Gareth Thomas, _Down’s Syndrome Screening and Reproductive Politics: Care, Choice and Disability in the Prenatal Clinic_, Abingdon UK: Routledge, 2017, 199 pp., ISBN: 9781138959132, £110.00 (hbk), £34.99 (kindle)

Reviewed by Priscilla Alderson, University College London UK

How did Down’s syndrome come to be a major concern for prenatal screening? Among all the innate abnormalities and illnesses that can be detected prenatally, it is not painful or lethal or particularly physically disabling. And among conditions diagnosed in the early years it is not socially isolating like autism and deafness, or disruptive like ADHD, or very distressing like some mental health problems or terminal illnesses. In many cases, far from having severe learning difficulties, children with Down’s syndrome can do well in mainstream school, some go on to further education and many find employment. Down’s syndrome is therefore ‘compatible with life’ in terms both of survival and often of fulfilling quality of life.

Gareth Thomas traces the haphazard history of events that led towards the syndrome’s dominant place in prenatal screening. Around 150 years ago, when many more women began to survive beyond 35 years and to have more children at the older maternal age when the incidence of affected babies increases, universal schooling also began. All children were drawn into surveillance systems to assess their learning abilities; special schools and sub-normality hospitals were opened and thousands of children began to be identified as needing life-long institutional care. Types of ‘idiocy’ began to be classified and Dr Langdon Down identified Down’s syndrome.

By the 1970s, with slowly growing respect for disabled people’s rights, sub-normality hospitals were being closed; a 1971 Act declared ‘no child is ineducable’; parents began to be encouraged to take their babies with Down’s syndrome home instead of leaving them in hospital; and, with far better care, many of the children have flourished and can live until they are about 60. However, from the 1960s onwards there was also the rapid rise of prenatal screening technologies, and Down’s syndrome happened to be one of the most obviously identifiable conditions. Every woman can easily be screened by ultrasound scans for a small anatomical indicator and then be referred for further testing. Thomas concentrates on the preliminary screening/scanning stage. ‘We can do it therefore we will do it’ appears to be a driving motive for setting up the vast service, not ‘we need to do it’. Screening is the first step into the three-stage trap. The scan is presented as an enjoyable bonding time, when caring parents-to-be enjoy meeting their new baby and having photographs in a normal routine. Smiling staff joke and chat with parents while checking for abnormalities, and usually reassuring parents that fortunately everything is fine, they are safe from the implied horror of having a baby who is not perfectly normal, healthy and beautiful. If the scan indicates a risk that Down’s syndrome might be present, step two quickly moves from relaxed enjoyment into doubt and anxiety; amniocentesis (inserting a needle to take blood directly from the baby) is offered as a reassuring means of resolving painful uncertainties. It carries a 1% risk of inducing miscarriage. Step three is the offer of an
abortion if Down’s syndrome or other chromosomal abnormalities are detected, and at this stage nine out of ten women accept the offer.

The book reports Thomas’s ethnographic observations and interviews with staff, almost all women, in two prenatal departments, one NHS the other private. The practitioners’ daily work, their professional aims to provide an unbiased service, and their personal views are respectfully documented. The analysis is well supported by numerous references, and the social constructionist approach is well suited to document the ethnography and the socio-history of random events summarised above. Thomas’s work is informed by his life-long friendship with a young woman who has Down’s syndrome and by his two previous studies with parents of children who have the condition.

The key questions through the book ask why so many professionals and resources are devoted to efforts to detect and eliminate Down’s syndrome in the name of promoting informed choice, when so much anxiety, distress and destruction are generated, the choices are generally misinformed and, if accurate information could be given, different choices are likely to be made.

Chapter 3 ‘Hands-off work’ meticulously details how the ‘purity’ of the prenatal clinic as a life-enhancing endeavour is preserved, by allocating the implicitly dirty work of screening for Down’s syndrome to the lowliest staff, without allowing them adequate time, training, support or opportunity to inform parents-to-be fully and honestly. The title for Chapter 4, ‘a can of worms’ was provided by two practitioners who, with others, explain how they privately believe the system is ‘eugenic’, and that both staff and parents are ignorant about Down’s syndrome. Although the staff believe they manage to be unbiased when talking with expectant parents, much is conveyed by implicit messages. The fact that screening and terminations are offered in the clinic implies that these are acceptable if not healthy and morally responsible choices. Chapter 5, ‘The elephant in the consulting room’, shows how the staff avoid explaining what Down’s actually syndrome involves. If they are occasionally asked, they reply that they do not know enough to be able to give information, a strange reply from qualified healthcare professionals about their routine work. Instead, they concentrate on informing expectant couples about the clinical procedures and about confusing risk probabilities. Thomas examines many ways in which language paves paths towards the rejection of affected babies, such as the switch from positive talk about healthy ‘babies’ into negative talk about the possibly impaired and expendable ‘foetus’. Rare mention of symptoms of Down’s syndrome stresses ‘the face’, as if this not only fails standards of human beauty, but is also alien in an emotional and moral distancing that implies parents cannot expect the baby to reflect their own features. Chapter 6 shows how the idea that parents ought to expect perfection is avidly promoted, with its dark side that any anomaly is to be feared and rejected. Seemingly simple routines raise profound but evaded questions about the meaning and value of human life and of one’s potential child.

Thomas respects the staff and appreciates their difficulties, as if they are unfairly, perhaps unwillingly, overwhelmed by powerful social structures. And yet the systems only endure through their active agency. He notes the long history of people with Down’s syndrome being institutionalised, sterilised and killed, and in the final chapter he criticises the effects on families and on societies of medicalising Down’s syndrome and promoting the notion that disability is a ‘catastrophic outcome’ to a pregnancy (p. 180). When prenatal screening ensures that there are relatively few children and adults who have Down’s syndrome, and when screening routinely promotes negative messages about them to generations of new parents, then broader society is less likely to include and welcome them and disabled
people generally. This is indicated by the latest £multi-million cuts in disability benefits and services.

The central problem that screening can seem to be a normal, even trivial, part of prenatal routine is increasing, now that a simple maternal blood test at 10-weeks gestation can detect an array of abnormalities, including Down’s syndrome. While scanning and the risks of invasive amniocentesis at least need to be explained and consent requested, the simple method of the new blood test may further mask its profound implications. It may sideline the need for serious prior discussions, and be even harder to refuse.

Thomas concludes that prenatal screening is a mixed blessing when it can detect very severe anomalies but also induces great anxiety and uncertainty. Through its ‘terrible ordinariness’ (p. 189) (Arendt would say ‘its banality’) prenatal screening reshapes society’s concepts of what is human, normal and acceptable. It promotes the bioethical fictions that the clinic service is neutral and offers free, informed, non-directive choice. New technologies are introduced without greatly needed renewed public debate and new professional training, and Thomas lists urgent questions for public debate about the nature and purpose of prenatal care and whose interests are served by technical innovations. He believes ‘that sociologists are valuable assets for making sense of such changes’ (p. 189) and his book deserves to be widely read.