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‘We wouldn’t change him for the world, but we’d change the world for him’: parents, disability, and the cultivation of a positive imaginary

Abstract

Down’s syndrome (DS) occupies a curious position in the public imaginary in the United Kingdom (UK). There is a growing public, and positive, presence of people with DS in cultural outlets and across networks of people with experiences of disability. Simultaneously, there is a troubled history of institutionalization and stigmatization of people with DS, the condition is targeted in prenatal screening programs, and parents of children with DS struggle to secure sufficient resources and social support to thrive. Drawing upon a qualitative study where I examined such tensions, I show how parents of children with DS craft a positive imaginary of living *with*, not *despite*, disability. Parents articulate affirmative accounts that highlight the value, significance, and ordinariness of their, and their children’s, lives. Moreover, they actively participate in community-building practices with other parents, in which they collectively attempt to build a habitable world for their disabled children. Whilst recognizing the challenges posed by parenting a disabled child, parents are equally pulled into a project of cultivating positive conceptions of living with disability. In so doing, they fashion and present alternative narratives that revolt against dominant deficit understandings of pity, abjection, and misfortune.

Introduction

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 end 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.

During a joint interview with her partner (Ray), Eva discussed her experiences of parenting Martha, their six-year-old daughter who has Down’s syndrome (DS). Eva and Ray talked about how they readjusted expectations with respect to Martha achieving ‘milestones’, examples including crawling, sucking a straw, and opening a jar. Eva referred to Emily Perl Kingsley’s (1987) essay ‘Welcome to Holland’, in which Kingsley describes her experiences of parenting her child who has DS:

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, ‘Welcome to Holland’. ‘Holland?!?’ you say. ‘What do you mean Holland? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.’ But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay. The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

Citing this metaphor, Eva describes the need for recalibration when occupying a ‘completely different place’ than originally anticipated. However, her tone – like the remainder of the interview – is not melancholic or regretful. Rather, Eva shares her fervor and pleasure about her parenting experiences. Both Eva and Ray talk in glowing terms about life with Martha and about the (disability) ‘community’ that they are now active participants in. They excitedly outline the hopes and dreams that they have for Martha, with much laughter ensuing when Eva informs me that Martha has expressed aspirations over the past few weeks of being an airplane pilot, a ninja, a sailor, and a singer. Eva quips, with Martha singing Auli’i Cravalho’s *How Far I’ll Go* (from the 2016 film *Moana*) loudly in the background, ‘singing is the one thing she won’t be doing Gareth, she’s got one tone all the way through [laughs]!’. Eva then tells me:

We know a lot of young adults [with DS] in the community who’ve got a very full life in terms of work, friends and social activities and are happy in what they’re doing. We want Martha to have a job, be self-sufficient, be able to be living independently.

In this article, I draw upon a qualitative study, based in the United Kingdom (UK), with parents of children with DS. I explore how parents reflect on the significance of disability in their lives and the place of their children in the world. I show how parents craft a positive imaginary of living *with*, not *despite*, disability. They articulate affirmative accounts highlighting the value, significance, and ordinariness of their, and their children's, lives. Moreover, they participate in community-building practices with other parents, where they (collectively) attempt to erect a 'habitable' (Garland-Thomson 2015; Johnson 2021; Mairs 1996) world for their disabled children. Whilst parents acknowledged the challenges posed by parenting a disabled child, they are equally pulled into a project of cultivating positive conceptions of living with disability. Here, similar to Cheryl Mattingly's (2014:xvi) stance – stated in her ethnography of how African-American families care for children with serious chronic illness – I take parents' 'beliefs about the good seriously'. Indeed, throughout my study, and as reported in this article, parents revolt against dominant conceptions of parenting a disabled child as a source of despair, fear, and no future.

Parenting disabled children

Scholars in various fields – e.g. sociology, anthropology, and disability studies – have examined the experiences of parents, and particularly mothers, of disabled children. Parents have occupied a liminal and contested position in work relating to disability and, particularly, disability activism. Regarding the latter, parents (and, again, particularly mothers) have been framed by some as selfless trailblazers (Blum 2015). However, others (e.g. Green et al. 2017; McLaughlin 2006; Ryan and Runswick-Cole 2009) have highlighted how (abled-bodied) mothers are charged with being complicit in their child's oppression by promoting a medical/impairment-focused understanding of disability and obstructing their child's independence, choice, and activism. This frequently follows a narrative of 'child optimization', where parents are perceived as engaging uncritically with professional stakeholders, and managing and molding their child's bodies, to hide disability and produce a 'normal' child (Blum 2015; Mauldin 2016). This defines disabled children as problems to be solved and overcome, rather than highlighting modes of dis/ablism and the cultural devaluation of disability (Carey et al. 2019). Parents, then, operate within an odd nexus between being an 'accidental activist' (Panitch 2008) but in a neoliberal society promoting self-interest, independence, and individualism, and where there is little support for their children to fully thrive. Here, parents are frequently characterized as threatening their disabled child's empowerment, though more recent scholarship muddies the waters by resisting this polarization and exploring, instead, the complexity of parents' activism (Carey et al. 2019).

Outside modes of activism, scholars have demonstrated that the dominant narrative of parenting disabled children is one of burden, pity, and isolation (McLaughlin 2006, 2012). As such, parents encounter, and spend considerable energy attempting to resist, dominant and dehumanising stereotypes about the alleged tragedy of parenting a disabled child (Piepmeier 2021). 'Stigma' constitutes a common conceptual device used to make sense of perceptions held by, and interactions with, non-disabled others, specifically how tense and stigmatising encounters are a common occurrence for parents (Green et al. 2005, 2017; Manago et al. 2017) – and how a fear of stigma can dictate where, when, and with whom parents go (Fisher and Goodley 2007; Ryan 2005). Such research is often informed by Erving Goffman's (1963) conception of stigma, and particularly the notion of 'courtesy stigma', that is, how stigma extends to the close affiliations of the stigmatised (Gray 2002; Green 2003; Koro-Ljungberg and Bussing 2009). However, other scholars have highlighted how parents navigate the cultural and political economy of stigma (Thomas 2021a). For instance, David Farrugia (2009:1012) contends that whilst Goffman's paradigm has remained the dominant theoretical foundation for analyses of parenting stigma in medical sociology, this work – together with being apolitical – rarely considers the origins of negative stereotypes, positions the stigmatised as powerless victims, and fails to consider 'structural power relationships'. Equally, research by Ara Francis (2012) shows how stigma encountered by parents stems not from their child's attributes, but is a product of their children inhabiting a society dictated by principles of 'intensive motherhood' (Hays 1996) alongside the problematization and medicalization of childhood. The role of mother-blame is paramount to such experiences (Blum 2015; Ryan and Runswick-Cole 2009; Sousa 2011).

