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## Current Issues

*A World Without Down's Syndrome?* Online Resistance on Twitter: #worldwithoutdowns and #justaboutcoping

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\*This is a final draft of the manuscript accepted for publication in *Disability & Society*. Please refer to the original document for any citations\*

### Abstract

Presented by actress and comedian Sally Phillips, *A World Without Down's Syndrome* has brought important ethical debates regarding prenatal screening into the public domain. By talking to people labelled with Down's Syndrome, family members, activists and professionals, Sally has presented a nuanced and thorough examination of the type of world we are living in, and who we want to live in it. Following the documentary, Twitter users have continued the debates that Sally introduced and in turn, created a resilient platform for challenging public attitudes. In an attempt to explore the ways in which Twitter hashtags have provided a space for such important, and long overdue conversations, I would like to consider some of the tweets that followed the documentary more closely. While it would not be possible to provide a full overview of the topical conversations that the two hashtags have provoked, I aim to focus on some of the most prominent topics. The following then, will explore the potential of alternative narratives that resist, and disrupt, normative notions of the human using the hashtags #worldwithoutdowns and #justaboutcoping.

### Key words

Online resistance, Twitter, Down's Syndrome, Prenatal Screening, dishuman

On Wednesday 5th October 2016, Sally Phillips' *A World Without Down's Syndrome?* (BBC Two, 2016) was brought to our television screens. In just one hour, Sally Phillips has ignited long overdue conversations, uncomfortable questions, and important debates that urge a reflective consideration of how we, as a society, value human lives. Talking to people labelled with Down's Syndrome, family members and also medical professionals, Sally has touched upon many important and previously silenced issues:

- Society generally brings us to believe a narrative of Down's Syndrome that is tragic and disastrous.
- There are increasing societal pressures on new parents to abort unborn babies with Down's Syndrome.
- Society has accepted termination with little public debate regarding the ethical issues of prenatal screening.
- The voice and experience of individuals living with Down's Syndrome is excluded from debate.
- Will the new, more accurate prenatal screening test affect who we want to live in this world?

Conversations regarding these issues have since continued, facilitated by a burgeoning stream of activists, academics, family members, and friends alike. Most notably, *A World Without Down's Syndrome?* has fuelled an online dialogue, presented, amongst others, on the online interface of Twitter. Two Twitter hashtags, #worldwithoutdowns and #justaboutcoping in particular, have been inspired by the affirmative and resilient nature of this documentary. These tweets demonstrate an insurmountable sense of disruption, provocatively dismantling traditional narratives of Down's Syndrome. Enthused by the important questions that Sally Phillips has raised, these hashtags have affirmed alternative understandings of Down's Syndrome that disrupt normative assumptions of the human, and call for a long hard consideration of the type of world that we want to live in. At its very core, the message is loud and clear; we do not want a #worldwithoutdowns.

Many users thanked Sally Phillips for bringing such important issues into the public domain, when such issues had, for so long, been hidden by a medical guise of individual deficit. Just some examples being: 'Thank you for making a brilliant documentary. You raised poignant issues which are rarely discussed', 'Thank you ... for courageously & poignantly asking what kind of society we are building if it were to be a #worldwithoutdowns', and 'I laughed, cried, raged and cheered at the screen. Thank you ... for challenging us to consider the cost of a #worldwithoutdowns'. For one individual, *A World Without Down's Syndrome?* and the subsequent tweeting had left a lasting impression, claiming that 'if there was a prize for impact, awareness raising and challenging attitudes, #JustAboutCoping would be the runaway winner'. These tweets demonstrate the true impact of this documentary in the real world, a particularly important feature for work within disability studies where the intention to improve the lives of disabled people is fundamental. The online reaction on Twitter is proof of Sally Phillips' ability to do all of this by inviting the public to engage in critical and reflective thought that challenges misconceptions of humanity as well as providing a platform for the voices of disabled people to emerge upon.

In the documentary, Sally engages with professionals, parents, and individuals labelled with Down's Syndrome in order to consider the ethics of current prenatal testing. Notably, Sally meets with Finnish activist Halldóra Jónsdóttir who has protested the cultural questioning of her right to life in a context that has witnessed 100% of families in the last five years choosing to terminate unborn babies with Down's Syndrome. This is credited by one user, who notes that the documentary 'asked so many questions about what the future of antenatal screening may hold'. Within a system of ingrained ableism and disablism, these questions are not often left to dwell over. In a time where medical advancement is bound to an ableist criterion of the mind and body, prenatal screening is a topic of both necessary consideration and uncomfortable viewing. Indeed, this focus in *A World Without Down's Syndrome?* prompted some pro-choice feminists to protest against the supposed rejection of a woman's right to choose. This is, however, a misinformed critique, as the documentary appeals to a much more nuanced prenatal response to Down's Syndrome. Indeed, it is not a question of the right to choose, rather, the need for holistic, balanced advice that is detached from ableist ambitions of normalization. I emphasise here that I am not overlooking or discounting the right to choose. What I do challenge is the single offering of an uninspiring, and fundamentally ableist 'choice' to abort disabled foetuses.

Following *A World Without Down's Syndrome?* the recent petition Ensure NIPT users can access unbiased, balanced advice post prenatal screening (Petitions, 2016) similarly calls for 'choice' and has been extensively shared online using the hashtag #worldwithoutdowns. This

campaign calls for actual choice, not the ableist manipulation this often gets confused with. As explained by Twitter users, 'Choice isn't really choice if it is delivered in a way that's negative, biased and designed to maximise fear' and 'we are totally conditioned to fear disability. So sad & destructive. Keep educating people'. The point of this petition, and argument that I believe Sally is making, resonates with the very question that we are explicitly asked in the opening narrative of the documentary: 'What kind of society do we want to live in? And who do we think should be allowed to live in it?' (BBC Two, 2016). These questions are provocatively revealing, they dismantle the disabling assumptions and values that many unconsciously hold. Our encounters with these questions are critical, they incite uncomfortable moments of self-reflection and force us to meet with our inner ableism. *A World Without Down's Syndrome?* calls for us to confront this encounter rather than continue to avoid it.

