

## Redesign the Ill-Defined

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### Autism Spectrum Disorder and the implications of low socioeconomic status

*Should Autism Spectrum Disorder (ASD) be considered a disability? To analyze the term disability, this paper applied a meta-analysis research approach to examine the contrasting views in disability literature. An extensive literature search and review compared the two perspectives of the term disability (i.e., the social model and the medical model) and furthermore highlighted the relationship between an individual's social barriers and their socioeconomic status (SES) by demonstrating the experience of individuals with ASD living in economically disadvantaged communities. Results determined that individuals with ASD who live in low socioeconomic communities were unable to access effective resources due to social barriers such as stress, stigma, income, and financial aid, which resulted in a disability. In addition, the presented research outcomes have confirmed the importance of social change through ASD advocacy and self-education.*

**Keywords:** Autism Spectrum Disorder (ASD), socioeconomic status (SES), medical model of disability, social model of disability, ableism, disability

#### INTRODUCTION

I was in the first grade when I met Christian I was intrigued by his wit and intellect; he was able to tell time on an analogue clock faster than anyone in the classroom. Something was unique about Christian—he had (what seemed to be) his own teacher named Angie who would assist him during class time. Angie made special accommodations for Christian, but at age six, I was unable to understand why. Being the sensitive individual that I am, I built up the courage to respectfully ask Angie why Christian needed her help, and she replied “Christian has autism, and it is easier for him to do class work if I help him.” Angie’s response was fascinating, and I was determined to educate myself about autism and how it had affected Christian. Later that day, I stayed in for recess to understand Christian’s “atypical” behaviours, I helped him with his schoolwork, and even invited him to my upcoming seventh birthday party. As our friendship developed, I became so much more impressed with



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Christian as he continued to demonstrate exceptional abilities. I was frightened at the thought of knowing that Christian might be overlooked by others because of his unusual behaviours and social challenges. I was afraid that no one would understand Christian like I did; none of my other classmates cared to take the time to acknowledge his capabilities, mainly because, as I now know, his capabilities were concealed by the attributes of traditional education environments. My one-to-one efforts with Christian enabled me to look beyond his surrounding barriers and recognize his potential. Seventeen years ago, I made an implicit promise to Christian that I would continue to advocate for vulnerable populations through the provision of disability research and solutions to barrier-free design. Thus, the significant role that Christian played in my childhood led me to the topic of my article.

Autism Spectrum Disorder (ASD) is a developmental disorder which challenges an individual's social skills, communication, and behaviour (Perry et al., 2013). Challenges of ASD include, but are not limited to, lack of conversational abilities, trouble making eye contact, and sensitivity to various stimuli (Perry et al., 2013). These challenges can range from mild to severe, which in turn create a spectrum of disorders—low functioning refers to severe challenges and high functioning refers to mild challenges (Perry et al., 2013). Most definitions of ASD include the term “disability” to explain such social, communication, and behavioural challenges. For example, a brief definition of ASD provided by Centers for Disease Control and Prevention (CDC) states that “autism spectrum disorder (ASD) is a developmental *disability* [emphasis added]” (CDC, 2020).

In this article, I will argue that the presumed disability of ASD is not the result of a biological disfunction, but rather the result of the stigma created by the term “disability” itself, and by the broader societal barriers that individuals with ASD face (Walker, 1993)—especially when they are also constrained by low socioeconomic status. Socioeconomic status (SES) is quantified by an individual's income, education, and occupation (Chen et al., 2018). For example, low SES suggests low income, low education, and occupations requiring limited to no education, typified by low pay, and sometimes involving laborious working conditions (Chen et al., 2018). When individuals with ASD must also struggle with low SES, the barriers they face in everyday life only become more severe. Hence, this article seeks to examine if low SES contributes to the social and/or physical implications of the term “disability” by analyzing the challenges that an individual with ASD may experience—do the so-called disabilities or challenges associated with ASD result from one's environment? If so, are these barriers exacerbated by SES? I argue that most of the disabilities or challenges associated with ASD are due to social barriers that surround an individual; these barriers are thus exacerbated in low SES communities.

The article is divided into three sections. The first section introduces the social model of disability and contrasts it with an alternative, medical model. The second

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section draws on the social model of disability to show how socioeconomic factors add to the barriers faced by individuals with ASD. The third section introduces a redefined notion of disability by proposing three theoretical interventions and steps to catalyze change.