Yet, some scholars highlight how parents can resist stigma by, for instance, invoking *medical* (impairment-focused) and *social* (oppression-focused) meanings in ways that serve diverse ends, 'sometimes centralizing a medical label to challenge stigma, and sometimes recognizing disabling social structures, but deflecting stigma nonetheless' (Manago et al. 2017:169). Other parents revolt against stigma by highlighting the valuable benefits gained by having a disabled child (Fisher and Goodley 2007; Green 2007). Memoirs are a prominent genre in this regard, where parents reclaim their identity from different professions (e.g. medicine, education, psychology) and give positive meaning to raising disabled children (Sousa 2011). Scholars have contended that memoirs enact a visible, positive, and rounded portrayal of what it means to parent a child with DS, precluding the 'spread of false and potentially harmful cultural narratives about vulnerable groups of people' (Kaposy 2018:53). For Piepmeier (2012), memoirs 'humanize and value the children and reframe cultural views of "typical" personhood through the lens of disability'. Many memoirs 'portray children with disabilities as full, significant, valuable human

beings, worthy of love and respect', although Piepmeier is equally critical of them for citing grief as the prime emotion, for (over)emphasizing impairment, and for framing the child as a problem to grapple. Likewise, whilst Calton (2010) discusses how classed differences are often overlooked in memoirs, Sousa (2011) demonstrates how they become cultural texts which speak to the pressures placed upon women of disabled children to conform to 'good' mothering standards.

Nonetheless, the largely positive sentiments expressed in such memoirs deviates from earlier anthropological scholarship where there is a questioning of the subjectivity and personhood of disabled children (Weiss 1994) or, even, more ambiguous perspectives of parents (Das and Addlakha 2001). As Tine Gammeltoft (2008: 827) argues, rather than a clear distinction between *acceptance* or *rejection*, parents of disabled children in Vietnam:

...seemed to imagine and shape the subjectivity of their children in ways that were fraught with contradiction: while insisting fiercely on the humanity of their children and caring for them with love, most parents also depicted their children as pitiful; as being of less value than others and as a heavy burden on their families.

More recently, scholars show how parents, particularly in the Global North, positively include, and convey their gratitude for, disabled children in their daily lives (Rapp and Ginsburg 2001; Green 2007; Landsman 1998, 2008). This has been referred to as a 'corrective' approach, in which parents foreground the positive facets of parenthood (Ryan and Runswick-Cole 2009) and advocate for the personhood of themselves and their child (Landsman 2009). Mothers have also highlighted how children transformed their belief systems and offered them the gift of their own self-knowledge, that is, they attain a comprehension of *what really matters* in their life (Landsman 1998, 2009; Rapp 1999).

However, the success of such efforts is often affected by the in/visibility of their child's condition. The salience of stigma, indeed, can be governed by how effective parents are in convincing others that child's problems are 'biological' in nature (Farrugia 2009; Francis 2012). When a child's condition is invisible, perceived misbehavior is regularly attributed to the insufficient proficiencies of mothers (Blum 2015; Gray 2002; Green 2003; Runswick-Cole and Ryan 2019), whereas a child's 'physical' (visible) disability 'usually emphasised that others did not blame them for having caused their children's problems' (Francis 2012:936). Moreover, for Blum (2015:92), the tensions around stigma and visibility are 'more freighted within elite neighbourhoods, schools, and communities', and become dictated by distinct but interrelated dimensions of social privilege (class, marital status, gender, race).

Other scholarships highlights how parents encounter challenges when attempting to access public services and support for children as they grow older (Fietz 2019). Some look at specific institutions, such as healthcare environments (Farrugia 2009; Mauldin 2016), and how parents can creatively appropriate medical knowledge and challenge medically-sanctioned notions of ab/normality (Fisher and Goodley 2007). Yet, scholars in recent years have identified how neoliberal belt-tightening have impacted parents' access to resources (Thomas 2021a); they must navigate 'dense bureaucracies' (Blum 2015:36), with even the most affluent rarely shielded from neoliberal machinery. As Pelka (2012:131) contends, the work of parents in fighting for support and rights 'can hardly be overstated'. Runswick-Cole and Ryan (2019: 1129) argue, relating to mothers:

Mothers are forced to meet these challenges as they try to weave, ease, negotiate or batter a path for their children to lead flourishing lives. At times it can feel like being in the trenches with strong binoculars, scanning the terrain ahead with fear and horror. Many mothers quickly learn that it is not their children who need fixing but the world around them.

Such experiences have led to labels like 'warrior-heroes' (Sousa 2011), with parents (though predominantly mothers) behaving in ways that involve acts of bravery and determination in securing resources for their children. As Green et al. (2017:267-8), remind us, parents are forced to 'embark on an individual search for information and appropriate services and to fight for scarce resources in fragmented systems that often do not seem to value their [disabled] children as people'.

Parents of disabled children, in turn, have told stories about their joys and struggles (McLaughlin et al. 2008), and how their experiences 'involve a complex mix of the effects of bodily difference and the social barriers and cultural preconceptions imposed on individuals with such differences' (Green et al. 2017:276). Yet, this body of work is still rather modest, there is little undertaken in the UK (most of the research cited above was conducted in North America), and there are few studies examining the experiences, specifically, of parents of children with DS. In what follows, I provide a broad context of Downs' syndrome in the UK and how it occupies a curious position

in the public imaginary as something both to *celebrate* and to *screen out* (i.e. through prenatal screening programs). This context, I argue, informs participants' responses to, and accounts of, parenting a disabled child.

Down's syndrome in the UK

There is a growing public and positive presence of disabled people, including people with DS, in cultural outletsⁱⁱ, and across networks of people with experiences of disability (Ginsburg and Rapp 2013). A range of diverse media (TV/film, blogs, social networking websites, newspapers, memoirs, art exhibitions) offer opportunities for cultivating alternative engagements and reformulating new narratives which depart from common tropes of pity, suffering, and tragedy. Such proliferating cultural narratives of disability (Rapp and Ginsburg 2001) become utilized 'by social members to make sense of experience' (Green and Loseke 2020: 4) and also confront deficit models of disability by recuperating the humanity of people living with disability. With respect to DS, memoirs/stories of parents located in the Global North, UK included, are plentiful and easily accessible (e.g. Bérubé 1996; Enoch 2020; Soper 2007, 2009). A positive imaginary about living with DS is articulated in such memoirs and, as I argue elsewhere (Thomas 2021b), other cultural mediums (TV/film, newspaper articles, blogs) in the UK context.

