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**'The media love the artificial versions of what's going on':  
Media (mis)representations of Down's syndrome**

Gareth M. Thomas

**Abstract**

Whilst disability has historically been depicted in problematic ways in TV/film and print media, more balanced and progressive cultural representations are arguably emerging. However, few studies address how disabled people and their families (e.g. parents) encounter, and make sense of, media configurations ostensibly designed to promote a more positive and visible image of living with disability. Drawing upon interviews with parents of children with Down's syndrome in the UK, I sketch out how they feel about depictions that, arguably, depart from hurtful historical narratives of disability as tragic and pitiable. Parents praise, and mostly embrace, recent portrayals of people with Down's syndrome in media outputs. At the same time, they raise concerns around tokenism, stereotyping, focusing upon 'exceptional' people, and fuelling sanitised accounts which deny, or at least obscure, the harsh lived realities for many parents of disabled children. I conclude by arguing that whilst parents largely applaud and welcome positive public narratives, they also fear that such representations threaten to gloss over the pervasive mistreatment, disregard, and disenfranchisement of disabled people and their families.

**Keywords**

Disability; Down's syndrome; media; parents; popular culture; representation

**Introduction**

Disabled people have historically been *on display*, whether it be in circus shows, asylums, or on examination tables (Rice et al. 2017) – being 'visually conspicuous while politically and socially

erased' (Garland-Thomson 2002: 56). In recent years, scholars have analysed, and critiqued, a poor legacy of patronising, offensive, and prejudiced portrayals of disabled people in TV/film and print media which follow narratives of pity, inferiority, dependency, asexuality, isolation, and difference (Garland-Thomson 1997; Norden 1994; Oliver and Barnes 2012; Zola 1985). Barnes (1992: 19) criticises stereotypes in books, TV/film, and print media which 'medicalise, patronise, criminalise, and dehumanise disabled people'. He dissects how representations frame disabled people as (among other things) 'pitiable and pathetic', 'sinister and evil', objects of violence and ridicule, burdens, and 'super cripples'. Forming the bedrock on which attitudes and assumptions towards disabled people are based, these outputs 'are fundamental to the discrimination and exploitation which disabled people encounter daily, and contribute significantly to their systematic exclusion from mainstream community life' (1992: 19).

A common trope of such imagery is depicting disability only through a lens of impairment (Darke 2004); 'impairment is made the most important thing' and people with disabilities are 'objectified and distanced from the audience' (Shakespeare 1999: 164). The film industry, particularly, is charged with transforming disabled people into objects of cultural fascination defined by their perceived lack of human potentiality (Enns and Smit 2001). Norden (1994: 3) claims filmmakers, showing a penchant for constructing warped social imagery, urge us to regard disabled people in terms of pity, awe, humour, or fear, and how films not only perpetuate society's 'disregard' for disability, but also differ from disabled people's lived realities:

'[M]ore common representations include extraordinary (and often initially embittered) individuals whose lonely struggles against incredible odds make for what it considers heart-warming stories of courage and triumph, violence-prone beasts just asking to be destroyed, comic characters who inadvertently cause trouble for themselves or others, saintly sages who possess the gift of second sight, and sweet young things whose goodness and innocence are sufficient currency for a one-way ticket out of isolation in the form of a miraculous cure'.

Films and related media have been censured for aligning with a medical/tragedy model of disability (Green and Loseke 2020) which represents disabled people as 'pathetic' (French and Swain 2004: 34), as vulnerable and in need of charity (Goggin 2009), and as 'objects of spectacle' (Norden 1994: 1). Even when this framing is disrupted, disabled people are still rarely shown as 'ordinary subjects who happen to have an impairment' (Vertoont 2018: 828). For instance, recent portrayals of *extraordinary* disabled athletes have been critiqued for investing esteem in physicality, focusing only upon *physical* impairment/s, configuring disability as a primary identity marker and something to repair, fuelling expectations of overcompensation for acceptance, and obscuring socio-political structures that inhibit disabled people (Purdue and Howe 2012). For Grue (2016: 843), there is an expectation that Paralympians, though select elites, are 'credible role models for other people with impairments'. Whilst such *super cripp* imagery might empower some, it is illusory as it promotes an ideal beyond the reach of most. Grue (2016: 840) argues representations like this are problematic on account of 'objectification' (viewing disabled people as objects, not subjects), 'devaluation' (classifying them as having a low scope for achievement), and 'individualisation/mystification' (obscuring structural barriers/causes of disability by locating the 'problem' of disability in bodies 'overcome through individual efforts'). Outside of *spectacular* representations, more *unspectacular* media content is similarly denounced. In their separate analyses of *The Undateables*, a popular television series documenting the dating experiences of disabled people, Vertoont (2018) and Soorenian (2016) accuse the show as inciting disability voyeurism, aligning with a tragedy/charity model, and further setting disabled/non-disabled people apart.

