tool for gathering an *account* of parents' lives.

All data were analysed using 'situational analyses' (Clarke 2003). Clarke (2003, 553) offers 'situational maps and analyses' as supplements to the basic social process analyses typical of grounded theory, a 'very popular and epistemologically sound approach to qualitative research'. Clarke suggests that situational analyses attend to irregularities, fragmentations, positionalities and instabilities in which to comprehend complex worlds. For Clarke, the approach can be used to analyse observations, interviews, documents and other textual materials. Data were read alongside literature, allowing for an inductive and processual approach, until intricacies and relationships were identified. During and after data collection, I developed categories, interpretations and inferences highlighting key areas of enquiry and where my focus could be directed.

In what follows, I articulate how parents' lives provide an avenue for pursuing a dialogue between medical sociology and disability studies. I begin with their accounts of their children's *impairment effects*, specifically health complications and readjusting expectations. From here, I draw upon sensibilities from disability studies to show how parents enact a positive and affirmative comprehension of their lives, and how structural barriers inhibit their capacity to *live well*.

HEALTH TROUBLES AND READJUSTING EXPECTATIONS: 'IMPAIRMENT EFFECTS'

Most parents talked at some stage during the interview about their children's health complications. Certain health issues are more common among people with DS, including infections, heart defects, hearing and/or vision issues, sleep problems and thyroid disorders. Parents described frequent trips to hospitals and visits to/from professionals, such as occupational therapists and speech-and-language therapists. Although these services were not always easily accessible, parents worked hard to secure them to 'help [children with DS] to fulfil their potential' (Sophie). More commonly, though, parents talked about how daily routines were punctured in different ways. For instance, while Elizabeth and Terry talked about Abigail's (daughter) 'early illnesses and heart operation at 15 weeks old', Sarah and David discussed the health troubles of Louis (son), who has DS and a brain injury. They made no distinction between the two, instead talking in broad terms about his 'impulsiveness' (that David says 'has got worse the last few years') and 'varying degrees of cooperation' (Sarah). Sarah said:

> A school day is in some ways easier, although it will start with negotiating getting ready in the morning. And that can take 15 minutes or 45 minutes. It depends on tiredness, cooperation levels, the level of funny you feel that morning, what's on at school and whether he wants to engage in it or not. And I think that's normal for teenagers. It's just more magnified because of the disability…it's quite difficult for him to control [his] impulses…It's teenage hormones plus the fatigue which comes with his medical condition which isn't a good mix really. And then we'll get varying degrees of cooperation throughout the day…He's unpredictable and doesn't understand safety…I couldn't be in the office upstairs and expect him to be safe downstairs, because he isn't. And, he might suddenly decide he's going to bake something, and then he could put some of his toys or metal cars in the microwave and switch it on.

Sarah describes the unpredictability of their daily routine and, while disruption is 'normal for teenagers', this is 'amplified because of the disability'. While this is a situation, for Sarah, which she claims is 'lots and lots of fun', she also acknowledges Louis is 'impulsive', 'unpredictable' and does not 'understand safety'. Later in the interview, when citing such struggles and particularly Louis' poor sleep patterns, they describe such moments as 'very tiring' and say 'it's like you have to be on guard all the time' (Sarah also said her life is 'like being on a permanent degree course'), with David adding 'it's that 24/7… it's all the time'. Some parents, like Megan, also worried that their child was 'vulnerable'. Bella told a story about hiking with Freya (daughter) for 2 hours without a mobile phone reception. Bella described how she stopped to tie her shoelaces and asked Freya to stop, but Freya continued walking. While 'nothing happened', Bella said, she 'cried and cried and cried' since this moment revealed a 'scary' realisation that 'this was the situation' and "I can't do this by myself anymore…I would never, ever go for a walk with Freya by myself again".

The presence of health troubles and the disruption to daily routines is a path well-trodden in the medical sociology literature. Concepts have been established and remain dominant in the field of medical sociology (especially in the UK) to make sense of the lived experiences and narratives of people living with illness/disease (eg, Charmaz 1983; Kleinman 1988; Williams 1984). For instance, Bury (1982) argues that illness/disability is interwoven into people's biography and that serious, persisting symptoms disrupt their everyday lives. He calls this 'biographical disruption', the destabilisation, questioning and

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reorganisation of identity after the onset of chronic illness. As for parents, while the narratives did not follow similar scripts of despair and devastation (I expand upon this below), they talked about the disruption and anxiety caused by health troubles—as impairment effects (Thomas 2012)—and broader concerns around their child's well-being and safety.