At the same time, tracing the history of DS in the UK presents a problematic picture. In the nineteenth century, training schools – designed, in theory, to be restorative – were opened for learning-disabled people (people with DS included). However, institutions expanded and, following an economic downturn and colonization by medical professionals, they quickly became 'asylums' providing basic levels of care for subjects recast as test cases for the pursuit of scientific knowledge (Thomas 2017). This, in turn, contributed to shifting the public imagination, and igniting systemizing prejudices, of disabled people as sick, requiring intervention, and a burden to sequester from public view. This institutionalization was also connected to racial and eugenic thinking in the early twentieth century. Concerns around degeneration and the need of a 'healthy' populace (for military action) were expressed in national eugenic campaigns in the UK, where 'feeble-minded' individuals were figured as threatening wider society. Eugenic principles and policies eventually lost scientific credibility, but this was not before many people with DS (and other disabled people) had been institutionalized and sterilized. Following public outcry in the 1960s, and influenced by social/economic factors (including the disability rights movement), institutions closed and people with DS in the UK, by the 1980s, were moved into the wider community under policies of inclusion and community provision, though this was not without its problems, nor has it negated a historic and ongoing battle for inclusion, acceptance, recognition, and resources (Thomas 2017).

The development of clinical genetics and prenatal screening/testing techniques has, additionally, contributed to DS being subjected to a pervasive reproductive gaze in the UK. The troubled relationship between DS/disability and prenatal medicine is well-established (Parens and Asch 2000; Saxton 2006). Critiques are habitually centered on the 'expressivist objection', the argument that committing to developing modes of intervention to correct, improve, or prevent genetic conditions devalue the lives of tested-for fetuses and disabled people (Boardman 2014). Primary actors in prenatal medicine are seen as evoking an 'imaginary world', where disabled children guarantee hardship and misery, and where medical intervention is perceived as a boon (Gammeltoft 2014:154). Prenatal screening has been viewed by some – including parents of children with DS – as framing DS in negative terms, as worthy of detection and elimination (Alderson 2001; Kaposy 2018). In the UK, the implementation of non-invasive prenatal testing (NIPT) for DS, among other conditions, has been criticized by disability rights organizations as possibly causing an increase in termination rates for fetuses diagnosed with DS (Thomas et al. 2021) and, in turn, enabling 'a kind of informal eugenics in which certain kinds of disabled people are effectively "screened out" of the population before they are even born' (Don't Screen Us Out 2021).

Finally, as I argue elsewhere (Thomas 2021a), parents of children with DS frequently struggle to secure ample resources and social support. In the UK, disabled people and their allies, including parents, inhabit a society where lots of progress has been made. This is largely thanks to the disability rights movement; DS advocacy has historically had, and continues to play, a key role in the disability rights movement and broader shifts in attitudes about cognitive disability. However, disabled people continue to face oppressive practices and policies that dominate their lives (Garland-Thomson 1997; Goodley 2014; Kafer 2013). This mistreatment is driven by 'disablism', the 'social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorized as "impaired" by those deemed "normal"' (Thomas 2010:37). Disablism inevitably shapes the experiences of parents of children with DS in the UK.

It was this paradox – that a positive public imaginary of DS and increased *acceptance* of, and opportunities available for, people with DS sits in a wider context of disablism, an unsettling relationship with prenatal medicine, and a legacy of institutionalization, sterilization, and stigma – that I sought to address in the study reported in this article. Disability, and especially learning disability, is at the margins of anthropological and sociological thinking (Ginsburg and Rapp 2020; McKearney and Zoanni 2018; Shuttleworth and Meekosha

2011). DS is even further marginalized. Studies on DS commonly exist outside of social scientific sensibilities, one exception being research on the social/ethical implications of prenatal screening/testing. With some exceptions (e.g. Johnson and West 2020; Sargent 2018, 2020), research is mostly based upon quantitative, crude assessments of 'quality of life' for people with DS and families, and calculations of the merit of 'interventions' and psychological deficit evaluations of *stress/coping/adjustment* for parents. I depart from this scholarship by presenting a social scientific analysis of how parents fashion a positive imaginary of living *with*, not *despite*, disability (and, specifically, DS).

There are two further things to note here. First, I acknowledge that people with DS still operate in the same social, economic, and political contexts as other disabled people. As such, it may appear unwarranted to focus *only* on DS, and that doing so fosters an impairment-focused understanding of disability. However, I contend that DS is unique and worthy of individual analytic attention. As well as the complications associated with lumping together all disabled people (Davis 1995; Shakespeare 2017), DS occupies a peculiar position as a *visible* disability that is familiar and present in popular cultural outlets, yet which has a troubled history and presence (e.g. in prenatal medicine). As such, I argue that DS – as an individual focus – is worthy of attention in the social sciences, in the same way that recent contributions on autism (e.g. Leveto 2018; Milton 2016; Silverman 2012) and deafness (e.g. Friedner 2020; Mauldin 2016; Mills 2012; Nakamura 2006) make clear.

Second, there is a methodological, and arguably moral, problem of talking only to parents, rather than to people with DS. Discussing people who are not representing themselves seemingly undermines the principles of the disability rights maxim 'nothing about us, without us'. This is a limitation of my project. Nonetheless, I believe that focusing on parents within this context is crucial. Blum (2015) and Runswick-Cole and Ryan (2019) identify how parents, and particularly mothers, are regularly on the frontline of navigating bureaucratic institutions. Moreover, we know too little – outside of scripted memoirs (Hanisch 2013; Piepmeier 2012; Sousa 2011) – about the lives of parents of children with DS and their experiences related to being at the vanguard of countering deficit framings of disability, engaging with institutional practices and policies, and expanding understandings of what it means to live with disability. Finally, as others have outlined (Green et al. 2017; Landsman 2009; Ryan and Runswick-Cole 2009), mothers have frequently been pathologized and held to gender expectations, such as that they should sacrifice everything to take care of a disabled child. As such, it is vital that mothers, as well as fathers, are provided an opportunity to share their views as key stakeholders, albeit not exclusively, and to convey how they may accept, reject, or reconstruct cultural representations of their lives (Landsman 2009). In what follows, I outline the methodology of my project.

Study

This article draws upon a study undertaken between July 2018 and May 2019. It involved three modes of data collection: 1) interviews with twenty-two parents of children with Down's syndrome [DS]; 2) an ethnography of a large congress bringing together people with DS and their families/allies (e.g. advocates, professionals, researchers), and; 3) analysis of textual matter (e.g. newspaper articles, memoirs). I draw exclusively upon interview and ethnographic data in this article, though mostly the former. Ethical approval was granted by the Cardiff University School of Social Sciences Research Ethics Committee.

