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Review

A Review of "The Oxford Handbook of Down Syndrome and Development"

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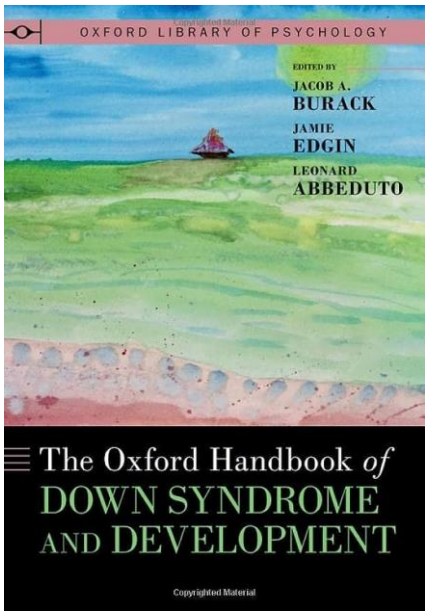

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Down syndrome (DS) is a genetic disorder caused by an extra copy of chromosome 21, and it is the leading genetic cause of intellectual disability (Lubec & Engidawork, 2002). Moreover, it has received considerable attention from researchers for many years (Roch et al., 2020) with interdisciplinary activities significantly developing since the 1950s, both in research and clinical practice (Brown et al., 2022). This condition has had a substantial impact on our society as it has helped raise awareness and sensitization towards intellectual disability and diversity. People with DS and their families have advocated for inclusion and equal opportunities, gradually prompting society to recognize their abilities rather than solely focusing on their limitations.

In Latin America, the reported incidence of DS reaches 1.88 cases per 1,000 live births, and Chile has the highest rate in the region (Nazer & Cifuentes, 2011). This poses significant challenges and requires professionals equipped with the necessary tools to provide focused and effective intervention.

The Oxford Handbook of Down Syndrome and Development, published by Oxford University Press and edited by three distinguished researchers (Jacob Burack, Jamie Edgin, and Leonard Abbeduto) (2023) is an excellent resource for speech-language therapists, researchers, and other healthcare and education professionals seeking to update their knowledge in the field. Additionally, it is the first textbook to integrate the development of people with DS from a global perspective throughout their lifespan, making it a novel contribution to knowledge. Before this publication, most available books focused on a specific area or particular stage of development. The only academic manual published on the global development of people with DS is Children with Down Syndrome: A Developmental Perspective (Cicchetti & Beeghly, 1990). However, said book focuses solely on childhood, thus excluding relevant topics related to adulthood and aging. Furthermore, as expected, the study of Down Syndrome has increased considerably since 1990, both due to the increase in the number of researchers and the advances in methodologies used (Burack et al., 2022).

It is noteworthy that the editors, thanks to their relevant clinical and research backgrounds in neurodevelopmental disorders and intellectual disability, managed to assemble evidence from different fields of study to compose a work of great academic value. Moreover, the preface was written by Professor Sue

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Buckley, an academic and Director of Science and Research at Down Syndrome Education International (DSE).

Two key arguments can be found in the book that define its essence. Firstly, it emphasizes a comprehensive perspective of people with DS. This is evident in the importance placed on understanding environmental factors that influence skill development and in the construction of knowledge about the life experiences of individuals with DS. In turn, this is consistent with the history of the study of people with trisomy 21, started by pioneers Janet Carr and Edward Zigler, who as early as 1963 and 1967 (respectively) emphasized aspects such as well-being and individual factors. Thus, they contributed to a shift in the narrative surrounding DS, from focusing on deficits or limitations to centering the person and their way of being (Burack et al., 2022).

Secondly, the theoretical perspective of viewing DS as a functional adaptive system with a different initial state stands out. The emergent characteristics of DS are adaptations to atypical restrictions, which in turn act as new developmental limitations, and some of these may exacerbate the divergence of trajectories (D'Souza & D'Souza, 2022). Accordingly, various authors in the book highlight the power of research on developmental trajectory or growth models that enables an exploration of the nature of differences and provides a richer vocabulary for characterizing developmental delay (Richardson & Thomas, 2015). When studying developmental disorders, we must understand what changes are occurring and when in order to establish similarities and differences between children with disorders and typically developing children.

The book consists of 24 chapters, comprising theoretical articles and integrative reviews on various areas of development in people with DS, from birth to adulthood. All chapters include a summary that allows the reader to gain an understanding of the breadth of the topics to be covered, and a significant portion begins with a historical contextualization, highlighting the advancements made in each area. The literature reviews are rigorous and culminate with unresolved research questions and projections in the field. The 24 chapters are organized into five thematic sections. The first section, focusing on historical and contemporary scientific approaches, serves as an anchor to understand the entirety of the book, in line with the perspectives and theories presented in these chapters. The second part addresses social development, covering relevant topics in early childhood that emphasize the role of the environment in development, such as dyadic interaction, parenthood, and the influence of siblings. The third section, the most extensive in the book, focuses on cognition and neuropsychology. It encompasses sensory and perceptual development, motor skills, language, and cognitive development, with emphasis on attention, working memory, and executive functions. The fourth section includes chapters on comorbidities, such as cognitive impairment, Alzheimer's disease, and autism spectrum disorder. The final part focuses on interventions and guidelines for the future, reflecting on the gaps in knowledge that exist and the opportunities for the field to make scientific and clinical advances.

