# 1. Introduction

Health inequalities are a major concern in Israel and globally . The World Health Organization (WHO) aimed to address health inequalities through the “The Global Action Plan for Healthy Lives and Well-being for All” under Article 4, “Social Determinants of Health (SDH)” which was adopted as part of the United Nations’ Sustainable Development Goals (WHO, 2021a). Following the global trend, since 2010, Israel’s Ministry of Health (MoH) has focused on reducing inequalities as one of its strategic aims (Avni, 2016; MoH, 2021a). In the health field, examinations of inequalities, in both policy (Green, Dickinson, Carey & Joyce, 2020) and research (Filc, 2009) often focus on the socioeconomic characteristics of an individual, including ethnicity, gender, social class, immigration status, income, and others. However, disability as a social phenomenon that contributes to health inequalities remains under-investigated. Emerson et al. (2011), who identified this gap in the SDH framework, called for the endorsement of the social model of disabilities (SMD) (Shakespeare, 2006), in SDH research. According to this model, disability is a social construct rather than an inherent characteristic of the individual and that endeavoring to remove societal structures that limit access to resources could contribute toward narrowing this gap in the research and to further reducing health inequalities.

Adopting the position of Emerson et al. (2011), this study investigates autism using the framework of SDH. Autism, also known today as autism spectrum disorders (ASD) or autism spectrum conditions (ASCs) (hereafter, “autism”), is a neurodevelopmental difference[[1]](#footnote-1) defined in the medical literature by three major characteristics: impairment in social interaction; impairment in communication; and restricted, repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2013). While identified as a separate category only in the 1940s (Kanner, 1943), following a rapid rise in diagnoses in the last three decades (Baxter et al., 2015; Raz et al., 2014), autism is now considered one of the most prevalent developmental differences. As a neurodevelopmental difference, autism influences the entire life trajectory of a person from infancy to adulthood (Maddox et al., 2021) and, in the current social context that is structured by and around nonautistic individuals, autism can result in significant disabilities. This project, focuses not on autistic people of all ages but, rather, specifically addresses the discriminating socioeconomic context that marginalizes autistic adults.[[2]](#footnote-2) Autistic people aged 18 and above have thus far largely been neglected by both the autism and the academic communities (Warren et al., 2012; Pellicano, Dinsmore, & Charman, 2014;). There are some who even argue that this lack of attention is the result of a conscious and intentional choice (Ne’eman, 2011).

 Nevertheless, as autism is usually considered a health outcome in the scientific literature and the SDH literature (Trudel-Fitzgerald et al., 2016), and not as a social position,[[3]](#footnote-3) the research stance on autism should be clarified. There are two approaches to defining a social position: a “positive” approach that reveals the social structures that agents from within the social group create, and a “negative” approach that presents the oppression a certain group experiences (Holler, 2018). In the case of autism, both approaches are well-established in the scientific literature. From the “positive” perspective, two factors have contributed to situating autism as a social position: the establishment of the neurodiversity movement, that presents autism as an aspect of human variation rather than as an abnormal mind structure (Jaarsma & Welin, 2012), along with the formation of autistic communities worldwide (Kapp, 2020), including Israel (Gil, Shoham & Shelly, 2016). From the “negative” perspective, marginalization of autistic people in the healthcare system (Mason et al., 2019), and in other areas of life (Gotham et al., 2015), has been reported in numerous studies. In Israel, however, only a handful of studies have demonstrated how the discrimination of autistic adults relates to social determinants in employment (Garar-Bashir, Rivkin & Lef, 2014; Waisman-Nitzan, Gal & Schreuer, 2018) and no study has explored the marginalization of autistic people in the healthcare system. As this study was conducted within the context of the healthcare system, and is directed toward health professionals in Israel, this gap in the literature is addressed by analyzing barriers to healthcare services in Israel faced by autistic people. Showing that autistic people are struggling to overcome barriers unique to their situation in terms of their individual encounters with the system confirms the relevance of this study’s perspective that autism should be regarded as a social position in health research. This type of inquiry corresponds to health inequality research that usually either demonstrates disparities in health outcomes between different social groups, or examines disparities in accessibility to healthcare services.

