# 8. Discussion

Using a mixed method approach, this dissertation analyzed the field of autistic adult health in Israel for two important reasons. First, it may contribute towards improving the lives of *all* autistic adults in Israel who are, as my research argues, a diverse, underserved marginalized social group which includes several discriminated sub-groups within it. Secondly, this study may contribute to our understanding of the manifestations of health inequalities and the mechanisms that contribute to their formation. To achieve these aims, I applied three theoretical frameworks that lend themselves well to a discussion of health inequalities: from public health literature – the social determinants of health framework (SDH) (Solar & Irwin, 2010); from disability studies – the social model of disability (SMD) (Barnes, 2020), and, from sociology – the concept of intersectionality (Dhamoon & Hankivsky, 2011).

Being the first study to explore autistic adult health in Israel, my findings, first and foremost, contribute to the gradually expanding, yet still limited, field of autistic adults research (Kirby & McDonald, 2021; Nicolaidis, 2019). In addition, the study provides a novel perspective on inequalities between autistic adults, which have received scant attention in the scientific literature (Bishop-Fitzpatrick & Kind, 2017; Singh & Bunyak, 2019), while offering new insights on the operations of autism organizations in Israel that complement the existing literature (Raz et al., 2018; Rimon-Zarfaty et al., 2020). Moreover, beyond contributing to the field of autistic adult health in Israel, my research provides a distinct analytical approach that, I argue, should be adopted within the fields of autism, SDH, and HSMs, and regarding health inequalities. As such, the contribution of this research is also theoretical. Finally, conducting the first participatory health study with autistic adults in Israel, I was able to formulate additional methodological insights that have broader implications for participatory and health research.

In line with the three domains to which this study has contributed, the closing chapter is organized as follows. The first section describes my empirical contribution to the investigated fields of knowledge. The second section reviews my main theoretical contribution to health inequalities research. This is complemented by a model that portrays the analytical approach I adopted, which, I believe, could be applied more broadly to further enhance our understanding of health inequalities. The methodological insights of this study are then discussed. I conclude this chapter by discussing the limitations of this study and providing some closing remarks. The next chapter details the policy implications of my findings.

## 8.1. Empirical findings summary

This section discusses the empirical contributions of this study to the scientific literature. I present the value of my findings and discuss their contributions and implications.

### 8.1.1. Accessibility barriers to healthcare services faced by autistic adults

In the first chapter, I demonstrated that autistic individuals suffer from barriers in access to healthcare services and connected bureaucratic processes in Israel, and argue, based on these findings, that autistic people should be regarded as a distinct social group. My analysis classified the accessibility barriers that were identified into three main categories that correspond with the unique traits of autism according to official diagnostic descriptors (APA, 2013): communication differences, repetitive behaviors, and sensory differences. Among the features that characterize the communication style of autistic individuals and, in turn, become barriers for communicating with healthcare services, the following were found: distinct rationales for communication; difficulties in expression; longer processing times; alternative modes of communications; difficulties with the concretization of the message, and difficulties in asking for assistance. Next, familiarity and a need for certainty, which is a manifestation of the repetitive behavior trait, was identified as an accessibility barrier. Finally, sensory barriers, including overwhelming sensory experiences and misunderstanding and misinterpretation of symptoms by the individual and by healthcare providers were also identified. While this study is the first to explore accessibility barriers in the unique cultural and structural context of Israel, it should be stressed that similar barriers have been identified in the other contexts (Calleja et al., 2020; Mason et al., 2019; Walsh et al., 2020), albeit with nuances in their articulation within the healthcare systems in question.

The survey findings exemplify the magnitude of these accessibility barriers and the urgency of addressing the issue. A worrying 74.4% of responders reported they experience four barriers or more, and 42.5% reported ten barriers or more in their responses to the autistic barriers short form used in this study, which was adopted from previous research on barriers (Raymaker et al., 2017). Moreover, some barriers were identified by more than 50% of respondents, including– difficulties with filling in paperwork (67.7%); difficulties in understanding the processes of the healthcare system (61.7%); difficulties in scheduling appointments (58.5%); difficulties being in a waiting area (56.3%); difficulties translating physicians’ requests into actions (53.2%); and difficulties in following examination and treatment continuation (53.2%). These barriers, most of which could be addressed by introducing accessible working processes into the healthcare system, should be addressed first. In addition, the survey findings indicate that communication and bureaucratic difficulties constitute barriers to mental health and allied health services specifically, signifying that there are accessibility barriers across the Israeli healthcare system. Lastly, the fact that 20% of the survey responders continued to visit their pediatricians in adulthood, even past the age of 30, is strong evidence of the importance of actively addressing the need for familiarity and certainty so barriers to healthcare services can be removed. These quantitative findings correspond with the findings of similar surveys conducted among autistic adults in other countries (Doherty et al., 2020; Raymaker et al., 2017). However, when comparing the frequency of accessibility barriers that were reported, the percentages of reported total barriers and specific barriers are higher among Israeli respondents, which might signify the healthcare system in Israel is less accessible for autistic individuals than in other countries.

My analysis of accessibility barriers adds two additional complementary perspectives that could contribute to overcoming these barriers. First, it includes, like most qualitative research on accessibility barriers, coping strategies for autistic adults and parents of adults. Such strategies include, for example, detailed preparation before medical procedures; having a mediator present at the medical encounter, and extending the length of the visits with the provider (see additional strategies in the next chapter which deal with policy recommendations). Most of these strategies correspond with those presented in the scientific literature (Dern & Sappok, 2016; Nicolaidis et al., 2015; Walsh et al., 2020). Secondly, my analysis adds an exploration of the mechanisms by which these barriers affect health. Three mechanisms were identified: providing unsuitable care; avoidance of care, and using restraints to provide treatments. Although this type of analysis is absent from most literature exploring barriers to healthcare services faced by autistic individuals, other research concerning the utilization of healthcare services by autistic adults has identified the prevalence of the use of avoidance (Lum, Garnett & O’Connor, 2014; Strömberg, Liman, Bang & Igelström, 2021), and restraints (Lunsky et al., 2015; Tint et al., 2019) with autistic adults. I argue that these mechanisms should be independently addressed by policy makers and be used as a measurement of programs that aim to reduce barriers.

Accessibility barriers to healthcare services affect autistic adults around the globe and, as my research demonstrates, in Israel. These barriers, as my findings indicate, substantially affect most of the autistic population and have a negative effect on their health (Fortuna et al., 2015; Hirvikoski et al., 2018; Hwang et al., 2019), and quality of life (Roestorf, Howlin, & Bowler, 2021). Access to the healthcare systems can be improved by adopting structural changes, suitable interventions, and providing accommodations . Moreover, as part of the broader analytical approach I adopt in this study, I argue, based on my findings demonstrating that accessibility barriers stem from the unique traits of autism, that autistic people should be regarded by health authorities as a distinct social group. As such, efforts that are applied to reduce inequalities within the system, for example, by addressing cultural barriers, should be applied to barriers experienced by autistic people in order to provide them with equal access. This perception of autism corresponds with SMD, and the scientific literature concerning neurodiversity and the autistic community (Gil, Shoham, Shelly, 2016; Jaarsma & Welin, 2012; Runswick-Cole, 2014).

### 8.1.2. Discrimination faced by autistic adults in the Israeli healthcare system: The sociopolitical context

The second chapter of the dissertation moves on from the barriers autistic individuals face in their encounters with the healthcare system to the broader sociopolitical context that deprives autistic individuals of equal access to the healthcare system– the social determinants of health inequalities (SDHI) (Graham, 2004). I have identified three systemic factors that limit the introduction of mitigation strategies to enhance autistic adults’ access to the healthcare system in Israel, and an additional three SDHIs that deprive autistic individuals of equal access to public resources.