Yet, there is a growing recognition that more optimistic and progressive cultural representations – though far from perfect – are emerging in TV/film and print media<sup>1</sup>. Oliver and Barnes (2012: 103) suggest that whilst disabled people have been historically represented as 'more than or less than human, rarely as ordinary people doing ordinary things', the turn of the twenty-first century 'has witnessed something of a sea change in cultural representations of people with impairments'. This has emerged following an acknowledgement that these dominant images violate the actual experience of being disabled, provide poor role models for disabled people, and do little to break down prejudice (Oliver and Barnes 2012). Increased visibility not only offers an outlet for creating communities and expressing defiance/resistance (Ellis 2015; Wilde 2018), but for erecting new

imaginaries of difference which, as a mode of alternative engagement, offer disabled people and their families recognition and respect (Ginsburg and Rapp 2015). This proliferation of positive cultural representations of disability arguably constitute a challenge to common stories 'depicting the disabled person as either deficient because of disability or heroic in motivations and attempts to overcome disability' (Green and Loseke 2020: 5).

The cultivation of new positive imaginaries is the starting point for my article. I carried out research with parents of children with Down's syndrome (DS)<sup>ii</sup> on how wider narratives of people with the condition chime with, complicate, and/or contradict their lived realities. I recognise the limitation of this approach; interviewing parents exclusively might silence people with DS and neglect the divergent views among parents and their children. Nonetheless, the perceptions and experiences of parents are important to unpack since they frequently encounter various barriers and cultural narratives about their children. Moreover, I was primarily interested in how media configurations intersected with their everyday lives – and research often shows us how parents, and particularly mothers, are gatekeepers of their disabled children's lives (Runswick-Cole and Ryan 2019).

Drawing upon interviews with parents of children with Down's syndrome (DS), I explore the cultural configuration of disability and sketch out how parents praise, and embrace, what they perceive to be more positive, visible, and rounded portrayals. Simultaneously, parents complicate this account by sharing their disquiet around tokenism, stereotypes, focusing upon 'exceptional' people with DS, and fuelling sanitised accounts which deny and obscure the tough lived realities for many parents of disabled children. I conclude by arguing that whilst parents largely applaud and welcome positive public narratives, they also fear that such representations threaten to gloss over the pervasive mistreatment, disregard, and disenfranchisement of disabled people and their families.

This article contributes to, and extends, the literature outlined above in two ways. First, scholars analysing the construction of categories and the role of culture in shaping understandings of disability, often based in North America (Davis 1995; Enns and Smit 2001; Snyder and Mitchell 2006; Garland-Thomson 1997), are frequently located within literary studies. For Shakespeare (2017), such contributions do not ground claims in the (qualitative) stories and experiences *of*

disabled people and their families. Whilst there is a burgeoning attention afforded to disability in the media (e.g. Ellis 2015; Ellcessor and Kirkpatrick 2017), much of this dissects the workings of single case studies and/or focuses on the *medium* rather than how disability is shaped *across* platforms. If we recognise the media as a potent site for representation, a powerful educator for cultural attitudes/values, and an important source of information about disability in the absence of lived experience (Haller 2010), it is vital to gather the views of people holding a stake in such configurations. Whilst a small selection of studies do this, this is minimal and under-baked. This article addresses this gap.

Second, disability is too often framed in such accounts as a universal category. This universal term unfairly and inappropriately creates rigid categories of existence that lump together different people and conceals the complexity of different, distinctive conditions (Davis 1995; Shakespeare 2017), as well as diverse ways of living and public reactions, in ways that might harm disabled people. There is a risk, for instance, of making assumptions about one's capacity; 'disabled people are believed to be disabled all the way down. If you have trouble seeing, you must have trouble hearing and thinking' (Siebers, in Levin and Siebers 2010). Adapting Ginsburg and Rapp's (2013) concept of 'disability worlds', I attend to *Down's syndrome worlds*, of how people with the condition are configured in public cultural representations<sup>iii</sup>.

I focus on Down's syndrome (DS) for two reasons. First, the complicated history of DS – including the institutionalisation, sterilisation, and euthanasia of people with the condition, alongside the growth of clinical genetics and prenatal screening/diagnostics which allows for the detection of DS – is a challenging backdrop to more affirmative recent representations that stress the value, worth, and humanity of living with DS. Second, DS remains on sociology's margins (as does disability more broadly). Recent research (not sociological) on DS largely focuses on quantitative and crude assessments of 'quality of life' for people with DS and their families, along with calculations of the merit of 'interventions' and psychological deficit evaluations of 'stress', 'coping', and 'adjustment' for parents. I suggest attending to DS as a category enacted in social and cultural worlds (rather than a more a pathological medical understanding) allows us to see how DS occupies a unique position that merits analysis in its own right.

