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Dis-Mantling Stigma: Parenting Disabled Children in an Age of ‘Neoliberal-Ableism’

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Abstract

Stigma is a dominant presence in many fields, yet the term frequently remains ill-defined, individualist, and dislocated from matters of power, inequality, and resistance. Extending a budding literature on rethinking the sociology of stigma, I draw upon interviews with parents of children with Down’s syndrome to revisit one of sociology’s most enduring concepts. I explore how parents articulate new imaginaries of difference which depart from narratives of disability as tragic and pitiful, and promote notions of dignity and worth. Parents talk of their children as a reason for celebration and pride, discuss their experiences of convivial community relations and public interactions, and praise evolving configurations of disability in popular media. Yet parents simultaneously highlight painful, convoluted, and exhausting experiences with institutions (education, healthcare, welfare) as part of what they believe to be a wider (structural) hostility to disability which force them into a series of ‘fights and battles’. Whilst parents resist deficit framings of their children, and their lives more broadly, parents lament dwelling in a society whereby disabled people endlessly navigate enmity and indifference. In this article, then, I *dis-mantle* common conceptions of stigma by revealing not only its interactional properties, but also its political economy, in which disabled people are devalued, discounted, and cast as disposable in an age of ‘neoliberal-ableism’ (Goodley 2014).

Introduction

Stigma is a dominant presence in many disciplines, from sociology to social policy, from social psychology to public health. Yet despite becoming part of our academic vocabulary, it frequently remains ill-defined, individualist, and dislocated from power, inequality, and resistance. For Müller (2020: 11), recent research on stigma: 1) redefines it as ‘marginalising stigma’, whereby stigma attaches to always-negative outcomes; 2) assumes individuals hold no ‘power or agency to resist or fight stigma’, and; 3) fails to define stigma, especially within a (bloated) collection of work on stigma and HIV/AIDS or mental health. Likewise, Link and Phelan (2001) argue that recent research on stigma is under-theorised with little explicit definition of how to conceptualise it across disciplines, and as excessively focusing on *individuals* rather than *structures*. They propose, thus, returning from a social psychological understanding of stigma to a sociological one.

When researchers do define stigma, they often turn to Goffman (1963). As conceived by Goffman, stigma refers to a mark of infamy, disgrace, or reproach, one that causes embarrassment and shame. In interactive moments, the micro and banal add up to ordinary, yet powerful, symbolic rituals and ceremonies, and it is in collective recitals that people manage impressions, sustain performances, and negotiate identities. This co-presence regulates the social order, yet the subtle scaffolding of interaction is compromised when a stigmatised other enters the scene. As a language of relationships, stigma emerges when one ‘[possesses] an attribute that makes [him/her] different from others in the category of persons available to [them], and of a less desirable kind’ (1963: 5). This ‘blemished person, ritually polluted, to be avoided, especially in public places’ is ‘reduced in our minds from a whole and usual person to a tainted discounted one’ (1963: 1-5). Presenting an ‘undesired different from what we anticipated’, they disturb the social scene for ‘the normals’, who do not depart from the ‘particular expectations at issue’ (1963: 5).

The legacy of Goffman's analysis of indisputable, although many contest his claims. Key criticisms centre on his silencing of stigma-knowers, overlooking *intra-* and *inter-*stigma, and failing to recognise that 'axes of risks for stigma' – eg race, gender, bodies, place – rarely travel solo (Brewis and Wutich 2019: 185). Disability studies is particularly vocal in its critique of Goffman (eg Gleeson 1999), but some of its scholars express more ambivalent and sympathetic readings in contemplating whether, and how, he remains useful for their field (see: Brune and Garland-Thomson 2014). Nonetheless, criticisms focus on his detached and othering tone, flattened language, short-circuiting of stigma's operations, assuming disability as deviance, oversight of what is meant by 'norms', and his apolitical, ahistorical, and essentialist analysis (Brune and Garland-Thomson 2014). An enduring critique, and one which seemingly aligns with the 'social model of disability', is how his unapologetic devotion to the quirks of human interaction, and how stigma is produced here, disregards structural forces that shape disability and how personal interactions are the outcome of social, economic, and political forces (Gleeson 1999). This also blunts any consideration of resistance or recognition of how only dissecting coping strategies (ie 'stigma management') leaves an unjust world intact.

