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# Un/Inhabitable Worlds: The Curious Case of Down's Syndrome

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In her superb exposition of staring, Garland-Thomson (2009) draws attention to Chris Rush's artistic piece *Swim 2* (<http://www.chrisrushartist.com/html/portraits.html>) which depicts a woman with Down's syndrome in a regal pose (figure 1).



<http://somatosphere.net/assets/image1-173.jpg>

Figure 1: 'Swim 2' by Chris Rush. All rights reserved.

She continues:

The portrait invites us to stare, engrossed perhaps less with the “strangeness” of this woman’s disability and more with the strangeness of witnessing such dignity in a face that marks a life we have learned to imagine as unliveable and unworthy, as the kind of person we routinely detect in advance through medical technology and eliminate from our human community (2009: 83).

Garland-Thomson appears to mark two separate ‘orientations’ (Friedner 2015): one in which Down’s syndrome is afforded a positive social imaginary marked by dignity and worth, and another in which this condition is categorised as an existence without value. Likewise, I see two different and competing ways of enacting Down’s syndrome, that is, as both a negative pregnancy outcome (via prenatal technology) and as joyous and enlightening, and not the misfortune one may initially imagine on receipt of a diagnosis (via parental accounts). I explore these contentions below.

### **Prenatal Technology: A Troubled Relationship**

Down’s syndrome is one of the most common genetic conditions in the world, affecting approximately one to two of every 1,000 live births in England and Wales alone (based on NHS statistics). People with Down’s syndrome are likely to have several symptoms such as learning difficulties, shortened limbs, reduced muscle tone, restricted growth, and a flat facial profile. However, it is by no means a simple or straightforward diagnostic category. Down’s syndrome is often identified in medical discourse as ‘compatible with life’ which translates to people being likely to survive childbirth, although symptoms and prognosis vary considerably in each case. Indeed, its main attribute is the irregularity of its manifestation. Nonetheless, owing to medical advances and an increased knowledge of treatment and care, people with Down’s syndrome can live beyond sixty years.

Down's syndrome holds a central position in the politics of reproduction within the UK national healthcare system (among others). In my ethnographic study of prenatal screening, I explore how Down's syndrome is constructed in everyday encounters in the clinic and how both professionals and patients make sense and meaning in their worlds.

In my research, I found, among other things, that a discussion of Down's syndrome is avoided in prenatal screening consultations. This relative silence is upheld owing to three things: i) the UK public, as a collective group, is construed as knowing what Down's syndrome is; ii) the everyday organisation of care dictates that a full, or even short, discussion of the condition is difficult and unviable in time-restricted encounters, and; iii) professionals commonly admit to having minimal knowledge of Down's syndrome, thus highlighting certain healthcare training needs. This absence is supplemented by negative discourses embedded throughout prenatal care categorising the condition as a 'risk' or 'problem'. This plays a crucial role in (re)producing its status as a negative pregnancy outcome. To illustrate this point further, I provide an extract from a consultation that I observed between a midwife and a patient/expectant mother:

Midwife: So the test has changed slightly since your last pregnancy.

Patient: OK.

Midwife: We check four hormones in the blood now so we use the quadruple test rather than the triple test which you had before. It has a 70% detection rate and, as you know, it tells you whether you're a high-risk or low-risk. If you're low-risk, we do nothing else but that doesn't mean the baby has no chance of having Down's syndrome.

Patient: Yes.

Midwife: If you're high-risk, we call you within five working days of the result and we offer you an appointment to discuss your options within twenty-four hours. We offer an amnio[centesis] which tests the fluid around the baby and can say for sure whether your baby has Down's syndrome or any other problems. But it does have a miscarriage rate of 1%. So would you like to have the initial testing?

Patient: Yes.

Midwife: OK. [...] The cut-off is 150 or 151. If it's anything less than that, it's a low-risk so 1 in 151 and lower than that and we will let you know what your risk factor is. And so a high-risk would be something like 1 in 145. [...] So if you consider that you come back as high-risk, you might consider having an amnio[centesis].