Nonetheless, parents often claimed that they are fortunate that their child did not experience the same fate as others (ie, children *more* impacted by impairment effects). For example, Amelia said:

> We are really lucky, we're blessed. We're lucky that Aiden [son] does not have any major health complications. He's a healthy little boy but that may not be the case for all families in this situation. That must make it harder for them but we've been very lucky and blessed.

Amelia recognises her favourable position here; Aiden did not have 'major health complications', although this was possibly the case for others. Sophie and Jamie suggest that Noah (son) is 'healthy' compared with other children with DS who required more medical intervention, which would be 'an additional pressure and an additional drain' (Jamie). Jamie comments that this relates to the 'levels of the condition' and that they are 'very fortunate' and, for him, 'Noah is just another kid amongst a group'. Similarly, Charlotte and Henry talk about Laurie's (daughter) previous sleep problems that have now subsided:

> **H**: [Laurie] doesn't have overly complex needs. Laurie used to be a bit wakey in the night, more kind of sleep apnoea, disturbed sleep, [but] never any other problems. We certainly know some kids with and without Down's syndrome that have terrible issues sleeping, but we've always been really lucky with our kids.
> **C**: And we are religious sleep trainers aren't we, as well?
> **H**: Yeah, just for our own sanity more than anything. We want a bit of time in the evening.
> **C**: It's all based around routine. I think that's the key to a successful day. Especially if you've got children under ten. And even maybe up to a bit older…Routine is like the key to everything.

Charlotte and Henry describe themselves as 'really lucky' as Laurie 'doesn't have overly complex needs'. Similarly, when comparing children who can and cannot walk, Megan said that she felt 'blessed' since Ezra (son) and Chloe (daughter) "are not that disabled…because they're all different, aren't they…we feel like we're raising typicals". Parents frequently made comparisons to children with and without DS, seemingly grounding this *luck*—at the same time—in their own parenting efforts (I return to this point later). This included establishing a new routine; "it did become very, very clear to us that any individual with Down's syndrome thrives with routine" (Charlotte). Readjustment was also mentioned by several parents here, particularly in the context of their children's expected developmental milestones. Eva and Ray discussed this in relation to the different milestones of Martha (daughter) and Martha's siblings:

> **R**: You tend to celebrate the smaller things, the achievements that other children's parents might take for granted with their kids.
> **E**: We did with the other two, we took it for granted. Sucking out of a straw took us two years, didn't it?
> **R**: It was like going from rolling to crawling and then bridging gaps.
> **E**: Three years before she could walk between this settee and that settee. Opening a jar, Martha has just done it now and she's six…we'd been doing her [occupational therapy] exercises and for years trying to get her to do buttons and zips and that type of thing…It is the really small things. Putting the thumbs up, she's just mastered being able to [sign] 'okay'…I don't know if you've read that poem about a trip to Holland. You're expecting to go to Italy with the pasta and the Colosseum, and then you ended up in Holland which is lovely, but it's a completely different place, windmills and the pace of life is slower—and that's okay.[5]

Eva and Ray discuss readjusting their expectations around milestones that they had previously 'taken for granted'. While sometimes a source of frustration, delayed expected milestones frequently gave more cause for pride and celebration. Fred claimed that for Albert (son), who is 'non-stop' and a 'very restless sleeper', milestones are "a little bit slower, but when he hits them, it's amazing". Albert's improved speech is viewed as a 'big thing' and 'so cool', with Fred saying Albert has 'smashed' preconceived ideas conveyed by healthcare professionals of what he would be capable of (eg, walking at 2 years old, when told he would walk at 4 years old). Likewise, Roger said that Isaac (son) has given him a 'recalibration of things', redefining what constitutes 'success' with reference to Isaac possibly not 'achieving good exam results, going to the right University, this, that, and the other'…it's not the only form of success, is it?'