## **Methods**

This article draws upon a study undertaken between July 2018 and May 2019. It involved three modes of data collection: 1) interviews with 22 parents of children with Down's syndrome (DS); 2) an ethnography of a large congress bringing together people with DS and their families; 3) analysis of newspaper articles. I draw exclusively upon interview data here. Interview participants were recruited via gatekeepers accessed through personal networks and charity organisations. The eligibility criteria were that participants were parents of a child with DS and lived within a two-hour drive. Social media sites and email distribution lists were used to distribute information sheets and consent forms, and potential participants telephoned/emailed me or contacted gatekeepers.

Participants were invited to take part in a face-to-face interview in a location of their choosing. On two occasions, interviews were carried out by phone due to their stated preference. Twenty of the participants were in a relationship (ten couples) and were interviewed as a couple (all requested this). Both parents interviewed individually (mothers) were married, but their partners were unable to participate. Parents were between the ages of 35-70 and children were aged 1-15 years old. 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 data would be kept confidential and safe, and I would make every attempt to ensure that anonymity is preserved (pseudonyms have been provided).

All data was analysed using 'situational analyses' (Clarke 2003). This is a renovation of grounded theory in which the researcher 'becomes not only analyst and bricoleur, but also a cartographer of sorts' (2003: 571). For Clarke, the relatively basic process of ground theory is not sophisticated enough to 'fully take into account the sea of discourses in which we are continually awash in the postmodern era' (2003: 559). We should, therefore, supplement ground theory approaches with 'situational maps and analyses' (2003: 553). She suggests situational analyses, influenced by the postmodern turn yet 'epistemologically/ontologically based in the pragmatist soil that has historically nurtured symbolic interactionism and grounded theory' (Clarke 2003: 555), draws attention to irregularities, fragmentations, positionalities, and instabilities in which to comprehend

complex worlds. For Clarke, this approach is valuable for multi-site research (i.e. when conducting observations, interviews, and document analysis). As such, I used Clarke's approach to analyse and compare fieldnotes, interview transcripts, and documents.

I began my analysis by reading data firstly on their own, and secondly alongside existing literature to allow for an inductive and processual approach. I did this until I was able to establish intricacies and relationships. From here, and during the project, I developed categories, interpretations, and inferences highlighting key areas of enquiry and where my focus could be directed. Saturating categories and grounding my theory, I fashioned findings into a coherent pattern and continued research until some chance occurrence cast light on a new way of analysing the data. I opted for analysing data by hand as computer technology allowed me to manage large volumes of data, but threatened to trade resolution for scope. I mostly analysed data by hand, creating 'situational maps' (Clarke 2003) that constituted some attempt to analytically tidy up the inherent mess of data collection. Ethical approval was granted by (Anonymised).

## **Findings**

### Down's syndrome in the media

Parents recognised that there is, broadly speaking, a more positive, rounded, and visible account of Down's syndrome (DS) in media content. In their view, imagery contributes toward dismantling offensive and crude historical stereotypes representing people with DS as 'of lesser value' (Thomas 2004: 21-22). For several parents, they initially encountered a negative image of DS when informed of their child's diagnosis, in leaflets distributed by healthcare professionals, and via online sources when seeking information on the condition. Parents talked about their efforts to undo hurtful stereotypes in public forums, for instance, by registering their child with modelling agencies, appearing on television programmes, and producing/sharing positive stories on social media and blogs. Whilst not all parents did this, they all discussed the role of TV/film and print media in changing 'perceptions' and creating 'awareness' (both terms were consistently used). For Eva, such productions 'promote diversity more than anything and the inclusion of every child'. Elizabeth claims:

I personally feel like the things that I see [in the media] about Down's syndrome are much more positive than they were twenty or thirty years ago.

For Fred, this imagery is helpful for individuals who have little-to-no knowledge of DS:

I think the media does improve [knowledge of DS]. If someone doesn't have Down's syndrome in their lives, I think it does improve their perception of it...It's just normal.

Parents felt a positive public imaginary of DS 'normalises' disability, a term consistently used by them yet which has been subjected to intense analysis and scrutiny in disability scholarship (Davis 1995; Garland-Thomson 1997). Television programmes/adverts were heralded as 'making [DS] more normal' (Amelia), reflecting how television is not 'simply representational in respect of prevailing social relations and systems of value, but is fundamentally constitutive of social life' (Tyler 2015: 505). Charlotte suggests:

You do see a lot more [people with DS] in the media and advertisements now. You also see more people who have a more physical disability, such as people using a wheelchair or with cerebral palsy. I was so happy to see [company] advert [featuring someone with DS]. It's amazing. All these disabilities need to be an everyday sight because then it normalises it and people don't go [gasps]...We're seeing it more and more because it's a part of life.