Nonetheless, investigating health inequalities from the perspective of SDH mandates the investigation of not only the individual barriers to healthcare but, also, the social conditions that determine health. SDH research either tries to identify social factors that influence health or tries to uncover the systemic circumstances affecting a specific social group that deprives them access to known factors that determine good health. For example, access to quality housing is demonstrably linked to good health. Such systemic circumstances that contribute to health outcomes are defined in SDH literature as the “social determinants of health inequalities” (SDHI) (Graham, 2004). In this study, I adopt the SDHI approach to SDH research and examine the sociopolitical context that deprives autistic adults of equitable access to healthcare services they require. This problem facing the autistic community has yet to be explored in Israel.

Yet inequalities do not end with the marginalization of individuals, nor with the systemic marginalization of one social position. As scholars who adopt the analytical framework of intersectionality (López & Gadsden, 2016), including those who are concerned with SDH research (McGibbon & McPherson, 2011), have argued, examining each social position successively obscures the multifaceted discrimination of those whose identities cross more than one discriminated social position. For example, women are certainly discriminated against in our societies (Fogiel-Bijaoui, 2016), but women of color experience further discrimination due to their intersected social position of marginalized gender and marginalized ethnicity (Shields, 2008). Therefore, to comprehensively understand inequalities in relation to autistic adults in the Israeli context, it was necessary to also explore the marginalization of autistic adults whose identities intersect with additional marginalized position(s) in the Israeli context.

While, to the untrained eye, this analytical framework may be seen as merely establishing a hierarchy of discrimination within marginalized groups, scholars have utilized this framework to examine and explain the reasons for inequalities. This framework has been used to expose oppressive social structures and to depict the actions of social actors that attempt to preserve or redistribute power to their own benefit (Dhamoon & Hankivsky, 2011). Employing intersectionality therefore allows for the examination of the causes for inequalities *between* different groups of autistic adults. Exploring the reasons for inequalities between autistic adults can be conducted using diverse methods, among them analyzing the discourses of stakeholders concerning the reasons for inequalities (Avni, 2016), and by investigating the unique characteristics of the field that could have given rise to these discourses. In my study, to fully explore these inequalities, I utilize both methods. The role of autism advocacy organizations that are shown to be influential actors at the autism policy field is investigated by the latter method of examining the field’s unique characteristics(Orsini & Smith, 2010).

## 1.1. Objectives

This project required that I to go down the inequalities “rabbit hole” and examine it in minute detail. My first goal in this study is to expand the scope of scientific literature from its narrow focus on autistic children and autism etiology by shifting the focus toward autistic adults, an exponentially expanding population group (which will grow considerably more in the future given the greater number of youth diagnosed as autistic) that has thus far been neglected by scholarship and policy, especially in Israel. Then, starting by examining autistic adults’ barriers to healthcare services, I aim to investigate the extent to which autistic people are deprived of equal access to healthcare services, while establishing that autism should be regarded as a social position. I then explore whether said social position is systemically marginalized at the sociopolitical level in Israel, that is, whether autistic people are deprived of access to services due to discriminatory social structures.

However, because I adopted an intersectional perspective, in which marginalization must be analyzed in terms of its operation at various levels, further analysis was required to establish patterns of discrimination operating *within* the already marginalized autistic community. Therefore, I examine the unique experiences of autistic people, where their social position intersects with additional marginalized social positions. Finally, drawing on intersectional scholars, I investigate the reasons for these varying degrees of marginalization. I accomplish this by first examining the discourses surrounding the reasons for inequalities, and, second, by examining the role of autism advocacy organizations, as they are an important factor in the autism policy field in terms of contributing toward inequalities within the community, as will be demonstrated further on. Focusing on one case study while changing the lens through which I observe the issue of inequalities allowed me to obtain unique perspectives on this important social phenomenon that presents serious problems to the autism community, as well as to scholars and policy makers in Israel and around the globe.

