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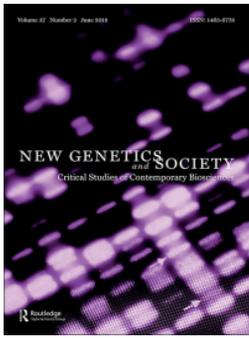
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## Down's: the history of a disability

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chronic disease, improve the participants' access to health care, and make a "definitive strike" against the racialization of scientific research (xx). He calls on social scientists to "perpetually compete with the emerging genetics stranglehold on explaining disease causality" (190). He wants to "stimulate discomfort in the way diabetes is currently conceived such that the ensuing conflict over what might be done about it will produce a better collective and individual response to this public health and anthropological problem" (xxi). Montoya even "anticipates the end of the genomics era" (1). But he knows that science studies has not yet had this impact: its "critical analytics, no matter how convinced we are of their validity, have failed to interrupt the nonrandom patterns of injustices and inequities" (180). Will scientists and doctors read this book, and the broader science studies literature, and see the light? I am not hopeful. Is there something else that scholars can do to make this happen? The book provides few answers.

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**Down's: the history of a disability**, by David Wright, Oxford, Oxford University Press, 2011, 256 pp., £14.99 (hardback), ISBN 978-0-19-956793-5

Wright's book on the history of Down's syndrome, one of the most prevalent and perhaps the most discussed genetic condition, is focused on the changing attitudes toward intellectually disabled people. It also documents the scientific understanding of this condition that culminated in the transformation of Down's syndrome into a genetic disease, and ends with a description of the consequences of that redefinition. Although the question of treatment of people with disability has been studied by other historians such as Mark Jackson and Matthew Thompson, Wright's book provides an elegant synthesis of studies on this subject, with considerable contributions of his own. One of the book's strong points is Wright's innovative investigation of the work of John Langdon-Down. Wright also provides an original account of controversies on treatment of Down's syndrome children, their institutionalization and segregation. His book links the treatment of people with this condition with the more general topic of attitudes toward intellectual disabilities (once called mental retardation). The book follows then this recent transition to a different, and more enlightened attitude toward individuals with the condition: the gradual closing of specialized institutions, the integration of children with Down's syndrome in mainstream settings and the improvement of their ulterior life conditions. Today, Wright optimistically concludes, some people with

Down's syndrome are able to lead semi-autonomous lives, work, have an independent social life and sexual partners.

This is an innovative study, on an important and little studied issue. My main problem with this book is not what it tells, but what it leaves silent. Wright attests at the beginning of his study that he has a passionate interest in the topic. His sister Susan, born with Down's syndrome, was able to achieve satisfactory, semi-independent life thanks to the radical change in societal attitudes toward her condition. Wright implicitly claims that all people with Down's syndrome should be able to live a semi-independent, happy and fulfilling life, as his sister does; if this does not happen, then society is at fault. He strongly insinuates that the reason the great majority of pregnant women who, when diagnosed with Down's syndrome fetus, decide to terminate the pregnancy – a development presented by Wright as a part of “death making” society – are biased social attitudes toward this condition, perhaps coupled with their selfishness.

Indirect pressures on women diagnosed with Down's syndrome fetus to terminate the pregnancy, denounced by Wright, are indeed inadmissible. But a pressure to maintain such a pregnancy may be equally problematic. Wright omits to tell his readers that a prenatal diagnosis of three 21 chromosomes does indicate that the child has a Down's syndrome, but not the severity of her/his intellectual and physical disability. Approximately 20% of individuals with Down's syndrome are defined as having a mild intellectual disability, 20% a profound one; the remaining 60% are somewhere between these extremes. Moreover, a significant proportion of Down's syndrome children have important health problems. Unsurprisingly, the “poster people” for Down's syndrome are among the high-performing ones. Usually they are also those who, like Wright's sister, were able to benefit from supportive family and from public aids, frequently secured thanks to their families skill in navigating the official support system. To claim that the most successful cases should represent the future of every Down's child is, however, deeply misleading. It does not take into account important differences in public resources available for education and medical care of disabled people, important differences between socioeconomic status of mothers and families of such people and their psychological makeup, and above all important differences in the severity of impairment of individuals with Down's syndrome: some people with this condition can keep a regular job, but some never learn to speak. And many will need a high level of parental support until the end of their parents'/mother's life.

As a rule, parents take care of their children when they are small, and not infrequently are helped by their children when they grew old. Parents/mothers of intellectually disabled children know, however, that they will always stay on the giving end. It is not rare today for a woman in her 70s to have the sole responsibility of an adult child with Down's syndrome who, in addition, may suffer from an early onset of Alzheimer's disease, one of this condition's late effects. And, in today's economic and political climate, it may be difficult to tell a pregnant women that she should count on an important increase in the level of public support for people

with intellectual disabilities in the near future. A woman diagnosed with a Down's syndrome fetus nearly always faces a very painful personal decision, but also a risk that she be negatively judged for that decision. If she decided to maintain the pregnancy, she may be criticized for potential harm to her family and society. If she decides to interrupt it, she may be criticized for selfish behavior, absence of maternal virtues and a "eugenic" rejection of the diversity of human kind.

In the 1980s, it was (still) possible for a woman, as the anthropologist Rayna Rapp did, to explain that her and her husband's decision to terminate a pregnancy with a Down's syndrome fetus by the realities of raising a child who can never grow to independence, and the awareness that in order to provide an adequate care for such a child, it is probable that one of or both of them will need to give up work, political commitments and social existence beyond the household. Today, partly because of – otherwise very important – interventions of disability right activists such as Wright, it became far more difficult for a woman to state that she had elected not to have an intellectually impaired child because of a risk of a severe limitation of her own life options. A book which – with the best possible intentions – minimizes the real-life problems of care of people with Down's syndrome, and implicitly condemn women who elect to terminate a pregnancy with a trisomic fetus, can make a very difficult situation of these women even more challenging.

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