Fieldwork was carried out at the World Down Syndrome Congress in July 2018 in Glasgow, Scotland. The three-day congress was a space for people with DS, families, advocates, professionals, and academic researchers to share knowledge and insights with people from different countries and contexts. It offered participants access to medical research, educational developments, and information on matters including family life, employment, social/family/sexual relationships, independent living, and leisure/sporting participation. There was also a series of social events, including entertainment and evening activities (the stated 'core pillars' were 'research, lived experience, practice, and performance'). The congress took place in a large exhibition center as part of the Scottish Event Campus. Participants (myself included) attended sessions, plenaries, workshops, exhibitions, and performances. I observed several sessions from early morning to late afternoon on each day (including evening events). I sat at the back of most sessions, with a large number of attendees – and plenty of people with laptops, mobile phones, and notepads – making my presence unobtrusive. My presence at the conference inevitably involved interaction with people with DS, families, allies, and other stakeholders, but data collection was exclusively focused upon 'public events'. As such, ethical approval covered my observation and note-taking of the congress. Whilst conference fees and registration prevent anyone's attendance, the conference constituted a public space. Nonetheless, I took the decision to anonymize speakers' names since these details did not seem appropriate to include in my analysis. Fieldnotes were taken on a mobile phone and/or notepad during sessions and once I had left the site. In my fieldnotes, I paid attention to how ideas and experiences of disability were cultivated and performed in public forums. The fieldwork is limited by only observing one site over three days. This was a small-scale project with limited financial resources. Even so, it would have benefitted from other

opportunities to explore how people with DS, their family members, and others enact positive imaginaries about living with disability.

Interviewees were recruited via gatekeepers who are part of personal networks and charity organizations. The eligibility criteria were that participants were parents of a child with DS and lived within a two-hour drive (due to limited funding and geographical mobility). I understand the possible limitations of this approach; local histories and politics may mean perceptions and experiences I gather are rather uniform. That said, as well as supplementing interview data with ethnographic fieldnotes and analyzing textual matter, parents noted how similar experiences and perceptions were often shared across geo-political contexts. Twenty-two parents were interviewed for this study. Twenty of the participants 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. Both parents interviewed individually were married, but their partners did not participate. The parents were aged 35-70 and children were aged 1-15 years old. Parents were mixed with respect to backgrounds, educational history, and employment status. My sample is limited, though, by recruiting parents who were already part of local/national networks, meaning I am likely to have neglected parents who do not share such connections. For further details on methodology and analysis, see: Thomas 2021a, 2021b.

Findings

In what follows, I describe how parents craft a positive imaginary of having a disabled child, articulating the value and ordinariness of their lives. From here, I describe their participation in what they called a 'Down's syndrome community', and how engaging with other parents and their children with DS offers a means to work towards creating and nurturing an 'inhabitable' world for them and other families of disabled children. Finally, I outline how parents offered resistance narratives in which they deviate from common conceptions of living with a disability as tragic and with no 'future'. Instead, they shared their hopes and aspirations for their children and, in so doing, cultivated an understanding of a future *with* disability.

A Positive Imaginary

During fieldwork and interviews, parents cultivated a positive imaginary that identified the worth of their, and their children's, lives. They promoted a corrective approach, conveying their lives as celebratory and not the disaster it was initially believed to be, despite common expectations being that they should be pitied or only feel sadness, grief, guilt, and anger (Shakespeare 2017). Parents' stories followed a common arc in memoirs: initial stress and sorrow (at being thrust into unexpected and disruptive, and initially undesirable, projects of parenthood) followed by a personal transformation, in which a dramatic reorientation of values challenged taken-for-granted assumptions and expectations (Green et al. 2017; Landsman 1998, 2009; Johnson 2021; Sousa 2011). Parents described a turning point in their biography, a 'recalibration' (Eva, Roger) of their own values and principles in ways that retain the personhood of their child (McLaughlin 2006). Parents did not deny the challenges of parenting a disabled child; they discussed navigating hospital visits when their child fell ill, together with more 'everyday' difficulties, such as poor sleeping and unpredictable behavior (Green 2007; Mattingly 2014; Thomas 2022). They also bemoaned the 'low expectations' (Megan, mother) of others and the 'fights' and 'battles' which ensued when navigating dense bureaucracies (Blum 2015; McLaughlin 2012; Thomas 2021a).

Parents' narratives, as such, cannot be viewed as presenting an unflinchingly positive, even sentimental and one-dimensional, impression of their lives. Yet, my contention is that parents emphasized how their experiences were primarily 'rewarding, affirming, enjoyable, and heartwarming' (McLaughlin et al. 2008:96)ⁱⁱⁱ. This is the key message that parents were keen to share throughout my study. Whilst parents largely cited how life had improved for disabled people since the days of institutionalization, and they spoke of how public interactions often unfolded in a convivial and straightforward manner (very few cited instances of discrimination and stigma), they felt a need to unsettle, denaturalize, and reimagine what they saw as dominant negative stereotypes and assumptions about disability (Garland-Thomson 2005). This negative perception was particularly embedded, for parents, within prenatal medicine. They told stories of healthcare professionals who delivered their child's diagnosis in a cold and insensitive manner, providing unhelpful and 'mortifying' (Sophie) scripts of life with DS that fueled misconceptions and exaggerations of family life as tragic and disastrous. This experience, for Charlotte, became a motivation to 'show life with [DS] in all its varied ways as being an overwhelmingly positive thing'.

Throughout the fieldwork and interviews, parents noted a desire to 'bust myths' and 'increase awareness'. Henry, for instance, wanted to 'put a positive spin on it', identifying the need to share 'lived positive experiences to try and wash those preconceived ideas that I definitely had before we had Daisy'. Parents lamented deficit framings and expectations of people with DS, such as lacking independence and sharing an appearance; '[having a child with DS] doesn't mean you're destined for a life of basin haircuts, dungarees, and holding hands when you're 35' (Richard). Disturbing traditional narratives of DS also involved debunking crude and infantilizing myths of children

with DS being happy, affectionate, and musical. In a plenary for at the World Down Syndrome Congress, one mother of two young twins with DS explained that the 'aim' of her online blog is to:

Shatter the stereotype that people with Down's syndrome won't achieve anything. They're not just happy and musical...For [sons], Down's syndrome is way down on the list of things that define them.