Parents' claims reflect broad trends in autobiographical accounts of parents to children with DS, where stories of initial difficulties are housed within later revelations of adjustments, triumphs and joy (Piepmeier 2012; Kaposy 2018). The notion of readjustment is another key theme in the medical sociology literature, with Williams (1984) suggesting that people engage in 'narrative reconstruction' when explaining and making sense of illness/disability. Here, people are able to 'reconstruct a sense of order from the fragmentation produced by chronic illness' and 'reaffirm the impression that life has a course and the self has a purpose' (194: 177, 179). Considering parents' positive framing of such adjustment, their accounts arguably reflect Frank's concept of 'quest narratives', where illness/disease constitutes a source of insight and ignites transformation, growth and development(Frank 1995). However, drawing only upon ideas from medical sociology is insufficient for making sense of the complex worlds of parents. In what follows, I contend that disability studies helps to understand how parents erect more positive imaginaries of their lives, and how the experience of disability in the family plays out through interactional *and* structural arrangements.

LIVING (POSITIVELY) WITH DISABILITY: BEYOND A 'DEFICIT' MODEL

Parents talked in varying degrees about their child's health complications and developmental progression (and readjustment with respect to expected milestones). Analysing such 'impairment effects' (Thomas 2012) is the wheelhouse of the medical sociologist. Yet, if taking the above quotes in isolation, it might be reasonable to conclude that parents' lives are defined by worry, vigilance, suffering, and tolerance. This feeds into common, yet limited and problematic, understandings of disability as 'a personal misfortune or tragedy that puts people at risk of a non-quality existence' (Siebers 2010, 25). As Shakespeare (2017, 48) claims, we have a "distorted view of disability…we tend to exaggerate, project, and mistake what life is really like for people with disabilities…we wrongly assume that difficulties for people result in misery for people".

This was not the case for parents; they were unanimous in departing from a deficit understanding of their lives. While acknowledging that parenting a disabled child can be 'tiring, distressing, upsetting and heart-breaking', it is also 'rewarding, affirming, enjoyable and heart-warming' (McLaughlin et al. 2008, 96). Indeed, Fred claimed while parenting Albert 'can be really challenging', he 'just brings something that wasn't here

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before'. Parents *cripped* popular accounts—usually built on robust foundations of dependence, tragedy and despair—to re-story life with a disabled child and stress 'the good lives they lead and joy they being' (Shakespeare 2017, 122). Parents did not shy away from the more challenging aspects of their lives, yet equally said that 'there are lots and lots of positives' (Roger). Henry claimed:

> We're very, very lucky that we've got an incredibly outgoing, sociable, absolute lunatic of a daughter. I wouldn't hesitate in being overwhelmingly positive about our experience, nothing bad about it at all. Challenges, yes, challenges with every child, whatever.

Parents, like Henry, acknowledged how challenges were common with a child with or without DS. Roger said:

> There's no doubt that it's an added challenge. But if you're told that you're going to have a child with DS, I would say there's no reason why you can't have a perfectly normal, happy life as you would have planned anyway, but there are additional challenges. Maybe there'll be some health challenges, and that's a bit of the luck of the draw, but I suppose you can say with any child. There may be some emotional challenges, and it will test your resilience as a parent, perhaps more than if you didn't have that…But you don't have to have a disability for a really hard life.

Valerie claims in the same interview that 'no kids come with guarantees, do they?' She makes a comparison with people in prison who "don't have any extra chromosomes, but I'm sure their parents will say that their lives have been very hard". She adds that "the rest comes down to you". This is a common sentiment among parents; they identified how their child had a 'positive impact on the whole family and the wider audience' (Jamie), yet this was expected because "we are positive, because he's our genes you'd expect that, not because he has Down's syndrome" (Sarah). Parents also described how their children have given them the gift of their own self-knowledge. Sophie said:

> I've grown so much…[having Noah] has just opened up my eyes. It just shows you what life is all about. He just shows what actually matters, not all the bollocks before.

I argue that, to fully analyse parents' lives, we can turn to contributions within disability studies. Disability studies dismantles damaging and dominant pathological, apolitical and reductionist configurations of—and promote more affirmative and liberatory understandings of—disability. The subfield of childhood disability studies (or disabled children's childhood studies) urges for such a corrective (Curran and Runswick-Cole 2014; Curran, Liddiard, and Runswick-Cole 2018). At its heart a transdisciplinary approach (Boggin 2018), childhood disability studies shifts the focus from a deficit and impairment/medicalised model of childhood to a rights-respecting model that deviates from normative, ableist expectations that contribute to the stigmatisation and exclusion of disabled children (Curran, Liddiard, and Runswick-Cole 2018). Moreover, it provides a means for examining the hopes, aspirations and desires of young disabled people, for opening up a more positive view of disabled childhood and the contributions of young people, and for utilising the social oppression paradigm to study their lives (Curran and Runswick-Cole 2014; Curran, Liddiard, and Runswick-Cole 2018).

