

## **Book Review of Kimberly Maich & Carmen Hall (2016). *Autism Spectrum Disorder in the Ontario Context: An Introduction. Toronto, ON: Canadian Scholar's Press.***

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### **Introduction**

**A**utism spectrum disorder (ASD) is a neurodevelopmental disorder that includes a combination of a number of symptoms and characteristics. ASD involves challenges with sociocommunicative interactions as well as restricted, repetitive patterns of behaviour. *Autism Spectrum Disorder in the Ontario Context: An Introduction* provides a comprehensive overview of ASD, including its historical roots, past and present views of the disorder, numerous evidence-based interventions (EBIs), a glimpse of ASD across the lifespan, and an examination of Ontario-specific policies and programs related to ASD. The book is intended for anyone working with individuals with ASD. This book is informed by both Kimberly Maich and Carmen Hall's professional and personal experiences with ASD. Maich is a mother to a son with ASD, as well as a professor with teaching interests in special education for students with ASD at Memorial University of Newfoundland. Hall is a professor and the coordinator of a Graduate Certificate Program in Autism and Behavioural Sciences at Fanshawe College.

The book begins with a brief exploration of the history of ASD. Maich and Hall first illustrate how the pioneers of ASD research postulated the origins and causes of autism. The authors list the initial conceptions of ASD, such as "a form of schizophrenia" (p. 5) and "infantile autism" (p. 30). Individuals with autism were seen as "victims of isolating, disengaged, parents" and that autism was "caused by unaffectionate mothers" (p. 9). Accordingly, the book displays how attitudes of autism shifted following the 1960s to include broader definitions; one of these is the current definition, ASD. Recognizing autism as a spectrum disorder acknowledges that its symptoms and characteristics fall along a continuum, and also suggests a highly individualized experience. Current understandings of this condition highlight the variability of the expression of autism in individuals, in severity, abilities, and even personality. Accordingly, the authors characterize autism research and interventions as having a therapeutic focus and working towards improving daily functioning for those on the spectrum.

The book also provides a brief look at ASD across an individual's lifespan. In doing this, the authors emphasize that those with ASD are able to reach life's major milestones, as any "normal" person would. However, what is considered to be normal by society is socially constructed. Social constructions are phenomena or practices to which we (as individuals) give form and meaning, as we live our lives with one another (Diaz-Leon, 2015). Being "normal" means growing up, going to school, making friends, getting a job, and living independently. As this book relies on dominant biomedical understandings of ASD, this implicitly produces understandings of ASD as a disorder "in need of a return to (normative) order" (McGuire, 2011, p. 62). Thus, there is an implicit importance placed on individuals with ASD to have a "normal life," to achieve, and to strive to be productive in mainstream society.

### **Critique**

Descriptions of autism and explanations of its causes have changed considerably since its original conception. Yet, a closer look at the language used in this book helps identify issues with ASD language itself. In general, the language used to describe and explain ASD has powerful effects, which can shape people's perceptions and misconceptions about ASD. For example, through their descriptions of ASD, the authors reinforce the medicalization of ASD. Specific words reflect the medical model of disability, which focuses on what is "wrong" with the individual, with the sole intention of fixing or correcting the illness (Manago, Davis, & Goar, 2017). When describing ASD symptomatology, the authors select the terms unusual, psychosis, mania, and troubled, to name a few. In the second chapter, the authors share a story of a mother who describes autism as "the worst-case scenario," followed by the words "that ominous a-word" (p. 48). Such negative illustrations are common throughout the book. Autism was initially viewed in the early to mid-1900s as a medical problem and its earliest studies emerged exclusively from psychology. Therefore, the terms used to frame ASD as a medical problem or as a threat to be cured continues to be

accepted, used, and reproduced. Here, the authors are, at times, forced to use language they do not always agree with; however, the authors do their best not to simply reduce those with autism to their illness. The authors demonstrate, through their analysis of ASD across the lifespan, that autism is not what someone *has*, but who someone *is*.