Charlotte offers several examples of what she perceives to be positive configurations of DS, and disability more broadly, in media outputs, and how this should be an 'everyday sight because then it normalises it'. Like other parents, Charlotte tells me that she 'takes pleasure' in seeing people with DS, as 'an extension of our community', in popular representations and how she celebrates their achievements. Valerie and Roger similarly discuss the portrayal of DS in the media:

**R:** It's really positive. I think there is a change with all disability. I think people are getting better at recognising disability and it becomes into more of the mainstream, so that's a positive thing.

**V:** We watch the Paralympics. It's things you can aspire to. It doesn't mean it's going to be the case for everyone, but to know that it can be done, I think just breaks that myth. It drives me mad when I see a young adult or adult [with DS] walking around town with dungarees on and someone holding their hand. Oh my gosh! Why are we doing this? The more we see on TV of people doing things independently, that's got to be better, hasn't it? It's got to break that myth that they've got to have someone always doing something for them...People will think "actually, I saw that thing on TV" or "I saw a bloke with Down's syndrome and he was working". I think that's got to be positive, because it normalises it.

#### The frictions of representation

Parents captured how configurations – part of a 'disability world' (Ginsburg and Rapp 2013) or, more accurately, a *Down's syndrome world* – constitute a symbol of tolerance and acceptance which conveys 'we are moving in that right direction...it's just showing [disability] is part of every community and its part of life' (Eva). Yet, parents simultaneously highlighted frictions, ambiguities, and critiques here. The following exchange in an interview with Charlotte and Henry shows this:

**H:** I'm very positive about the depictions of people with Down's syndrome in the media. Maybe that is because Laurie doesn't necessarily have overly complex needs...Around the time of Sally Phillips' documentary<sup>iv</sup>, there definitely were people who said it's not just all positive and rosy, and you need to show the other side of things.

**C:** Things like that you never see in the media. With adverts, the media is aspiration, isn't it? You're never going to see children's true colours, are you?

**H:** No, but I think also because the majority of people in the [DS] community are trying to put that positive spin on it...It's about lived, positive experiences to try and wash away those preconceived ideas that I definitely had before [son]...When you see child models, actors, when it's all over the media, I think it can only be a good thing.

**C:** We're getting more awareness through.

**H:** It's such a great thing when people are exposed to something entirely new and they didn't realise that they can see that those preconceptions are being destroyed or challenged.

**C:** But it balances out. With NIPT (non-invasive prenatal testing), you can imagine that has been in the media a lot. There are challenges that the Down's syndrome community faces about the negative press around [NIPT] that it's not a balanced experience. So, it can't be a bad thing if we're showing life with Down's syndrome in all its many varied ways, as being an overwhelmingly positive thing. Because it needs that balance...It is a wonderfully positive thing.

**H:** I could definitely see how people would be more challenged by it if they do have a child or young adult with more complex needs and what they're exposed to on TV is none of those complex needs. If you've got a child with a dual diagnosis, for example, it's not all fun and joy.

Charlotte and Henry acknowledge several complications of cultural representations of DS, namely how a positive imaginary of DS that *they* embrace cannot satisfy *all* parents of disabled children (especially those with more complicated lives), and how this exists in tension with problematic framings of disability in, for example, public discussions of prenatal testing (other parents raised this same apprehension about NIPT). In what follows, I sketch out the primary concerns of parents.

### 'Suffering'

Parents applauded what they perceived as more progressive imagery of DS in public outlets, yet they also felt some representations traded upon pitiful, and deficit-focused, understandings of disability. Several parents talked about how people with DS were often referred to in media outlets as 'a Down's syndrome person' (Roger), a frustrating classification as it fails to acknowledge that such individuals are unique and not defined by their impairment. Moreover, Eva expressed her disdain at newspaper articles referring to people with DS as 'sufferers' (*Eva's emphasis*):

The Daily Mail makes my blood boil. They don't just say suffering or sufferers for people with DS. They use it for a lot of conditions. But when that happens, everybody gets on

Twitter and shows pictures of their child *suffering*. We'll have [daughter] *suffering* eating an ice cream with it all over her face, jumping off a swing, and they'll get a strapline in there and hashtag the Daily Mail to educate their journalists to write with a little bit more consideration.