Patient: OK.

[Midwife walks with patient to another room for the quadruple screen].

This consultation raises several concerns: the one-way traffic of the interaction; the possible undermining of the dominant healthcare principle of non-directiveness ('*So if you consider that you come back as high-risk, you might consider having an amnio[centesis]*'); the classification of the patient *herself* as high-risk or low-risk, and; unclear language (the terms 'screen' and 'test' being used interchangeably despite their different meanings, '*The cut-off is 150 or 151. If it's anything less than that, it's a low-risk so 1 in 151 and lower than that and we will let you know what your risk factor is*', etc.). What is more, the midwife says that an amniocentesis can detect '*Down's syndrome and any*

*other problems*'. This, in conjunction with the prominence of the risk discourse (a risk, in turn, is to be avoided and implies danger) and the relative absence of Down's syndrome (that is, a meaningful discussion of the condition) in consultations, frames it as a harmful and damaging pregnancy outcome.<sup>[i] (#\_edn1)</sup> What I argue throughout much of my work is that while Down's syndrome is a complex and often inconsistent condition (i.e. in relation to prognosis and symptoms), this intricacy and diversity is masked by the universal constitution of it – at least within the medical realm – as a risk, a problem, as *abnormal*.

Although the consultation cited above is only one example, it is indicative of trends observed throughout my ethnography (as I have demonstrated in complimentary publications). Here, I show how the everyday and banal social practices of the clinic constitute certain (future) bodies as valued or unvalued; certain ways of *being* in the world are threatened, denied, or enacted as damaging and unwanted. In short, I identify how in the clinic, Down's syndrome is imbued with negativity; it holds a metonymical status for the abnormal, that is, as something which *should* be detected and, if a diagnosis is established, something which constitutes a reason for termination of a pregnancy.

This categorisation is vital to prenatal screening – as a process – being continued. In order for screening to endure in its current form, Down's syndrome must be treated as abnormal and as an inherently negative outcome.<sup>[ii] (#\_edn2)</sup> One may argue, then, that parents may not necessarily be given an opportunity to take on the role of 'moral pioneers' as Rapp (2000: 3) describes in her seminal ethnography on amniocentesis. That is, the notion of 'choice' becomes problematic, if not redundant, once Down's syndrome is constructed in such a manner. This perhaps contradicts much recent literature on choice, neoliberalism, and liberal eugenics in the clinic. This negative constitution of Down's syndrome possibly explains – or is at least one component of – the termination statistics for the condition in England

and Wales. In 2012, of 1,259 prenatal diagnoses of Down's syndrome, 90% ( $n=983$ ) were terminated, 7% ( $n=76$ ) were live births, and 3% ( $n=34$ ) were natural miscarriages or stillbirths (the outcome of 166 prenatal diagnoses is unknown). From the first report in 1989 until 2012, the annual rates for termination following a prenatal diagnosis of Down's syndrome have ranged from 88% to 94%. [\[iii\]](#) ([#\\_edn3](#))

### **A 'Down's Syndrome Public'**

The negative configuring of Down's syndrome in the medical realm exists in tension with the optimistic imaginary reflected in empirical studies (Flaherty and Glidden 2000; Skotko 2005; Van Roper and Choi 2011) and autobiographies of parents with a child who has Down's syndrome. Focusing on the latter, both mothers (Clark 2008; Groneberg 2008; Lewis 2008; Soper 2009) and fathers (Austin 2014; Bérubé 1996; Daugherty 2015) have recounted their positive experiences of parenting a child with Down's syndrome, recognising their situation as one which should not always be viewed as unwanted, pitiful, or tragic. Parents, indeed, often detail the joy of raising such a child, albeit while recognising the initial difficulties encountered when coming to terms with this reality and the significant challenges (e.g. medical, social, familial, educational, vocational, political, and economic) they have faced/will face on this journey.