### MODELS OF DISABILITY

To understand why the term “disability” exists, we must understand how it is discussed in existing literature. There are many ways of conceptualizing disability, but here I will focus on two main models: the medical model of disability and the social model of disability (Berghs et al., 2016). I will use deafness as an example to distinguish the contrasting views of each model.

Consider the medical model as a standard medical approach to medicine—this model defines disabilities as a problem that exists within a person’s body (Goering, 2015). The medical model would argue that a deaf individual has a “deficiency” that prevents them from successfully participating in “normal” social interactions (Power, 2005); from this perspective, this person would require additional treatment or care to “fix the problem,” such as a hearing aid or cochlear implants (Goering, 2015; Power, 2005). In short, the medical model suggests that an individual with a disability requires medical intervention such as medication, technological supplementation or replacement, or physical rehabilitation to mitigate the existing disability (Goering, 2015; Power, 2005).

In contrast to this view, the social model distinguishes *impairments* from *disabilities* (Berghs et al., 2016). That is, the social model conceptualizes an impairment as a “lacking mechanism of the body,” while a disability is a “disadvantage or restriction of activity” (Oliver, 1996). In short, the social model argues that an individual faces debilitating challenges because external obstacles limit the capacity of their impairment (Oliver, 1996). The social model highlights the distinction between impairment and disability, which in turn separates the association between an individual’s cognitive, behavioural, or physical condition and their capabilities. Therefore, it is important to understand the social model as a disconnection, dissociating an individual’s impairment from their capabilities. If a deaf or hard-of-hearing individual is labelled as disabled, their potential is often overlooked due to the negative connotation of the term “disability.” Disentangling the association of the impairment with a disability would diminish the social oppression that one experiences because of their impairment; therefore, it is important to adopt the social model for analysis within any social context.<sup>1</sup>

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<sup>1</sup> The example of deafness used to highlight the distinction between the medical and social models of disability was chosen because of the high level of social segregation between members of the Deaf community and mainstream (hearing) society, and the widely held view that hearing technology can serve as a “remedy” for many hearing impairments. That said, as outlined in Bauman and Murray (2017), contemporary perspectives in the field of disability

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Many researchers and advocates are committed to the social model, and mainly to the idea that society is responsible for the concept of disability (Berghs et al., 2016). According to the Union of the Physically Impaired Against Segregation, a disability is imposed on top of the already existing impairment because associated stigmas unnecessarily isolate and exclude full participation in society (Lott, 2017). A disability is then a presumed inability effected by the social oppression yielded by restrictive barriers and exclusion from societal participation (Oliver & Barnes, 2012). For example, a disability study published by the U.S.-based National Academies of Sciences, Engineering, and Medicine presented data suggesting that the cultural norms that are created within a society severely affect the physical and social environments of an individual with a labelled disability (Brandt & Pope, 1997). More specifically, they explain these cultural norms as a way in which society has constructed environments due to their experience. In short, they suggest that if 78% of the population experiences life in a particular way, any relation between a person and their environment that differs from this will be considered abnormal (Morris et al., 2018).

### ASD AND SOCIOECONOMIC STATUS

With the social model of disability in hand, we are now able to see how it also applies in the context of ASD. For example, an impairment to the social model is like the neurodiversity of brain development in individuals with ASD: it is a variable that cannot be changed (Goering, 2015). However, a disability to the social model would be the inaccessibility to resources necessary for rehabilitation and support (i.e., therapy sessions, individualized learning programs, and funded community supports); this is a variable that *can* be changed (Berghs et al., 2016). If an individual with ASD experiences challenges with independent learning or task completion, the inability to complete the required assignment becomes a disability (Matthews, 2009). Yet, if that individual were provided accommodations, such as one-to-one learning styles, smaller class sizes, or an extension in allotted time, the disability would then be eliminated (Matthews, 2009). In essence, the social model underlines the importance of resource allocation and a barrier-free design to support individuals with ASD (Berghs et al., 2016; Goering, 2015; Matthews, 2009).

Barriers that negatively impact individuals with ASD are strongly impacted by socioeconomic factors, which function as another kind of social barrier. Social barriers are defined as restrictions that relate to the social determinants of an

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studies generally position deafness outside of the realm of disability, “reframing representations of deafness from sensory lack to a form of sensory and cognitive diversity that offers vital contributions to human diversity.” The notion of *Deaf-gain* has been posited in opposition to the impairment-minded concept of *hearing loss*, placing “Deaf communities and their languages within the framework of biocultural diversity” and focusing on the extrinsic value of Deaf communities and their signed languages to understand “the plenitude of human being” (Bauman & Murray, 2017).