Among the factors that limit the introduction of mitigating measures are two marginalizing perceptions held at the administrative level and by professionals working in the healthcare system – the idea that autism is a disease that requires treatment as opposed to mitigation, and the concept that disability is physical only demanding structural mitigations, leaving invisible disabilities unrecognized and mitigations in service provision lacking. The lack of knowledge on the part of professionals across the healthcare system was recognized as another SDHI that limits the introduction of mitigation strategies. Its implications, both on the provision of unsuitable care and the diversion of autistic adults to child therapists, was also covered, illustrating additional ramifications of this SDHI. Similar limiting factors have been identified in previous research, but marginalizing perceptions have been classified under the broad umbrella of stigma, and have been regarded as barriers at the professional level, and not as a systemic issues (Calleja et al., 2020; Doherty et al., 2020; Malik-Soni et al., 2021; Mason et al., 2019; Nicolaidis et al., 2015; Walsh et al., 2020; ). Reframing these issues as systemic, in terms of the SDHI perspective, was, in my estimation, essential since it enabled me to identify the roots of the inequalities at the systemic level and provide systemic recommendations to address these marginalizing factors. Although, following recent efforts that I mention in Chapter 2, these factors are gradually starting to change, there remains much to be done to eliminate accessibility barriers.

Additional SDHI that were identified in Chapter 2 as factors that deprive autistic adults of equal access to resources are poor mental health policies and the lack of provision of allied healthcare services in adulthood. The exclusion of autism from Israel’s comprehensive mental health reform was identified as a major SDHI that resulted in several policy failures. These include, blocking mental health support for non-pathologically defined mental illnesses; the over-diagnosis of mental health disorders; the need to choose between different rehabilitation services; setbacks in autism training provision; and an approach to care that separates the body and the mind. While these policies were enacted in the Israeli context, their ramifications are similar to systemic barriers identified in other contexts (Debra et al., 2021; Corden, Brewer & Cage, 2021 Walsh et al., 2020; Zeidan et al., 2019). The effects of these marginalizing circumstances on health are exacerbated by the substantial mental healthcare needs of autistic adults. These needs, as both my qualitative and quantitative findings demonstrate, are considerable and apply across the spectrum. In the survey, 91% and 54.4% of respondents had been treated or diagnosed with one additional or two or more additional mental health disabilities respectively and 54.8% reported receiving mental healthcare in a community setting. These extensive needs, which have been comprehensively identified in Israel for the first time by this study (on individuals with Asperger in Israel, see Drori, 2015), correspond with those found in the international scientific literature regarding autistic adults (Fortuna et al., 2015; Hossain et al., 2020; Lai et al., 2019; Weiss et al., 2018; Zerbo et al., 2019) and is considerably higher than reported in general population in Israel (Elroee, Rozen, Elmakaias & Samuel, 2017).

The second mental health related SDHI that was identified concerns difficulties acquiring an autism diagnosis in adulthood through the public healthcare system in Israel. This lack of policy was found to have several implications. On the personal level, it keeps undiagnosed autistic adults in a continuous state of confusion and suffering from unmet needs, while also preventing them from obtaining access to appropriate services and relief offered by autism organizations. At the population-wide level, it has created a costly private diagnosis market, and left diagnosis procedures unregulated. While these results are a consequence of local policy, the scientific literature demonstrates that autistic adults from other countries suffer from similar barriers to diagnosis with similar adverse effects (Arnold et al., 2020; Crane et al., 2018b; Huang et al., 2021; Leedham et al., 2020; Lewis, 2017). Given that the survey findings indicate that diagnosis in adulthood is prevalent, with about 20% of respondents being diagnosed in adulthood, this issue cannot be ignored.

Finally, similarly to other contexts, a lack of designated support for autistic adults was identified as another SDHI in Israel. Specifically, my findings demonstrate that autistic adults are either not formally entitled to allied health services at all or only entitled to limited services through programs in which they participate. Among survey responders, 64% identified three or more unmet or insufficiently met needs for services with, social counseling (45%); communication assistance (40.4%); sexual counseling (38.2%); speech therapy (31.5%), and occupational therapies (31.4%), being the most needed. These findings correspond with findings of needs assessment surveys conducted in other countries, with some differences in terms of specific services (Bureau of Autism Services, 2011c; Lai & Weiss, 2017; Turcotte et al., 2016). Furthermore, despite the common presumption in Israel that these services are not warranted in adulthood, my qualitative inquiry demonstrated that they are actually needed across the spectrum and that they should be tailored to the changing needs of the individual, a notion that has also been recognized in previous research (Hillier et al., 2021; Thompson et al. 2018). This discrepancy between needs and available services was reported despite the fact that, according to the survey findings, 80% of respondents used private funding to get services. It should be noted that, in contrast to the other SDHI identified above, the lack of allied healthcare services, does not necessarily directly affect health outcomes despite being provided for or regulated by the MoH and, therefore, related to the healthcare system. These services are needed to ensure quality of life and, more importantly, full participation in community (United Nations, 2006). This full participation demands that they enjoy equal access to other social determinants of health, such as employment or housing, which were identified as having a direct effect on autistic adults’ health (Benach et al., 2014; Dudley et al., 2019).

This part of my study, which joins both the continuous attempts of scholars and policy makers to understand what policies would best address autistic adults needs (see, for example, the Autism Policies research of the AIMS-2-TRAILS, 2021), and the efforts to identify barriers of autistic individuals to resources, is the first to be conducted in Israel. Unfortunately, it demonstrates that the sociopolitical context in Israel marginalizes the autistic adult population in many areas related to the healthcare system. Therefore, to address health inequalities, policy makers should consider amendments to the above-identified policies, as recommended in the next chapter.

### 8.1.3. Marginalized within the marginalized – discriminated social groups among autistic adults

Employing an intersectional perspective, in the third chapter of my dissertation, I demonstrate that autistic adults from discriminated social groups are further marginalized in the Israeli sociopolitical context. That is, the marginalization of autistic adults described above does not affect all autistic people in the same way. Those who belong to lower socioeconomic groups, residents of the periphery of Israel, members of the Arab and ultra-Orthodox communities, women, and those from the LBGTQ community are all further deprived of the already limited resources available to autistic adults in Israel or have additional unmet needs. My study is the first to have demonstrated inequalities in service provision among autistic adults in Israel, and it adds to the limited scientific literature that has examined inequalities between adults within the autistic community (Bishop-Fitzpatrick & Kind, 2017; Singh & Bunyak, 2019).

My findings show that those from lower socioeconomic classes are deprived of services due to financial constraints and a lack of accessible information regarding services. This signifies that social capital is a mediator of services for autistic adults in Israel. In addition to marginalization based on socioeconomic status, autistic adults living in periphery regions of Israel were also found to be discriminated against. This discrimination is the result of a serious lack of qualified professionals on the periphery and of long distances caused by the uneven distribution of services across Israel. These mechanisms of discrimination are comparable to those that have been recognized in the scientific literature in Israel and in other countries (Habayeb et al., 2020; Fong, Lee & Iarocci, 2021; Manor-Binyamini & Shoshana, 2018; Roux, Rast & Shattuck, 2020; Singh & Bunyak, 2019), suggesting that the marginalization of autistic people is a consequence of decisions made or not made at the administrative level. Thus, with suitable policies these inequalities could be overcome.

My analysis further indicated that Arab and ultra-Orthodox autistic adults are also further discriminated against in the Israeli context. This marginalization is the result of language and cultural barriers as well as lack of designated services for these communities. The marginalization of these communities, my research shows, could be reduced by expanding the pool of professionals from these communities and by using cultural and lingual mediators, a technique that is known to assist with mitigating the problems if they are properly trained (Al‐Krenawi & Graham, 2001; Hsieh, 2009; Ioan, Rusu & Hanganu, 2020). These findings correspond with parallel investigations conducted among parents of autistic children from these communities (Manor-Binyamini & Shoshana, 2018; Shaked, 2005), and with the literature on the marginalization of ethnic minorities in other contexts (Singh & Bunyak, 2019).

Autistic women are another social group that was shown to be deprived of equal access to social services in the Israeli sociopolitical context in my study. This case of gender inequalities differs both from other forms of gender discrimination in health and from the social groups covered above, as autistic women also constitute a numeric minority among autistic people (Loomes, Hull, & Mandy, 2017). My findings indicate that this numeric gap can be attributed, at least partially, to diagnosis challenges which result from lack of knowledge among professionals and limited research concerning autism in women. In addition, I demonstrate that services are usually inappropriate for women’s needs, and do not cover women-specific issues, such as hygiene or safety. Furthermore, owing to the fact that women constitute a numeric minority in the autistic community, group services, such as social and support groups, in which women find themselves practically alone, are inappropriate for their needs and, at times, might even be threatening. A similar incompatibility of diagnosis procedures and services for autistic women have been reported in other settings (Bargiela, Steward & Mandy, 2016; Gesi et al., 2021; Milner et al., 2019; Tint & Weiss, 2017). Coupling the marginalizing context of autistic women and the pronatalist perceptions of the public in Israel (Portugese, 1998), it is hardly surprising that the women interviewed expressed feeling neglected by a system that does not provide them with the conditions they need to become mothers. Finally, the survey demonstrates statistically significantly higher utilization of healthcare services by autistic women in comparison to men both in terms of hospitalizations and in community mental health services. This could either reflect negative health outcomes, which have been previously reported (DaWalt et al., 2021; Kirby et al., 2019), or, less likely, better access to healthcare services among autistic women.

