# 1. Introduction

Health inequalities are a major concern both globally and in Israel. The World Health Organization (WHO) aimed to addressed health inequalities through the “The Global Action Plan for Healthy Lives and Well-being for All” under article 4 “Social Determinants of Health (SDH)” who were adopted following the United Nation sustainable development goals (WHO,2021a). In Israel, following the global concern, the Ministry of Health (MoH) have chosen since 2010 reducing inequalities as one of its strategic aims that directs the ministry activities (MoH, 2021a; Avni, 2016). Inequalities when referred to in the health field both in policy (Green, Dickinson, Carey & Joyce, 2020) and research (Filc, 2009) often examine socioeconomic characteristics of an individual including ethnicity, gender, social class, immigration status, income, and others, leaving disability as a social phenomenon that contributes to health inequalities under investigated. Emerson and colleagues (2011) who had identified this gap in the SDH framework, called for the endorsement of the social model of disabilities (SMD; Shakespeare, 2006), in SDH research. This model that asserts disability is a social construct that reflect not an inherent characteristic of the individual but disabling society structures that prevents access to resources from different individuals, can assist to narrow this gap in research and reduce health inequlities.

Adopting the position of Emerson and his colleagues (2011), this research asks to investigate 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). Although identified as a separate entity only in the 1940’s (Kanner, 1943), today after rapid rise in diagnosis in the last three decades (Baxter et al., 2015; Raz et al., 2014) autism is considered one of the most prevalent developmental differences. As a neurodevelopmental difference autism influence the entire life trajectory from infancy to adulthood (Maddox, Dickson, Stadnick, Mandell, & Brookman-Frazee, 2021); and in the current social context that is structured by unautistic individuals, autism can result in significant disability. This project, however, not focuses on autistics from all ages, but on the discriminating socioeconomic context that marginalize autistic adults.[[2]](#footnote-2) This age group of autistic older than 18, had been hitherto largely neglected by the autism and the academic communities (Pellicano, Dinsmore, & Charman, 2014; Warren et al., 2012), some would argue knowingly and intentionally (Ne’eman, 2011).

Nevertheless, as autism is usually considered in the scientific literature and the SDH literature as health outcome (Trudel-Fitzgerald, Chen, Singh, Okereke & Kubzansky, 2016) and not as a social group or more accurately a social position,[[3]](#footnote-3) the research stance on autism should be clarified. There are two approaches to define a social position as such, a “positive” that demonstrate the social structures the agents from a social group create, and a “negative” that present the oppression certain group experience that defined it as one (Holler, 2018). In the case of autism both approaches have been well established in the scientific literature. From the “positive” perspective the establishment of the neurodiversity movement that assert autism is part of human variation not an abnormal mind structure (Jaarsma & Welin, 2012) and the formation of autistic communities worldwide (Kapp, 2020) and in Israel (Gil, Shoham & Shelly, 2016), situate autism as a social position. From the “negative” perspective marginalization of autistics in the healthcare system (Mason et al., 2019) and in other areas of life (Gotham et al., 2015) had been shown in numerus studies. In Israel, however, only handful of studies had shown the discrimination of autistic in relate to social determinants (in employment: Waisman-Nitzan, Gal & Schreuer, 2018; Garar-Bashir, Rivkin & Lef, 2014) and no study have explored autistic marginalization in the healthcare system. As this research was conducted from the prism of the healthcare system and is directed for health professionals in Israel, this gap in the literature was the first to be addressed by analyzing the autistic individual’s barriers to healthcare services in Israel. Showing that autistics are struggling to overcome unique barriers in their individual encounter with the system, establishes my research standpoint that autism should be regarded in health research as a social position. This type of inquiry corresponds with health inequlities research that usually either tries to demonstrate disparities in health outcomes between different social groups or try to examine disparities in accessibility to healthcare services.

Nonetheless, investigating health inequlities from the perspective of SDH mandate exploration not only of the individual barriers to healthcare but the social conditions that determine health. SDH research either tries to identify social factors that influence health, for example housing, by demonstrating it affect health outcomes, or try to demonstrate the systemic circumstances affecting a specific social group that deprive them access to known factors that determine health. The latter is defined in SDH literature as social determinants of health inequlities (SDHI; Graham, 2004). My research adopts the SDHI approach to SDH research and examines the sociopolitical context that deprive autistic adults from access to needed healthcare services. This context has never been explored in Israel regarding autistic adults.