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individual's health (Berghs et al., 2016). Some examples of social determinants include income and social status, personal health practices and coping skills, as well as employment and working conditions (Simcoe Muskoka, n.d.). Financial status and stress among individuals with ASD are inevitably worsened in low SES communities simply because they are less likely to be employed (CDC, 2020). In 2017, 35.5% of individuals with a legal disability were employed throughout the United States, while 76.5% of people without legal disabilities were employed (CDC, 2020). That makes the rate of employment of those without a legal disability double that of individuals with a legal disability (CDC, 2020). Burchardt's (2004) research seeks to emphasize that social barriers and individual limitations hinder the autonomy, value of freedom, and earnings among individuals with ASD, variables that the researcher uses as a measure of one's well-being. Burchardt argues that when the social determinants of health of any given person are essentially decreasing because their disabilities are limiting their capacity, their basic human rights are being cheated. She argues that this is unfair and ethically irresponsible of society. That is, social barriers limit human rights because with a lowered SES, an individual is unable to overcome the exclusion caused by the lack of resources.

According to Statistics Canada (2006), parents of children with ASD experience financial disadvantages. Due to the lack of appropriate public care supports, they must often change or reduce their work hours, for they must care for their children more actively. The additional demands that come with having a child with ASD cause increased stress levels, which could ultimately lead to an upturn in developing health problems (Statistics Canada, 2016). What's more, if these children are not getting the appropriate care that they require to be cognitively stimulated and progress, further repercussions could develop (Hoefman, et al., 2014). These demands cause worsening health effects, which lead to an inequitable balance of social determinants, ultimately creating a disability within a social environment (Hoefman et al., 2014). Moreover, those who have children with ASD report higher levels of parental stress compared to parents of children with other developmental impairments (Perry et al., 2013). That is, because cognitively impaired children require extra care, ASD correlates with higher levels of parental stress (Perry et al., 2013). Let's revisit Christian and Angie for example. Christian required Angie's assistance within and beyond the classroom, for not only was Angie's assistance required for Christian's math lessons, but Christian used Angie's support during lunch period. Without Angie's support, Christian would have been unable complete activities independently, establishing a need for extra assistance and supplementary care. The lack of extra assistance and care could ultimately hinder the growth and progression of children with ASD and increase the incapacities of a disability by disallowing children to complete most tasks successfully and effectively (Perry et al., 2013). Therefore, removing social barriers such as income and stress levels would diminish limitations, refine societal inequities, and improve the well-being and

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progression of children with ASD (Statistics Canada, 2006; Hoefman et al., 2014; Perry et al., 2013).

While low SES and stress go hand in hand, it is important to consider that individuals with ASD living in low SES communities experience additional stressors resulting from physical barriers, such as environmental challenges including accessibility and funded initiatives, which can limit their growth and progression.

Physical barriers are defined as structural obstacles in surrounding environments that prevent or block mobility and access (CDC, 2020). Some examples of physical barriers include lack of transportation, resources, and appropriate treatment (CDC, 2020). If we look at the issue of transportation (i.e., cars and public transit), a study conducted by Pendall et al. (2020) shows that individuals who live in low SES communities are less likely to afford a car; this study also shows that automobiles have a positive effect on accessibility to higher paying jobs. Moreover, we must consider how transportation influences accessibility. With a lower SES, transportation is limited because it is likely that an individual living in a lower SES community cannot afford a car. If this individual has a child with ASD who relies on transportation to access necessary healthcare, accessibility will be limited, which therefore creates disabling challenges within the environment. The lack of fundamental necessities such as healthcare, school, and work become a physical barrier, which then creates a disability (Pendall et al., 2020).

### **PUTTING THE SOCIAL MODEL OF ASD INTO PRACTICE**

There are three steps necessary to catalyze effective change: (1) change the way *you* think; (2) advocate for change; and (3) revise enacting policies.