Discrimination against LGBTQ autistic people must also be considered. This consideration is needed due to the high prevalence of non-heteronormative sexual orientations and gender identification among autistic individuals, as indicated by my interviews and in the scientific literature (Hall et al., 2020; Turner, Briken, & Schöttle, 2017). This issue is exacerbated by the limited understanding exhibited by autistic adults concerning the social marginalization of the LGBTQ community in Israel as demonstrated in my research. Thus, I argue, as others in different contexts have, that dedicated services that address this community’s special concerns should be developed in Israel George & Stokes, 2017; (Glidden et al., 2016; Hall et al., 2020; Jacobs et al., 2014; van Schalkwyk et al., 2015).

Three points must be considered. First, some social groups that might be expected to be subjected to similar marginalization and were demonstrated to suffer from inequalities in diagnosis, including those whose family origin is not European or American, and Jewish immigrants (Kamer et al., 2004; Kerub et al., 2018) were not identified in my research as being subjected to further discrimination. This could be attributed either to sample limitations, despite efforts to interview individuals from these communities, or to the reduced effect of marginalizing practices on these populations in adulthood. Second, most statistical analyses did not demonstrate statistically significant differences between groups in the two major outcomes that were measured, including the number of barriers and number of needs. Lastly, Beenstock, Pinto and Rimmerman (2021), who are the only scholars to have examined young autistic adults in Israel, did not find inequalities in outcomes between socioeconomic classes or in terms of residency in the periphery while reporting higher participation in employment among Arabs. My findings presented in Chapter 4 are consistent with the abovementioned scholars’ conclusion that higher employment rates among Arab autistic people could result from the importance of family-based social capital. However, I attribute most of these differences to methodological limitations. These discrepancies between the qualitative and quantitative findings, and mine and other scholars’ findings, indicate that additional studies of inequalities among autistic adults in Israel need to be performed.

Finally, the examination of inequalities between autistic adults with or without intellectual disability (ID) or reduced functional abilities, as it is often referred to in the Israel context, demonstrated inconclusive findings. In the qualitative analysis some interviewees claimed that those with low abilities are marginalized, others reported middle functioning individuals do not have dedicated services for their needs, while others argued that it is those who are considered high functioning who are deprived of equal access to services. In the survey, however, when using proxy categories for functionality, including those who responded to the survey – the autistic individual or a family member, and having or not having guardian – a statistically significant difference in the number of reported barriers to health was observed between the categories (mean=7.98 (SD=5.30) vs. 5.24 (5.11); t(110) = -2.278, p<0.01, and 7.88 (5.22) vs. 5.67(5.30); t(110) = -2.181, p<0.05, respectively), while those who had a guardian or a family member who answered the questionnaire encountered more barriers. While the survey findings might indicate “low functioning” autistic individuals are further marginalized in the healthcare system, these findings combined, reflect the invalidity of the current widely-used category of functionality (Alvares et al., 2020). The reported inconsistency corresponds with conflicting results of previous research (Taylor & Henninger, 2015; Vogan et al., 2014; Zeidan et al., 2019). I argue that these categories should be neglected, as they create more confusion, fail to capture individual complexity, and are ill-equipped to describe differences within the spectrum. Alternatively, a genuine scientific effort to define these categories, across contexts, should be made to prevent the creation of divisiveness between the autistic community and policy makers, which could raise the risk of the autistic population having its access to services rationed according to their position on the spectrum, reflecting a neoliberal rationale.

Understanding inequalities in the case of autism, as Chapter 3 of my dissertation demonstrates, must take into account the intersected identities of autistic individuals. More broadly, it illustrates that the sociopolitical context that marginalizes certain social groups must be understood in a comprehensive manner that considers different social positions intersected within this group. This perspective is crucial analytically but also, more importantly, on a practical level, in order to construct policies that address the needs and tackle the marginalization of *all* autistic individuals, or, more broadly, of allpeople with disabilities, or who are oppressed by the health sector and beyond. Neglecting these intersected social dimensions will necessarily provide only a limited picture of health inequalities and, as a consequence, will limit policy makers’ options to address them.

### 8.1.4. Limited and limiting discourses on inequalities among autistic adults and their reasons

My analysis demonstrates the political discourse in Israel regarding inequalities among autistic adults and indicates that autistic individuals from low socioeconomic backgrounds, from the periphery, and from the Arab community are marginalized in Israel. Nevertheless, a few lacunas in this discourse have been identified. First, several communities that were identified in my analysis as being further marginalized within the autistic adult population in the Israeli context are absent from policy discourse. These include ultra-Orthodox autistic people, autistic women, and autistic people from the LGBTQ community. Furthermore, current discourses surrounding inequalities among autistic people deal only with the consequences of existing policies, ignoring altogether the implications on inequalities of policy issues that have yet to be translated into concrete actions. Lastly, in relation to this research’s primary focus of investigation – the healthcare system, there is no discussion in the literature or among policy makers of inequalities among autistic adults. Therefore, it can be concluded that the current discourse regarding inequalities among autistic individuals in Israel is limited.

Three discourses regarding the *reasons* for inequalities among autistic adults were identified: the “it is like other health inequalities” argument, the “it is a result of the lack of diagnoses” argument, and the “it is a lack of awareness” argument. I claim that, while these three arguments may indeed contribute to inequalities among autistic individuals, they are discourses that limit a nuanced discussion of the issue in several ways. Arguing that intra-autistic inequalities is an additional manifestation of social or health inequalities, fails to acknowledge the autism-related features of discrimination, or in other words, the importance of the intersected identities of *autistic* adults *specifically* with other discriminated social positions. This discourse omits cardinal aspects of autistic marginalization. The argument that autistic people from marginalized communities do not have services because there are not enough autistic people from these groups to demand it, not only re-marginalizes those from disadvantaged communities that have had to struggle to get a diagnosis. but also shifts the onus onto the recipients of the services and away from the authorities that are supposed to be providing the services. As I demonstrate, demand is a function of how services are defined. For example, providing an option for free accessible transportation to geographically distant services for those living in the periphery of Israel can reshape the demand. The awareness argument, which is based on culturalist discourse, again structures the discussion on inequalities around the service recipients, disregarding altogether the role of the hegemonic culture and the reciprocal relationships between the culture of the marginalized and the culture of the privileged. Consequently, it overlooks factors such as trust and mistrust between these cultures that influence compliance with authorities (Hermesh, 2020). Furthermore, I illustrate that this culturalist argument, that conceptualizes marginalized communities as underdeveloped, discourages members of these communities from participating in the discussion on inequalities.

Finally, the discourse analysis revealed that both the “it is a result of the lack of diagnoses” argument and the “it is a lack of awareness” argument are based on a policy decision that, in itself marginalizes autistic individuals – the decision to create services upon demand. Demand-driven services, I argue, shift the discussion away from the authorities and puts the onus on the end user to apply for the provision of services. In addition, this policy requires the individual to advocate for services; to be an active social agent, which is deeply flawed because, as I demonstrate in Chapter 1, autistic people have enormous difficulty in self-advocating in neurotypical society. Moreover, as my analysis illustrates, this approach further marginalizes individuals from disadvantaged groups, as it obliges them to apply for and demand services, disregarding altogether the barriers created by the stigma and the frequently limited agency from which they suffer. Therefore, this approach to services development directly contributes to inequalities among autistic people and should be revised. If this approach is maintained, autism amendments, such as adopting an assertive outreach approach (Dike Van De Mheen, 2003) or allowing neurodiverse suitable demand mechanisms, should be introduced.

