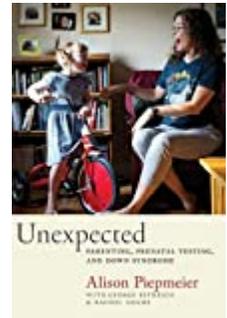


**Alison Piepmeier, George Estreich, Rachel Adams.** *Unexpected: Parenting, Prenatal Testing, and Down Syndrome.* New York: New York University Press, 2021. xxiv + 171 pp. \$89.00, cloth, ISBN 978-1-4798-7995-3.



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This is a remarkable book that raises incredibly difficult questions for and about individuals, their families, and the way societies treat some of their most vulnerable members. It is, in many ways, a painful read, although much of the content is warm, inclusive, and genuinely hopeful. The narrative style is very readable and engaging. Unlike some academic texts dealing with “disability issues,” I would not hesitate to recommend this book to people on the same journey as Alison Piepmeier and her family. She shares incredibly personal insights and experiences and has strong views about the care of her daughter and the rights of all disabled people. While Piepmeier rages against the inhumanity and hypocrisy of organizations that could and should support all families but instead operate discriminatory policies, she remains totally supportive of the choices made by individuals.

Piepmeier is completely nonjudgmental and has inspired sufficient confidence in her interviewees for them to share deeply personal decisions that reveal their attitudes toward their re-

productive choices and their experiences of caring for disabled children. The book is an incredibly rich source of material for future studies. These will surely follow because the contradictions between the rapid advance of prenatal screening technologies and the current trend to restrict abortion laws in the United States are creating an ethical minefield in a rapidly changing terrain that individuals, families, doctors, activists, and legislators will need support to navigate. Piepmeier makes a very convincing argument that these issues are of fundamental importance to all of us interested in protecting and advancing the human rights of people living with disabilities. However, she also suggests that to be heard in debates that attract strong passions and loud voices in support of entrenched positions, we need to work harder and smarter to bring the insights available from thoughtful and inclusive disability studies to new audiences.

To this point I have treated Alison Piepmeier as the sole author. This accreditation reflects the fact that the book is centered on her personal

story. It also explicitly draws on both an incomplete manuscript begun by Piepmeier and the legacy of her lifetime of academic and other writing across a range of topics. Tragically, Alison Piepmeier did not live to complete her project and it is her co-authors, George Estreich and Rachel Adams, who managed to produce a book that both honors Piepmeier and successfully finds its own unique voice. This is a different book to the one Piepmeier would have written, a point explicitly made at various points in the text by her co-authors, but it is perhaps all the more valuable for that as the sense of conversation and challenge is heightened by the interaction of the three authors.

The main conclusion that I took from the book was the sheer complexity of the issues raised and the difficulty of coming to a firm position on any, let alone all of the debates that the book introduces. *Unexpected* certainly offers a nuance that is too often missing from other publications. I was reading about Piepmeier's experiences of both prenatal testing and parenting her daughter during the same weekend that I picked up a magazine supplement with a Sunday newspaper. In the "real life" section three women shared their stories: "We all think we had our babies at the right age!" The lady interviewed as the older mother explicitly mentioned seeking tests for Down syndrome because she had decided that "having a baby with special needs wouldn't be fair."<sup>[1]</sup> Like Piepmeier, I totally accept that the woman was making a valid personal choice based on her family circumstances, but I wonder if the magazine's readers fully understand that the potential implications of this decision were a fairly late (even second-trimester) abortion to deliberately prevent the birth of a disabled baby who might otherwise have had many decades of life. Piepmeier does not shy away from these issues, and instead problematizes them.

Here the non-US reader can encounter some difficulties because *Unexpected* is unashamedly grounded in US policies and procedures and

therefore the context for decision making is provided by legal frameworks and healthcare systems that feel very alien. This problem is heightened because *Unexpected* is deliberately speaking to an American audience, seeking change from within the system, and assumes a level of prior knowledge not necessarily available to international readers. In several places I wanted and needed more details to fully understand the points being made about, for example, unequal access to prenatal screening (presumably linked to insurance coverage) and the implications of this. The emphasis on the unanticipated consequences of rampant commercialization within this sector in the United States registered as important, but mercifully of limited relevance to the UK experience—at the moment.

However, many of the wider issues considered in *Unexpected* transcend national borders. Chapter 2, titled "The Inadequacy of 'Choice': Disability, Feminism and Reproduction," was particularly thought-provoking. Second-wave feminism certainly prioritized reproductive choices but, given the constraints that many women live under, the supposed choice is actually no choice at all and the fallacy of having a choice may well be experienced by individual women as disempowering. Piepmeier brings some really interesting theoretical analysis as well as personal insight to these issues although her immersion in current US political debates over abortion can sometimes be confusing for outsiders. However, the UK reader should be careful about dismissing these issues as irrelevant to them, as abortion laws in Northern Ireland have recently been hotly debated in ways that have not consistently emphasized the rights of women but have tended to distinguish between normal and "other" pregnancies without fully explaining the implications of this approach. The views of people living with disabilities and the parents of disabled children have certainly not been central to the media coverage of this topic.