This relates to another disgruntlement both within, and outside of, disability studies: Goffman, and broader conceptions of stigma, do not consider the role of powerⁱ. Recognising that stigma is 'dependent on social, economic, and political power', Link and Phelan (2001: 375) argue for a post-individualist analysis of stigma which considers exploitation, control, and exclusion, and how it becomes exercised via (in/visible) cultural distinctions of value and worth. Similarly, Scambler (2018, 2020) contends that whilst Goffman retains his theoretical acuity and insight, we should move beyond his narrow conception of stigma and, more broadly, individualist approaches that remain limited and unambitious. Arguing for a post-individualist sociology of stigma that 'goes beyond' face-to-face interactions, Scambler insists on recognising the causal role of social structures (gender, class, race) together with how stigma is 'weaponised' as part of a calculated strategy favouring capital accumulation over justice, and how blame is *added* to the shame associated with stigma via political will. Relatedly, Tyler (2020: 7) says that the social sciences neglect stigma as a form of power and violence, and how it is 'propagated as a governmental technology of division and dehumanisation'. Thinking of stigma within a 'political register', as something embedded in the social relations of capitalism, Tyler condemns passive psychological conceptions of stigma that focus on individual experiences 'in ways that occlude an understanding of stigma as a material force, a structural and structuring form of power' (2020: 8-9). Moving beyond the 'individualistic, ahistorical and politically anaesthetised conceptualisations of stigma' prospering in the discipline (2020: 8), for Tyler, means we can dislodge stigma from its settled meanings and reorient stigma studies to analyse macro structures – one recognising it as a form of violence causing social and political injuries, transforming social values, and playing a key role in the distribution of material resources.

My article does not dissect, dismiss, or clobber Goffman's contribution, or argue whether we should still seek his guiding hand. Much ink has been spilled on such matters. Instead, the above arguments – of taking *stigma power* seriously and identifying how common treatments of stigma are individualist and atheoretical – provide a crucial backdrop for showing how stigma, as an ongoing process and tool of oppression, plays out in an empirical context. My study, based on interviews with parents of disabled children (with Down's syndromeⁱⁱ), contributes to a growing body of research on rethinking the sociology of stigmaⁱⁱⁱ, extending this by locating arguments in an empirical evidence base (*and* theoretical/conceptual terms) and recognising the value of examining stigma in *both* interactional (micro) and structural (macro) ways. Specifically, I show how parents formulate new imaginaries of difference that depart from historical narratives of disability as tragic and pitiful. Parents talk of their children as a reason for celebration and pride, and discuss their experiences of convivial community relations and public interactions. Such affirmative accounts constitute a 'cripping' (Kafer 2013; McRuer 2006) of parenting disabled children, that is, of disturbing and reimagining normative scripts which assume a life of tragedy and hardship.

An interactional analysis of stigma would likely stop here, concluding that parents avoid, or at least resist, stigma (eg in public settings). Yet, parents simultaneously tell of agonising and prolonged experiences with institutions (education; healthcare; welfare) and, in so doing, identify a wider structural hostility in which they continuously *fought and battled*. I argue this is part of what Goodley (2014) and others call 'neoliberal-

ableism' (Goodley 2014), whereby disabled people and their allies see their rights eroded under neoliberal regimes. Under such conditions, while parents resist harmful configurations of disability as a 'grim imagined future' (Kafer 2013: 2), they are compromised by broader structural conditions in which they and their children encounter hostility and indifference. I claim that attending to parents' dealings with what they call 'the system' allows us to *dis*-mantle common conceptions of stigma by locating it in a political economy of power, in/exclusion, and inequality. Thus, I demonstrate the value of analysing 'symbolic and individualized stigma' realised in *micro* individual interactions, as well as 'structural stigma' emerging from the exercising of power at the *macro* level (Hannem 2012: 24).

A further contribution of this article is recognising disability as of central importance for the sociological imaginary. Disability is, too often, at the fringes of sociological thought, despite its relevance to significant conceptual debates in the discipline. Swayed by Wright-Mills' (1959) call for an imaginative sociology which links *personal troubles* to *public issues*, Shuttleworth and Meekosha (2012: 363) urge scholars to deconstruct sociology's normalising and universalising tendencies that are 'part and parcel of the same assumptions in which some voices are privileged and others are silenced'. Sociology is implicated in potentially dismissing and further stigmatising disabled persons and allies by reproducing a hierarchy of knowledge that relegates them to the margins of sociological thought. By *dis*-mantling one of sociology's most enduring concepts, I concurrently make a case for disability's vital position in the discipline^{iv}.

Methods

This paper 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; 2) an ethnography of a large congress bringing together people with Down's syndrome and allies (family, advocates, professionals, researchers), and; 3) analysis of textual matter (e.g. newspaper articles). I draw exclusively upon interview data in this article. Interviewees were recruited via various gatekeepers who are part of personal networks and charity organisations. The eligibility criteria were that participants were parents of a child with Down's syndrome and lived within a two-hour drive (due to funding and geographical mobility). Information sheets and consent forms were distributed via email distribution lists and social media sites with restricted access. From here, gatekeepers to distribution lists/sites provided me with the contact details of people interested in participating, although some participants contacted me directly via social media.