These findings, despite stemming from the discourse on inequalities among autistic adults in Israel, have ramifications for the discourse on inequalities among autistic individuals in other contexts (see Literature Review) and for other health and social issues. The limitations identified in this case should be utilized to explore possible ambiguities in current policy discourse on health inequalities. These include disregarding marginalization of social groups that are not represented at the discussion table; discussing only currently enforced policies, leaving the influence of unregulated issues on inequalities unexplored;[[1]](#footnote-1) masking unique mechanisms of inequalities that are relevant to the issue at hand while using broad arguments which assume that inequalities in one social field are identical to those in another; using discourses that obscure the responsibility of authorities, such as the culturalist discourse (which is prominent in Israel[Avni, 2016]),[[2]](#footnote-2) and discouraging marginalized communities from participating in policy processes by utilizing the culturalist discourse. Finally, as the demand-driven approach to service development has been adopted by MOLSA with regard to other populations too, the drawbacks of this approach should be accounted for, equally, with respect to other social and health inequalities (Baird, McIntosh & Özler, 2013; Dike Van De Mheen, 2003).

Analyzing the discourses surrounding the reasons for inequalities among autistic people enabled me to further explore the marginalization of discriminated-against autistic communities in the Israeli context. As discourse dictates actions (Lupton, 2003), limiting discourses on inequalities, like those I identified, also limit the actions that should be taken to reduce these inequalities. Assuming the goal of policy actors discussing health inequalities is to reduce them, the disadvantages of current discourses should be taken into account in the case of autism and in terms of other health inequalities. In addition, authorities should take into consideration that the limiting discourses might assist them, as the suppliers, in avoiding a thorough discussion on the nature of services they provide, or, to put it differently, might help them shirk their responsibilities and overlook reasons for inequalities that can be avoided or prevented.

## 8.2. The contribution of health social movements to inequalities: Replication of power by the privileged among the oppressed

To start exploring the unique features of the autism field in Israel that are concealed by the limiting discourse on the causes inequalities among autistic adults, in the last chapter of the dissertation, I delve into the role played by a cardinal actor on the autism field, autism organizations, and explore the effects of their actions and policies on inequalities. Despite autism organizations and, more broadly, HSMs often being perceived by policy makers and in the scientific literature as social actors that either advocate for access to care and improved quality of care or voice patients’ claims (Brown & Zavestoski, 2004), I argue, based on my analysis, that this notion must be challenged., as the reality is more complex. This is because, as I demonstrated in the case of Alut, the oldest, largest, and historically most influential autism organization in Israel, these organizations can themselves contribute to the formation of inequalities among the individuals they claim to represent. Using the analytical framework of intersectionality, I demonstrated the causal link between the actions of the socially privileged founders and representatives of Alut, and the further marginalization of autistic individuals from already marginalized social groups. It is crucial to stress that my study explored social dimensions that are not related to dimensions within the field of autism, such as the distinction between organizations *for* and *of* autistic people (Raz et al., 2018).

My analysis established that Alut was, and is, an influential actor in the autism policy field. Although this influence has changed over the years from playing an integral part of the state apparatus for the creation of autism policy to that of an external consultant whose participation and agreement nonetheless remains, essential for introducing any change in the autism field in Israel. I then turned to an exploration of the consequences of Alut’s main advocacy efforts regarding autistic adults – the establishment of residential facilities for autistic adults called “houses for life.” I show that, while working intensively with authorities to promote the establishment of these facilities, Alut insists on a very high deposit as an enrollment fee, along with monthly fees paid by the autistic adult parents to Alut. These were demanded, on the one hand, so the organization could provide high-quality residential services for autistic adults, but on the other hand, they were demanded for the only *publicly funded* residential services for autistic people available at that time. As a direct result, autistic individuals from low socioeconomic classes and those who reside far from the center of Israel were left without any public solutions.

Despite this enrollment fee and the monthly fees being cancelled about a decade ago, following a ministerial decision, Alut continued advocating for “houses for life” as the main residential option for autistic adults. I further demonstrate that this advocacy effort indirectly marginalized autistic adults or their families, especially those from disadvantaged social positions, who prefer less secluded residential options that are more integrated with the community. While those from privileged social positions have gradually established private services for themselves within the community or make do with the minimal services that are available publicly in the center of Israel, those from marginalized communities, including Arab autistic adults, autistic adults from low socioeconomic classes, and those who live in the periphery, found themselves further marginalized, as no alternative community services were available for them. Thus, I conclude, Alut’s actions directly and indirectly marginalized autistic people from underprivileged communities and contributed to inequalities between autistic adults. Today, although the authorities are starting to develop community services partially in the wake of the adoption of the United Nations Convention on the Rights of Persons with Disabilities (The United Nations, 2006) and partially due to advocacy efforts by other autism organizations, there is still a major shortfall in community services to support autistic individuals. This should also be viewed as a challenge and an opportunity to reduce inequalities within the autistic community.

These policy decisions are not random; they have their roots in the human dynamics operating within Alut in the form of the representatives who directed the organization and claimed to represent the entire autistic community. Therefore, using an intersectional framework, I analyzed these representatives’ intersected identities as marginalized parents of autistic individuals and additional social axes. This analysis, which is the first to explore the social positions of the founding and central representatives leading the main autism organization in a country, revealed that these representatives were, and some still are, part of the most privileged financial and social elite of Israel. In contrast to the autistic adults from marginalized social groups who were identified as being deprived of equal access to social resources in Chapter 3, or who were alienated by the “houses for life” policy, the parents who founded Alut were Jewish, belonged to the highest echelons of Israeli society, were educated, resided in the center of Israel, and enjoyed an abundance of social capital. It was these privileged parents who advocated for discriminatory policies that directed public funds toward their children at the expense of autistic individuals from marginalized communities whom they claimed to also represent. This unjust situation, which translated the social capital of these privileged parents into material capital for their autistic children, while depriving others of public resources, demonstrates the interrelations between different social positions of the individual with the social axis of oppression at the population-wide level. In addition, this case constitutes a vivid example of how social capital gets translated into material capital (see Bourdieu, 1980; Hilgers & Mangez, 2015).

After presenting these findings, I argue that health researchers and policy makers need to consider the fact that HSMs are gradually becoming central actors in the health field (Brown & Zavestoski, 2004) and take a more critical stance on the matter, taking into consideration additional social positions, beyond the marginalized patient position. This is true for autistic organizations in other contexts, especially given the intensive involvement of privileged or even elite actors in setting their agendas (Caruso, 2010; Ne'eman, 2011; Steuernagel, 2005), this is also true for HSMs that operate in other fields (Watkins-Hayes, 2014), and should hold true for disability organizations.

Nevertheless, the criticism of HSMs should be made while considering the contexts in which they operate. As I extensively cover in Chapter 3, Alut’s representatives’ actions were taken within an oppressive context that not only blamed them for their children’s condition, but also left them and their children with no solutions whatsoever. Under oppressive social conditions, the struggles of HSMs, including Alut’s representatives’ struggle for quality residential facilities, was, and is, just. This combination of injustice and justice in the HSM’s actions, that stem, I argue, from the intersected identities of their representatives, should be taken into consideration when analyzing these types of organizations and their actions. However, neglecting the unjust dimensions of these organizations could translate into further widening the inequalities between privileged and marginalized populations.

To reconcile this complexity in practice, we should consider one of two options– a practical, short-term option and a radical, structural one. The practical option would see authorities being more attentive to the social needs of patients and individuals with disabilities in order to avoid unjust circumstances as much as possible. If a need is raised by HSMs, their proposed solution should be analyzed from an intersectional perspective to avoid promoting policies that would contribute to the formation of inequalities. The call to use intersectionality in policy formation has already been made by other researchers (Dhamoon & Hankivsky, 2011; Hankivsky & Cormier, 2011) and has been put into practice in certain contexts (Hankivsky & Jordan-Zachery, 2019). My analysis demonstrates that these practices must also be applied in the Israeli context.