According to French and Swain (2004: 34), suffering/sufferer is 'perhaps the most widely used terminology in tragedy discourses to characterise the experience of disability'. Language, for Haller (2010), shapes the public's understanding of disability; media is central to this, yet their use of terms does not always reflect the language employed by disabled people and their families. If we take language seriously as a 'site of struggle' (2010: 60), we can recognise why the discourse of suffering perturbs, and often infuriates, parents.

#### 'Tokenism' and stereotypes

Parents similarly resented crude, flattened, and infantilising stereotypes of their children as 'happy' and 'loving'. Whilst recognising the positive intentions behind them, such caricatures were vexing and many parents, as part of their claim for *normality* (their term), identified how children were not always happy: 'people are like "oh, he's always such a happy, smiley child". If only you knew!' (Sophie); 'I'd love [the media] to show [a child with DS] having a tantrum to come away from the stereotype that they're loving' (Helen); 'If you see [son] when he's hungry or tired or both, he's not so loving then!' (Fred). Several parents also raised concerns that people with DS were used for commercial advantage. Highlighting a 'surge' in representations of disabled people in advertisements, Jamie feels this may amount only to 'tick boxing, jumping on the bandwagon to say "we're on board with this, we're politically correct"':

I think it's exploitation. It can still have a positive result for the [DS] community, but I think it's a 50-50 split, maybe biased even more, "this is for our good" versus the good of [people with DS]. With big media, you often hear these squirrel water-skiing anchor stories at the end, the novelty story. It almost feels like big media throwing these in as the politically correct message "we're on the right track doing the right thing", "girl with Down's syndrome who's knocking the New York catwalks dead". And they move on. It's gone the minute it

switches off. So, I think overall, [media coverage] probably helps in a way, but maybe not for the right reasons.

Likewise, Sophie doubts that ‘the meaning behind [media coverage] is to support, it’s more like, “we look good”’. For Paul, this presumption of inclusion is potentially tokenistic, and media coverage has not ‘helped in terms of what goes on in the background’ (I return to this sentiment later). Some parents, like Helen and Fred, also identify how there is not *enough* representation and how they want people with DS to be recognised not solely by their disability, but through other personal attributes:

**F:** It’s finally getting better. But when we saw someone with Down’s syndrome on Coronation Street (British soap opera), it was like, wow, now suddenly there’s loads of shows with one. And there’s an advert with one. And it’s like, can we have an advert when there’s just people with Down’s syndrome? Do you know what I mean? Not, not the token one.

**H:** Anything positive is great. But I just think we shouldn’t have to highlight, “oh look, there’s a person with Down’s syndrome on Coronation Street”. It should be “there’s an actor” and that’s it. Why do we have to label him as the actor with Down’s syndrome? I can see they’re trying to show diversity. But like [Fred] said, why not have two or three?

For many of the parents, people with DS ‘seldom appear in media texts as multidimensional, active citizens with their own experiences and life stories’, but are included *because of* their [visible] disability (Vertoont 2018: 828). They convey apprehension about over-determining the disability category whilst neglecting other identity markers<sup>v</sup>, thereby not representing people with DS as ordinary subjects with an impairment (Vertoont 2018). Garland-Thomson (1997: 10) reminds us:

‘The very act of representing corporeal otherness places [disabled people] in a frame that highlights their differences from ostensibly normate readers. Although such representations refer to actual social relations, they do not of course reproduce those

relations with mimetic fullness. Characters are thus necessarily rendered by a few determining strokes that create an illusion of reality far short of the intricate, undifferentiated, and uninterpreted context in which real people exist'.

Several parents were concerned that disability, when becoming central to plots/storylines, were built upon stereotypes of dependency, vulnerability, and helplessness. For Shakespeare (1999: 165), using disability as character trait, plot device, or atmosphere 'is a lazy short-cut', critiquing the inaccuracies and unfairness of this configuration that woefully misrepresents disabled people, reinforces harmful attitudes, and ratifies 'crude, one-dimensional and simplistic' images. Jenny discusses several television programmes following a 'negative' plotline, condemning one show whereby someone with DS was reported as a missing person:

You just think, why have you missed that opportunity yet again? Why have we made such a stereotypical yesteryear assumption about DS? There are blatant missed opportunities in the media and then other things that are just quietly happening, like *Call the Midwife*. That's been good and lovely because they've got a character and he's just part of the furniture...I like it when they're just there...It would just be nice if that family walking past in the background, if their child was in a wheelchair or that child had Down's syndrome.