I have encountered similar interpretations both in my personal life (I grew up with Brittany, an ex-neighbour and family friend around my age who has Down's syndrome) and my research on parents' experiences of the diagnosis and living with a child who has Down's syndrome. In an earlier project, I capture how parents – both mothers and fathers – report limited evidence of stigmatisation, on account of their child, in everyday public interactions. Explanations for this include the medical visibility of Down's syndrome (therefore offering a visual vindication for non-conforming conduct), the infantilisation of children with Down's syndrome (the young appearance of

people with Down's syndrome means that their misbehaviour is infantilised, i.e. constructed as conduct 'normal for a child') [iv] (#\_edn4), and the public acceptance of Down's syndrome (i.e. parental perceptions of a greater tolerance toward their children in contemporary society).

In another study, I capture how mothers frame the presence of Down's syndrome as a source of happiness, strength, and personal growth. [v] (#\_edn5) While mothers often describe initial negative and rueful reactions after a diagnosis, interpreting Down's syndrome as a loss of maternal expectations and the 'death' of an imagined child, they universally articulate a position of self-acceptance and identify how more positive emotions were experienced later in their child's life. This move – from a lack of orientation towards their child to feelings of recognition, love, and valorisation – is achieved over time and in several forms, such as drawing on the support of family members, partners, and other parents of children with Down's syndrome who help them to normalise, and construct a positive acceptance of, their situation. I also explain how mothers construct what I have elsewhere called a 'courtesy identity'. This is a play on Erving Goffman's (1963) concept of courtesy stigma to show how parenting a child with Down's syndrome and being part of this 'world', rather having a stigmatising quality, becomes an integral and positive element in a mother's reframing of self. One mother explains:

[My son] gave me a purpose in life. He brought a different perspective to how life can be and brought out qualities in me that I didn't know I had. [ . . . ] I'm a mother, teacher, cook, cleaner, therapist, psychologist. I'm his intuition, his middleman, his speaker. I would be lost without him, with so much time to spare and no purpose in life.

Many of the mothers I spoke to describe how they rework their identity-kit and how they become advocates or political activists for their children. What is more, some mothers embrace their status of being, as one mother claims, a 'Down's syndrome mother'. This discourse is often supplemented with mothers *becoming mother* to other children with Down's syndrome whereby they articulate an inclusive and collective sense of parental responsibility, the restitution of kinship here serving to enlarge what another mother calls the 'Down's syndrome family'. Not all mothers explicitly identify themselves along these lines yet they acknowledge their advocacy role, how their child has changed how they see the world, and how they have become better parents because of their child, thus enabling them to transform their lives and orient themselves towards their child and similar others. Thus, a potentially 'discrediting' (Goffman 1963) identity is reworked into a crediting one by seeing the child as offering mothers 'the gift of their own self-knowledge' (Rapp 1999: xiii).

Such strong identities and positive sentiments have gained greater traction in recent years through various forms of media, including parents' blogs and social networking websites. As an example, the World Down Syndrome Day (<https://www.facebook.com/groups/WorldDownSyndromeDay/?fref=nf>) page on Facebook (with, at the time of writing, just under 19,000 members) provides parents with an outlet to not only voice concerns and ask questions to 'wise' others (Goffman 1963) but also to welcome new members into their community (or the 'Down's syndrome family', if we are to use the term cited above), share amusing and heartening media (poems, photographs, videos, etc.) of and about their children, and celebrate life events such as birthdays, successful surgeries, awards and prizes, prom night, the first day of school, and so on. The World Down Syndrome Day Facebook page, among many others, is also replete with positive news stories. Looking back over the past few months, one can view tales ranging from a marriage proposal (<https://www.youtube.com/watch?v=lnaajSxOsWI&feature=youtu.be>) to the renaming of a school gym after a cheerleading student with Down's