Events at the World Down Syndrome Congress were clearly designed to project positive imaginaries of living with DS; they are, in essence, structured and scripted accounts, explicitly public in orientation. Yet, parents expressed similar sentiments in interviews, with online spaces heralded as one forum in which they figured their lives as positive. Amelia created a blog for her son, Aidan, to 'increase awareness' and 'show everyone that he's this amazing boy', whilst 'debunking some of those myths that everyone with DS is happy...that isn't the case for Aidan!'. Likewise, Eva said that she shares 'the good and the bad' experiences with other users; 'I put pictures on [social networking sites] of Martha when she's not happy' to show that 'our child's no different to yours'. Sophie saw her Facebook page for Noah (son) as 'embracing the whole thing', whilst her partner, Jamie, said the intention of this page was:

...to show how we're trying to raise a happy balanced child amongst [siblings]. Noah is very content and that's the message you're trying to send out. Down's syndrome is not something to be afraid of. Noah is just part of the family.

Likewise, Jenny said:

That's why I've thrown Michael's hat in because I want a teenager with a shadowy moustache and braces, standing there looking quite cool, not overweight, behaving appropriately, telling his mum to get off if I tidy him up or do anything with him. That's how it should be.

Parents often told me that their lives were ordinary and 'normal' (or 'normal, but with additions' [Charlotte]). Comparisons to non-disabled siblings were common in making such claims. Interestingly, whilst a few parents questioned the 'normal' category as a construct (Green et al. 2017; Landsman 1998), the majority of them said their lives were 'nothing out of the ordinary'. There was no description of children as 'gifts' (Soper 2007, 2009) or 'angel-children' (Hanisch 2013), nor did parents overdetermine the disability category or craft their story in ways that espouse a 'heroic overcoming of disability' (Blum 2020:61).

One, I would say ungenerous, interpretation of this account – of 'normality' – is parents align with an assimilationist perspective, thus negating the celebration of provocative and disruptive alternative figures who can confront dominant socio-cultural ideologies (Garland-Thomson 2011). Instead, I argue, parents have somewhat 'normalized' their own experiences; they see their children as 'fully human and valuable as any other children', whilst also defining their own parenthood, whilst 'counter to expectations, as nevertheless normal in its own terms' (Landsman 1998:93). It seemed, to me, that parents widened the boundaries of the 'normal' category to include a wider spectrum of bodies and minds. To be clear, parents did not *deny* impairment; they did not 'flee the category' of disability (Garland-Thomson 2005:1567). The recognition (and, in turn, validation) of impairment by professional stakeholders was crucial for securing resources (the 'visibility' of DS was valuable in this regard). So there is a tension here, between discourses of 'sameness and difference' (Rapp 1999:293). Whilst parents claimed their experiences were 'normal', they equally recognized difference (such as when they connected with other parents of children with DS – see below) and re/made images of disability outside the entire (normative) value system of society. In short, they redefined and sought new forms of normality for them and their children, one that embedded impairment into their lives and foregrounds difference (McLaughlin 2006), whilst still suggesting that 'we're just like everyone else' (Elizabeth). This aligns with a recognition of disability as human variation rather than as 'an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate' (Garland-Thomson 2005:1557). As Kaposy (2018:1) reflects:

People with [DS] are able to develop, grow, learn, and live much like everyone else. They are beloved members of families. People with [DS] go to school, make friends, graduate, have jobs, get married, have sexual relationships, pursue hobbies and interests, start businesses, pursue higher education, and so on...Because of their differences from others, people with [DS], their supporters, and their organizations have to make a special effort to present the normality of their lives.

This 'special effort' was lamented by parents like Charlotte and Henry, who expressed frustration at having to 'prove our lives are actually okay, and that our children are actually going to be okay'. Yet, whilst their attempts to *bust myths* and *increase awareness* were not uniformly positive and embraced, parents largely talked about such efforts in neutral terms (their major frustrations, as I discuss elsewhere [Thomas 2021a], were when

navigating institutions and securing resources for their children). Parents discussed their 'responsibility to educate [other people], but in just a normal, quiet way, not shouting from rooftops' (Sarah). Henry said how he was involved in 'educating [Daisy's] age groups and different age groups about what DS is'. Here, parents claim that (non-disabled) others can be 'educated' by encountering their child (Hanisch 2013). William said:

[We should] just teach children as much as possible, as early as possible, and having some good role models [of people with DS] running their own shop or being good in theatre and playing music, sports, this type of stuff. I think this helps and shows others what you can actually do.

Piepmeyer (2012) claims that parents of children with DS, as 'knowledge producers', hold a key role in communicating a 'critical stance on mainstream culture' and 'changing the cultural meaning of disability, and therefore the broader understanding of citizenship and civic identity'. This can be cultivated not only in public forums that are seemingly designed to enact a positive imaginary (e.g. the World Down Syndrome Congress), but also in their everyday lives. Being thrust into a disability world meant that parents became accidental ambassadors for cultivating tolerance and understanding^{iv}. Examples include: offering to provide 'more balanced' resources to healthcare professionals responsible for delivering a diagnosis of DS to prospective and current parents; correcting people who refer to individuals with DS as 'sufferers', and; challenging people who describe their child as 'happy' and 'loving' or who react with surprise behaved in a 'normal' manner.

Parents' 'public storytelling' (Ginsburg and Rapp 2013:62) – of their lives as valuable and, essentially, normal – punctures popular conceptions of disability and contributes to 'new cultural understandings of human cognitive diversity' (Rapp and Ginsburg 2011:379). Expanding the 'social fund of knowledge about disability' (Rapp and Ginsburg 2001:537) involved producing connections with others who have experience of disability. Indeed, parents frequently shared stories (via online sites and at social events in-person) of people with DS that served as correctives. Linda, for example, said that on one social networking site, users shared 'fierce looking photos' of athletes with DS^v. Such images, for parents, help to 'change perceptions' (Ray) and are indicative of a more tolerant society. Visibility is crucial here. The stakes of in/visible disability have been identified elsewhere, where people with 'invisible disabilities' face difficulties in receiving a diagnosis and resources (Blum 2015; Fisher and Goodley 2007) and, in some cases, encounter allegations of *faking it* (Green et al. 2005). Here, the presence of people with DS in public as *visibly disabled* did not invite disapproval or stigma, as has been reported elsewhere (e.g. Garland-Thomson 2009). For parents, the presence of people with 'visible' disabilities in the landscape of popular and commercial culture is embraced as 'a sign of the growing public incorporation of this historically stigmatized difference' (Rapp and Ginsburg 2001:548). Eva claimed:

If I see anything positive where there's a young child [with DS] advertising clothes, holidays, or anything, I always take a screenshot of it and I'll Tweet it and I will Facebook share it and say #beallthatyoucanbe, #inclusion, #Downssyndromeawareness. Friends in our community that don't have a child with [DS], friends from school, family members in Australia, in Germany and everywhere else, often they will re-share things and it's got a rolling ball effect. For World Down's Syndrome Day on March 21st, I do a presentation for the school parents talking about [DS] awareness and we sell badges and we sell cakes with "Down's Syndrome Awareness" on it and parents ask questions.