Yet, inequlities does not end at the individual marginalization, nor at the systemic marginalization of one social position. As scholars who adopts the analytical framework of intersectionality (López & Gadsden, 2016), including those who concern with SDH research (McGibbon & McPherson, 2011), have argued, examining one social position at a time misses the multifaceted discrimination of those whose identities crisscross more than one discriminated social position. For example, women are no doughty discriminated in our societies (Fogiel-Bijaoui, 2016), yet women of color experience further discrimination due to their intersected social position of marginalized gender and marginalized ethnicity (Shields, 2008). Therefore, to comprehensively understand inequlities in relation to autistic adults in the Israeli context it was necessary to also explore the marginalization of autistic adults that their identity intersect with additional marginalized position(s) in the Israeli context.

Although to the untrained eye the purpose of this analytical framework might seem to merely draft a hierarchy of discrimination within marginalized groups, scholars have utilized this framework to examine and comprehend the reasons for inequlities. Among those reasons, the usage of this framework allowed to expose oppressive social structures and to depict the actions of social actors that attempt to preserve or redistribute power (Dhamoon & Hankivsky, 2011). In light of this perception employing intersectionality mandate examination of the causes for inequlities *between* different groups of autistic adults, if those are identified. Exploring the reasons for inequlities between autistic adults could be conducted by diverse methods among them are analyzing the discourses of stakeholder on the reasons of inequlities (Avni, 2016), and by investigating the unique characteristic of the field that could have affect them. In my research, to get to the roots of inequlities, I utilize both methods, while in the latter I investigate the role of autism advocacy organizations that are shown to be influential actors at the autism policy field (Orsini & Smith, 2010).

## 1.1. Objectives

This project requested to go down the inequalities “rabbit hole” and examine it through and through. Framing my investigation as dealing with autistic adults, an exponentially expanding population group that have been hitherto largely neglected from scholarly and policy especially in Israel, my first goal was to narrow the unequal focus of the scientific literature on autistic children and autism etiology. Then starting by examining the autistic adult individual’s barriers to healthcare services, I aimed to demonstrate autistics are deprived from equal access to healthcare services, while establishing autism should be regarded as a social position. I next intended to explore whether this position is systemically marginalized at the sociopolitical context in Israel, or in different words whether autistics are deprived of access to needed services due to discriminative social structures.

However, if adopting an intersectional perspective as I did in this research, marginalization cannot be regarded as one entity, and further analysis of the unequal distribution of the marginalize structure’s effect on autistics was needed. Therefore, I aimed to examine the unique experiences of autistics that their social position is intersected with additional marginalized social positions. Finally, following intersectional scholars, I aimed to investigate the reasons for the unequal distribution of marginalization. First by examining the discourses on the reasons for inequlities; and second by examining the role of autism advocacy organizations, which are an important actor in the autism policy field, in contributing to inequlities. Focusing on one case study while changing the lens by which I observe the issue of inequlities was meant to allow me to acquire unique perspectives on this influential social phenomenon that trouble scholars and policy makers in Israel and around the globe.

In addition to the theoretical perspective on inequlities this inquiry meant to achieve, it also aimed to provide policy makers and the autism community tools to prevent marginalization. Being the first health system management research who focuses on autistic adults in Israel, I aimed to provide policy maker and health professionals means to enhance the accessibility of autistic adults to the Israeli healthcare system. The investigation of the SDHI of autistic individuals in Israel meant to expose policy issues that deprive autistic individuals from access to services they need. Thus, providing autism organizations and policy makers in Israel a set of issues that should be addressed in the following years to improve the health and wellbeing of this growing population. The intersectional analysis, which aimed to explore the unique marginalization of certain social positions within the autistic community, aimed to depict issues that policy makers could address so current and future policies will assist the *entire* autistic population while narrowing the gaps between autistics and not further widening it. As the Israeli MoH aims to reduce inequlities, while this whole research project could assist reaching this goal the examination of the reasons for inequlities intended to expand the understanding of those handling this issue. This was aimed to achieve both by exposing the limitations of current discourses on inequlities in this case, which might be relevant also to other cases, and by illustrating the importance examining inequlities in contextual manner to expose specific influential 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 research outcomes. Implementing a sequential exploratory design to mix-methods, the first phase was qualitative and included 42 in-depth interviews with autistic adults, their relatives and professionals from the autism field analyzed using thematic analysis. These interviews were accompanied by an extensive archival work on the autism field and specifically autism policy field in Israel. The quantitative phase included a survey that had 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 theoretical analysis this research 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 owing their unique autistic traits. Furthermore, it illustrates these barriers are systemic and not intrinsic to the individual and that they can be dismantle using suitable mitigation strategies that will dis-disable the autistic individual. By showing it is the system that inflicts barriers as the SMD claim, I reinforce the argument that autism is social position also from health research perspective and should be investigated as such by the SDH conceptual framework. I further argue that like cultural inequlities, autism and to further extent disability should be framed in the Israeli healthcare system as a social group that deserve equal access to healthcare. To provide the autistic community with a stronger argument for changing this disabling reality, the chapter also briefly discusses the health implications of these barriers and analyses the mechanisms by which these barriers directly negatively affect the health of autistics. These mechanisms, I argue, should also be addressed as part of the mitigation efforts of healthcare services.

