

COMPTE RENDU / REVIEW

Review of: Kaposy C. (2018) *Choosing Down Syndrome*Meghan Chevalier¹**Résumé**

Avec l'avènement du test prénatal non invasif, Chris Kaposy croit que plus de gens devraient choisir d'élever des enfants atteints du syndrome de Down. Kaposy plaide en faveur du modèle de handicap social et recommande une approche normative pragmatique comme norme. Il utilise des données quantitatives et qualitatives pour étayer sa position.

Mots-clés

trisomie 21, test prénatal, avortement sélectif

Abstract

With the advent of Non-Invasive Prenatal Testing, Chris Kaposy believes that more people should choose to parent children with Down Syndrome. Kaposy advocates for the Social Disability Model and recommends a normative pragmatic approach as standard. He makes use of both quantitative and qualitative evidence to support his position.

Keywords

Down syndrome, prenatal testing, selective termination

Choosing Down Syndrome [1] by Chris Kaposy situates itself within a modern era of prenatal testing. The book is motivated by the advent and proliferation of Non-Invasive Prenatal Testing (NIPT), which seems to be occurring without sufficient reflection. Kaposy questions the potential repercussions of widespread use of NIPT in the larger framework of prenatal testing for Down syndrome and selective termination. *Choosing Down Syndrome* puts forth thorough and convincing arguments for choosing to parent children with Down syndrome, addressing previously published sources on the topic. Kaposy clearly outlines the structure of each chapter in the book's introduction, and what Kaposy intends to argue is clear.

Choosing Down Syndrome begins by establishing itself within a context of ongoing debates regarding the ethics of prenatal genetic testing for Down syndrome. NIPT offers a low-risk, highly accurate screen for Down syndrome. Ultimately, Kaposy suggests that more people should choose to parent a child with Down syndrome following a prenatal diagnosis, rather than terminate their pregnancy. To support this claim, Kaposy begins with an analysis of several autobiographical accounts written by parents of children with Down syndrome. He subsequently presents empirical research about families of children with Down syndrome, while discrediting suggestions that the happiness that these families experience is due to adaptive preferences, i.e., the preferences that people develop based on a limited amount of potentially oppressive and less than ideal options. Kaposy then discusses the morality of bringing into the world a child with a disability, as well as the morality of selective termination. The penultimate chapter considers how the identity of a person with Down syndrome is perceived by society, and Kaposy recommends a normative pragmatic approach as standard. This means that we should employ the Social Disability Model (the perspective that disability results from the failure of society to accommodate individual needs, rather than from the individual themselves) while recognizing their disability as a medical condition when it is in their best interest, such as in therapeutic or educational contexts. The concluding chapter of the book examines the capitalist influence on selective termination. Kaposy argues that biases against people with Down syndrome result from their difficulty in achieving the type of monetary success that is valued in a capitalist society.

The primary strength of Kaposy's arguments comes from his decision to use both qualitative and quantitative supporting evidence. The qualitative analysis of autobiographical accounts written by parents of children with Down syndrome and quantitative empirical findings are mutually supportive. Kaposy includes autobiographical accounts (Chapter 3) before addressing empirical research statistics (Chapter 4), emphasizing the importance of these autobiographical accounts and avoiding this chapter being read through solely a statistical lens. The points raised in Chapter 3 are later supported by statistics, but the order in which they are presented allows the autobiographical accounts to be read independently as legitimate and valuable evidence.

After discussing and evaluating autobiographical accounts and empirical statistics, Kaposy considers questions of morality with respect to continuing pregnancies and selective termination. He clarifies and questions potential motives for selective termination. Kaposy writes with a nuanced understanding of context. For example, while some could view legislation that has been passed to promote accessibility and inclusivity as indicators that society is progressing away from biased attitudes, Kaposy discusses the presence of informal bias. Further, when addressing previously published literature, he examines and critiques their definitions of important concepts, such as disability, well-being and quality of life. Kaposy effectively challenges assumptions about people with disabilities, simplistic arguments, and arguments based on intuition in other works. In a well-rounded approach, *Choosing Down Syndrome* calls into question both individual and structural issues that contribute to the bias toward people with Down syndrome.

Throughout *Choosing Down Syndrome*, Kaposy writes with transparency. He acknowledges a perceived conflict of interest, the fact that he parents a son with Down syndrome, and handles potential criticism well, demonstrating that this perception is a by-product of the bias he is arguing exists. Further, he admits the faults of the Social Disability Model to which he often alludes. From my perspective, these critiques do not weaken Kaposy's arguments, but rather demonstrate that he has thoroughly considered the validity of his arguments and understands the social and academic context in which he is writing.

While Kaposy acknowledges disabilities other than Down syndrome and explains that they are beyond the scope of this book, a broader context of prenatal testing and disability would lead to a better understanding of populations with disabilities, as well as the Down syndrome advantage, that appears when families of children with Down syndrome function better than families of children with other disabilities. Though passages are occasionally wordy, *Choosing Down Syndrome* is written in accessible language. A shorter, practical and therefore more accessible resource for prospective parents would be a welcome companion to *Choosing Down Syndrome*.

Conflit d'intérêts

Aucun à déclarer

Conflicts of Interest

None to declare

Édition/Editors: Aliya Afhdal & Patrick Gogognon

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Reçu/Received: 22 Oct 2018

Publié/Published: 12 Mar 2019

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1. Kaposy C. *Choosing Down Syndrome: Ethics and New Prenatal Testing Technologies*. The MIT Press; 2018