Similar to parents who used hashtags #worldwithoutdowns and #justaboutcoping to upset 'traditional narratives' of DS relating to prenatal medicine (Burch 2017:1086), parents in this study, like Eva, used social media to show the value of positive imagery and of sharing this with others, including people with no experiences of DS/disability. Established events, such as World Down Syndrome Day, were also a forum for this; they are 'special' since they offer an opportunity to observe other people with DS who are 'really talented' and to 'reconnect with my friends around the world to celebrate' (Bella). In what follows, I further explore this notion of connecting with others and how this feeds into cultivating a positive imaginary of living with disability.

'Down's Syndrome Community'

Enacting a positive imaginary of Down's syndrome (DS) is not homogenous or without its problems. Highlight reel images of children with DS – as always enjoying life and surmounting barriers – threatens to downplay and disregard more complex realities, such as development differences, family income, and varying access to services^{vi}. Yet, parents, whilst not necessarily espousing a Panglossian view, countered what they saw as negative stereotypes and perceptions. They crafted resistance narratives that defended their position and 're-humanized' their children (Johnson and West 2020:7). We might think of these as 'crip' accounts, a 'non-compliant, anti-assimilationist position that disability is a desirable part of the world' (Hamraie and Fritsch 2019:2). A narration of disability presence meant that parents are part of a 'disability world' (Ginsburg and Rapp 2013), provoking new ways of understanding difference.

Scholars have highlighted how parents cultivate positive conceptions of living with disability (Fisher and Goodley 2007; Green 2007; Landsman 1998, 2009). Yet, such work frequently individualizes experiences of articulating resistance narratives (e.g. Manago et al. 2017). Instead, I argue that the cultivation of affirmative understandings of parenting a disabled child is a collective, interdependent act. Parents in this project carved out spaces of connection and imagination with other parents of children with DS, participating in what was often referred to as a/the *Down's syndrome community*. Participating in this community began, for many, following their child's diagnosis, when they located (or were put in contact with) local groups for parents of children with DS – in both offline (support groups, fundraisers, social events) and online (blogs, social networking sites)^{vii}. In this study, being 'pulled into this community' (Jenny) is framed in positive terms, and especially early in a child's life and/or when this was their first child. Valerie said:

I was a first-time mum. All mummies go off to mother and toddler groups to meet other mummies and have a whinge about sleepless nights and all the other things that come with it. But when you go along to those toddler groups, and your baby looks a little bit different to the other babies, and is doing different things, and you're worrying about different things, you can end up feeling like a bit of an outsider. So it was really nice to meet [mother of child with DS], and we were able to find some other people who do the same as us.

Participating in a DS community allowed parents to access information on available support such as training and information sessions (e.g. speech and language therapy, education services, puberty/adolescence). It also provided an outlet for parents to forge alliances (Ryan and Runswick-Cole 2009). Eva, among others, felt 'very lucky' to be part of this 'very small supportive community':

I'll run things by them, "do you think this might work?" We'll share resources and it's a friendship group that I never knew existed, but I could not live without them now at all. They're fundamentally the most supportive in any aspect because they give us much more support than the professionals, to be honest, because if we've got a problem with Martha struggling with something in school, we put it on one of the forums and someone's been there, got the t-shirt, and has tried five different methods.

Rather than acting privately as 'vigilantes on lone quests for justice' when failed by the State (Blum 2015:29), parents described forging networks for connecting and communicating, in which they shared tips, videos, and techniques of development – and worked together in attempting to create more accessible lives for children with DS. In the absence of adequate professional support, parents plug gaps by sharing advice (often online) and seek support themselves by treating others as a 'sounding board' (Sarah), particularly those 'who are a bit further on, who've done it, who know where they went wrong'. Sharing stories and advice became crucial when navigating access to resources (e.g. education, healthcare, welfare) in a context where parents are often left to 'work everything out for ourselves' (Fred), with some recognizing their classed privilege in this respect (i.e. having the 'intellectual, emotional, and financial' capital to 'claim for things' [Richard]).

Interestingly, parents' efforts did not necessarily translate to a concrete agenda for political mobilization and no parents explicitly labeled themselves as 'activists' despite seemingly taking on such roles (e.g. applying to local authorities for financial support, participating in tribunals) and talking in a more 'social model' framework of disability (Ryan and Runswick-Cole 2009). It seemed that *advocacy* and *activism* existed on a continuum; this was a source of irritation for some parents, like Hannah and Tim, who wanted other parents to be more 'political'. Nonetheless, this was not a formal activist group as described by the likes of Allison Carey and colleagues (2019), nor did parents establish connections with other disability groups. Parents did, however, collectively advocate on behalf of their children, and such experiences did not occur in a historical void. Some parents acknowledged the debt owed to previous trailblazing parents; they inherit a legacy of efforts to challenge dominant understandings, stereotypes, and low expectations of DS, and to fight for a more tolerant, inclusive society. The disability rights movement, deinstitutionalization, and landmark policies in the UK shifted the terrain of parent advocacy in previous years.

Parents' ongoing attempts to humanize their children and to secure resources, as part of a *DS community*, is informed by such a context, with parents now able to pursue inclusion and accessibility as an expectation as well as to project a positive public imaginary and change cultural narratives of disability (Fietz 2019; Sousa 2011)^{viii}. Indeed, the obvious achievements and progress of the disability rights movement has made it possible for parents to collectively craft and articulate more affirmative narratives, and to engage in practices to improve their lives. Indeed, parents described a vibrant community with the shared project of conveying their lives outside of a deficit model. Sarah said:

Three months ago, Louis had his first ever haircut. He did it on his own. David dropped him at the door, he went in, managed the whole thing himself, and that's massive for Louis in terms of independence, but he's also got massive sensory issues, so the haircut itself has taken years to acclimatize him to. I posted that [on social media], because there are lots and lots of parents of young children, or even 10- or 12-year-olds, and it's a meltdown situation with a haircut. And I said, "this is great news for us today, hang in there, because it's taken us this many years to get there, and it is possible, and I'm so proud that he's achieved that today". And people said this is fantastic, and now we feel it might happen for our child.