In the documentary, Sally destabilizes the traditional narratives and assumptions by engaging with individuals who have Down's Syndrome and are achieving. For example, she talks to Coronation Street Actor Liam Bairstow who has overcome many of the television industry's barriers to inclusion. In addition, she draws upon her own experience as a mother as being like a comedy, and not the tragedy that she was told it would be. Similarly present upon the resistant aftermath of *A World Without Down's Syndrome?* friends, family members, and individuals have used the just about coping hashtag to share alternative realities that challenge the common codification of Down's Syndrome according to medical classification. As one user notes "The #justaboutcoping hashtag is wonderfully life affirming, served with a side of on-point sarcasm". Indeed, sarcasm is at the forefront of this particular movement, as users share photographic evidence that demonstrate moments of joy, laughter, friendship, and achievement, alongside intentionally provocative comments that state '#JustAboutCoping for 19 long, horrendous years. How could I live with such a bore?' and 'This suffering is just bang out of order. I can't bear it any longer. Make it stop'. Others have used the hashtag to share the wonderful experiences of Down's Syndrome in an equally affirmative attempt to counter traditional assumptions of devastation. Again accompanied by photographs, users write that they are just about coping with 'their pride and sense of achievement', 'an outdoor assault course', and 'to live life to the max'. The disruptive potential of these statements must not be underestimated. They cleverly destabilise traditionally medicalised narratives, positing the suggestion that, as one user puts it, 'medical theory doesn't always translate to real life accuracy'. This tweet captures an encounter in the documentary, where Sally talks to a mother of a child with Down's Syndrome, who has refused screening for her current pregnancy because she values her own experience more than the biased, negative trajectory delivered by her doctors. Thus, by using real-life experience, the use of #justaboutcoping and #worldwithoutdowns continue the work of the documentary in turning so-called truths inside out, and reveal their fabricated existence within an ableist imagination. For Goodley & Runswick-Cole (2016, p. 4) such confrontation is imperative for 'disability [to] emerge not just as the Other side of the oppression coin but also as a resistant alternative'.

*A World Without Down's Syndrome?* and the subsequent Twitter following has confronted traditional deficit-focused narratives, and brought misguided, ableist assumptions into critical conversations. Within this dialogue, we witness an increasing expression of the values embedded within the social model of disability. While reference is not specifically made to this, with exception of a small number of tweets, the focus upon an unaccepting, and inaccessible world clearly brings these ideas into play. Claims that 'My daughter has Downs Syndrome I'd not change her for the world but I would change the world for my daughter' and 'Don't let the world we live in change you, change the world we live in' are telling of rising resistance to disablism. What is more, Sally Phillips' claim in the documentary that 'If we have

a society that is unable to care for people, then the problem is not the person' has been retweeted several times. The location of 'problem' within society is fundamental to dismantling traditional assumptions that support the abortion of disabled fetuses. Explicated by the hashtags #worldwithoutdowns and #justaboutcoping, then, it seems that Twitter users do have a definitive answer to the questions posed by Sally in the opening of the documentary. Indeed, users suggest that a world without Down's Syndrome 'would be a disaster' and 'an awful place'. The prospect of such is unimaginable, as one user notes, 'What a terrible world that would be'.

The aim to confront ableist narratives of disability is at the heart of *A World Without Down's Syndrome?* and its success to do so can be measured by the support received on Twitter. Together, a resistive force is created that carries particular relevance to recent work within the area of critical disability studies. The theory of the dishuman forwarded by Dan Goodley and Katherine Runswick-Cole (2016) contends to the potential of disability to disrupt notions of the human, by inviting exciting ways of reconsidering our understanding of humanness. Like Sally Phillips' *A World Without Down's Syndrome?* 'Dis/ability studies ask us to consider how we value the human and what kinds of society are worth fighting for' (Goodley & Runswick-Cole, 2016, p. 3). Asserted by one user of Twitter, 'I dare any of you, or any expert, to adequately define "normal". Beauty is in diversity, we are all individuals'. From this perspective, any thinking of the human requires thinking about diversity. Similarly put forward by Sally in the documentary, 'Imperfections are where humanity is most visible', therefore, 'If we deny someone the chance to be born because we've decided they won't meet a predetermined measure of status or achievement, then we fail to grasp what it is to be human' (BBC Two, 2016). *A World Without Down's Syndrome?* then, indicates the need to move towards 'a time when thinking about the human will always involve thinking about disability' (Goodley & Runswick-Cole, 2016, p. 13). It is this nuanced, unconfined, and flexible notion of the human that we need to embrace in disability studies.

As I reflect on *A World Without Down's Syndrome?* there is one particular tweet that beautifully captures my thoughts. It is: 'Thank you #worldwithoutdowns for restoring some faith in humanity. Twitter was set alight with positivity and real humanity tonight'. Indeed, it seems only right to end this piece with a thanks to Sally Phillips herself, for her thoughtful and authentic documentary that has dismantled discourse, evoked conversation, and challenged disabling attitudes. The critical potential of disability is brought to life in *A World Without Down's Syndrome?* showing the human body as a substance more than numerical measurement. Indeed, this documentary reminds us of the possibility of disability to transcend the boundaries of humanity, self and the Other (Runswick-Cole, 2016). By doing so, the human as a fleshy, uniquely wonderful anatomic being can be valued for its beautiful fluidity and individuality.

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