Participants were invited to take part in a face-to-face interview in a location of their choosing (ordinarily their house). Two interviews were carried out by phone. This preference was due to what one participant referred to as the 'chaos of parenthood'. It felt more appropriate to adhere to their requests as opposed to imposing unwavering demands informed by strict methodological borders (ie insisting upon face-to-face interviews). Of the participants, twenty were in a relationship (ten couples) and were asked whether they would like to be interviewed together or separately; all selected to be interviewed together, perhaps due to the prospective time constraints of interviewing them alone. Both of the parents (mothers) interviewed individually were married, but partners were unable to participate due to additional commitments. Parents were between the ages of 35-70 and children were aged 1-15 years old. Parents were mixed with respect to backgrounds, educational history, and employment status. Yet my sample is limited by recruiting parents who were already part of local/national networks – meaning I am likely to have neglected parents who do not share such vital connections. Interviews lasted between 1-2 hours. I informed participants that they can withdraw at any time, 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 make every attempt to ensure their anonymity is preserved (pseudonyms are provided here).

All data was analysed using 'situational analyses' (Clarke 2003: 571), a renovation of grounded theory in which the researcher 'becomes not only analyst and bricoleur, but also a cartographer of sorts'. 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. I opted for analysing data by hand as previous experience of computer technology allowed me to manage large volumes of data, but threatened to trade resolution for scope. Ethical approval was granted by (XXXXXX).

'Normal, but with additions'

In what follows, I outline how parents formulate new imaginaries of difference that depart from narratives of disability as tragic. Parents identified their children, across the age-spectrum, in overwhelmingly positive terms. Whilst challenges and obstacles were identified, parents were quick to demonstrate that they were 'lucky' (Amelia), 'blessed' (Eva), and 'proud' (Bella, Megan). A 'cripping' (Kafer 2013) of parenting a disabled child involved recognising that disability can, for parents, co-exist with normative notions of 'the good life' ordinarily associated with ability and capability (XXXXXX). Sophie and Jamie talked about Noah's (son) 'positive impact on the whole family':

S: Sisters [are thought to] stand in the shadow. They don't get the same attention. The siblings suffer because that child needs so much attention and extra care. It's bullshit! I think Lily is an amazing, caring big sister, and I think Noah has a big impact on the way she is.

J: Noah's had a positive impact on the whole family...on everybody that he's interacted with, in this family and the wider audience...Would the world be a better place without Down's syndrome? Absolutely not. Because you need to understand the good feelings, like empathy and compassion, versus just self, self, self.

Jamie highlights Noah's 'positive impact' and how he offered 'the gift of [his] own self-knowledge' (Rapp 1999: xiii). Indeed, several parents talked of being grateful for having *any* child. Discussing this, Megan said having twins with Down's syndrome was a 'blessing':

It's exciting, it's fun...When they were born, you receive so many negative comments from [healthcare] professionals from pregnancy to when they were born, and people surrounding me were very negative. But [Willow and Penny] are telling a different story. Each of them is telling different narratives about their lives...They're walking, they are fighting, they are wicked, typical 5-year-olds...It's a joy to have them because I want children...They have beautiful souls and are beautiful individuals.

Similarly, for Richard, parenting a disabled child is compatible with '[having] a perfectly normal, happy life as you would have planned anyway'. Many parents talked about their 'normal' or 'typical' lives, describing detailed (and chaotic) daily routines and activities. Charlotte and Henry described a 'typical day' as follows:

H: A typical day is trying to fight to get Daisy to get dressed, Zack to have breakfast, shouting at them to get shoes on. "Get out the door, get your shoes on, we're going to be late!" I'm sure it's typical for every family.

C: They'll come home, and they get some time with screens as in every household across the UK. And then teatime and reading and getting ready for bed and playing. It's so standard. There's nothing unusual about it...We have the same sort of struggles [as non-disabled families], trying to get the children motivated to get themselves dressed and ready for school...Normal is not standardised, is it? Normal is normal for every single family. We always describe ourselves as normal, but with additions. So yes, we have to add extra things into our day, which become kind of second nature...We're so normal.

H: I spent time around friends' [with non-disabled children] houses and it's always interesting to do a comparison; "is what we do standard?" And it's absolutely 100% standard.

Whilst some parents rejected the label of 'normal', others used this term (or 'typical') to describe their daily lives. Watson's (2002) participants similarly described themselves as 'normal' and refuted suggestions that disability/impairment affected their sense of self. Ray and Eva referred to this 'pursuit of ordinariness' – of 'ordinary practices' (McLaughlin and Coleman-Fountain 2018: 64) – to, it seemed to me, avoid Martha (daughter) being configured as a tragic figure:

R: Martha's just like anyone else. She has moods. She enjoys things.

E: She's a typical six-year-old...She's not learning as a typical six-year-old, she has differentiated work, etcetera, but her behaviour and aspirations to be like her peers, to be cheeky, to stay up late and want to go to bed with chocolate at 10pm...Life is mundane, well, it's busy mundane, but it would be with any six-year-old. She goes to after-school club, she goes to breakfast club, she gets on the bus to go to school with her friends.