A peculiar dilemma is observable here. Parents embrace narratives that emphasize the *ordinariness* of their lives, yet they also cultivate a community based on *difference*. My interpretation is that forging interpersonal connections with other parents (and, in turn, their children), based on shared difference (Rapp and Ginsburg 2001) and across 'boundaries of class and circumstance' (Sargent 2020:10), provides a vehicle for redefining new forms of *normality*, one that identifies difference but which widens the boundaries of the normal category to include them and their children. The formation of affective ties with other parents, but particularly mothers, as 'pack animals' (Valerie) – locally (online/offline) and globally (online; at the World Down Syndrome Congress) – was vital for this. They became entangled in each other's lives, responding to needs and building communities of care, albeit mostly at a local (i.e. UK) level.

Presenting the 'Down's syndrome community' as a unified and harmonious entity, though, would be disingenuous. It experienced fractures and existed in tandem with tension and (not always expressed) disquiet. Outside of obvious critiques, such as that not all parents will perceive online technology as a barrier-free utopia, some parents: disliked 'competitive' (Bella) comparisons between children (especially as parents often cited the 'spectrum' or 'wide margin' [Linda] of people with DS); felt coverage of 'high-functioning' and 'high-achieving' children with DS may be unfairly perceived only as the product of 'good Mums' (Linda); labelled other parents as 'complaining' (Fred) and 'whingeing' (Jenny) despite urges to remain 'positive' (Fred) and 'constructive' (Jenny); charged other parents with sharing 'highlight reels' that 'may lead some parents to worry about "why don't I feel that way?"' (Richard) and; worried popular outputs focus upon younger and 'higher-functioning' people with DS, meaning that older people with DS risk being overlooked.

The complexity and contradictions of disability stories meant that some parents may not feel 'represented' (Linda) and so become excluded from an allegedly inclusive community. The views of charismatic and devoted people may shape perceptions of a disability which can both helpfully stress the 'value and dignity' of their lives whilst generating problems for others, since this dominant view 'makes the development of other views difficult' (Löwy 2018:198). Another possible issue, although this was not explicitly noted by parents, is the gendered dynamics of the community-building. It is worth noting that it was frequently women who described participating in the DS community. Mothers and fathers described their collective, sometimes separate, efforts to erect a positive imaginary of DS, yet it was mothers who often described their involvement in the community. This potentially demonstrates how women are figured as responsible for the material and emotional care of disabled children and adults – and, as such, are most likely to be reprimanded, blamed, and stigmatized in the event of non-conformity to expectations, especially when disability is 'invisible' (Blum 2015; Farrugia 2009; Fisher and Goodley 2007; Francis 2012; McLaughlin 2006; Runswick-Cole and Ryan 2019).

Engaging in a *DS community*, then, is not undertaken without issues. Yet, it did offer an outlet for parents to work towards creating a habitable world for them and for other families of disabled children, and to occupy a space without judgment and need for explanation and 'where their new normality is appreciated, celebrated and cared for' (McLaughlin 2006:8.2). Whilst not explicitly identifying as activists, they collectively advocated for their children, and others like them, in ways that attempted to change cultural narratives about DS (Piepmeier 2021) and departed from common disability narratives that emphasize pity, catastrophe, and abjection (Garland-Thomson 2005).

Such work made it possible, also, to imagine a positive future. Alison Kafer (2013:2) contends that disability is commonly perceived as a site of no future; a disability-free future is valorized and expected, with disability viewed as 'a fate worse than death' and as prohibiting a 'full life'. Moreover, Helena Fietz (2019) suggests that, during her research in Brazil, parents expressed concerns about who would, following their death, care for their disabled child. In this study, some parents had ambivalence about what the future held for them and their child (but often added that this was the same for their child's [non-disabled] sibling/s). Many parents, however, perhaps on account of their child's age (all were aged 1-15), were optimistic about the future. When asked about Albert's (son) future, Fred replied:

I think he's going to have a really good future. I genuinely think he's going to work. Because he's just a boy, isn't he? He's got his delays, but he is so adaptable. [Helen and I] have got this saying: "We wouldn't change him for the world, but we'd change the world for him". But I do think the world is changing. I think it is getting better...I went to [fast food restaurant] where I could see [a woman with DS] with the white [manager's] shirt on. She was telling them what to do, and I just sat there in amazement. It's just nice seeing it, like, there is a future for Albert.

Many parents, like Fred, cited normative ambitions about the future, such as gaining employment, living semi-independently, and having friendships and romantic relationships ('I reckon she's going to have a boyfriend, she'll want to get married, she'll run him ragged!' [Charlotte]). Linda imagined Christopher (son) being employed in the service industry and engaging in 'normal living' like his siblings; 'if Christopher goes for a pint [of beer] on a Saturday afternoon with his brothers, then they go off nightclubbing and he comes home, happy days!'. Participation in the DS community was essential for resisting understandings of the future as one of isolation and pain, of pity and neglect, of banality and dependency (Kafer 2013). During interviews and at the World DS Congress, parents highlighted, how seeing other children, and adults with DS in popular media outlets and in their local area (examples included people employed by restaurant chains, museums, and other settings), provided them with 'hope' (Bella). This included citing 'inspirational' figures and 'role models' with DS, such as individuals appearing in television programs, films, fashion shows, sports competitions, advertising campaigns, theatre, art exhibitions, and news stories as business owners or other public figures. For parents, this exposure is enabling (Fisher and Goodley 2007) and helps to transform 'the broader social imaginary and refigure the cultural landscape for new generations of families engaging with the social fact of disability' (Rapp and Ginsburg 2001:547). Here, people with DS are not thought of as a 'burden on society' but as '[adding] to society' (Ray). Eva claimed:

We know a lot of young adults in the community who've got a very full life in terms of work, friends and social activities and are happy in what they're doing. We want Martha to have a job, be self-sufficient, be able to be living independently. There's one young adult in the community that we've met numerous times. She was a local councilor and represents [charity] in the UN. And she's phenomenal...We've got other positive role-models like Sarah Gordy, who's a phenomenal actress but also drags forward awareness for [charity] and other societies...There are so many positive role-models out there.

The presence of 'positive role models' in the DS community meant that, for parents, 'the next generation of parents would grow up thinking of that as normal' (Charlotte). It allowed parents to see their, and their children's, future as *livable*; parents *crippled* common narratives by re-storying disability and enacting a 'crip futurity' (Rice et al. 2017:214). I have argued elsewhere (Thomas 2021a) that the imagining of a positive future is threatened by the structural violence enacted against disabled people and their families (including parents of children with DS) as well as the haunting threat of prenatal testing that prompts anxiety about the 'eradication' of people with DS. Whilst parents cited such concerns, they equally imagined alternative futures in the face of ugly predictions. The positive imaginary collectively enacted by parents, especially as part of a collective disability community, allowed them to imagine 'dis-topias' (Rice et al. 2017:213) and depart from futures usually envisioned in gloomier terms.