After establishing autism also dictates the social position of an individual alongside ethnicity, gender, and other social denominators, the second chapter move beyond the individual perspective to the system perspective and asks to analyze the socioeconomic political context that influence this position in Israel – the SDHI. Coming from a position of health system management research the chapter analyzes the gaps in healthcare provision and policy that deprive autistic adults needed services. It first analyses the main reasons the neurological differences that dictates act as a barrier to healthcare services has yet been recognized and addressed, including disabling conceptions within the healthcare systems, and lack of knowledge among professionals. Then the chapter analyses three major healthcare policy issues that immensely effect autistic adults access to needed services and directly and indirectly affect their health: the exclusion of autism from the mental health reform, preventing diagnosis of autism in adulthood and limited public access to additional paramedical services. The chapter argues that without contextualizing the experience of autistic adults their marginality could not be comprehensively understood.

The third chapter further complicate the question of inequalities using the analytical framework of intersectionality. The chapter explores how the social position of autistic individuals that their personal identity crisscrosses their neurological difference with additional marginalized social position is affected. It first illustrates based on qualitative and some quantitative findings several intersected identities are further marginalized in the Israeli context. Among these groups are autistics from low socioeconomic status, autistics who reside in Israel periphery, Arab autistics, Ultraorthodox autistics, autistic women, and autistics from the LGBTQ community. Following this analysis, I argue that to fully understand inequalities SDH research must analyze SDHI in a multifaceted manner. After establishing there is marginalization of certain groups within the autistic community, the chapter turn to analyze the discourses on inequalities between autistic adults in Israel. I argue these discourses are limited, that the discourse on cultural differences mark autistics from discriminated social positions as underdeveloped, and above all these discourses fail to recognize the field specific mechanisms that nurture inequalities. I then demonstrate the demand-oriented services development, that is adopted by the authorities, nurture inequlities, and I argue this is one of the mechanisms that current discourses on inequlities fail to recognize.

Since one of the main limitations of current discourses regarding inequlities between autistic adults is the failure to evaluate the unique aspects of the autism field, the fourth chapter request to analyze the contribution to inequlities of autism organizations which are an influential actor in the autism policy arena. I first examine the social position of the leading representatives of Alut, the largest, oldest, and historically most dominant parent organization in Israel, who claimed to be the representative of all autistics in Israel. I demonstrate my findings support the position of Alut suggested by Raz and colleagues (2018) and Rimon-Zarfaty, Raz, Bar-Nadav & Vaintropov (2020) in relation to organizational and intrinsic autism field axes, that is an organization only of parents *for* autistics, that both advocate for and provide medical model of disability solutions for “low functioning” autistics. Then I turn to evaluate the social position of the leading parents using intersectional lens. I demonstrate the representative parents were from privileged social position, that is Jewish, from high socioeconomic status, and residing in the geographical center of Israel.