More broadly, I argue that to understand health inequalities and their causes, their structural tendency to proliferate in neoliberal capitalist systems should be considered. Given that HSMs, which are considered to be the “guardians” of the oppressed by health authorities, have been found in my analysis to also promote oppression along other social axes, redistributing public resources to benefit more privileged groups at the expense of marginalized groups. Is it possible that in neoliberal capitalist systems that see inequalities as an integral part of the nature of society, health inequalities will exist and flourish given that those with social power will inevitably, intentionally, or unintentionally, preserve their power while oppressing those from disadvantaged communities? If health inequalities do indeed harm health (Wilkinson, 2005) and international as well as national organizations strive for their elimination, should our (radical) target be to dismantle the power structures of society, including capitalism, racism, sexism, ableism and other axes of social oppressions? Although these are far-reaching targets, it is essential to understand that as long as these structures are in place and are continued by those who are in a position to benefit from them, as my analysis demonstrates, health inequalities will remain an integral part of our reality. This conceptualization is needed for research, for setting our policy and political agendas, and possibly for redirecting our actions to other avenues (Raphael, 2009).

The implications of these findings on other fields of knowledge must also be considered. The influence of HSMs on medical knowledge production has been researched extensively. In the case of autism Eyal (2010, 2013), describes how the interweaving of an expertise network with the parent-advocate-therapist-researcher actors facilitated the allowed the dismantling of flawed perceptions and the production of new knowledge and perceptions regarding autism. I argue that adding an intersectional perspective to this analysis may reveal that these agents, who have reformed knowledge, are privileged agents that could utilize their capital to resist medical preconceptions and construct alternatives. This is true also in other fields of medical knowledge (Epstein, 1996) and might also explain why alternative modes of understanding autism by marginalized groups continues (Decoteau, 2017). A second perspective researchers need to consider, based on my findings, is the consequences of intersected identities of other types of actors in the health policy field. The identity of actors such as health council members, public representatives at the health basket committee, position holders at medical associations, and even middle level bureaucrats should be examined to understand if, and how, their identities influence or contribute to health inequalities. In other words, researchers should consider the “invisible” privileged identities of those with power that may be contributing to the formation of discriminatory structures.

Although missing from current discussion on health inequalities, my findings demonstrated that in the Israeli case, Alut, the main organization advocating for autistic individuals, has contributed to the formation of inequalities in terms of access to public resources. I further argue that it was the organization’s representatives’ simultaneously intersected identity of marginalized and privileged that led to these marginalizing actions. This perspective on HSMs is lacking from the scientific literature regarding HSMs and social movements (Watkins-Liu, 2018; Wojnicka, 2019). Illustrating how the transfer of capital across fields through intersected identities at the individual level translates into marginalization at the population level is also novel to scholarly inquiries of health inequalities. If policies that correspond with these findings are adopted, I hope this contribution would further enhance our ability to also tackle health inequalities.

## 8.3. The dynamic asterisk analytical model: Reconceptualizing the social determinants of health by integrating intersectionality, disability, and “privilegionality”

In health science, our ability to understand the forces that affect health inequalities is gradually improving. The combination of theories I utilize in my work, in conjunction with the perspective I chose to employ on the privileged actors, is a new theoretical approach that, to my knowledge, despite strong arguments in its favor (Lapalme, Haines-Saah & Frohlich, 2020; Nixon, 2019; Young et al., 2020), has never been practically executed. In this section, I explain the analytical approach I utilized throughout my study, theorize it, and briefly explore how it could further enhance our ability to understand health inequalities and, hopefully, contribute towards reducing them.

The social determinants of health (SDH) framework has served as a framework for studying and tackling health inequalities for the last three decades. Using this framework, the scientific community has identified the “cause of causes,” the social determinants that affect health inequalities, and their uneven distribution (Marmot, 2005; Marmot et al., 2008). From employment (Hergenrather et al., 2015), to neighborhood (Gustafsson et al., 2014), from housing (Taylor et al., 2016) to education (Braveman & Gottlieb, 2014). Researchers have exposed the effects of social determinants on health and their uneven distribution within and between countries (Marmot, 2005). This approach has also led policy makers to act to try redistribute these determinants more equally in order to close health gaps (Government of Canada, 2021; WHO, 2021b). Yet, despite these efforts, health inequalities are still prevalent (WHO, 2021c) and some argue that the social determinants that affect health may have even worsen (Piketty, 2014).

Before exploring intersectionality, the second framework I utilize, and how it can be used to better understand why the efforts to enhance equitability have only partially succeeded, it is crucial to stress the importance of separating three different concepts that constitute the SDH framework. These are the social position, social determinants, and the sociopolitical context that influences their distribution. While this differentiation was explained accurately by Solar and Irwin (2010), and I further elaborate on it in my theoretical framework in the literature review (Chapter 2), I briefly recap it here. As Graham (2004) notes, we must differentiate between the determinants themselves (e.g. employment, water, housing, and more) and the sociopolitical conditions that cause these determinants to be distributed unequally, for example, housing policies or antidiscrimination laws that affect employment. Graham (2004) defined these conditions as the social determinants of health inequalities (SDHI). Solar and Irwin (2010) demonstrate the socioeconomic position, which I refer to as “social position” in my research, needs to also separated from the SDH framework, as it dictates, in itself, which sociopolitical context applies to the individual. This differentiation allows the researcher to analytically understand each component on its own and to draft the relations between these concepts.

To demonstrate this differentiation, I use the example of housing. Shelter and housing affect health in different ways, for example, by combatting obesity and diabetes among women and children (Taylor et al., 2016). Therefore housing can be considered an SDH. The policies that dictate who is entitled to public housing or affordable housing, and whether rent control will be enforced or not, dictate the distribution of housing and they are, therefore, an SDHI. However, housing status also creates a social position – homelessness. Socially, being homeless does not only mean being without a roof over your head, this social position has further implications, for example, stigma (Rayburn & Guittar, 2013) and problems finding employment (Groton & Radey, 2021). Therefore, as a social position, homeless individuals are also affected by an additional set of policies or SDHIs. More importantly, however, this social position is a relative position. It is relative to those who have shelter. The latter are the ones who impose the stigma and they are the ones who may lose or benefit from eliminating this determinant, for example, by providing housing for all. In addition to being a product of social structures, social positions can rise from innate factors, such as sex or ethnicity, and, as I also argue, following Emmerson et al. (2011), disability. These social positions, in turn, are influenced by certain sociopolitical contexts, and their position is also always relative. The relative position between two or more social positions that stem from the same inherent factor, for example, men and women, could be defined as the system of oppression. In this system, the SDHI operate differently on these social positions.

Although understanding the SDH using these categories is important, intersectionality as a theoretical framework argues that identity cannot be conceptualized as a single social position, because each individual or group of individuals are positioned at the junction of several social positions. Using this framework, social scientists have demonstrated the multidimensional marginalization and experiences of individuals whose identity combines more than one discriminated social position (e.g., Ben-Moshe & Magana, 2014; Hankivsky & Cormier, 2011; López & Gadsden, 2016). Furthermore, and more relevant to my theoretical approach, intersectionality has been utilized to explain the mechanisms by which systems of oppression act in tandem and support each other to preserve power dynamics (Whitesel, 2017). In health scholarship, the importance of this analytical concept has also been recognized by many scholars (Dhamoon & Hankivsky, 2011, Hankivsky & Christoffersen, 2008; Kapilashrami, Hill & Meer, 2015; McGibbon & McPherson, 2011) including in the autism field (Singh & Bunyak, 2019). However it has not yet been utilized to explore and conceptualize the experiences with the healthcare system of individuals whose identity intersects with marginalized social positions and the effects of these intersecting social positions on their health.

This neglected issue is the point where the SDH framework and intersectionality meet. While the SDH framework departs from the position that determinants are distributed in an inequitable manner and there is a need to “tackle the inequitable distribution of power, money, and resources” (CSDH, 2008), intersectionality can assist in understanding why and how power (as well as capital and resources, which are different forms of power) is distributed unequally and where exactly it should be confronted. It is important to note, that inequitable distribution has been tackled effectively using strategies like political empowerment, market responsibility, and fair financing (Marmot et al., 2008). However, we are still missing parts of the power puzzle with which intersectionality can help (Carbado 2013 p.817, in: Wojnicka, 2019).