Comparisons with non-disabled siblings, or other families without disabled children, were commonplace. I interpret this as an attempt to demonstrate how life was 'nothing out of the ordinary' (Amelia) and how 'we're just like everybody else' (Elizabeth). Challenges were inescapable, but normalised within a frame of being 'normal for teenagers' (Sarah), for example, and with reference to siblings. An important disclaimer was that 'normality' is fragile and easier to achieve, and sustain, in the absence of serious health conditions. Moreover, there were moments when they wanted their child's 'limitations' to be recognised, in terms of 'understand[ing] certain behaviours' (Sophie) and accessing resources (I return to this later). Parents, too, keenly highlighted how achieving 'normality' was attributable to their intensive labour and high 'standards' and 'expectations' (both terms were used by parents). For example, Jenny and Paul disliked Ethan (son) being referred to as 'high-functioning' as it made their parental efforts invisible by disregarding that 'there's a lot of parenting that's gone on' (Jenny). Having a disabled child required lots of foresight and organisation as well as being 'pushy' (several parents used this term). Valerie and Richard said:

V: Things seem quite normal, but actually it's because we've done all the scaffolding. Everything is in place to make it very easy, and to make it very normal, because actually we work hard in the background to make it that way.

R: It is hard work and it is harder if you have a child with a disability, because the world isn't laid out that way, so you have to be very resilient and you have to be very motivated and think ahead, because it's not going to necessarily be done for you.

I return to this sentiment – that 'the world isn't laid out' for disabled people – later in the article.

Disability in public

Describing their lives in this way, parents resist normative understandings of child disability as unfortunate and disastrous. Likewise, outside the family unit, parents highlighted the positive positioning of their child in public settings. Sarah, for example, said how Louis (son) was 'known in our community':

He's very much liked and tolerated by some of the young people. Outside, they'll stop and [Louis will] ask them a question, and they'll always answer and engage with him. When they were younger, he was like a superstar in their eyes. Now they're older and don't go to school with him anymore, it's more at the level of, I understand you've got a disability, and therefore I'm going to tolerate you. And none of them are unkind. We've only met a few instances of unkindness over the years.

Like Sarah, many parents conveyed few, if any, negative experiences in public spaces with their child. Their child's *known-ness* was frequently discussed with respect to visibility. People with Down's syndrome can regularly share some physical traits. As such, parents felt that 'disability [is] written all over the face' and this constituted an 'advantage' (Richard)^{vi}. Richard drew a comparison to children with *invisible* conditions, such as autism, when 'it's not necessarily apparent that they might be different...sometimes people's reactions to people who...look very normal, is that [bad] behaviour is [because of] bad parenting'. Blum

(2015) argues that mothers of children with ‘invisible’ conditions are deemed less legitimate, and deserving of sympathy and support, than those with ‘visible’ disabilities. Whilst some parents in this study initially worried about stigmatising reactions in public spaces owing to their child’s *visibility*, convivial community experiences were often, if not exclusively, shared. For Linda, this appeared related to Christopher’s (son) *visibility as disabled*:

In the rugby club, where [siblings] play, Christopher goes in. He runs around. He orders his sausages and chips. He orders his juice. Everyone knows him...They all love him...When we went on tour last year, we were waiting for the medals. When they were given, the coach put Christopher on the stage, and he loves being on the stage. He was getting all the crowd screaming “YEAH!” And this went on for about 20 minutes. I don’t think there was a dry eye in the house!

Even in instances where their child was not well-known to others, parents discussed how such interactions commonly proceeded without conflict. Sarah and David described visiting restaurants with Billy, whereby most people are ‘lovely’ (Sarah) and ‘react very positively and engage with him’ (David). Whilst positive interactions were common, parents were quick to maintain the social order and ensure that their child’s presence did not eventually disturb the equilibrium. They keenly outlined their efforts in teaching children the *norms* of interaction as part of dismantling stereotypes, even when interpreted as well-intentioned, of disabled children. Parents welcomed positive exchanges where their children were treated like ‘superstars’ (Sarah) or ‘celebrities’ (Richard), but simultaneously did not entertain *too much* special treatment. For Sophie, she did not want Noah to be ‘fussed’ or ‘put on a pedestal’, as ‘we just want him to be like any other child’; ‘all he needs you to do is just be normal’.

