

Down's Syndrome Screening and Reproductive Politics: Care, choice, and disability in the prenatal clinic. By GARETH M. THOMAS. Pp. 220. London: Routledge. 2017. £110.00 or £35.00 as an ebook. ISBN:978-1-138-95913-2

In *Down's Syndrome Screening and Reproductive Politics* Gareth Thomas uses an ethnographic approach to explore how screening for Down's syndrome has become a routine and normal part of prenatal care, focusing on the healthcare professionals involved in providing screening. This approach provides fertile ground for a number of unique observations that are rarely wrestled with in the literature surrounding prenatal screening and Down's syndrome.

Beginning with a short introduction, Thomas provides a coherent and insightful socio-historical narrative that sets the scene for the rest of the book. It describes some of the significant moments over the last 200 years that culminated with screening for Down's syndrome becoming a routine feature of prenatal care. The term 'mongolism'; first coined in 1838 and described what we now know as Down's syndrome. People with the condition were still being forcibly incarcerated and/or sterilised well into the 1970's in some places. Screening for the condition began in the late 1980's with the first routine screening programme beginning in Newport and Cardiff in 1990. This section provides an invaluable overview of the social, technological, political and cultural developments that led to screening for the condition becoming a routine aspect of prenatal care in the UK and around the world.

Predominantly, research has explored how screening can affect pregnant women. Here, however, Thomas adds something both distinctive and challenging. He describes immersing himself in the culture of the two UK prenatal clinics where his ethnographic research took

place. This enabled him to observe what he describes as the frontstage and backstage interactions that took place. By observing healthcare professionals in both their public (frontstage) and private (backstage) capacity Thomas is able to provide a broader and richer picture of their perceptions of prenatal screening and their role in its provision. This approach makes it possible to observe the private misgivings about screening for Down's syndrome shared by some professionals.

For instance, one female sonographer describes fearing that screening for Down's syndrome is 'eugenic' because unlike many other syndromes, it is compatible with life. She then describes what she believes to be a 'cultural shift towards perfection' (p. 109), which combined with the routinisation of prenatal screening, establishes only the illusion of informed consent. Professionals were observed to rely upon assuming parents had given their informed consent to screening and by providing non-directive care shifted any responsibility for the procedure to the prospective parents-to-be. This seemed to function as a means for the midwives and sonographers to rationalise any backstage reservations they had about the moral ambiguity of Down's syndrome screening.

Thomas notes that in the clinic's backstage, professionals frequently describe Down's syndrome in positive terms. However, this positive framing was not observed in the 'frontstage' screening consultation discourse - instead the condition was constructed (albeit unintentionally Thomas believes) as a negative pregnancy outcome. Thomas explains the inconsistency between what professionals *say* and what they *do* by appealing to the concept of motility. Motility refers 'to how people or things are moved in different spaces of discourse' (p. 9). It is this motility that allows professionals to switch between constructing the condition in positive or more negative ways depending on the context and space.

Furthermore, a Down's syndrome diagnosis itself was frequently described negatively within the context of the screening consultation. Professionals often utilised terms such as 'risk' and 'problem' which signify something negative to be avoided. This was further complicated by the discursive shift between a baby and a foetus following a diagnosis. Those shifts in language can both reinforce negative assumptions about disability and have a dehumanising effect on the foetus with Down's syndrome. The absence of neutrality might be tied up with the negative cultural assumptions about disability and the expectation that pregnancy must end with the archetypal child. The availability of a termination following a diagnosis only seems to lend support to the cultural expectation for perfection, functioning as a means of quality control. Conceivably, the routinisation of prenatal screening has played a significant role in radically altering the foetal-maternal relationship into something increasingly tentative and conditional. This means that if the foetus no longer meets our culture's standards of normalcy her continued right to existence becomes questionable – a right that must be argued for, rather than merely presupposed.

Some of the professionals Thomas observed during screening consultations demonstrated low levels of knowledge of Down's syndrome, and did not always communicate the variability of the condition. Thomas notes 'This knowledge is not attributable to ineptitude but, rather, is a product of relegating (and subsequently downgrading) screening to professionals who may not always have a clear grasp of the condition.' (p. 127). Many of the professionals (midwives and sonographers) by their own admission described not possessing an extensive knowledge of the condition and feeling uncomfortable about being asked questions from parents-to-be. Should the absence of a more extensive knowledge of the condition be representative of a wider problem, then this research may encourage those providing screening to attain a more appropriate level of understanding about the condition. Thomas' evidence of low levels of knowledge are all the more surprising, because many of the same

professionals claimed that the public perception of Down's syndrome was largely negative and poorly informed.

Thomas argues that screening is downgraded and perceived by professionals as a mundane and trivial task. By downgraded Thomas describes '...practices which denigrate and minimise the importance, value, and reputation of someone or something.' (p. 48). He subsequently refers to three interrelated observations that support this, these are: (1) the initial undertaking of screening is relegated from the domain of consultants to midwives and sonographers, until a Down's syndrome diagnosis is made and further diagnostic tests or a termination might be considered, (2) professionals describing screening as *just a chat* which reinforces the routinisation narrative, and (3) professionals considering screening to be a valueless task that is not worthy of their primary attention.

A further problem Thomas highlights is that for prenatal screening to continue to be regarded as a routine component of prenatal care, Down's syndrome *must* be considered abnormal, and therefore an inherently negative pregnancy outcome. Although he is very careful to qualify it, it is difficult to disagree with Thomas' conclusion that 'Down's syndrome screening could be considered as a mode of contemporary eugenics, in that it effaces, devalues, and has the potential to prevent the births of people with the condition.' (p. 182): something that must prompt us to consider the moral problems of new technology such as non-invasive prenatal testing (NIPT). How can the language of 'choice' have any real meaning when screening for Down's syndrome can be done earlier, more accurately and with little risk? If and perhaps when NIPT becomes more widely available it is not difficult to imagine what this 'choice' will entail for the foetus with Down's syndrome. Arguably Thomas's ethnography demonstrates that the foetus with Down's syndrome is ascribed very little moral value in the context of prenatal care.

In summary, *Down's Syndrome Screening and Reproductive Politics* is a clear, thoughtful and measured presentation of Thomas' arguments. He comes across as a measured researcher and is careful not to overstate his claims as he sets out to demonstrate that screening for Down's syndrome has become a routinised part of pregnancy, is downgraded by professionals in their daily practices and discourse, and that the condition represents a negative pregnancy outcome. This is done succinctly and cogently and will be of interest to scholars and students interested in bioethics, medical sociology, genetics and the ongoing debates in reproductive ethics and politics.

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