Jenny and others wanted their child's *differentness* to fade into the background rather than being a plot device or character trait. This is part of what Jenny calls 'mundane stuff', whereby she offers examples of actors/actresses as shop workers and school crossing patrol officers 'in the background'. For Jenny, simply being part of 'boring, everyday' life 'educates' audiences about disability. Paul calls this 'normalising rather than sensationalising disability...it's making it the norm'. Indeed, when DS becomes the main 'story', Linda worries her son will be too 'noticeable'; 'I want [son] to blend in'. This idea of more 'mundane' portrayals relates to another concern among parents: the media's focus mostly on 'exceptional' people with DS.

### 'Exceptional' people

There is a longstanding critique of Paralympic representations only investing value in physicality, promoting the ideal of willpower, and discounting complex embodiment (Grue 2016; Purdue and Howe 2012). Similarly, whilst some parents felt that athletes and 'high-achieving' people with DS can be perceived as role models and an indication of what is possible, others highlighted how not all children with DS are in a position to match such lofty expectations. This is not an issue for Valerie and Roger; not everyone will be able to accomplish similar achievements, but 'aspirational' figures are vital for dispelling myths that 'having a child [with DS] means you are destined for a life of basic haircuts, dungarees, and holding hands when you're 35' (Roger). Yet, for others, these representations were homogenous (i.e. not reflecting diversity) and focused upon 'exceptional', or what some referred to as 'high-functioning', people with DS. Jenny refers to this imagery as 'artificial':

I don't think [son] and [others] will ever get the airtime they deserve because the media love the artificial versions of what's going on...That seriously gets under my skin and it's probably because of the amount of time we've put trying to get everyone to see how we can just be run-of-the-mill. That's important because that's what all our other children [without DS] are...But people [with DS] out there in the media...there's a bit of a falseness about the whole thing...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 to him. That's how it should be...It's that thing of people forgetting, just like when you have your typically developing child, there's a spectrum of ability.

Bella similarly claims it is 'amazing' to witness success stories of other people with DS – citing Madeleine Stuart (model), Tim Harris (restaurant owner), and John Lee Cronin (business owner) – but she recognises that 'this is not the majority, where others can't do these things and who have health issues'. Parents note that the broadening and deepening of positive imagery may 'shift cultural taboos that have limited people with disabilities', but their children and others with

DS 'merit and require more complex representations of their lives' (Malinowska 2017: 375). Sarah and David reflect upon this *spectrum of ability*:

**S:** You've got people like Sarah Gordy in *Downton Abbey* and Daniel Laurie in *Call the Midwife*. It's lovely to see, but I don't think you get the real picture of someone with Down's syndrome from those snippets.

**D:** The people you mentioned, I acknowledge it, but then I completely dismiss it as that's nothing like...

**S:** ...the life we live. Because what you see is a cameo.

**D:** [People with DS] don't fit boxes. They're all completely individual like every child is individual. My sense of it, when people speak to us about [son], is that if they've tapped into anything from the media, it's only surface-level...They don't have any understanding of what's going on or what it's like with some of the challenges you face. You'd have no idea of that, you don't see that at all. When people say something, they're speaking with stereotypes.

The 'challenges' of parenting a disabled child, for Sarah and David, are glossed over within positive, yet 'accessible' or 'non-challenging' (Charlotte), representations. For Malinowska (2017: 368), when positive images of disabled people circulate in popular culture, they are expected to demonstrate ability and meet naïve expectations of 'surmounting bodily disadvantages, limiting social structures and cultural oppression', a position disability activists have refuted. Likewise, Sarah and David, and others, claim some parents feel 'under-represented' (Valerie), especially as their child grows up. Valerie says:

When you've got the mums that I meet who are pregnant or who've got new babies, for them to see positive images on TV, and that level of acceptance, is really positive and helpful for them. But when I speak to mums of older children, particularly those that ended up with a dual diagnosis, more complex needs, it can be quite challenging. To look at those images, and it's all lovely and positive, and all children with Down's syndrome are fabulous, and they're all swimming in the world championships, and they're all actors...for

some families, they're very under-represented, aren't they? They think "this doesn't apply to me, my kid may look a bit like yours, but actually they're very different". And I think sometimes for those families, it can be quite difficult...Because people's perception almost becomes that having Down's syndrome means that you can be a great actor, and that's fabulous, but actually it's not universal is it?

### 'Fights' and 'battles'

Related to concerns of under-representation, whilst some parents felt that 'what we see in the media is representative of our experience' (Henry), others said it did not reflect their lived realities – they provide a best-case scenario. Linda explains:

Sometimes you have to show that it's all well and good looking cute on This Morning (British television programme), but I don't think we're getting to the crux of the argument...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 [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?...[Son] doesn't drive you nuts. It's those things around it that drive you nuts...I worry about [media] images because there's so much wrong with the system per se that you need to be altering...The [media] images aren't doing anything for me.

