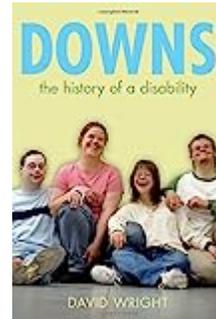




**David Wright.** *Downs: The History of a Disability.* Oxford: Oxford University Press, 2011. xiii + 239 pp. \$24.95 (cloth), ISBN 978-0-19-956793-5.



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## A Conundrum and Phenomenon: The Complex Story of Down Syndrome

Of the many disorders that cause intellectual deficits and disability, Down syndrome is perhaps the most identifiable and well known within the general public. Unlike other developmental disorders, the aberrant chromosomal genotype associated with Downs consistently manifests in a group of common physical characteristics across individuals that are obvious and, for many, easily recognizable indicators of the disorder. As one of the oldest identifiable singular disorders associated with limited intellectual abilities seen across all peoples and within all strata of society, Down syndrome can be described as a global human phenomenon and conundrum that has challenged societies for centuries. Until now, few authors have taken on the task of presenting a comprehensive description of the disorder as a human condition, scientific focus, and societal challenge. Most texts offer only one view of Downs, leaving the interested reader to further, independent study and personal synthesis of the historiography of this complex human condition. In his book, *Downs: The History of a Disability*, David Wright offers us a very readable, well-researched, interesting his-

toriography of the disorder as a human and societal phenomenon that provides a comprehensive synthesis of all relevant perspectives that should not be missed.

Wright opens his book by narrating his personal experience of the disorder—as the sibling of a sister with Down syndrome. This is conveyed to readers through a synopsis of the challenges and joys his family, particularly his parents, encountered as they sought to meet his sister Susan’s needs and life goals. For me and others who work with individuals with developmental disabilities and their families on a daily basis, Wright’s description of his parents’s battles to secure both services and inclusive school settings for Susan details a realistic, open, and honest portrayal of life for families and children with Down syndrome. Though one would like to be able to say that the experience of the Wright family in the 1970s is now anachronistic, with services and opportunities much improved in the past four decades, those of us in the field must acknowledge that though we have made the notable progress articulated in Wright’s last chapter, that progress is limited and not ubiquitous.

To write a comprehensive history of a single disorder, particularly one generated by a singular chromosomal aberration and so consistently manifested, is a challenge that is easily done poorly. By contrast, Wright has woven the scientific and social story of Downs across time and the globe in a very effective manner. Throughout the text, Wright creates and maintains focus on the individual and human conundrums associated with the condition right down to the challenges associated with naming it; a seemingly simple task that continues to this day to be rife with social and political implications. In simplest historical terms, John Langdon Down is credited with having established the syndrome as a distinct medical condition in 1866, but as a human variation, Down syndrome had been in the population since its beginnings. However, in reality, the identification of the syndrome, particularly in light of early conclusions within the scientific community that it was a genetic throwback to a lesser primate form, was neither scientifically neutral nor simple. Wright offers the historiography of the evolution of the scientific and political trajectory dealing with these people of small stature, with wide, round faces, oblique eyes, disproportioned tongues, and small hands with only single palmer creases first identified by John Langdon Down as being Mongoloid—a name that continues to be heard used.

The condition of intellectual deficit, whether developmental or acquired, is evident in extant history spanning more than four hundred years. Social and therapeutic treatment of individuals who demonstrated such deficits as well as the legal and political challenges created in providing for their care is, in itself, an interesting, deep, and complex history. To describe the treatment and responses to one singular group within the entire population deemed to be either idiots (i.e., those with developmental deficits) or lunatics (i.e., those who acquired intellectual impairments through accident or disease) in isolation is a formidable task. In *Downs*, Wright uses his discussion of his population of interest to frame the historiography of societal responses to idiocy and lunacy across the ages and continents. In effect, Wright provides us with a comprehensive, if at times dense, chronology of the global ebb and flow of discovery and articulation of knowledge about intellectual deficits and Down syndrome across almost four hundred years of human history.

Throughout the book, Wright frames intellectual disability as a social and human phenomenon that creates a variety of conundrums for individuals, families, and society as a whole. His consideration of the intellectually

impaired from diverse philosophic perspectives, particularly those of the Enlightenment, is most interesting. In one section, he specifically compares the approaches to this topic and assumptions about education or remediation taken by John Locke in England and Édouard Séguin and Jean Itard in France. In addition to offering a very intriguing and applicable analysis, Wright sets the stage for the story of Down syndrome as both a medical disorder and personal condition that alters one's position in the greater society. Moreover, Wright establishes the humanistic arguments for social care and supports challenges to such responses as isolation, segregation, and eugenics, a topic covered in depth later in the book. This philosophic discussion also articulates the early attempts at educational intervention and highlights the importance of education in effecting meaningful life outcomes for individuals with intellectual disabilities—an underlying, subtle theme that runs through the text.