While Piepmeier is not the only scholar and activist seeking to move the debate away from a narrow and problematic focus on women's rights to a much wider commitment to reproductive justice, she does offer particularly powerful and unusual testimony that urgently needs to become a much bigger part of the conversation. Having shown that women's right to choose is often no choice at all, as some women's circumstances force them to either terminate or continue a pregnancy with little reference to their own needs and preferences, it is both interesting and important to note how notions of reproductive justice seek to empower individual women while including, rather than excluding, consideration of the rights and well-being of other actors. Chapter 2 comprehensively reviews the relevant historiography, with particular emphasis on disability issues, and discusses its potentially transformative power in terms of current political debates. Yet, for all the attention given to changing the "big picture," Piepmeier never loses sight of the individuals and families who are most closely affected by these issues.

In the UK, we prize the National Health Service (NHS) and celebrate its universalism and supposed inclusiveness. However, all the evidence suggests that, historically, the NHS has not treated disabled people well. People living with learning disabilities have, arguably, suffered from too much medical control (particularly in the era of large-scale, long-stay institutions) and too little medical care (with medical neglect a factor flagged by various inquiries into the premature death of patients now as well as in the past). In these circumstances, it seems that disabled people will not be the beneficiaries of prenatal screening as the NHS expects women to "choose" to terminate pregnancies where testing suggests "problems." I had not fully grasped the thinking on this point until I attended a conference sometime around 2005 where two young female doctors working on a new screening program for a genetic marker (not Down syndrome) linked to a severely disabling and life-limiting condition in boys ex-

plained that the very costly test was only justified in terms of the lifetime care costs saved by terminating all the affected pregnancies. The doctors, who chose to present themselves as being on a mission to prevent human suffering, went on to explain their surprise that many of the patients they worked with did not automatically go down the abortion route but had to be "encouraged" to do so. Parents who expressed the hope that prenatal diagnosis would allow them to "prepare for the birth and afterwards" or "seek a cure" were presented to an increasingly hostile conference audience (mostly academics, not medics) as dangerously deluded.

Piepmeier draws on her own life experiences to explain how attitudes to a much-wanted pregnancy do not necessarily change just because healthcare professionals start to talk about problems. In this context, extra scans and hushed consultations become an unwanted and even unwarranted additional source of anxiety for the mother and her family. Drawing on the experiences of her interviewees as well as herself, Piepmeier reveals that many doctors are surprisingly ill-informed about the real-life experiences of people living with disabilities, and their pessimism (and in some cases barely concealed hostility to disabled people on eugenic or other grounds) was a huge problem for would-be-parents to cope with. This is obviously true, but I think *Unexpected* misses the opportunity to make the link to the burgeoning literature exploring many women's negative experiences of medicalized pregnancy and birth distinct from any mention of disability issues. The problem for parents of disabled children is that the intrusive, but often unhelpful, involvement of health professionals can be more intense and continue for longer than that experienced by other families. Piepmeier tries to make the case that we should make less of a distinction between the needs of all children and children with special needs as a step toward embracing, rather than rejecting, notions of human diversity.

This works to a point, but Piepmeier's argument that all parenting necessarily involves a great deal of personal sacrifice, unremitting hard work, and uncertain reward is not necessarily going to encourage would-be-parents to take the plunge or help with any specific difficulties encountered when parenting a child with disabilities. Piepmeier writes from the perspective of a committed feminist as well as a disability advocate. She draws from both theoretical traditions for creative inspiration and practical support, and through commitment to ideas of, for example, reproductive justice, creates a space where women and their children, and indeed others, can be empowered and have their rights respected and needs recognized and met. However, not everyone sees a straightforward alignment between feminist priorities and the well-being of other groups in society, and some of the well-known tensions between women's rights and the care needs of others are not fully unpacked in *Unexpected*. My concern was that many of the arguments for better support for families implicitly assumed that more domestic help and childcare should be made available. The inequalities in terms of accessing this provision were briefly touched on, but the potential to exploit vulnerable workers employed as caregivers and the quality of care likely to be provided by overworked, undertrained, and poorly rewarded staff received barely a mention.

It is a paradox that people who are able to write about the challenges of parenting a disabled child tend to have far more resources available to help them than families we can only learn about through other means. Piepmeier is a particularly impressive scholar, but admits that she shares much in common with the writers of the parental narratives she surveys in chapter 4. Many of them are unrepresentatively white, middle class, and well educated (often with a liberal arts background). With Piepmeier's project curtailed by her illness, she is only able to consider a limited number of narratives, but, in fairness, this is a major limitation of the whole genre. Despite Piepmeier's

validation of the choices made by individuals, she also makes clear her growing frustration with the published memoirs of parents of children with disabilities. While these can be an important source of information and support for other parents, they can also "fortify cultural stereotypes that portray children with disabilities as damaging forces in their parents' lives" (p.81).