Similarly, parents disliked crude, infantilising stereotypes of their children as ‘happy’ and ‘loving’ (a typecast particular to Down’s syndrome), and how this sometimes governed people’s behaviour in public spaces. They recognised the positive intentions behind such framings, but many parents, as part of their claim for normalcy, identified how children were not always happy (‘Aiden can be grumpy’ [Amelia]) or affectionate (‘you come and film Isaac at 7am when I’m trying to get him out of bed if you like. He’s not very loving then!’ [Valerie]). Parents often explicitly engaged in practices and activities to signal the *normalcy* of their lives, such as talking about their ‘normal’ lives and ‘mundane subjects’ (Henry), registering their child with modelling agencies, appearing on daytime television programmes, writing blogs, and sharing positive stories on social media. Such engagements were often highlighted with reference to a generic aim of ‘increasing awareness’ (Amelia) and ‘changing perceptions’ (Ray) – part of what, I argue, constitutes a ‘revolt’ (Tyler 2013) against prospective stigma (ie parents frequently *expected* negative reactions on account of historical deficit framings of disability).

Moreover, parents highlighted the growing presence of Down’s syndrome in the public imaginary enacted via popular media (eg TV/film, newspapers, blogs). Such attempts to produce a more positive, visible, and rounded portrayal of disability were identified by several parents as a symbol of tolerance and acceptance, and a departure from historical deep-rooted narratives of disability as ‘a terrible unending tragedy’ to be avoided (Kafer 2013: 2). The burgeoning popular presence of people with Down’s syndrome (e.g. on television) was noted, and applauded, by parents, as it ‘normalised’ disability, although they had concerns around ‘tokenism’, relying on lazy/disablist stereotypes, and focusing on well-resourced and ‘exceptional’ disabled people^{vii}. Nonetheless, many parents felt that this positive disability imaginary played some role in their convivial community relations and public interactions (eg of ‘increasing awareness’). This departs from qualitative studies claiming that stigmatising public encounters tend to be a frequent occurrence for parents of disabled children, especially mothers (for a review, see: Green et al. 2017).

In describing convivial public interactions and praising evolving configurations of disability in popular media (albeit with caveats), a stigma theorist, likely swayed by Goffman, might end their analysis there, concluding stigma is avoided, and sometimes actively resisted, by parents of disabled children (eg in public settings). Yet parents simultaneously described distressing and exhausting dealings with different institutions when attempting to access services and resources. In what follows, I make a case for interpreting their ‘fights

and battles' as part of a political economy of stigma – and, in so doing, show how a relentless devotion to mundane interactional matters risks discounting the contexts, power, and origins of stigma which generate, and amplify, existing exclusions and inequalities.

'Always fighting'

Several parents discussed their children's physical challenges (eg dual-diagnoses and sleeping patterns) and the need to be patient and vigilant (Sarah referred to parenting a disabled child as 'being on a permanent degree course'). More common in parents' narratives, though, was a discourse of 'fighting' and 'battling' with respect to accessing services and resources. This chimes with Ryan's (2017: 244) claims about parents attempting to buck the 'misery taint' associated with learning disabled children, but ultimately battling and fighting within 'an inhuman system in which certain people do not count'. In this study, whilst some positive experiences were shared with respect to locating support (eg helpful health professionals, accommodating schools), many parents lamented painful and prolonged communications with local authorities, healthcare institutions, educational settings, and welfare/social services. Accessing Disability Living Allowance (DLA) was frequently discussed as a gruelling obstacle. Amelia said:

[Applying for DLA] is just so hard. It's like you have to exaggerate [Aiden's] disability to make him seem worse than he actually is and make-up stuff so you can get support. It's ridiculous. It's really bureaucratic and you get asked questions like "how long will he have Down's syndrome for?" Really?! They make it as if you almost have to prove he has a disability.

For Amelia, accessing welfare was difficult, and also constituted a form of violence by 'exaggerating' Aiden's impairment. DLA applications, for some parents, involved '[making] out the worst-case scenario' (Linda). Sophie and Jamie similarly lament that 'bureaucracy is the biggest struggle' (Jamie). Sophie claimed:

[Noah's] classed as disabled by everyone, yet when it comes to DLA, you have to explain why he should be having it. It's idiotic. There are people working there that are honestly asking questions like, "So, when did that Down's syndrome start?" Are you actually in the right job? Should you be working here?...There's no support, absolutely none. And then it becomes quite convenient that your child is as normal as possible...Noah starts nursery school in September. I've got zero experience [with this], so this is where you connect with people that have been through it and they can give you a helping hand. Otherwise, if you didn't have that support, you would fail that system and the system would fail you purposely. They exploit you. They know you don't know what you're talking about.

An anti-welfare rhetoric has intensified in austerity Britain, in which people claiming 'welfare' are subjected to pejorative configurations which mark them as apathetic, shameful, and irresponsible (Scambler 2020; Shildrick 2018; Tyler 2020). A considerable body of literature shows how adult claimants feel stigmatised by accessing welfare (eg Patrick 2017), yet children in poverty are perceived more sympathetically by the public and, thus, remain relatively immune from moral condemnation. Interestingly, in this study, parents describe how the welfare system's failings remain intact for them; they equally feel both stigmatised and undermined by the relevant authorities^{viii}. Here, it seems stigma is 'deliberately designed into systems of social provision in ways that make help-seeking a desperate task' (Tyler 2020: 18).