syndrome ([http://www.huffingtonpost.com/2015/03/12/cheerleader-down-syndrome-bullied-desiree-andrews\\_n\\_6853032.html](http://www.huffingtonpost.com/2015/03/12/cheerleader-down-syndrome-bullied-desiree-andrews_n_6853032.html)), [vi] (#\_edn6) from a child starring in a TV advert (<http://www.independent.co.uk/news/people/news/adorable-2yearold-toddler-with-down-syndrome-stars-in-target-advert-9940827.html>) to another being given a national ‘goal of the month’ award after scoring a penalty at half-time during a Scottish football game (<http://www.independent.co.uk/sport/football/scottish/11yearold-celtic-fan-with-downs-syndrome-wins-scottish-goal-of-the-month-by-record-margin-in-heartwarming-gesture-10059371.html>).

These outputs ignite the formation of what Ginsburg and Rapp (2015) call a ‘disability public’, a term used to ‘call attention to how people with disabilities and their allies are interpellated and materialised through a range of media, across widely distributed networks of people with shared experiences of disability’. For Ginsburg and Rapp, these constitute an emergent form of recognition and a location for alternative engagement. Adopting this concept, I suggest that media and other outputs – books, blogs, websites, social networks (Facebook, Twitter), YouTube clips, art ([Judith Scott](http://judithandjoycescott.com/) (<http://judithandjoycescott.com/>), [Chris Rush](http://www.chrisrushartist.com/html/portraits.html) (<http://www.chrisrushartist.com/html/portraits.html>), and [Josie Webster](http://www.heartandsold.org.uk/artists/josie-webster) (<http://www.heartandsold.org.uk/artists/josie-webster>) pieces/exhibitions, [Shifting Perspectives](http://www.shiftingperspectives.org/small.html) (<http://www.shiftingperspectives.org/small.html>), etc.), and documentaries/television and film (e.g. [Where Hope Grows](https://www.youtube.com/watch?v=tN7TlwduYsM) (<https://www.youtube.com/watch?v=tN7TlwduYsM>), [Lauren Potter in Glee](http://www.imdb.com/title/tt1327801/) (<http://www.imdb.com/title/tt1327801/>)), among others – help construct a Down’s syndrome public in which new social imaginaries of human difference are erected and people who have Down’s syndrome, together with their parents, are (re)constructed as occupying ‘inhabitable worlds’, giving them a *future* as well as a meaningful *present*.

## Final Thoughts

This imaginary and formation of a Down's syndrome public – enabling what Ginsburg and Rapp (2015) call an 'existential repositioning' – is in tension with the troubled relationship that the condition holds with prenatal technology. What I have shown here, to put it simply, is that there are two competing ways of enacting Down's syndrome (at least in my own research and observations). Within the medical realm, where discourse shapes how people come to view and experience bodily difference, the condition is configured as a negative outcome. Among parents of those with Down's syndrome, everyday life is constituted – despite a range of clear and complicated challenges – as celebratory, life-changing (for the better), and not the disaster it was initially believed to be.

While the unborn foetus with the condition is commonly constructed, especially within medical discourse, as problematic, as inherently inhibiting (for both the child and parent), and, ultimately, as disposable, the born child with Down's syndrome is accepted and often embedded in positive configurations. The existence of two orientations to Down's syndrome, as outlined in this article, is undoubtedly a simplification of an immensely complex issue and I certainly do not mean to suggest that these are its *only* two orientations. However, they are two which have appeared in my own work. Thus, by troubling and dissecting the taken-for-granted category of one of the most common yet complex genetic conditions, we can see how 'Down's syndrome worlds' can be made both inhabitable and uninhabitable.

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## Notes

[i] (#\_ednref1) Interestingly, many health care professionals in my study were critical of prenatal screening for Down's syndrome. In addition to being described as inaccurate (depending on which form of screening is undertaken, i.e. nuchal translucency or quadruple screening) and inciting anxiety in pregnant women, screening was defined by some as a 'eugenic' practice, with one midwife referring to it as '*killing another human being because they happen to be a bit different*'. This is because several of them that I interacted with viewed Down's syndrome as compatible with life. Such criticisms, however, were often silenced owing to them, as part of their professional duties, enacting what they viewed as the principles of informed choice and non-directive care. Expanding on this point is outside the scope of this article.