In this study, parents were keen to highlight the positive contributions of their children. Moreover, parents talked about the need for dismantling 'myths', such as that their lives were miserable (or, at times, their child is unequivocally 'happy' and 'loving'). Charlotte and Henry, among others, felt like "we've got to prove our lives are actually okay, and that our children are actually going to be okay". The desire to 'educate' (Sarah) and 'increase awareness' (Amelia) was part of this. Indeed, Roger was keen to show that parenting a child with DS does not "mean you are destined for a life of basin haircuts, dungarees, and holding hands when you're thirty-five". This also meant, though, not overdetermining the disability category; parents were keen to convey the 'normality' of their lives, especially compared with friends/others without children with DS. The notion of normality or normalcy, or ordinariness, is subject to intense analysis in both medical sociology and disability studies (eg, Davis 1995; McLaughlin 2017; McLaughlin and Coleman-Fountain 2018). In a study with young people living with serious health conditions, Atkin and Ahmad (2001) discuss how young people attempted to take control of their lives and how they valued a 'normal' life, yet this was threatened by health complications along with life transitions, social relationships and sexism, racism and disablism. In research by Prout, Hayes, and Gelder (1999), parents of children with asthma were involved in managing their child's condition, and in making sense of their own *ordinariness*.

In a similar way, parents talked about their own *normal* or *ordinary* lives. They described chaotic schedules with many extracurricular activities and social events. Their lives, they maintained, were 'nothing out of the ordinary' (Amelia), with Charlotte suggesting that her and Henry describe themselves as 'normal, but with additions'. Likewise, Elizabeth said that "we do what other people with a girl who is 13 do—we're just like everyone else". Jenny similarly said about Ethan (son):

> For us, he's Mr Average, Joe Bloggs[6] …As a family, without doing anything other than getting on with our ordinary life, I think we advocate for Joe Bloggs, typical cracking on with it, Down's syndrome linked families. Without even doing anything, just getting up, brushing our teeth and getting out of the house in the morning. Nothing happens in this family that is particularly unique because of Down's syndrome.

Parents like Jenny made comparisons with their child's siblings and, specifically, their equal treatment and *normal lives*. Jenny said, for example, that Ethan is a 'brother irritant like any typical developing child would have been'. Jamie and Sophie similarly said:

> **J**: We've got four kids and one happens to have Down's syndrome, but they're all the same [laughs]. They do everything babies do, when they're babies. They do it in their own time. They eat, they cry, they poop.
> **S**: He's very much like his sister was. An absolute pain in the arse! [laughs]
> **J**: But they've got their own characters, as do all kids. Noah's just another kid, simple as that.
> **S**: It really is…But I never allowed Noah to become complacent or become lazy. I've got higher expectations of him than any other child. He is pushed, pushed, and pushed. I bring him up bilingual. He has private speech and language therapy. His speech is taking much longer but, then again, his sister took much longer to speak as well.

Jamie conveys the 'normality' of their lives and how their children are 'all the same', although with 'their own characters'. Sophie adds that she 'never allowed Noah to become complacent or be lazy'. Others parents talked in a similar way; they wanted their own parental efforts and advocacy to be recognised, and for others who had low expectations of their children (eg, teachers) to be corrected. Parenting a disabled child required 'lots of planning and foresight' (Roger), and it was not simply

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due to a 'high-functioning' personality or 'some special gene 21' (Jenny) that children are thriving, with Jenny saying that 'there's a lot of parenting that's gone on and a lot of support…that has quietly gone on that means Ethan [son] is the best version of himself'. Similarly, Valerie said, "we've got three kids and one of them happens to have an extra chromosome…you work hard over the years with all your kids just to try and get them to do the best they can". Parents, then, conveyed that their lives were 'normal', but this was often the product of their own parenting efforts and 'fights' (I return to this sentiment below).

