



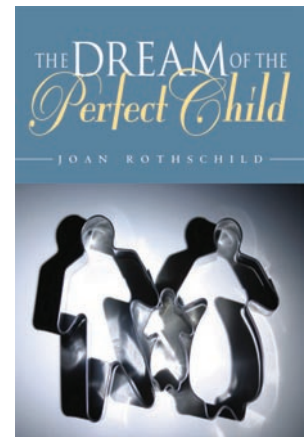
# The dream of the perfect child

Joan Rothschild

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Recent advances in genetics and prenatal testing create the hope of children born free of the accidents of genetic roulette and the vagaries of birth. It is this dream that Joan Rothschild explores in her rich, thought-provoking book *The dream of the perfect child*. While acknowledging the “remarkable achievements” of DNA analysis, ultrasound, preimplantation genetic diagnosis, and related procedures, her book advances a far-ranging critique of current prenatal testing and its effects. Rothschild’s thesis is that contemporary reproductive medicine is heir to a discourse of human perfectibility that has transformed a natural parental desire for healthy children — a “desire we all share” — into the “cruel illusion” of the perfect child. It is this illusion that Rothschild hopes to dispel. Specifically, she targets the “dark underbelly” of perfection: the language of defects, abnormality, and risk that allegedly leads to a “hierarchy of birth.” In her terms, criteria of selection imply criteria of rejection.

Rothschild holds that the use of such criteria has two negative consequences. First, in defining and labeling an ever-expanding list of “unacceptable” traits, prenatal testing leads to overuse of abortion. While formally pro-choice, Rothschild does little to hide her disapproval of those who would terminate pregnancies for minor defects or manageable conditions compatible with a good life. Second, the use of criteria of rejection inevitably results in a devaluation of the lives of the genetically “flawed” or physiologically atypical — lives deemed “not worth living.” Rothschild finds evidence of this implicit devaluation not only among parents pursuing the dream of perfect progeny but also among medical pro-

fessionals whose language and practice reflect the norms of biological reductionism and bioethicists who largely accept the medical status quo.

How warranted are these criticisms? Rothschild may very well be right that prenatal testing and genetic medicine have contributed to an increase in the number of pregnancies terminated, some no doubt for medically unnecessary reasons. Who would argue with the recommendation that parents should be better informed about what screening tests can and cannot tell us? Certainly those faced with negative test results need to know about available treatment options and have an accurate understanding of the lives of those with cognitive and physical impairments. Combating misinformation and misconceptions would help reduce the frequency of abortion based on mistaken beliefs.

More questionable, however, is the book’s tendency to skew its account of the price of prenatal testing by focusing on relatively easy cases. Rothschild points out that the vast majority of children with Down syndrome, for example, can be mainstreamed in schools and integrated socially. But precisely because of this, it is not a fair case to use in support of more general conclusions. One wants to hear more from Rothschild about the hard cases. What of prenatal diagnoses where the outcome is bleaker, less amenable to a simple change of social attitudes? Rothschild leaves unclear when, if at all, she regards a diagnosis serious enough to warrant ending a pregnancy. The apparent implication is that parents who choose not to continue a pregnancy on grounds of negative test results do so out of misinformation or prejudice about the disabled

and the lives they live. But in the most tragic cases — the worst cases of spina bifida, neural tube disorders, sex chromosome anomalies, or Huntington disease — a more accurate grasp of the facts may intensify rather than alleviate fears.

While Rothschild rightly insists that a wide range of possible lives can be meaningful, her book remains silent on the real life tribulations of children born to lives of serial surgery, isolation chambers, multiple weekly therapies, chronic pain, and a lifetime of dependency. The main problem here is not social attitudes. Even in the best of all possible worlds, children and families faced with certain of these conditions will suffer greatly. It’s a difficult truth — one Rothschild seems not to want to acknowledge — that the lives of many of those born to such circumstances will be genuinely bad. Thinking that a life with a great likelihood of suffering and pain and a small possibility of meaningfulness and satisfaction is not the kind of life one wants to bequeath one’s children is not the same thing as denying the value of a life already in place, whatever its challenges and limitations. The value of a life derives from the value of the person living it and requires no further validation. Surely Rothschild would agree. But her tendency to conflate judgments about possible lives with judgments about living persons obscures this point.

Despite the objections raised here, Rothschild’s book deserves wide attention from those directly involved in prenatal care and genetic medicine. Although many will disagree with some of its conclusions, this lucid, often fascinating investigation raises important questions about where the dream of human perfectibility threatens to take us.