Parents illustrated their frustrating, and too frequently fruitless, navigation through various circumstances and bureaucracies. There was a perception that 'the system's weighted against kids with disabilities and Down's syndrome in particular' (Terry), with Terry citing low employment rates, the growth of prenatal testing, and poor treatment in hospitals (and specifically 'do not resuscitate orders'^{ix}) as evidence of this. Furthermore, many parents felt that positive news stories in popular outlets (eg TV, newspapers) 'don't help in terms of what goes on in the background' (Paul). Linda said:

We need to be going to the higher end, the best education, the best skills, the best workforce. That person needs help...We don't need to be on TV. We need the [resources] so you don't

have to fight. It shouldn't be down to parents to have to provide anything. The services are there. Why can't we access them? Why is it so hard? ...Christopher doesn't drive you nuts. It's those things around it that drive you nuts...I think by fundraising and doing stuff, it's lovely to have a day out, but I don't really need that. What I need is the fact that I know he's going to have a good provision in education. What I need is that he's going to have speech and language therapy... there's so much wrong with the system *per se* that you need to be altering.

Whilst some parents felt a diagnosis of Down's syndrome made it easier to 'prove' disability, Paul worried that the 'normalisation' of Down's syndrome, as described earlier, may lead to services being withdrawn; 'it wouldn't help your fight necessarily'. Parents welcomed departing from a tragedy or pathological framing of their lives, yet also did not want to shirk from the realities and did not want the challenges of parenting a disabled child to be discounted. Parents also identified the limited pool of resources available to people with disabilities and their allies in austerity Britain, in which different groups compete for services; 'its dog eat dog' (Jenny). With fading and 'hidden' (William) support, parents frequently liaised with other parents of disabled children via online and offline groups (as Sophie describes above) to share advice and resources, as part of a 'disability commons' (Runswick-Cole and Goodley 2015: 163).

Yet gathering information and pursuing access to resources was not only time-consuming and demanding, but was a task often left to mothers (Blum 2015; Runswick-Cole and Ryan 2019). Mothers like Megan felt an intensity of responsibility on the frontline, in which they managed daily trials and engaged in complex decision-making processes:

In all areas, it's always push, push, push, which is stressful...Because we've got two children, we applied for Carer's Allowance. It was turned down. It's hard work to always fight for something...When they say there is more help and you have to fight for it and you're eligible to get it, that's where the stress comes from. Not only for Carers' Allowance, but in other areas too...Why is the system like that? That's where we are. That's our culture...We're not pretending to show the world that they're not disabled.

In most (if not all) cases, tales of fighting were told by mothers. But 'fighting' also had a classed component; parents recognised the benefits of their own, or others', class and educational privilege when dealing with institutions/providers. Discussing access to occupational therapy and speech therapy, Elizabeth claimed:

The occupational therapist was really difficult to get initially, but once we were on the list, it's a fantastic service. But there is a little bit of fighting to get what you need. It's kind of knowing that the service is out there, and then it helps when you're well-educated, middle-class people, which is unfair because it really shouldn't be like that. But that's how life is, unfortunately.

David and Sarah discussed how they had faced two tribunals: one was an education tribunal and the other was to appeal a DLA decision. Sarah's background as a solicitor, they claimed, was essential for 'fighting', but worried about parents who 'don't know how to do that, because they either are afraid to, or, don't have the confidence, or are afraid to rock the boat, or they just don't know that they can'. Limited provisions mean 'someone is going to lose out and it's generally the child whose parents are not informed, not educated, don't have the resources or emotional energy to fight'. David claimed:

Why is it so hard to get the resources? You feel like you're totally up against everybody. The State, the education authorities, whatever...It's just a fight, it's always fighting...Sarah and I are quite lucky. We've got our own business. We can choose what time we do stuff. Some parents don't have the facilities, the resources. How will they cope? I have no idea.^x

Such fights – continuous and exhausting endeavours – require parents to become 'experts' as, otherwise, 'it's very, very hard to fight' (Valerie). Parents, particularly mothers, identified the value of being organised, resilient and well-informed, yet this requires time, resources, and cultural, economic, and social capital.

Even when holding such resources, parents rarely emerged unscathed and without considerable financial, practical, and emotional costs. It was unsurprising to them, thus, when parents simply gave up and accepted their inferior position. I am reminded here of Ingstad and Whyte's (2007: 5) arguments about changes in disability legislation, activism, and political awareness in the Global South:

'[T]he challenge is to see how much – or how little – the world has changed for the majority of disabled people and their families living in a great variety of particular situations...The conditions of life for most people with disabilities may not be changing as rapidly as political awareness'.