In describing their lives, parents also said that public interactions (in which they were with their children) were regularly convivial and without any conflict. While public spaces can be sources of anxiety and fear for some parents of disabled children (Blum 2015; Ryan 2005), this was not the case for parents in this study. While Sophie said that "most people we meet are amazing", David claimed "we can give you thousands of positive experiences, then probably count on one hand the negative experiences…most people react very positively and engage with [Louis]". There were instances of explicit support, such as Christopher's (Linda's son) siblings wearing odd socks in a sporting tournament along with their teammates and opponents (to signify the uniqueness of a third chromosome and typically linked to World Down Syndrome Day). More often, though, were mundane moments of dignity and affordance. For example, Valerie and Roger described how workers at a well-known food-chain restaurant had 'looked after' Isaac when he was on a date:

> **V**: It was very nice and positive. [People with DS] have got it written all over their face, so you can't escape it, but actually people are really supportive and encouraging. You think, yeah, you should be doing this, this is great.
> **R**: When Isaac was little, I did worry about bullying in school because it's written all over his face, he's an easy target, he's very vulnerable. I can just imagine people taking the mickey, calling names and perhaps doing it in a way that he doesn't necessarily understand. But it hasn't really happened, has it? The response we've had from people has been very, very positive.

Later in his interview, Roger said that Isaac was a 'celebrity' in the 'local community' because he has lived there since he was very young, and because Isaac 'stands out'. Parents recognised the visibility of their child's condition as an *account* in interactions, making comparisons with *less visible* conditions such as autism that, they believe, might invite greater hostility and indifference from members of the public (Blum 2015). This seemingly departs from accounts located in medical sociology-that assume visible illness/disability invites consternation, and 'passing' constitutes the primary strategy for avoiding interactional fractures. Instead, parents felt that the public presence of people with DS was vital for 'exposure' (Jamie) and 'inclusion' (Sophie).[7]

In this section, I have captured how parents offered affirmative, yet not sentimental and one-dimensional, narratives of their lives. Their accounts are similar to those observed in the study by Liddiard et al. (2019) with five disabled young women living with life-limiting/life-threatening impairments. At odds with assumptions of limitations and a poor fit with a 'good life', they conveyed their hopes, dreams and impact on others. In this study, parents talked in equally positive terms; I contend that disability studies offers concepts and ideas to fully comprehend and articulate this. However, disability studies also shines a light on oppressive practices and policies that dominate the lives of disabled people. The 'social' focus of disability studies is reflected in the observations of many parents that their lives were made more difficult when dealing with institutional settings and bureaucratic arrangements, or what they regularly referred to as 'the system'.

'THE SYSTEM': A SOCIAL OPPRESSION PARADIGM

The central source of parents' everyday troubles—and of their general frustration, upset and angst—was not their child's *impairment effects*, but their 'fights' and 'battles' (eg, for education, welfare, employment and healthcare services) in a society that does not sufficiently support them (Thomas 2021). Megan said:

> When you get to know people and professionals, it's very stressful…There are eye appointments, repeated every month, which should have been only ever six months. And I've got children to absent from the school to go there, and when they are absent, whether that's medical reason or not, they are considered as absent. So their attendance is down. So, because the attendance is down, plus the low expectations, because they don't realise how clever my kids are, plus the lack of speech therapists to come in and do therapy. I think the accumulation of those perfectly set up, make a child with Down's syndrome even more disabled. Where is the help?…It's a fight.

Metaphors of fighting and battling were frequent in parents' interviews. Elizabeth suggested that "one thing about having a child with special needs is you do spend an awful lot of your time fighting…with, I don't know what you'd call them, authorities, just the system". Similar to others, Elizabeth believes *the system* is 'not actually created for people to manage their way through easily'. Some parents, like Jamie, connected this to UK austerity politics, where resources are depleted and 'more [people living with] disabilities are vying for funds which is not unlimited…so they're allocating based on demand and tick-boxes'. David reflected on Louis' (son) future education trajectory and their worry that he would 'transition to nowhere' (Ginsburg and Rapp 2018):

> **S**: We're still not a hundred percent sure we'll get the post-16 [education] setting that we think is right for Louis…And there is such a lack of provision that parents end up fighting for the few places that exist that might fit their child. And then someone is going lose out. And it's generally the child whose parents are not informed, not educated, don't have the resources or the emotional energy, to fight. You're exhausted. Or they put all of their energy into a tribunal for a statement or an EHCP [Education, Health and Care Plan]. They get it, and then the setting isn't implementing it, and they've lost their fight to make sure it's carried out for the child.
> **D**: Of course resources are tough. What does that mean? You just have to give up, do you?
> **S**: It's so short-sighted because there's been a lot of research that you might have come across that says if you put in the right support for a young person like Louis over their lifetime, it can save a million pounds in social care and health costs…If you spend 50 thousand pounds now, you can save a million. That, for me, is a no brainer.