Throughout the interviews, parents acknowledged the presence of more positive and visible configurations of their children, whilst simultaneously sketching out how parenting a disabled child involves a series of individual (physical/health issues) and structural (healthcare, education, welfare) impediments. They often referred to the latter as 'fights' and 'battles', expressing irritation about bureaucratic obstacles and poor access to resources amplified in the era of austerity. Parents, but more frequently mothers, must 'fight for scarce resources in fragmented systems that often do not seem to value their children as people' (Green et al. 2017: 267-268). Dealing with institutions and providers – which may lead, in turn, to positive media images of DS to be possible (i.e. allowing children to thrive) – was viewed by Linda as having a classed dimension. Privileged

parents remain the most empowered to advocate for children by both demanding services and challenging professional authority. Not all parents of children with DS will be able to do this (Anon), yet their struggles and frustrations were rarely highlighted in media accounts. There was a concern among some parents that over-determining the 'positives' of DS in popular accounts might not only silence parents facing difficult circumstance and discount (classed) differences in relation to access to resources, but that services might be withdrawn if perceived to be thriving ('it wouldn't help your fight necessarily' – Roger<sup>vi</sup>). In short, parents explained how their lived realities contradict, and work against, what is ostensibly designed to be a more positive public imaginary enacted in powerful cultural outlets<sup>vii</sup>. I conclude the article by reflecting upon these frictions.

## **Discussion**

I have shown how 'positive' media coverage of Down's syndrome (DS), attempting to erect what Ginsburg and Rapp (2015) call an 'existential repositioning', is not always embraced by parents. Parents do praise a more recurrent and progressive imagery of DS which departs from historical conceptions of pity, charity, and vulnerability. Yet whilst such imagery is mostly applauded and viewed as well-intentioned, frictions and ambiguities emerge. Parents simultaneously express concerns of tokenism, stereotypes, only endorsing exceptional people, and discounting the lived realities for, and structural violence enacted against, many disabled people and their families. It is this point – that the positive and visible popular narrative of DS is complicated by a socio-political context in which disabled people experience hostility, exclusion, and indifference – that I conclude my article with.

Grue (2016: 840) argues that whilst the argument has been made that 'a positive depiction of people with impairment is a good thing in itself', some 'ostensibly positive portrayals of marginalised and oppressed groups and individuals contribute to marginalisation and oppression'. Oliver and Barnes (2012: 103) claim that the best to be said is that 'dominant images are being challenged, but they are far from being replaced by more authentic ones'. Indeed, Oliver and Barnes decry a mainstreaming of more media-friendly aspects of impairment – as highlight reels – and tell us little about the reality of living with impairment in a disabling society. This reinforces negative imagery by presenting 'the acceptable face of impairment rather than the reality of

disablement' and, in so doing, 'undermine[s] and obscure[s] the ongoing struggle for meaningful change' (2012: 102). As Haller (2010: 52) says:

'Therein lays the tensions between the internal pride, identity, and culture of the disability rights movement and the misinterpretation by the wider society, represented by the media, that active people with disability are "inspirational" or are "superior" in the face of "tragedy". The disability rights movement is trying to move forward a serious political agenda, but the media focus on blind people who go bowling or a teen with a severe facial disfigurement who copes with life regularly'.

Similarly, Darke (2004) critiques ostensibly positive depictions in the media which remain, for him, clichéd and stereotypical. Referring to these outputs as 'impairment imagery' rather than 'disability imagery', he argues that disability is only acknowledged as 'impairment almost devoid of political significance or social construction' (2004: 100). This 'significant de-politicisation of disability' favours a fragmented, impairment-orientated output that is 'fundamentally voyeuristic and exploitative' (2004: 100). It also conforms to an aesthetic of normalcy – that there is 'an essentially correct way to have been born, look like and be' – that depicts disabled people as 'abject' and 'bordering on inhumanity' (2004: 103). For Darke, this also generates a one-dimensional view of disability which is 'rooted in normalised idea(l)s of white middle-classness', thus overlooking other intersections (e.g. gender, race, age) and making it clear to disabled people that they 'must be like this or that (that is, normalised and educated)' to be accepted and valued (2004: 102).