The social model of disability helps us to recognize how society is responsible for the misuse of the term “disability.” If disabilities are socially constructed, then they can be socially dismantled. This notion follows from the idea of norm change, a concept which suggests that moral discussion, or “moral talk,” operates as a tool to change social norms. According to Westra (2021), norm change can alter society’s expectations, which in turn motivates the adoption of new, positive social norms. To deconstruct existing social norms, Westra argues that norm change must convey information about morality in a way that illustrates how people ought to think and act. That is, this change must challenge social norms by endorsing a normative standard about the accepted and unaccepted kinds of behaviour. For example, after reading this paper, you may (or may not) endorse my normative standard about how we should be conceptualizing ASD. Thereafter, you may choose to disseminate this information by telling your peers, educating yourself through various forms of media, or by simply changing your perception on disability literature. As a result, we form an alliance, and become a group of influential norm changers who can surely dismantled the existing social conceptions of ASD. A small adjustment to your belief goes a long way, especially if that small adjustment challenges social norms. In short,

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this change starts with *you*. To efficiently modify existing social constructs, we must challenge social norms, and provide clear, concise, and educational information concerning the benefits of the social model. Moreover, we must provide objective insight to disability literature by discerning the ideas of impairment versus disability by highlighting the existence of social restrictions in surrounding environments, mainly in low SES communities. By changing social norms through the act of moral discussion, we can effectively eliminate the barrier of discrimination by challenging normative reason and behaviours, which will ultimately diffuse the social barriers that separate ASD from success (Westra, 2021).

To paint a clearer picture, let's imagine that we are all influential norm changers who have successfully identified the stigmatizing misconceptions of ASD, but are now looking for the solutions to eliminate barriers. The second necessary step towards modifying existing practices is advocating for change. Advocacy is the "act or process of supporting a cause or a proposal" (Miller et al., 2018). Studies show that formulating a strategic plan is crucial for efficient advocacy (Miller et al., 2018). That is, we must provide tactical practices that will encourage adjustment to social barriers. For example, similar studies have demonstrated the effectiveness of educational campaigns that target human rights activism (Aaron, 2020). An example of such educational campaign is the Autistic Self Advocacy Network (ASAN, 2021). This non-profit organization is run by/for individuals with ASD. Their main objective is to advocate for inclusion in decision-making policies regarding legislation, depiction in the media, and disability services (ASAN, 2021). For example, one of the more monumental initiatives that the ASAN has participated in is the modification in ethical, legal, and social policies concerning ASD research. With the help of Harvard Law School, ASAN put forth a framework that implemented two policies discussing DSM-5 criteria and the impact of proposed changes. These policies addressed the concerns of autism research, such as participation in research methods, intervention goals, and effectiveness, and balanced these concerns with a modified research guideline. Therefore, ASAN was able to effectively modify the existing policies regarding ASD research because of continued support and advocacy. Consequently, by participating in initiatives such as ASAN, we can advocate for change by allowing vulnerable, marginalized groups to be heard.

The most difficult step towards modifying existing practices includes the revision of enacting policies. Existing evidence suggests that practitioners must adopt a revised notion of disability to support the needs of individuals with ASD living in low SES communities. If most life experiences among a society are conceptualized within the parameters of a particular social norm, then any idea or behaviour outside of this social limit will be considered unordinary or atypical. (Morris et al., 2018). Yet, perhaps the reconceptualized understanding of ASD will encourage our societal parameters to extend and include a model of disability that reforms social norms, advocates for change, and refines policies that adhere closely to the social model

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(Morris et al., 2018). In addition, researchers and educational campaigns such as ASAN should be directing their data towards provincial governments to implement ethical strategies that will benefit marginalized groups. It will be difficult, but these necessary modifications will provide life-changing experiences to individuals with ASD, as they undoubtedly deserve.

### CONCLUSION

Christian and Angie illustrated the importance of resources, equity, and opportunity by highlighting the advantages and barriers to Christian's environment. The story of Christian and Angie gave insight to the subjective reality of individual barriers and initiated discussion regarding the adoption of the social model into disability literature and the encouragement of social change. This study concludes that most of the challenges associated with ASD are a direct result of the social barriers that surround that individual and are therefore exacerbated in low SES communities. The examples provided in this article have *shown* that the "disability" of ASD is socially constructed. This article has established many ways in which society can deliver the necessary resources through change, advocacy, and education. If we challenge social norms, advocate for change, and participate in educational campaigns, we can redesign the ill-defined notion of ASD by removing the restricting walls of limited growth and welfare.

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