Parents such as Sarah and David identify how resources are largely scarce and, usually, it is parents with the appropriate cultural and economic capital who prosper at the expense of others; "it's just easier for us to fight for that because we're relatively able to speak our minds, logically communicate, use the system to our own advantage" (Terry). Stories of tribunals (eg, education, welfare) to access support were common in parents' accounts. Eva described her and Ray's attempts to secure one-to-one support for Martha to assist with everyday activities, including using the toilet:

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> It's absolutely exhausting. Three o'clock in the morning we were compiling evidence. And having to go in and sit there and justify everything and it was really, really, really hard times…It's a real battle because they want to save a penny if they can save it.

Parents talked about accessing welfare, such as disability living allowance, in a similar way. While a (visible) diagnosis made the process easier when encountering 'blunt assessment tools' (Roger)[8], parents resented both the bureaucratic acrobatics required to obtain support together with the violence of 'having to make out the worst case scenario' (Linda). As parents were 'fighting to get what you need' (Elizabeth), they discussed the need to be 'pushy'—'the system makes you pushy' (Jenny)—to 'give yourself a chance of achieving anything' (Paul). As Eva claims, parents cannot 'sit on your laurels, you don't take no for an answer'.

The recognition of such structural obstaclesparallels a disability studies perspective. Disabled people face an array of social and environmental barriers (Barnes and Mercer 2010; Goodley 2014). The physicality of urban spaces, for example, reproduces sites of exclusion and demarcation, yet landscapes of power and geographies of domination are not limited to architectural structures; attitudinal barriers can be just as, and sometimes more, restrictive and demeaning (Garland-Thomson 2009). Within the context of accessing services, others have shown how people living with disability face challenges in receiving the (already depleted) support that they require (Garthwaite 2011; Runswick-Cole and Goodley 2015). In this study, parents felt that these fights and battles were avoidable and fracture their otherwise 'normal' or 'easy' (Linda) lives. Jenny laments that "the fights stand in stark contrast for us as a family" as "everything we do about Ethan is just the norm". Other parents with the knowledge, resources and time plugged the gaps of sketchy provisions and an inadequate system by sharing information with, and drawing on the expertise of, other parents (eg, in offline and online outlets). This community of care was essential for parents, but could not fully resolve the fatigue and frustrations caused when dealing with institutional actors. Parents did occasionally cite outstanding professionals who helped children to thrive (Ryan 2020), yet such experiences were in the minority. Parents, like Paul, said that "your resilience is tested" when parenting a disabled child, reflecting "we've had days when we've just gone, is it worth all this hassle of carrying on fighting, why don't we just accept it?" While some parents were affected by this more than others, all of them bemoaned institutional barriers that increased the prospect of a less-than-optimal outcome. It is in this wider context of service retrenchment and austere policymaking, for Mauldin and Brown (2021, 15), that we can recognise how 'medical sociology and sociology of disability scholars are working toward the same basic goal, which is to enhance the lives of people with disabilities'. To conclude this article, I further reflect on the possibility of more dialogue between these two disciplines.

CONCLUSION

Drawing upon data from a qualitative study with parents of disabled children, I have demonstrated the value of bringing together ideas, tropes and sentiments from medical sociology *and* disability studies. I captured the disruption to everyday routines along with the readjustment of expectations (eg, milestones). Such a consideration of 'impairment effects', and the experience of living with disability, are commonly seen in medical sociology. Yet, simultaneously, parents cultivated affirmative understandings of their lives. Their children were viewed as sources of joy, hope and vitality, with parents seeing themselves as 'normal'/'ordinary'. However, this was threatened by distressing and prolonged interactions with institutional actors (eg, welfare, education, healthcare). It was clear, then, that while impairment effects implicated their everyday lives, they were much more likely to discuss the positive impact of their child on them/their family together with the structural barriers that, as Megan claimed, 'make a child with Down's syndrome even more disabled'. There is a risk of promoting a rigid dichotomy of impairment effects versus oppressive practices here. I agree with Shakespeare and Watson (2010) that we must understand disability as a 'complex dialectic of biological, psychological, cultural and socio-political factors'. Nonetheless, parents were more inclined to identify the violence of oppressive paradigms. This, I argue, shows that by extending the (currently limited) dialogue between medical sociology and disability studies, we can take a nuanced approach to disability (including the impact of impairment effects) that examines the structural problems faced by disabled people and their families/allies.