In addition to the theoretical perspective on inequalities, this inquiry aims to achieve, it also hopes to provide policy makers and the autism community with tools to prevent marginalization. Being the first health system management study focusing on autistic adults in Israel, the hope is to provide policy makers and health professionals with the means to enhance accessibility to the Israeli healthcare system for autistic adults. The investigation of the SDHI of autistic individuals in Israel is aimed at exposing policy flaws that deprive autistic individuals of access to services they need. In this way, I plan to provide autism organizations and policy makers in Israel with a set of recommendations for improving the health and wellbeing of this growing population. The intersectional analysis, which explores the unique marginalization of certain social positions within the autistic community, raises issues that policy makers can address so that current and future policies can assist the *entire* autistic population while narrowing the gaps between autistic people. As the Israeli MoH aims to reduce inequalities, this research project could contribute toward attaining this goal, both by exposing the limitations of current discourses on inequalities in this case of autistic individuals, which might be relevant to other cases of discriminated against populations, and by illustrating the importance of examining inequalities in a contextualized manner to expose specific contributing factors.

## 1.2. Overview of Research Methodology

To achieve these aims, I adopted a critical realism paradigm and conducted a participatory mixed method study. An advisory committee of autistic individuals was established at the initial phases of the study, which reviewed and commented on every step of the process and on research outcomes. Implementing a sequential exploratory design to mixed methods, the first phase was qualitative and included 42 in-depth interviews with autistic adults, their relatives, and professionals from the autism field. These interviews were analyzed using thematic analysis. The analysis of the interviews was accompanied by extensive archival research in the autism field, specifically, the autism policy field in Israel. The quantitative phase included a survey comprised of two questionnaires, one for autistic adults (n=58) and the other for their guardians (n=54), on health needs and barriers to healthcare services. In accordance with the research paradigm and the participatory approach, in addition to the theoretical analysis, this study finally provides policy recommendations.

## 1.3. Chapter overview

The first chapter analyses the autistic individual’s encounter with the healthcare system in Israel. It demonstrates that autistic adults encounter barriers to healthcare services due to their unique autistic traits. Furthermore, it illustrates that these barriers are systemic and not associated with the individual, and that they can be eliminated using suitable mitigation strategies that will improve access for the autistic individual. By showing that it is the system that inflicts barriers (as the SMD claims), I reinforce the argument that autism is a social position from the health research perspective and should be investigated as such within the SDH conceptual framework. I further contend that, in a manner similar to that applied to cultural inequalities, autistic people, and disabled people more broadly, should be framed in the Israeli healthcare system as a social group that deserves equal access to healthcare. To provide the autistic community with a stronger argument for changing this disabling reality, this chapter also briefly discusses the health implications of these barriers and analyzes the mechanisms by which these barriers directly negatively affect the health of autistic people. These mechanisms, I argue, should also be addressed as part of the mitigation efforts of healthcare services.

After establishing that autism also dictates the social position of an individual, alongside ethnicity, gender, and other social determinants, the second chapter moves beyond the individual perspective to the system perspective and analyzes the socioeconomic political context – the SDHI – that influences the individual’s social position in Israel. Drawing on health system management research, the chapter analyzes the gaps in healthcare provision and policy that deprive autistic adults of services that they need. It first analyzes the main reasons neurological differences act as a barrier to healthcare services and why this factor has not been recognized and addressed. Reasons include disabling conceptions within the healthcare systems, and a lack of knowledge among professionals. The chapter then analyses three major healthcare policy issues that significantly affect autistic adults access to the services they need and directly and indirectly affect their health. These are the exclusion of autism from the mental health reform, barriers to the diagnosis of autism in adulthood, and limited public access to additional paramedical services for autistic people. The chapter argues that without contextualizing the experience of autistic adults, their marginality cannot be comprehensively understood.