As privilege social position alone cannot explain by itself contribution to inequlities, despite being argued by interviewees, I next turn to explore the effect of the policies regarding autistic adults Alut have promoted. To do so I first examine the organization influence on policies regarding autistic adults throughout the years and demonstrate that although the organization position within the policy field had changed it remined very important. Then I analyze the effect of the main policy regarding autistic adults Alut have promoted, the establishment of permanent residential facilities called ‘houses for life’, on marginalized groups within the autistic community. This analysis reveals that both directly and indirectly this policy discriminated autistic adults that their social position intersect autism with marginalized groups. Following these analytical steps, I argue that Alut’s representatives intersected identity that combined the marginalized identity of parents of autistics with privileged social positions contributed to the creation of inequlities between autistic adults, by diverting resources to “privileged” autistics. Nonetheless, at the last section of this chapter I claim, these parents’ actions could not be understood outside the discriminative context they operated in, which neglected the needs of their children altogether. Furthermore, I suggest that the involvement of Alut in reducing between autistics inequalities in recent years are related to the process Rimon-Zarfaty and colleagues (2020) have identified as the founder culture reaction to environmental changes. I conclude my work by discussing the broader implications of my research findings and by suggesting policy recommendations based on these findings.

## 1.4. Research significance

This research significance is analytical, methodological and practical. From an analytical perspective this research contributes to several fields of knowledge. First, within the scholarly of health inequalities and SDH this research unique and multifaceted perspective on inequlities further demonstrates the importance to utilize both the SMD and intersectionality framework to advance our knowledge on inequlities and the mechanism that nourish them. Beyond demonstrating the incomplete understanding avoiding the use of these analytical frameworks in SDH research produce, the focused exploration of one case study allowed me to highlight blind spots within accepted reasoning to inequlities such as the culturalist explanation.

Beyond the SDH field, examining the role of autism organizations in contributing to the creation of inequlities between autistic adults provide a novel analytical perspective on autism advocacy organization 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 research conducted regarding autistic adults’ health needs and barriers to healthcare services in Israel this research contributes to the scholarly regarding barriers of autistics to healthcare services, their healthcare needs and the growing scholarly regarding the influence of local policies and context on autistic adults’ life. Moreover, the intersectional perspective I suggest on the autistic adults’ experience contribute to the scholarly on inequlities between autistics.

Methodologically, conducting participatory research to study the question of inequalities is in itself serve as a contribution to the SDH field as it entangles the analytical observation with hand-on practice of the oppressed themselves. Furthermore, being the first participatory research conducted with autistic adults in health sciences in Israel, it paves the road for other to adopt this important, ethical practice. Yet, my methodological contribution is beyond the praxis itself as during the research conduction process two methodological flaws that themselves contribute to inequalities were identified and discussed. First, participatory research despite its ambition to strengthen marginalized populations has a potential to marginalize sections of these population if not conducted from an intersectional lens and with the proper modification (Weksler-Derri et al., 2019). Second, much like feminist research (Hesse-Biber & Leavy, 2007) there is an urgent need to develop neurodiverse research approach that will take in consideration the unique perspective of autistics in research conduction, otherwise research can be marginalizing.

Being the first health-related research regarding autistic adults conducted in Israel its conclusions and recommendations provides real-world benefit that could and is already serving the investigated autism community. Exposing the barriers of autistic adults to access healthcare services in Israel have already assisted in drafting accessibility policy for this populations that will hopefully be adopted soon 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 who started to advocate to change them. While inequalities between autistic children, as I illustrate, is being debated in the political arena the marginalization of autistic adults from discriminated social position have yet reach the corridors of the parliament; my findings I hope will be adopted by the autism community and policy makers so gaps could be narrowed. Lastly, although the analysis of the discourse on inequlities and the contribution advocacy organizations had to inequlities is focused on the autism case, its ramification as I discuss are much broader. The recommendations I suggest following my conclusions to integrate intersectional analysis in policy conduction 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 situate autistic person as the less valuable, as an abnormal entity. [↑](#footnote-ref-1)
2. The terms 'autistic adults' and 'adults who has autism' are both common in the literature. However, the first term was chosen to respect the terminology autistics persons prefer for themselves. Some autistics claim it reflects the fact that autism is an innate character of the person, not an external pathogen or disease that need to cure or eliminated (Sinclair, 2012). The second term is reflecting a more common point of view in the scientific literature which is mostly held by practitioners and parents. This term asserts that beneath the autism there is a 'hidden person'. This linguistic tension’s manifestations in policy will be further explored later in text. [↑](#footnote-ref-2)
3. Solar and Irwin (2010) discuss as part of the SDH framework they suggest the term socioeconomic position (or social position). They argue it is general definition for the diverse social aspects that influence the individual’s agency. In the scientific literature other terms are utilized including social class, background etc. As this research corresponds with the SDH literature this term was chosen to represent be the overarching term. [↑](#footnote-ref-3)