Following the historical accounts, the book further describes what the authors identify as the most effective interventions (i.e., EBIs, otherwise known as Evidence-Based Interventions) offered by experts (e.g., qualified therapists, behaviour analysts, trained clinicians, and instructors, etc.). Most interventions are EBIs, while others have not been substantiated as effective or are considered pseudoscientific by experts. The authors provide an extensive discussion of the range of EBIs, divided into communication-based, social skills based, and behaviour-based, each as their own chapter. However, while there seems to be a plethora of autism interventions, missing from this diversity is a focus on sport. For example, Special Olympics Ontario is one context of how sports can be used as an intervention. Special Olympics provides year-round sports programming for individuals with intellectual disabilities, including those with ASD. The benefits include improved physical fitness and conditioning, improved balance and coordination, sensory stimulation, and increased social skills and self-confidence (Special Olympics, 2018). Only recently has research shown the utility of sport for ASD interventions (Moore, Clapham, & Deeney, 2018; Rosso, 2016). Despite this gap in the literature, central to all EBIs are the links to psychology and quantitative research. The EBIs also tend to target important milestones in life that are possible for individuals with ASD, such as pursuing post-secondary education and gaining employment.

The book demonstrates that EBIs are an integral part of daily living for those with autism. Current EBIs (e.g., CBT, reinforcement, time delay, extinction, etc.) are intended for treating autism and changing behaviour to increase desired behaviours and decrease unwanted behaviours. This focus reinforces the medicalization of ASD. While EBIs should not be denied as a useful therapeutic tool, understanding the ways in which they might enhance the lives of individuals with ASD, beyond correcting repetitive and restrictive behaviours, would also be important. In addition, quantitative methodologies are not intended to investigate lived experiences and the meanings ascribed to them by individuals, especially the points of view of those with ASD. Even though the authors summarize each EBI, they fall short in explaining some of the inherent limitations of EBIs. For example, EBIs often emerge from controlled studies; this means that participants are placed in relatively controlled environments, such as a lab or another clinical setting. Evidence derived from a practice setting may not necessarily apply in real life settings (e.g., home, school, extracurricular programs). Thus, the research that contributes to the creation and validation of EBIs needs to have considerations beyond psychological concepts and should also incorporate more mixed methods research. At present, there is a lack of interventions designed by researchers that target non-clinical environments and/or different research methodologies. By not including interventions that go beyond psychology and quantitative research, the book presents numerous interventions that are ironically limited in scope.

In the concluding chapter, Maich and Hall acknowledge that every person, including individuals with autism, “comes with a context” (p. 303). While they do not describe the social context or the factors that affect individuals with autism and their families, they do mention the social model of disability, which understands disability as socially created (Kattari, Lavery, & Hasche, 2017). Unfortunately, the authors do not elaborate how ASD is socially constructed. Here, the book would benefit from drawing on qualitative-based studies, which would in turn perhaps provide a more comprehensive or holistic viewpoint of ASD. For instance, qualitative education researcher Patricia Douglas is leading a new storytelling project (Enacting Autism and Inclusion), which focuses on the knowledge and experiences of individuals with autism, to rethink inclusion in education (Douglas, 2016). Instead of seeing ASD as merely a disease, one can come to understand the lived experiences of those with this condition and their families. It becomes a story about a child who may be struggling with everyday tasks, or families who must negotiate a context that is not always inclusive nor accepting of their child, as well as the challenges they face

## Conclusion

One unique contribution of the book is a look at ASD across the various stages of life. The book also illustrates the everyday realities of individuals living with autism and their families. This is accomplished through the inclusion of stories of parents, service providers, and academics shared through text boxes embedded within each chapter. It also creates an emotional appeal to the readers, helping them understand the realities of people with ASD as individuals. Overall, the book is organized in a way that helps create a picture of what it is like to live or care for someone with ASD.

In sum, the book is a good starting resource for anyone who is interested in learning more about autism, especially for those with personal experiences with ASD, such as parents raising a child with autism or teachers who may encounter students with autism in their classrooms. Students with interests in disability studies, particularly around ASD, may also find this book extremely useful. The Ontario context is important because it provides the reader with not only a local understanding of autism, but it also celebrates Ontario-specific contributions to the autism community. This book places interventions at the fore and even contains several toolkits and online resources towards the end. While it seems like the authors have provided a thoughtful text, the reader must be mindful that certain perspectives have not been considered. What is needed in concert with this book are more sociological perspectives as well as the voices or stories from those with autism themselves.

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