As alluded to above, the terminology associated with Down syndrome is almost as complicated as the disorder itself. Wright does an excellent job articulating and evaluating the process of the naming of the disorder and its evolution across time and continents. He tackles the origin and debates over the term "Mongolism" and its derivations with detail and clarity. As Wright explains, due to the physical characteristics common to people with the syndrome, the term "Mongolism" or "Mongol Imbecility" was applied. Later as attention to racial issues and the science of genetics emerged, the syndrome was renamed to reflect the name of the man credited with its description and was used in the possessive form of Down's syndrome. Over time, the possessive was dropped resulting in the current nomenclature used by both the World Health Organization and the American Psychiatric Association in their *Diagnostic and Statistical Manual of Mental Disorders*. The French medical community opted to use the genetic identifier instead and have consistently referred to the condition as Trisomy-21. The story of the description of the disorder as well as its naming presented by Wright is interesting and was not one I had seen previously dealt with in such a comprehensive, clear manner. As a scholar and practitioner in the area of developmental disabilities, I have frequently been challenged to apply or explain the contemporary nomenclature of this disorder; many, even within our field, still use the possessive form or even Mongolism. As such, I appreciate Wright's explanation and will store it within my resources for future use.

Aside from the obvious quality, depth, and breadth of the research conducted, this work reflects a passion for

critical analysis of the processes of delineation of abnormality within a society and interpretation of aberration as a human condition as well as the evolution of social response to variations within the population. Wright offers a very interesting examination of the scientific and medical endeavors and thinking that contributed to confirmation of the chromosomal abnormality associated with Down syndrome. He offers us a critical analysis and overview of the ethical and academic processes of discovery as well as insight into the interpretations of those, including John Langdon Down, who ultimately deemed their life's work a failure because they did not discover the means of curing or preventing the disorder. While this aspect of the history is interesting, well written, and accurately presented, it is the way Wright presents the historiography of societal response to the intellectual and physical characteristics associated with Down syndrome that is so captivating.

Throughout the book, Wright weaves a story of choices and the consequences of those choices by the executioner and the subject. We read a complex story of the creation of social constructs and responses to developed constructs: What is normal? How do we know? Who decides who is and who is not normal? What are the responsibilities of the state to those who are forever children? What threats do forever children pose to the society at large? How can those threats be ameliorated, controlled, prevented, or eliminated? What is ethical? What is truth? What is fiction? Who decides? Who controls? Throughout the book, one is struck by the cyclical nature of definition, response, and justification evident across the four centuries discussed. It should be noted that although Wright begins with discussions of earlier periods, the majority of his book focuses on the period from the 1800s to the present. Themes of power, poverty, wealth, control, fear, racism, and ableism cycle and echo throughout the book as Wright guides us from one decade or one century to the next. The parallelisms and repetitions presented serve to make clear that while much has changed, much, particularly paternalistic responses and gross assumptions about the potential for industrious, enjoyable, satisfactory life, remains within our constructs regarding individuals with Down syndrome.

Of particular note is the theme of eugenic responses that weaves its way throughout the book. Eugenics is the science of manipulation of the gene pool through controlled breeding to reduce or eliminate undesirable traits, or by contrast to increase the presence of desirable ones. The history of human eugenics is most commonly a description of the former and has focused

on the ways that those with power have altered, controlled, or destroyed others deemed to be a miscreant, deviant, feeble-minded, or otherwise undesirable variation of humankind. Wright discusses some of the more well-known examples of eugenic actions, specifically forced sterilization, in his text. He includes the stories of Carrie Buck and the Kallikak family, and, of course, he covers the Nazi actions conducted throughout the war period in Europe. As with most topics, Wright does an excellent job articulating the social constructs applied by the variety of power holders to justify the incarceration, sterilization, and even murder of those deemed worthy of eugenic action. It is the more comprehensive coverage of issues associated with elective abortions or infanticide of children with Down syndrome or other disorders revealed in prenatal testing or immediately following birth that demonstrates not only Wright's passion for the issues associated with Down syndrome but also his courage as an author and scholar. It is in his discussion of this topic, more than any other in the book, that Wright shines a light on the limited progress in terms of our humanity and acceptance of human variation that we have made since those early years of institutionalization articulated in the beginning of the book. This content is frequently hard to read as it contains tales of children being allowed to die by the will of their parents and at the hands of medical doctors; stories of parents suing doctors for failure to provide prenatal testing that would have revealed the Trisomy-21 chromosomal anomaly and resulting in the birth of a child with Downs who would require major support, have limited life outcomes, and lead to hardship for the family; and accounts of parents opting for elective abortion of children based on the results of prenatal chromosomal testing. Wright does temper this discussion with evidence that trends toward elective abortion of Down syndrome children seems to be decreasing as many of the medical and life outcomes have improved since the legalization of abortions across the globe began in the 1970s.

For a short text, only 186 pages, Wright has developed a comprehensive accounting of Down syndrome. He makes clear the challenges of naming a disorder and finding mutual agreement across fields and continents. He presents an interesting and accessible story of the scientific endeavors that made clear the genotype that revealed the phenotype common to most individuals with Downs. Without specifically stating his perspective, Wright offers the readers a historiography of a medical disorder known to many through a contemporary disabilities studies lens familiar to few. He chal-

lenges the reader to view this history as more than the story of scientific discovery, but as the story of a people viewed as different, frequently feared, often pitied, and generally misunderstood by the greater society. It is hard to imagine that anyone can exit this text at the end of the last chapter without acknowledging that the journey from page 1 to the end offers a critical, thought-

provoking analysis of the conundrum and phenomenon that is Down syndrome. Wright may have taken on this task as a historian and scholar, but he approached it with the heart and passion of a brother of a loved sister who has Down syndrome; only someone with that close, personal experience could present the history of Down syndrome in such an enlightened and affective manner.

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