The third chapter explores the complexity of the question of inequalities using the analytical framework of intersectionality. The chapter examines how the social position of many autistic people is influenced not only by their neurological difference but, also, by additional factors contributing to societal marginalization. Based on qualitative, and some quantitative findings, I illustrate how several intersected identities within the autistic community are further marginalized in the Israeli context. Among these groups are autistic people from underprivileged socioeconomic backgrounds, autistic people who reside in Israel’s periphery, autistic Arabs, ultra-Orthodox autistic people, autistic women, and autistic LGBTQ people. Following this analysis, I argue that, to fully understand inequalities, SDH research must analyze SDHI in a multifaceted manner. After establishing that marginalization of certain groups within the autistic community does exist, the chapter turns to analyzing the discourses on inequalities between autistic adults in Israel. I argue that these discourses are limited; that discourses about cultural differences frame autistic people from discriminated social positions as underdeveloped, and, above all, that these discourses fail to recognize the field-specific mechanisms that foster inequalities. I then demonstrate that the model of demand-oriented service development that is adopted by the authorities entrenches inequalities, and I argue this is one of the mechanisms that current discourses on inequalities fails to recognize.

Since one of the main limitations of current discourses regarding inequalities between autistic adults is the failure to evaluate the unique aspects of the autism field, the fourth chapter analyzes ways in which autism organizations, which are influential actors in the autism policy arena contribute to inequalities. I first examine the social position of the leading representatives of Alut, the largest, oldest, and historically most dominant organization for parents of autistic people in Israel, who claim to represent all autistic people in Israel. My findings support the positions of Raz et al. (2018) and Rimon-Zarfaty et al. (2020) that Alut, as an organization, serves only the parents of autistic individuals and advocates for the medical model of disability and provides solutions for “low functioning” autistic people. I then evaluate the social position of the leading parents through the lens of intersectionality. I demonstrate that the representative parents are from privileged social positions, that is Jewish, high socioeconomic status, and reside in the geographical center of Israel.

As privileged social positions alone cannot explain all the inequalities (despite some interviewees arguing along these lines) I next turned to exploring the effect of the policies regarding autistic adults which Alut has promoted. To do so, I first examined the organization’s influence on policies regarding autistic adults throughout the years and demonstrate that, although the organization’s position within the policy field has changed, it remains very influential. I then analyze the effect on marginalized groups within the autistic community of Alut’s main policy regarding autistic adults: the establishment of permanent residential facilities called “houses for life.” This analysis reveals that this policy both directly and indirectly discriminates against autistic adults whose autism intersects with other marginalized social positions. Based on these analyses, I argue that the over-representation of high-status parents in the structures of Alut contributes to the replication of inequalities between autistic adults by diverting resources to “privileged autistic people.” Nonetheless, in the last section of this chapter, I claim that these parents’ actions cannot be understood outside the discriminatory context in which they operate: a context which neglects the needs of their children altogether. Furthermore, I suggest that the involvement of Alut in reducing inequalities between autistic people in recent years are related to the process Rimon-Zarfaty and colleagues (2020) have identified as the reaction of the founder culture to contextual changes. I conclude my study by discussing the broader implications of my research findings and by suggesting policy recommendations based on these findings.

## 1.4. Research significance

The significance of this study is analytical, methodological, and practical. From an analytical perspective, this research contributes to several fields of knowledge. First, within the scholarly field of health inequalities and SDH, the unique and multifaceted perspective of this study on inequalities further demonstrates the importance of utilizing both the SMD and intersectionality frameworks to advance our knowledge on inequalities and the mechanisms that sustain them. Beyond demonstrating the incompleteness produced when these analytical frameworks are not used in SDH research, the focused exploration of one case study enabled me to highlight deficiencies within accepted reasoning concerning inequalities, such as the culturalist explanation.