[ii] (#\_ednref2) I build on these ideas in several other publications and my forthcoming monograph *Prenatal Testing and the Politics of Reproduction: An Ethnography of Down's Syndrome Screening* (working title) to be published by Routledge.

[iii] (#\_ednref3) It will be very interesting to follow this trend over the next few years given that non-invasive prenatal testing (NIPT), a highly accurate form of screening for Down's syndrome and other genetic conditions, is currently being trialled in the NHS.

[iv] (#\_ednref4) Admittedly, parents in this study had children with Down's syndrome who were under the age of 21. If the child was older (i.e. a fully grown adult), this infantilisation would possibly not occur.

[v] (#\_ednref5) In this small-scale study, I focused exclusively on mothers. I made efforts to recruit fathers as well as mothers but this proved to be extremely difficult. The reasons for this are still unclear to me. One guess is that I recruited participants through the UK Down's Syndrome Association mailing list and Facebook groups for parents of children with Down's syndrome – spaces which were occupied largely by women. As such, my discussion here is one which, while important, is narrowed by its focus. However, it is clear in the autobiographical accounts of fathers who have a child with Down's syndrome (e.g. Austin 2014; Bérubé 1996; Daugherty 2015) that a focus on the experiences of men – or fathers and mothers together – would be valuable.

[vi] (#\_ednref6) This story was widely reported in the media after a cheerleader with Down's syndrome was bullied during a basketball game and, in response, players walked off the court during a time-out to confront the perpetrators.

## References

Austin, P. 2014. *Beautiful Eyes: A Father Transformed*. New York: W.W. Norton and Company.

Bérubé, M. 1996. *Life As We Know It: A Father, a Family, and an Exceptional Child*. New York: Pantheon Books.

Clark, B. 2008. *A Mother Like Alex*. London: Harper True.

Daugherty, P. 2015. *An Uncomplicated Life: A Father's Memoir of His Exceptional Daughter*. New York: HarperCollins Publishers.

Flaherty, E.M. and Glidden, L.M. 2000. 'Positive adjustment in parents

rearing children with Down syndrome.' *Early Education and Development* 11(4): 407-422.

Friedner, M. 2015. *Valuing Deaf Worlds in Urban India*. New Brunswick, NJ: Rutgers University Press.

Ginsburg, F. and Rapp, R. 2015. 'Making disability count: demography, futurity, and the making of disability publics.' *Somatosphere*. Available at: <http://somatosphere.net/2015/05/making-disability-count-demography-futurity-and-the-making-of-disability-publics.html> (<http://somatosphere.net/2015/05/making-disability-count-demography-futurity-and-the-making-of-disability-publics.html>) [Accessed: 04 Jun 2015].

Goffman, E. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon and Schuster.

Groneberg, J.F. 2008. *Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down's Syndrome*. New York: Penguin Group.

Lewis, S. 2008. *Living with Max*. London: Vermilion.

Rapp, R. 1999. Forward. In: Layne, L. (ed.). *Transformative Motherhood: On Giving and Getting in a Consumer Culture*. New York: University Press, pp. xi–xix.

Rapp, R. 2000. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. London: Routledge.

Skotko, B.G. 2005. 'Prenatally diagnosed Down syndrome: mothers who continued their pregnancies evaluate their health care providers.' *American Journal of Obstetrics and Gynaecology* 192(3), pp. 670–677.

Soper, K.L. 2009. *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*. Bethesda, MA: Woodbine House.

Van Riper, M. and Choi, H. 2011. 'Family-provider interactions surrounding the diagnosis of Down syndrome.' *Genetics in Medicine* 13(8), pp. 714–716.

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