A major contribution in this article, then, is identifying and promoting the virtues of disciplinary pluralism and of partial, fluid allegiances. Doing this reflects the messiness and multiplicity of parents' lives that does not cleave at neat points. Likewise, I argue, disability is much too complex to be rendered to one discipline, framework or unit of ideas—and this article represents one means of condensing the complexity into a single account. With respect to analyses of living with/alongside disability in medical sociology, I would urge scholars not just to simply focus on impairment/s, suffering and/or finitude, as well as other challenges (eg, complex family dynamics), but to also critically attend to matters of disablism, that is, the systematic devaluation and disregard of disabled people. This echoes Turner's (2004, 313) call for a 'new' medical sociology to understand individual experiences and the broader canvass of complex practices and relations between both local and global processes, the latter pertaining to a political economy 'that indexes issues of wealth, power, status, inequality and injustice'. This means, in turn, not constituting disability as a purely medical category, but as an 'axis of inequality decoupled from any impairment' (Mauldin and Brown 2021, 4).

My position is that future work—where appropriate (not all work on disability and chronic illness will be)—must consider locating disability within a distinctly political register. Disability studies, however complex and multifaceted as a discipline it might be, overtly mobilises a political economy of disability, including disability activism, which is much less obvious in medical sociology. Moving forward, medical sociologists would benefit from viewing disability as a 'sociopolitically defined phenomenon' that emerges through an interplay of bodily difference and social marginalisation (Grue 2016, 957). Treating disability in this way will allow for more activist approaches to be integrated into the field (Ryan 2020) and to stay with the policy landscape in local and global contexts (eg, considering the brutal force of austerity measures). To contemplate disability, as Goodley et al. (2019) remind us, is to consider a politicised phenomenon defined and framed by precarity, crisis, inequality and uncertainty. It is also to contemplate a complex category, given the difference of experience dependent on the impairment and wider social environment (McLaughlin and Coleman-Fountain 2018; Shakespeare 2005). My hope is that medical sociologists recognise and absorb this comprehension of disability in their pursuits, and that future research with people living with disability dismantles the problematic idea that scholars in medical sociology and disability studies are interested in, and motivated by, markedly different, and profoundly unbridgeable, matters. This is an opportune

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moment to keep our options open, to broaden our scope through cross-pollination and to show how working together, rather than apart, benefits us all.

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NOTES

1. Similar to Mauldin and Brown (2021), I use the term disability here to refer to chronic illness and typically defined disability categories that correspond to self-definitions of disability status.
2. There is also the prospect of inter/national nepotism in which certain voices are silenced via practices of cultural imperialism. Goodley et al. 2019, 978–979 claim that US-based scholarship is 'notorious in its US-centric choice and use of disability theory and literature'; there is an urgent need, they say, to 'trouble the self-referential elitism of Western European and North American scholarship', while being mindful that poverty, conflict and marginalisation are not simply matters for people in Global South countries.
3. For example, scholars in critical disability studies have challenged the materialist line in disability studies. Moreover, Miles, Nishida, and Forber-Pratt (2017) published an open letter about 'White disability studies' and the need to acknowledge the 'racial as well as gender-based, class-based and other injustice-based disparities that exist within the disabled population' around the world.
4. Shakespeare and Watson (2010), for example, claim that many parts of the natural world (eg, mountains, beaches) will remain inaccessible for certain disabled people, historical buildings cannot be easily adapted and people with different impairments require different solutions.
5. Eva is referring to Emily Perl Kingsley's (1987) essay 'Welcome to Holland' about having a child with Down's syndrome.
6. A placeholder name in the UK when referring to an average/typical man.
7. Parents also mentioned a more positive public imaginary of Down's syndrome with reference to greater visibility in public forums (TV/film, social networks), accessible information on the condition (particularly online) and public campaigns (eg, World Down Syndrome Day). I have discussed this elsewhere, including parents' discomfort with media configurations of people with Down's syndrome (Thomas 2020).
8. However, some parents said that they were asked by welfare agents when 'Down's syndrome started' for their child.

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