I argue that, in a similar way, parents in this study praised changes in 'awareness' and 'tolerance' for their disabled children, yet simultaneously described challenging personal conditions. Parents did not explicitly use the discourse of stigma to articulate such experiences, yet I contend that a politicised and structural understanding of stigma is a useful conceptual lens for making sense of their accounts. Parents identified how challenges and obstacles were located not in children's bodies, but in hostile structural conditions in which they confront enmity and indifference (a position central to critical disability studies). They talked of operating within a system blighted by disablism, where they campaign for 'both the recognition of the value and humanity of their children and for appropriate education, health and social care resources for them' (Ryan and Runswick-Cole 2019: 1129).

I contend, then, that the structural challenges faced by parents, as outlined here, is an outcome of stigma power, and this stigma is amplified in a neoliberal regime which classifies disabled people, and subsequently their allies, as devalued, disregarded, and disposable. In an era of 'neoliberal-ableism' (Goodley 2014: 26), the broad logics of autonomy and self-sufficiency provide an 'ecosystem for the privatisation of ableism', in which disabled people are figured as not expressing 'person-value' (Skeggs 2011). Subsequently, parents must carefully, and constantly, navigate their way through practices and processes originating in structural constraints that have existed for a long time, but have only been aggravated in neoliberal times. Struggling to access resources required for a *good life*, I argue, is part of the political economy of stigma. I conclude this article by sketching out how we might rethink the concept of stigma within sociological thought.

Discussion

In this article, I have attempted to *dis-mantle* the concept of stigma with reference to the worlds of parents who have disabled children. I show how they cultivated imaginaries of difference that recognise the value, worth, and *normalcy* of their lives. Promoting a 'corrective approach', parents demonstrate how everyday life is constituted, notwithstanding clear and complicated challenges, as celebratory, life-changing (for the better), and not the disaster it was initially believed to be. Likewise, parents' affirmative accounts include reports of convivial community relations, collegial public interactions, and positive configurations of people with Down's syndrome in popular outlets (eg TV). A reasonable conclusion would be that stigma is avoided and resisted by parents in various ways. Yet, I claim, this is only a partial view; focusing only upon stigma as an interactional issue during 'mixed contacts' (Goffman 1963: 12) is a flawed and austere approach. My data demonstrates the value of examining the significant structural challenges faced by parents (particularly mothers) *through a lens of stigma*.

To be clear, I do not support abandoning interactional approaches to stigma; this study, and others (Blum 2015; Green et al. 2017; Ryan 2005), prove the value of analysing how parents of disabled children navigate the minutiae of everyday exchanges in public settings. Instead, I argue that we should dislodge the concept of stigma from its *exclusively* interactional roots and cultivate a more socio-political understanding of it – that is, of rupturing common understandings of one of sociology's enduring characters, and casting it in a new role (ie by looking both *above* and *below*). In a rare exploration of the relationship between disability, stigma, and neoliberalism, Charmaz (2020: 21) recommends revising the concept of stigma, and particularly Goffmanian interpretations of it, by analysing how 'stigma and exclusion are played out through interaction and structural arrangements' for chronically ill and disabled people. Drawing upon the claims of disability theorists, Charmaz suggests that this involves 'placing stigmatising experiences within larger structural perspectives, policies, and practices dominated by neoliberalism' (2020: 22).

With Charmaz, I contend that a more politicised conception of stigma offers an instrument for identifying and analysing the plight of disabled people and their allies in neoliberal times in which: welfare is demonised and abjection cuts deep into public consciousness (Tyler 2013); welfare reform disproportionately impacts disabled people (Alston 2019); individuals with learning disabilities (LD) are abused in NHS-funded units (BBC 2019); disability hate crimes have risen from 1,748 in 2011/12 to 8,256 in 2018/19 (Home Office 2019); support and funding for children with special educational needs/disabilities is fading and inadequate (NAO 2019); people with LD are dying prematurely and/or within hospitals at a higher rate compared to people without LD (LeDeR 2018); people with LD experience persistent health inequalities (Scambler 2018, 2020), including children with LD dying on average 23-29 years before peers (Ryan and Runswick-Cole 2019); poor employment rates and job opportunities for individuals with LD are observable (Runswick-Cole and Goodley 2015), and; segregated and sheltered housing schemes, and education and adult training centres, are closed (Goodley and Runswick-Cole 2015)^{xi}.

In a period of ‘disablist austerity’ (Dodds 2016: 149), where negligence and mistreatment are so pervasive that it appears to be a deliberate political choice^{xii}, I argue that a more socio-political conception of stigma helps us to make sense of such processes and arrangements. This contributes to recent work on rethinking the sociology of stigma (eg Scambler 2020; Tyler and Slater 2018; Tyler 2020), yet extends this by showing the merit of exploring the interactional *and* structural properties of stigma. Future research, I hope, will finesse and challenge quantitative and acontextual treatments of stigma by sharpening its political edges, whilst simultaneously working within the tensions and complications by appreciating the weight and worth of dissecting the banal, taken-for-granted moments of everyday life. A sociological approach governed by such principles – examining stigma as structural and subjective – might push a more complex understanding of the concept beyond the academy too.