In relation to this study, parents seemed concerned that positive imagery threatens to fuel a sanitised and cosmetic, rather than fully educative, image that discounts the role of socio-political structures in keeping disabled people, and families, *in their place*. There is a chance that they are further oppressed through positive imagery since it 'promotes a falsely progressive image of both media policies and disability itself' (Malinowska 2017: 366), that is, it glosses over a socio-political context treating disability as an unvalued bodily state. Such representation is cultivated, strangely, under a backdrop of austerity and indifference towards the lives of people with learning disabilities (including Down's syndrome [DS]). This is exemplified, for example, with respect to poor health

outcomes compared to non-disabled peers, limited employment prospects, rising disability hate crimes, dwindling support (e.g. education needs; welfare purse-tightening), abuse in NHS units, and DS/learning disability being cited as a reason for do-not-resuscitate orders (for a summary, see: Anon; Scambler 2018)<sup>viii</sup>. In describing their own *fights and battles*, parents in this study flag up the structural shortcomings of an ableist world. Disabled people's ability to live and thrive depends on the level of public investment, and whilst the disability rights movement has made considerable progress, there is much ground to cover until full disability equality is realised in the UK (Shakespeare 2017).

This is not to say that we need *better or more accurate* media representations of disabled people to confront hostile conditions for people with DS (and other disabled people). People with DS may be narrated by certain cultural narratives, and the complexity and mundanity of their lives would be best captured through more 'longitudinal', rather than 'snapshot', media depictions. We can assume, though, that the media reflects some feature of social reality (Haller 2010), media images are so pervasive that they have hold the potential to become 'mainstream society's perception of disabled people' (Norden 1994: 3) in the absence of lived experience (Barnes 1992), and creative industries hold the potential for advocacy and resistance (Shakespeare 2017). If we accept this, we must perceive media outlets as worthy of analysis, particularly as they 'ignite conversations, uncomfortable questions, and important debates that urge a reflective consideration of how we, as a society, value human lives' (Burch 2017: 1085).

Nonetheless, the media is not the only – or even the most effective – means of challenging unjust circumstances. Whilst parents accounts show us that the media is worthy of analysis, it would be a mistake to simply advocate that more authentic (i.e. less artificial) portrayals would help. A start would be media coverage which recognises, as Darke (2004) and others suggest, disability not simply as impairment, but as a distinct political category. With respect to the (impairment-focused) media configuration of DS, there is a danger of cultivating an 'optics' of tolerance and acceptance that hide attitudinal, architectural, and structural inequalities (Hamraie 2017: 3). Media content alone, in the absence of concrete actions, will not ameliorate disadvantages and inequities held in place by structural forces. Positive public images that 'see the glass half full, when it lies

shattered on the floor', means that the challenges encountered by parents may be perceived not as the product of structural relations, but as 'interior and easily overcome through an effort of the will' (Ehrenreich 2009: 45, 51). Under neoliberal conditions, they may be perceived as the ones to blame should they fail to match the lofty expectations espoused in media representations. It is clear that whilst such configurations should move towards a more political (not deficit/impairment) understanding of disability, this will only go so far. Challenging unjust and ableist conditions is vital and, as parents convey, merely cultivating a positive media image is not enough; indeed, what good is a positive imaginary supposedly symbolic of value and worth, if society continues to create and foster disabling conditions?

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## Notes

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<sup>i</sup> There are exceptions to this, including the representation of welfare claimants whereby disabled people are described as ‘scroungers’, ‘workshy’, ‘cheats’, and ‘undeserving’ (Briant et al. 2013).

<sup>ii</sup> Focusing only upon Down’s syndrome means I cannot address broader issues around disability (as an extensive category) and media representations. Nonetheless, as I convey throughout the article with reference to literature, comparisons are observable and many claims are translatable.

<sup>iii</sup> This is not always without controversy. In the Irish abortion referendum in 2018, the anti-abortion lobby used pictures of children with DS in advertising campaigns to deter women from terminating a pregnancy.

<sup>iv</sup> Henry is referring to ‘A World Without Down Syndrome’, a UK-documentary fronted by Sally Phillips, an actress and mother to Olly (who has Down’s syndrome), about the ethics of prenatal screening.

<sup>v</sup> Thanks to Laura Mauldin for this observation.

<sup>vi</sup> Roger appears to share Barnes’ (1992: 19) view: ‘logic dictates that if disabled people are perceived as “normal”, then there is little need for policies to bring about a society free from disablism’.

<sup>vii</sup> I recognise a similarity with Tyler’s (2013: 210) discussion of the Paralympics 2012, where the ‘joyfulness of the ceremonies and the melodramatic spectacle of the sport’ co-exists with an escalation of government programmes deepening austerity measures that subsequently alienate and punish disabled people.

<sup>viii</sup> We can also think about the COVID-19 pandemic and its impact on disabled people, including: public discourse around ‘underlying health conditions’ and ‘herd immunity’; the Coronavirus Bill (e.g. removal of social care); higher death rates and a lack of information on deaths of people with learning disabilities and; using the Clinical Frailty Scale (which *devalues* dependence) to determine admission to critical care and/or ventilator access (see: Liddiard 2020; McLaughlin 2020).