Beyond the SDH field, examining the role of autism organizations in contributing to the creation of inequalities between autistic adults provides a novel analytical perspective on autism advocacy organizations and, more broadly, of health social movements (HSM). This analysis also demonstrates how the interplay between representing marginalized social positions and holding privileged social positions might reproduce power hierarchies. Hence, the implications of this analysis reach beyond the HSM and are relevant also to non-profit organizations and other fields of knowledge. Finally, within the autism field, being the first study conducted regarding autistic adults’ health needs and barriers to healthcare services in Israel, this research contributes to the scholarly literature regarding barriers to healthcare services autistic people face, their healthcare needs, and the growing scholarly conversation regarding the influence of local policies and contexts on autistic adults’ life. Moreover, the intersectional perspective I suggest on the autistic adults’ experiences contributes to the scholarship on inequalities between autistic people.

Methodologically, conducting participatory research to study the question of inequalities serves as a contribution to the SDH field, as it incorporates analytical observations with actual reported practices of the oppressed themselves. Furthermore, being the first participatory study conducted with autistic adults in the health sciences in Israel, it paves the road for others to adopt this valuable, ethical practice. Yet, my methodological contribution extends beyond this praxis because, while conducting the research, two methodological flaws that contribute to inequalities themselves were identified and discussed. First, participatory research, despite its ambition to strengthen and support marginalized populations, has the potential to marginalize sections of these populations if not conducted from an intersectional perspective and with the proper adaptations (Weksler-Derri et al., 2019). Second, much like feminist research (Hesse-Biber & Leavy, 2007) there is an urgent need to develop neurodiverse research approaches that take into consideration the unique perspective of autistic people in the conducting of research, failing which research can be marginalizing.

Being the first health-related study regarding autistic adults conducted in Israel, the conclusions and recommendations of the study provide real-world benefits that could and are already serving the investigated autism community. Exposing the barriers to access to healthcare services in Israel faced by autistic adults has already contributed toward the drafting of an accessibility policy for this population that will hopefully soon be adopted by the MoH. The systemic investigation of SDHI exposed practices and policies that marginalized autistic adults. Some of the research recommendations regarding these policies have been already endorsed by the autism community in Israel, which has begun advocacy efforts to have them changed. While inequalities between autistic children, as I illustrate, are being debated in the political arena, the marginalization of autistic adults from discriminated social positions has yet to reach the corridors of the legislature. I hope my findings will be adopted by the autism community and policy makers so gaps can be narrowed. Lastly, although the analysis of the discourse on inequalities and the contributions of advocacy organizations to the continuation of inequalities is focused on autism, its ramifications are much broader. My recommendations to integrate intersectional analysis in policy creation and specifically examine the representative claims of health organizations could assist in reducing future inequalities.

1. I use the term difference instead of disorder to avoid using degrading, ableist, language that implies that autistic individuals are less valuable or abnormal. [↑](#footnote-ref-1)
2. The terms “autistic adults” and “adults who have autism” are both common in the literature. However, the first term was chosen to respect the terminology autistic people prefer for themselves. Some autistic people claim it reflects the fact that autism is an innate characteristic of the person, not an external pathogen or disease that needs to be cured or eliminated (Sinclair, 2012). The second term reflects a more common point of view in the scientific literature which is held mostly by practitioners and parents. This term implies that beneath the autism there is a “hidden person”. This linguistic tension manifests in and influences policy and will be further explored later in the study. [↑](#footnote-ref-2)
3. Solar and Irwin (2010) suggest using the terms “socioeconomic position” or “social position” when discussing the SDH framework. They argue these are general definitions for the diverse social aspects that influence an individual’s agency. In the scientific literature, other terms are employed, including social class, background etc. As this study corresponds with the SDH literature, the term “social position” was chosen to represent be the overarching concept. [↑](#footnote-ref-3)