With respect to disability, a revised understanding of stigma constitutes one means of elevating it from the margins of sociological thought, whereby analysts might link the *private troubles* of disabled people, and their allies, to *public issues* (Mills 1959). Disability studies and its related disciplines have made considerable attempts to do this (see: Shuttleworth and Meekosha 2012) – but much like the disability rights movement, problems and barriers remain despite huge strides being made^{xiii}. Recognising the place of disability within sociology also involves tapping into the diverse imaginaries of the Global South. Indeed, edited collections by Ingstad and Whyte (1995a, 2007) and Grech and Soldatic (2016) on disability in the Global South probe, contest, and reimagine common understandings of disability in established discourses, epistemologies, and practices. If we further cultivate a sociological understanding of disability (as a relational, transformative, contested, and political category), this must not marginalise experiences of those in the Global South.

Returning to stigma, whilst taking it seriously risks repeating the conditions of stigma (of strengthening its hold), it is so pervasive, especially in an era of neoliberal(able)ism, that it merits serious consideration by sociologists and other allies – both within the context of disability and beyond. It is difficult to locate an area of social life remaining untouched by stigma’s constricting grip. Further empirical studies, like the one outlined here, are essential for drawing attention to such matters.

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Footnotes

ⁱ Goffman has been censured for ignoring power and structure, but I am uneasy with this claim. I perceive power at play in *Asylums* (1961: 168), whereby inmates are stripped of individual identity markers, disposed of property, and suffer a personal defacement; '[the self] is not a property of the person to whom it is attributed, but dwells rather in the pattern of social control that is exerted in connection with the person by [them] and those around [them]'. Furthermore, in *Stigma* (1963: 138), Goffman suggests that whilst stigma emerges in interaction, we must understand 'the history, the political development, and the current policies of the group'. The snag is Goffman does not *sufficiently* theorise about power imbalances.

ⁱⁱ I purposely discuss disability (not Down's syndrome) as I intend to avoid an impairment-specific approach that frequently drives research on disability and stigma. Nonetheless, I appreciate how the fragile category of 'disability' breaks down once we pinpoint who make up *the disabled* (Davis 1995). This also chimes with recent work on disability in the Global South that recognises the heterogeneity of the 'disability' category across different settings; 'in many cultures, one cannot be "disabled" for the simple reason that "disability" as a recognised category does not exist' (Ingstad and Whyte 1995b: 7).

ⁱⁱⁱ See special issues in *The Sociological Review* (2018, 66:4] and *Symbolic Interaction* (2020, 43:1).

^{iv} Thanks to Reviewer 3 for urging me to more explicitly articulate this point.

^v The relations between 'disability' and 'normalcy' is a staple of disability studies (eg Davis 1995; McLaughlin et al. 2016; Michalko and Titchkosky 2009). For instance, McLaughlin and Coleman-Fountain (2018) capture how young people with cerebral palsy embody, conform to, and/or resist ideas of normalcy and difference. Starting from the position that disabled people, like non-disabled others, are involved in a set of everyday embodied practices influenced by an urge to *fit in*, McLaughlin and Coleman-Fountain outline how regulatory dynamics govern if/how young people background, or foreground, embodied difference. Equally, some young people challenge and resist encouragement by others to pursue a sense of ordinariness.

^{vi} This corresponds to a popular, yet problematic, conception - known as the 'Down's syndrome advantage' - that children with Down's syndrome are easier to rear than children with other learning disabilities.

^{vii} I explore this at length elsewhere (XXXXXX).

^{viii} Thanks to Reviewer 4 for this observation.

^{ix} Terry appears to refer to Down's syndrome/learning disabilities being recently cited as a rationale for a 'do not attempt cardiopulmonary resuscitation order' (LeDeR 2018).

^x An unfortunate irony, as identified earlier, is by recruiting parents who were already part of local/national networks, I may have inadvertently neglected parents who, as David claimed, 'don't have the facilities, the resources'. Yet my arguments show how parents of disabled children, regardless of their background, can still encounter challenges and frustrations.

^{xi} Consider, also, the COVID-19 pandemic and how disabled people were figured as collateral in the UK, as part of the 'everyday mundanity of disablism' in which disabled people must prove their 'value' and 'worth' (Liddiard 2020).

^{xii} As Ryan and Runswick-Cole (2019: 1131) suggest, it is not that powerful players do not understand the difficulties and inequalities faced; the reality is that 'successive British governments have known about the social injustices in the lives of disabled children and families and have done little to bring about change'.

^{xiii} Anthropologists focusing their research on disability make similar criticisms of their discipline (Ginsburg and Rapp 2020).