Conclusion

I have argued that parents of children with Down's syndrome (DS) cultivate a positive imaginary with respect to living *with*, not *despite*, disability. Parents highlighted their lives as ordinary, positive, and not the disaster it might be expected to be. Departing from deficit models of disability located in dominant discourses of pity, tragedy, and misfortune, parents account for their lives in affirmative terms. This involved their participation in a 'DS community', in which they – with other parents – engaged in a mutual support network to access support, information, and recommendations. This also revealed a shared experience amongst the parents and offered an outlet in which to attempt to build a 'habitable' (Garland-Thomson 2015; Johnson 2021; Mairs 1996) world for people with DS. The DS community was based on interdependence, providing a 'politics of crip alliance and solidarity' (Hamraie and Fritsch 2019:13). Dwelling alongside similar others meant that parents could convey their child's lives as a 'desirable life, as life worth living, and as a difference that matters' (2019:21). Indeed, by recognizing their inter-dependence with others, parents provide a 'philosophical challenge to the notion of independence as a crucial quality necessary for defining personhood' (Piepmeier 2012). Knowing that 'accessible futures require our interdependence' (Hamraie and Fritsch 2019:22), parents' shared re-storying of body difference was foundational for the integration and acceptance of their children in the social landscape.

Moreover, parents described their hopes, dreams, and expectations of their child's (and their own) future. Positive personal experiences and the presence of 'role models' gave hope for future employment, meaningful friendships and relationships, and living semi-independently. Interestingly, parents align with their children embodying some

principles of neoliberalism, such as being *productive* via participation in the labor market, whilst seemingly rejecting others, such as the pursuit of *independence* (i.e. parents cited the inter-dependence required for their children to thrive). In imagining futures in more positive terms, parents resisted dominant understandings of their lives – as parents of disabled children – as tragic, pitiful, and a site of no future. Taken together, their claims show how, despite the clear (often structural) challenges posed by parenting a disabled child, parents were able to craft alternative narratives that challenge cultural meanings associated with disability (Ginsburg and Rapp 2004). Their accounts provide an ‘intimate and public articulation of how our culture misrepresents disability’ (Piepmeier 2021:102), one which foregrounds love, hope, and positive evaluation. Hearing such stories, Piepmeier (2021:29) tells us, humanizes disabled children and promotes a fuller conception of personhood by making space for a ‘broader range of acceptable people...one that incites individual and societal transformations’. Such efforts can help to ‘make more individuals aware of the diverse ways people inhabit the world’ (Johnson 2021:20).

My argument started with an acknowledgement that DS occupies a strange position in the public imaginary in the UK. There is a growing positive presence of people with DS in cultural outlets, and this is also reflected in the accounts of parents in my study. Simultaneously, there is a history of institutionalization and stigmatization, DS is targeted in prenatal screening programs, and people with DS and their parents struggle to secure adequate resources and social support. It is this latter claim that I conclude with. Whilst the disability rights movement has made lots of progress and advanced the lives of disabled people and their families, there is still much work to be done. Macro-contexts ‘continue to shape how families encounter and make sense of [DS]’ (Sargent 2018:9); whilst services and resources are sometimes available, there is a gap between the rhetoric of inclusion and ‘the battles that still have to be fought on a daily basis to ensure their availability—battles which not everyone can or will fight’ (Rapp and Ginsburg 2001:541). The positive re-scripting of parents, whilst a welcome and important corrective to deficit framings, does not translate as (full) inclusion, nor is storytelling – historically being imagined as catalyst for social change – always politically effective (Puar 2017; Runswick-Cole and Ryan 2019). In the UK, the violence of austerity politics threatens the capacity of parents of disabled children to obtain sufficient reserves and support to thrive (Goodley 2014); parents of disabled children have repeatedly campaigned for ‘the recognition of the value and humanity of their children, and for appropriate education, health and social care resources for them’ (Runswick-Cole and Ryan 2019:1129). This should not be left to parents (particularly, mothers). In calling for an ‘unmothering’ of activism and advocacy, Runswick-Cole and Ryan (2019) promote a mode of collective action that is characterized as ‘the disability commons’ (Runswick-Cole and Goodley 2018).

I argue, then, that the positive imaginary erected by parents, as explained in this study, serves as a vital corrective that frames disability as a ‘valid way of being in the world’ (Garland-Thomson 2017:133). However, progress is still to be made, and it is a collective responsibility to break through silos of exclusion (Runswick-Cole and Ryan 2019). Future research could focus on how people with DS, parents, and other allies – in sharing the solidarity necessary for politically campaigning for better conditions – can confront inequitable social and material environments. Such research, then, might focus upon how unjust structural conditions are imagined and addressed, and how this ties into how the experiences of disabled people and their families offer openings for ‘expression, creativity, resourcefulness, relationships, and flourishing’ (2017:141). As Ginsburg and Rapp (2018:118) articulate, this research may index a shared horizon for both the anthropology of disability and disability studies. Whatever the focus, future anthropological work must recognize disability, and particularly learning disability, as holding analytical value, whilst providing disabled people and their families with the opportunity to share their stories and, ultimately, to gain a seat at the table.

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Notes

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- ⁱ I use the descriptor 'Down's syndrome' (DS) because this was used by parents in this study. 'Down syndrome' is more common in North America and elsewhere.
- ⁱⁱ This is not always without controversy. In the Irish abortion referendum in 2018, the anti-abortion lobby used children with DS in their advertising campaigns to deter mothers from undergoing a termination of pregnancy.
- ⁱⁱⁱ This is likely to be different for parents of disabled children with serious health complications (Johnson 2021; Mattingly 2014).
- ^{iv} Thanks to the reviewer who encouraged me to further articulate this point.
- ^v Describing representations as 'fierce' or 'cool' could indicate a masculinization and normalization of young men with DS. Thanks to the reviewer who made this observation.
- ^{vi} Löwy (2018) also argues that parents may avoid describing their situation in negative terms, as doing so may worsen a situation already defined by inadequate societal support, discrimination, and prejudice. Moreover, Löwy claims that parental accounts may contain 'idealised descriptions' (2018:219-220) that do not recognize more ambivalent feelings, mask complex family dynamics, and overlook the challenges faced by (often female) adult carers. In this study, parents talked, as I saw it, with candour and insight regarding the multiple difficulties of raising a child with DS. Nonetheless, all parents were intent on departing from a deficit framing of their lives.
- ^{vii} There is a large literature on how people living with chronic illness/disability experience online support and how this relates to identity work, notions of connectivity, experiential knowledge sharing, and collective voice and mobilization (for a review, see: Kingod et al. 2017).
- ^{viii} Thanks to the reviewer who encouraged me to further articulate this point.