There is significant emphasis on language development, with two chapters being dedicated to it: one focuses on its development and another on its intervention (sections 3 and 5, respectively). This is consistent with the profile of relative strengths and weaknesses that characterize DS, as oral language is a marked weakness in relation to cognitive development (Richardson & Thomas, 2015). Indeed, it is among the most affected domains of neurocognitive functioning in persons with DS and could be the greatest barrier to independent living and meaningful community inclusion (Abbeduto et al., 2007).

The chapter on language development begins with a description of typical development, subsequently addressing the prelinguistic and linguistic stages in DS (including phonological, lexical, syntactic, and pragmatic components), and concludes with a brief description of the influence of parents on communicative development. On the other hand, the chapter on intervention consists of a literature review on interventions implemented in children aged 0 to 8 years, focusing on those that follow a naturalistic model (Milieu Teaching) and programs based on Augmentative and Alternative Communication (AAC). This is because, according to the authors, many of the studied therapies are related to these approaches. This synthesis can be of great value for speech-language therapists in selecting evidence-based practices for people with DS.

Finally, I must applaud the last chapter (section 5), which captures the voices of individuals with DS and key stakeholders, who reflect on their life stories. According to the social model of disability, the voice is operationalized as the discourse of those to whom it apparently belongs (people with disabilities, family members, teachers, etc.), and knowledge is produced on this basis (Gómez-Guinart & Infante, 2021). I share the authors' stance that this way of concluding the handbook contributes to making people with DS and their needs and rights visible, placing them as sources of knowledge and inspiration for the readers of this volume.

In light of all the above, I would like to congratulate the editors and the authors of each chapter for their valuable contribution to

the understanding of DS. Reading this textbook will be useful to all those interested in training in this area with a research-based approach, allowing them to provide quality care to people with DS. For all these reasons, this is undeniably a recommendable book.

REFERENCES

Abbeduto, L., Warren, S. F., & Conners, F. A. (2007). Language development in Down syndrome: From the prelinguistic period to the acquisition of literacy. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(3), 247–261. https://doi.org/10.1002/mrdd.20158

Brown, R. I., Kyrkou, M. R., Watchman, K., & Hodapp, R. M. (2022). A Brief History of Down Syndrome: Key Moments and Reflections. En J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford Handbook of Down Syndrome and Development* (p. 0). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.1

Burack, J. A., Edgin, J., & Abbeduto, L. (Eds.). (2023). *The Oxford Handbook of Down Syndrome and Development*. Oxford University Press.

Burack, J. A., Lai, J., Stewart, J., & Landry, O. (2022). Developmental Traditions in the Study of Persons With Down Syndrome. En J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford Handbook of Down Syndrome and Development* (p. 0). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.2

Cicchetti, D., & Beeghly, M. (1990). *Children with Down Syndrome: A Developmental Perspective*. Cambridge University Press.

D'Souza, H., & D'Souza, D. (2022). The Emerging Phenotype in Infants With Down Syndrome: Adaptations to Atypical Constraints. En J. A. Burack, J. O. Edgin, & L. Abbeduto (Eds.), *The Oxford Handbook of Down Syndrome and Development* (p. 0). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190645441.013.34

Gómez-Guinart, K., & Infante, M. (2021). ¿Y si nombramos voz cada minúscula diferencia? Inclusión en jaque: Trayectorias empíricas de la voz desde el modelo social de discapacidad. *Education Policy Analysis Archives*, *29*(January-July), Article January-July. https://doi.org/10.14507/epaa.29.5675

Lubec, G., & Engidawork, E. (2002). The brain in Down syndrome (TRISOMY 21). *Journal of Neurology*, *249*(10), 1347–1356. https://doi.org/10.1007/s00415-002-0799-9

Nazer, J., & Cifuentes, L. (2011). Global epidemiological study of Down's syndrome. *Revista chilena de pediatría*, *82*(2), 105–112. https://doi.org/10.4067/S0370-41062011000200004

Richardson, F. M., & Thomas, M. S. C. (2015). Language development in genetic disorders. En E. L. Bavin & L. R. Naigles (Eds.), *The Cambridge Handbook of Child Language* (pp. 459–471). Cambridge University Press.

Roch, M., Pesciarelli, F., & Leo, I. (2020). How Individuals With Down Syndrome Process Faces and Words Conveying Emotions? Evidence From a Priming Paradigm. *Frontiers in Psychology*, *11*. https://doi.org/10.3389/fpsyg.2020.00692