Lately, health scholars have started arguing in favor of using intersectionality exactly for this purpose (Lapalme, Haines-Saah & Frohlich, 2020; Nixon, 2019; Young et al., 2020). Lapalme, Haines-Saah and Frohlich (2020) explain that intersectionality should be utilized to explore structurally marginalizing forces in policy, and give an example of such an undertaking with reference to the case of tobacco control policy. Nixon (2019) went a step further and suggested a new framework “the Coin Model of Privilege and Critical Allyship” that should be utilized to start to expose the position of the “invisible” privileged actors in societies and, specifically, in health, arguing it is essential to understand the sustainability of systems of power that operate conjointly.

Similar to Nixon’s (2019) coin model, I argue there is an urgent need to identify privileged positions and acknowledge that they benefit from the social structure and, therefore, the privileged should be a focus of health inequality research. I term this perspective “privilegionality” – research of the privileged. Nonetheless, Nixon’s model does little to provide analytical tools that would help expose the system of oppression(s), which she defines in her model, neither does it assist in understanding how systems of oppressions work conjointly with other systems of oppressions. To reveal this system, I argue, we should use the SDH framework and try to ascertain where SDHIs that cause the marginalization of certain social positions benefit individuals on other social axes. By doing so, we could reveal the concealed mechanism of power preservation we often neglect.

It should be noted that examples of obvious power preservation mechanisms could, unfortunately, be easily found. For instance, allocating more resources to Jewish students in Israel in comparison to Arab students (Svirsky & Dagan-Buzaglo, 2013) who are part of a marginalized community clearly could be considered a power preservation mechanism, by means of which power from the axis of ethnicity in Israel transfers to the socioeconomic axis and influences health. However, subtler mechanisms that transfer power through identities are much harder to expose. For example, has any research examined the role of medical associations which, on the one hand, are essential in promoting public health in many respects, yet on the other hand, as they are directed mostly by men (Israel Medical Association, 2021), might contribute to gender inequalities? Have we considered HSMs, which have the critical role of giving voice to the marginalized in our society, as actually contributing to inequalities themselves? The questions we often ignore are the ones the model I propose could help us explore.

To demonstrate the model, I utilize a graphic diagram (Image 9.1) which, based on its shape and dynamic nature, I call “The dynamic asterisk analytical model.” This diagram, as demonstrated below, incorporates the scheme drafted by Göran and Whitehead (1991), not because it best articulates the interrelations between different SDHs, but because it is widely known and utilized. Similar to Nixon’s (2019) coin model, each axis constitutes a different oppression system. For example, sexism is presented in pink and neurotypicalism[[3]](#footnote-3) in purple. However, unlike in Nixon’s work, these are longitudinal axes, not a two-dimensional coin, as oppression is not binary, as she also recognizes. On the right side of the diagram, where Göran and Whitehead’s (1991) diagram is visible, is the most privileged side (on the socioeconomic axis, classism, marked in blue on the right side, will be positioned as the higher income decile) and on the left are the most oppressed (the directions are marked by the arrow underneath; note that in the subsequent images, privilege is marked only by Göran and Whitehead’s diagram). Along each axis, I argue, different and relative social positions are affected differently by the sociopolitical context: the SDHI. Therefore, at each point, a different examination of the context is warranted.[[4]](#footnote-4) The junction where the different axes meet is the point where systems of oppression meet and intersectionality is expressed, and the experiences of marginalized individuals are exposed. This model should spur the examination of the sociopolitical context that dictates the strength of these intersected identities, their SDHIs, according to how the SDHs identified in Göran and Whitehead’s diagram are accessible or denied to the intersected identity. Although this context does not always change from one position to the other across an axis, for example, between the fourth and fifth deciles in the socioeconomic axis, others can dramatically change across axes, from taxation to healthcare accessibility.



Privileged

Oppressed

Neurotypicalism

Sexism

Classism

Figure 9.1

The benefit of this model, however, is that it can help visualize how different axes move across one another and, therefore, the diagrams can illustrate vividly how power can be transformed from one axis to the other. Despite being presented in this way in the diagram above, the junction point is not always in the middle. On the country most oppression systems are expressed with power preservation at the margins of these axes. To illustrate the dynamic utilization of this model, I next describe the analytical process I performed throughout this dissertation project.

In Chapter 1, I established that autism should be regarded as a social position. Adopting Emerson and colleagues’ (2011) claim, and utilizing the oppression perspective for recognizing a community (Holler, 2018; see explanation in the Introduction), I have established that in the Israeli context, as others have done before (e.g. Gil, Shoham, & Shelly, 2016), that autistic adults are an oppressed social group. In relation to the model, I demonstrated that the neurotypicalism oppression axis really does exist (Fig. 9.2, upper row). Then, in Chapter 2, I tried to ascertain what the SDHIs are of those on the far left of this axis, the sociopolitical context that influences the health of autistic adults (Fig. 9.2, bottom). In this chapter I demonstrated that this context marginalizes them in many ways. This kind of investigation is the type of research often adopted in social determinants of health research (for example: Siddiqua, 2020).



Figure 9.2

In Chapter 3, I started to cross this marginalized position with other marginalized positions (Fig. 9.3), and demonstrated that, at each intersection, autistic people from that intersected identity are further marginalized. For example, at the junction of neurotypicalism and sexism, autistic women are further marginalized (Fig. 9.3, top left). This intersectional perspective has been increasingly utilized in recent years by health researchers, but mostly for exploring experiences of marginalization in healthcare and, to a lesser extent, the SDHIs that deprive autistic people from access to social services and goods (Singh & Bunyak, 2019). It is important to note, as I also mentioned in Chapter 3, that the examination of the SDHIs of intersected identities was done only on two axes at a time – neurotypicalism and another oppressive axis. Yet additional oppressive systems should be added, if possible.



Sexism

Classism

Geography

Religious bias

Racism

Neurotypicalism



Hetrosexism

Figure 9.3

Finally, in the last chapter, I stay on the left, the oppressed side on the axis of neurotypicalism, but try to understand how and why throughout the short historical policy formation process of residential arrangements for autistic adults that I explored, the conjunctions between this axis and the socioeconomic, geographical, and ethical axes, which further marginalized this position, formed. Are they really, as policy actors discourse today claims, a result of existing inequalities, or did social actors position them in that way? I explored the actions of those on the other side of these axes, those at the intersection of the neurotypicality axis and privileged social positions (Fig. 9.4). This exploration revealed that these group of individuals in the current context have greater access to resources, but, more importantly, it illustrated that it is the privileged in power who constructed the sociopolitical context in a way that would favor those marginalized autistic individuals from privileged backgrounds. Essentially, moving the axis allowed me to conceptualize, analyze, and demonstrate that the privileged were able to translate their social capital into material capital and shift from one axis to the other.



Neurotypicalism

Geography

Classism

Figure 9.4

This model, I believe can help us visualize and conceptualize the creation of axes, their conjunctions and, most importantly, how power can be transferred from one axis to the other. If we find that the SDHIs at the point of intersection between neurotypicalism and classism at the marginalized positions (Fig. 9.3, bottom left), are different from those of the marginalized on the neurotypicalism axis and the privileged side of classism (Fig. 9.4) and ask what the reasons for this situation might be, we might find additional causes for inequalities. Then we could also start addressing them.

As health inequalities are avoidable by definition (Braveman, 2006), it means they are also not inevitable, but constructed by those with privilege in positions of power. To understand how these inequalities were created, so that future gaps can be avoided and equitable mechanisms can replace them, we should focus our efforts on the privileged and consider their, and indeed our own, roles in forming inequalities. This perspective of “privilegionality” requires that we explore the ability of social power to replicate itself. This type of research, I believe, must take, at least partially, an historical stance, as it aims to explore the development over time of mechanisms of power preservation, and not just to expose current power relations. It should also, as Lapalme, Haines-Saah and Frohlich, (2020) assert, focus on the policy that forms the sociopolitical context (see also Palmer et al., 2019 on the gaps in current literature concerning SDH).