While I totally understand why Piepmeier had to limit the number of parental narratives she surveyed, it is disappointing that she tended to concentrate almost exclusively on fairly recent publications from after the year 2000. There is a long tradition of such writing, and in the UK there is a considerable body of work that draws on both the original texts and the changing commentary on them offered by different generations of scholars from a variety of backgrounds. While many of the titles are discouraging, using outmoded and now offensive terminology, we cannot simply dismiss the experiences they capture. The pioneers of parental memoirs did not face the same choices as those undergoing prenatal screening today, but important themes such as learning that your child might have, or has, a disability, acceptance and rejection, telling other people, seeking support, learning to parent, making decisions for the future, are all present.

One reason why Piepmeier rejects some of the negativity of the parental accounts is that she argues that pioneer parent advocates and activists (a group that includes some, but by no means all, of the writers of early parental narratives) have changed the history so that later generations have to struggle less and can enjoy more. I must admit that I think this conclusion is wildly optimistic. The chronic undervaluing, exclusion, neglect, and abuse of disabled people is a continuing scandal that tends to be blamed on resource scarcity, but the fear and hostility that some actors exhibit toward people living with learning disabilities seems more deep-seated than this.

Piepmeier usefully draws attention to the way some parents of autistic children seek to explain their experiences in a way that unwittingly denigrates and dehumanizes people living with Down syndrome. This is an important point, and Piepmeier carefully explains how and why the published memoirs she draws attention to seem constrained and constricted by an implicit acceptance of a medical model of disability and “the powerful hold that formulaic narratives have” (p. 82). I quite understand that she wants us all to work together to change the narrative, but we need better stories to tell about disability issues as well as new ways of telling them. Piepmeier’s later writing captured the often optimistic phase of middle parenting, when the overwhelming needs of infancy are in the past but the struggles of adolescence are only dimly perceived. Rachel Adams, in chapter 6, poses the interesting idea that Piepmeier’s thinking on reproductive rights might well have developed over time to reflect her daughter’s progress through adolescence into womanhood. Adams reminds us of the grim history of reproductive controls (in the supposedly liberal West in the present as well as under overtly eugenic regimes in the past) that underline the failure to respect basic human rights, let alone to value diversity.

*Unexpected* certainly does not shy away from the idea that problematic policies and attitudes today have deep historical roots, but as a historian I found the focus on the post-2000 world a bit limiting. It was at least a generation before, in the 1980s, that prenatal screening and its implications were first discussed by advocates and activists (some but not all of them parents) in the context of Down syndrome. I still often revisit Joyce Mepsted’s book *Your Child Needs You: A Positive Approach to Down’s Syndrome*.<sup>[2]</sup> It discusses and problematizes genetic screening, and I think the authors of *Unexpected* would value its positivity and the dignified representation of children from birth to adulthood who are shown engaged in constructive activities such as reading, using a com-

puter, riding a bike, and driving a car, activities that are rarely associated with Down syndrome. However, the authors of *Unexpected* encouraged me to see something I had not previously noticed. All the images in Mepsted’s book show the children either alone, in the company of other disabled children, with parents or siblings, or with adult helpers. No other children or adults are depicted, and their absence is problematic.

Piepmeier challenges the isolation and exclusion of disabled children in chapter 3, which is curiously titled “The Welcome Table.” She explains how the word “table” recurred in conversation after conversation about disability issues and how the metaphor of the welcome table worked for her. I am usually quite hostile to using complicated metaphors—the world of learning disabilities (and the care sector in general) already suffers from an excess of jargon that acts as an unnecessary barrier when families want to understand what help is available, and it even prevents different groups of care professionals from successfully communicating with one another. However, the “table” metaphor manages to be simple, clear, and remarkably powerful as an explanation of the difficulties families face now and their aspirations for the future.

Piepmeier was fascinated by words and her co-authors help explain how she used the power of language to capture her own illness experience as well as explore disability issues. Unfortunately, the promise of this work, especially the important differentiation between illness and disability, was not fully realized because of the seriousness of Piepmeier’s condition and her premature death. However, in different and really interesting ways her co-authors pick up the baton and use Piepmeier’s work to challenge future scholarship to fully engage with these themes. *Unexpected* is about a deeply personal journey, but it offers a starting point for a radical rethink of how we think and write about Down syndrome now and in the past.

Notes

[1]. Susanna Galton and Josie Copson, “We All Think We Had Our Babies at the Right Age!” *Notebook: The Sunday Mirror Magazine*, August 15, 2021, 16-17.

[2]. Joyce Mepsted, *Your Child Needs You: A Positive Approach to Down’s Syndrome* (Plymouth: Northcote House Publishers, 1988).

If there is additional discussion of this review, you may access it through the network, at <https://networks.h-net.org/h-disability>

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