Several essential notes and limitations regarding this model must be stressed. First, although not being applied a great deal in health research, Bourdieu’s theory of field, habitus and capital is a coherent and comprehensive theory of how power moves between fields on which I draw to develop my model (Bourdieu, 1980; Hilgers & Mangez, 2015). Second, this model is built on the work of many brilliant scholars, mostly women, (Crenshaw, 1991; Graham, 2004; Marmot, 2005; Nixon, 2016; Solar & Irwin, 2010 to name some) who not only provided the terminology but also the ideas that were used to construct this model. I merged together their notions in one of many possible articulations, and I imagine others in the future will find others. This model, however, cannot be understood in isolation from their work. Third, it is crucial to stress that this model is just an analytical tool; it has no pretenses of providing explanations. In that sense, the role of HSMs in mediating power preservation was not exposed by the model, but by extensive research work. The model is there to assist in forming research questions that are directed toward exposing power preservation practices. Fourth, it can be understood from the model that at every intersection, there will be concealed practices of power preservation. Unfortunately, most oppressive processes are still either transparent or a result of well-established inequalities. Researchers should set themselves the goal of exposing additional mechanisms of power preservation by using “privilegionality.” Fifth, the model does not capture the dynamics of power relations on the individual level, as it portrays an image of constant axes with the privileged on one side and the oppressed in the other. On the individual level, however, power relations are much more complex and, in certain situations, these sides can be reversed. For example, imagine a powerful man of color (maybe a former president of the United States) meeting a white woman from a lower class or even a white man from lower class; in that case, oppression on the racism axis can theoretically be reversed. Similarly, with a powerful white woman (maybe the vice president) who meets a man of color from the lower classes, oppression on the sexism axis again can be easily reversed. This model, thus, should not be understood on the individual level, but on the societal level. Sixth, despite this model being focused on the transfer of power between oppressive axes, it should be borne in mind that marginality can also be transferred from axis to axis, as marginality, in itself, becomes a part of identity and, as a result, also affects social position and health (Lynam & Cowley, 2007). Finally, the cross-influence of axes is much more complex in reality than their precise intersection. For instance, failing to adopt employment policies for autistic adults could result in some autistic people becoming homeless, this directly affects the neighborhoods in which these autistic people live and their residents, who are likely to be from low socioeconomic classes. This in turn may affect their health. More broadly, it could be argued, we are all connected in society and trying to capture the entire complexity of these dynamics in a single model is, at the moment, not feasible.

Reducing inequalities has been declared a global sustainable development goal as these inequalities “threaten[s] long-term social and economic development [and] in turn, can breed crime, disease and environmental degradation” (United Nations, 2021). Furthermore, most member countries of the OECD have “endorsed, as major policy objectives, the reduction of inequalities in health status and the principle of equal access to health care based on need” (OECD, 2021). The dynamic asterisk analytical model I propose is designed to assist scholars, mainly from the health field, to further understand the mechanisms that preserve inequalities, by allowing the privileged to transfer their power, be it material, social, cultural or symbolic from one system of oppression to the other. Despite this line of thinking seeming almost trivial, the fact that this is so rarely executed in health inequalities research, indicates that we should consider this analytical approach to research more often and with greater urgency. It is time to move beyond the exploration of “the cause of causes” (Marmot, 2005), and start focusing our attention on “the causes of the causes of causes,” or in other words, better understand the mechanisms that preserve or even exacerbate the unequal distribution of access to social resources. This line of inquiry is urgently needed to tackle health inequalities more comprehensively.

## 8.4. Methodological contribution

Adopting a participatory approach to this research allowed me to acquire insights on the research process itself. Before turning to my input in terms of research methods, it is important to acknowledge that this approach is innovative in both health and disability research in Israel, and despite being favored by the autistic community, is rarely adopted by the scientific community (Fletcher-Watson et al., 2019; Pickard, Pellicano, den Houting & Crane, 2021). Like most disability research conducted in Israel, my work approaches the issue of disability as a policy issue and was funded by governmental bodies seeking to improve the lives of individuals with disabilities (Holler, 2018). Despite this, or perhaps because of this, in order to better serve the autistic community, the study attempts to dismantle the dominance of “experts” in the field and position the autistic community in front and center. The most prominent example is the participation of the research committee members in drafting the accessibility regulations for the MoH. Instead of hearing the “experts,” our collaboration positioned the autistic committee members as the experts within policy formation process.

Through my close work with the committee, I was able to acquire a unique window into the autistic mind and, as a direct result, an unique prism onto my work through which I could critically observe my process. As I show in Chapter 1, difficulties with the pragmatics of language and the tendency of autistic people to interpret language very literally, pose barriers to healthcare services. Yet, during the process, it became evident that these communication barriers are not just relevant to the encounter with healthcare system providers, but also to the encounter with research tools and researchers. Thus, the first argument of this section is that the development of neurodiverse research methods and instruments are needed so studies can both be accessible to the autistic community and research will be relevant for their lives.

A second methodological issue relates to the limits of participatory research. As I, and others, discuss in a recently published article concerning ethics (Weksler-Derri et al., 2019), despite the aura of inclusion surrounding the participatory approach, if it is not conducted carefully, from an intersectional perspective, this approach can actually also be marginalizing. As with HSMs, which I argue, should be carefully examined from an intersectional perspective, participatory research should be subject to the same critical assessment. Researchers claiming to represent the voice of a community should be cognizant of their limitations.

### 8.4.1. “Neurodiversed research”[[5]](#footnote-5): A reemerging field of knowledge production

The intimate connection I established with the autistic adults involved in producing this study enabled me to deconstruct my own research process and notice blind spots in my research and my own preconceptions. This helped me, first and foremost, to avoid ableist language that committee members considered discriminative (Bottema-Beutel et al., 2021). Yet, although these linguistic amendments are essential, if research is to respect and promote the investigated community, I argue that avoiding ableist language, including autistic researchers or the community in the process, or creating an neurodiverse academic space (Bertilsdotter Rosqvist et al., 2019) is not enough. Researchers should consider the development of “neurodiversed research” as a discipline that incorporates diverse aspects of research, including research goals, epistemology, and methods. Below, I give examples for adaptive methods for “neurodiversed research” and briefly discuss the issue of “neurodiversed research” goals.

Two communication difficulties that also emerged as barriers to the healthcare system influenced the way this study was conducted and prompted a rethinking of my research methods. The first was the literal understanding of language and the latter was the use of alternative communication methods. Although communication differences certainly have implications for qualitative research, as during interviews, communications mishaps are prevalent, even with non-autistic people, I focus this discussion on surveys, as communication misunderstanding are somewhat easier to illustrate, and because, usually, written communication is neglected from this discussion. Literal understanding of language or problems with pragmatics among autistic people is widely recognized in the scientific literature (Loukusa & Moilanen, 2009). Nevertheless, the implications of these linguistic differences on research among autistic people, to my knowledge have not been explored. During the participatory research following the advisory committee’s comments, it became evident that the tendency for autistic people to understand things very literally can affect two factors in terms of survey conduction. The first concerns the social embedded interpretation of written language and the second is the need for detailed and specific questions and answers.

As written language, like spoken language, has social conceptions embedded within it, some questions or answers in close questionnaire surveys can be misinterpreted by autistic individuals. One example of a misinterpretation of this kind was in the question regarding the effect of the mental health reform. As mentioned in Chapter 2, one of the reform’s goals was to integrate mental healthcare with non-mental healthcare in the primary setting. To explore the effect of the reform, the questionnaire included a question regarding the integration of mental health services in the community. Members of the committee drew my attention to the fact that *integration* is a vague, socially constructed term, and they could not answer this question in its current form. To accommodate their literal understanding, the question was amended by focusing on one aspect of this integration, the connection between mental health professionals and the primary physician. While this might seem like a negligible issue, the socially embedded meaning of written language could seriously affect autistic people’s understanding of the questionnaire and their ability to answer it.

The second issue related to the literal understanding of language meant that the survey had to be designed so that questions and answers were specific and allowed an *exact* answer. If a question had several possible answers but an exact option was not available, the autistic individual would tend to answer “impossible to answer the question,” as one of the committee members told me. For example, in a question that referred to educational background and asked about the highest education level attained, there were 10 different categories. One of the members told me, that this question could not be answered because she finished vocational training and started, but did not finish an academic degree, as the question allowed only one answer it became unanswerable. We agreed together to allow multiple answers to solve this issue. This was not the only case in which committee members argued that additional questions or answers were warranted to avoid possible misunderstandings. While the problems of literal understanding could be mitigated by adding options to the answer list, or by adding other clarifying questions, it complicated the survey (from a neurotypical point of view), and, was counter to the usual recommendations for producing effective surveys (aimed at neurotypical people), and as a consequence, made it harder for the guardians to answer the questionnaire. In addition, it made the statistical analysis of survey results much more difficult, as certain categories had to be regrouped with others.

This practice of elaboration and detailing every step differs from the textbook definitions of how to conduct surveys and guidelines for drafting questionnaires. Short questionnaires to enhance response rate, short uncomplicated questions, and answers with minimal details are usually recommended (Bradburn, Sudman & Wansink, 2004, pp.73–75; 283–314) but autistic people require the exact opposite. I argue that, although researchers should not disregard years of well-established survey practices, they should think carefully about the compatibility of conventional surveys for specific target populations. Beyond spoken language translation, researchers ought to start incorporating neurodiverse translations. These translations might include additional clarification of questions and answers to allow exact answers, and amending the language with the assistance of autistic people or specialists so embedded social assumptions can be avoided.

Furthermore, as some autistic people also have difficulties with certain types of communication, for example with written communication, additional efforts should be invested in mitigating the survey submission modes. For example, following the recommendation of the autistic research committee, I inserted an audio version of the questionnaire. Autistic people who have difficulties with written language could listen to questions and record their answers. Additional adaptation in the form of pictograms could also be beneficial. Fortunately, current survey software can accommodate these mitigations by allowing the insertion of additional translation options. These practices are essential if research is to be accessible for autistic adults or, preserving knowledge production tools in the hands of neurotypicals and eventually for their benefit.

Finally, it should be considered that avoiding ableist language and amending research methods are just the tip of the iceberg of “neurodiversed research.” Much like feminist research that is centered around women’s issues and their experiences and is dedicated to uncovering male biases, among other things (Hesse-Biber, 2013, pp.1–13), “neurodiversed research” should also strive for these sorts of interventions in the case of issues faced by neurodiverse individuals. One example of a “neurodiversed research” goal could be promoting what Iris Schined and I termed “bridging research.” This type of research should aim to bridge autistic and neurotypical thought. While autistic research should, for instance, try to explain to neurotypical people their distinct socialization process, neurotypical people should elucidate the reasons for neurotypical practices (AUTISTIC PEOPLESCIENCELADY, 2019) such as small talk, or making group decisions by voting instead of alternative methods, such as the five-finger consensus method (Nicolaidis et al., 2011). By adopting such research goals, this approach to research could also greatly impact our understanding of neurotypical societies and research.

Neurodiverse research should strive to dismantle normo-cognitive assumptions and interpretations of knowledge by allowing researchers novel epistemic, and methodological tools, much like the neurodiverse academic spaces Bertilsdotter-Rosqvist et al. (2019) call to develop. However, for the time being, and until this research perspective is established, given the expanding number of autistic individuals, estimated to be at around 1%–2% of society (Bio et al., 2018; Brugha et al., 2011), research should adopt a neurodiverse approach to research accessibility. Otherwise, this population will be excluded from studies, which is especially important to avoid in autism research, but also in many other disciplines, including health.

### 8.4.2. Participation of whom? Participatory research from an intersectional perspective

Participatory research, especially in autism research field, is considered a practice that overcomes traditional scientific marginalization of autistic individuals (Fletcher-Watson et al., 2019). Although as, mentioned above, this approach to research has many advantages, and I can personally testify that it transformed my perspective as a researcher and as a social actor, like any other action, it should be subject to scrutiny. However, reflecting on my participatory research through an intersectional lens, my research, too, might fall into the same trap of claiming to represent the autistic community while in effect representing those with privilege.

Before turning to intersectional perspective, limitations regarding participation within the autistic field need to be considered. As other participatory researchers who conducted participatory studies with the autistic community have testified, verbal autistic people without a cognitive disability are the ones who participate in research (Pickard et al., 2021). Autistic people on the other side of the spectrum are rarely included. Therefore, claiming to include *the whole* autistic community might be misleading. Furthermore, as participation is usually open only to formally diagnosed autistic people, in the Israeli context, where diagnosis in adulthood is not publicly funded, excluding autistic people from participation based on formal diagnosis could effectively exclude individuals of lower socioeconomic status. In my research, I have also included only verbal autistic people. I did, however, decide to include undiagnosed autistic people as committee members to try to avoid further marginalization. Despite eliminating this barrier, only one not formally diagnosed autistic, that I know of, took part in the committee. Future research should try and include non-verbal autistic people or autistic people with cognitive disability (see, for example, emancipatory research with cognitively disabled non-autistic individuals [Walmsley, 2001]) by accommodating research practices and allowing alternative communication methods.

When analyzing the identity of committee members from an intersectional perspective, although the research committee included more autistic women than men at times, and those who reside on the periphery of Israel, it failed to include autistic people from other marginalized groups. It did not include Arabic autistic people, ultra-Orthodox autistic people, autistic people from low socioeconomic backgrounds[[6]](#footnote-6) or Mizrahi autistic people. Therefore, claiming that by conducting participatory research, this research has narrowed inequalities in society misses the part it might have played in further marginalizing autistic people whose identity intersects with marginalized communities within the research sphere. As I hoped this research would narrow inequalities, this is clearly a weakness of the research process. Although the ethnic or socioeconomic background of autistic people participating in participatory research is not usually stated, I infer from the dominance of white autism researchers in participatory research (93%–100% [Pickard et al., 2021]) that this is the case also in other participatory studies.

The call for inclusion of autistic people from minority groups in autism research (Giwa Onaiwu, 2020; Maye et al., 2021) should be adopted in participatory efforts, too. This could be achieved by introducing novel requirements that target autistic people from marginalized communities, dedicating resources to ease participation, such as transportation reimbursements, or even a small compensation for participation, and moderating participation barriers through cultural and linguistic mediators. My experience led me to the conclusion that participatory research should be endorsed by the academic community, especially in the case of autism. Nevertheless, without practicing intersectionality and including participants from marginalized communities in research production, not only will our criticism of power structures be less accepted, but we risk limiting our understanding of these communities and contributing, ourselves, to preserving the power of the privileged in our societies. This view should be accounted for in autism participatory research, but it is also relevant to other researchers making use of participation as part of their research of marginalized groups.

To conclude, the participatory research I conducted and the theoretical framework I adopted allowed me to reflect on my research conceptions. First, I understood that, although the scientific community conceptualizes academic research as a unitary notion, such research represents only the conventional form of research – the “normal.” Therefore, other forms of studying reality are possible and should be explored. The autistic community should consider the notion of “neurodiversed research,” and start developing novel research goals, epistemologies, methodologies, and methods that reflect autistic thinking. Such options could be “bridging research,” which aims at narrowing the gap between neurodiverse and neurotypical people. In addition, mitigation strategies to adopt research for autistic should be implemented in all research, especially in studies concerning the autistic population. The second reflection regarding participatory research is that if the goal of this type of research is to transform power relations within knowledge production by allowing the inclusion of those who usually do not possess power in the knowledge production process, researchers ought to consider participation of marginalized communities within the marginalized researched populations. Failing to adopt an intersectional lens in participation-based research risks preserving the privileges of those who are privileged within the marginalized groups and further marginalizing the marginalized.

## 8.5. Research limitations and future research

This research had several limitations both in the qualitative phase and the quantitative phase. In the qualitative phase, despite efforts to interview autistic people and families of autistic people from marginalized communities, especially from the Arab, the ultra-Orthodox and the LGBTQ communities, these populations were underrepresented in the research. Most of the information regarding their marginalization comes from professionals working with these communities and not the members themselves. Therefore, my findings might fail to capture the full extent of their marginalization. Secondly, as I have a background in medical studies and I encoded the data myself, my position on the field might have affected my interpretation. Having the autistic advisory community review the codes list balanced my position. Nevertheless, not having an additional set of eyes on the data might have introduced a personal interpretation bias.

In the quantitative phase, several limitations should be noted. First, despite the efforts to disseminate the survey questionnaire in a variety of ways, including through institutions, and despite efforts to make the research questionnaire as appropriate as possible, there was a sampling bias in survey. This bias is expressed in the minimal participation of autistic people and of family members of autistic people from specific communities, including Arab, ultra-Orthodox, and religious communities. A second bias that is relevant, particularly for those who received the questionnaire through the Keshet center at Tel HaShomer Medical Center or their residential facility, is a risk for acquiescence bias, especially regarding needs or barriers to mental healthcare services provided by these organizations. Conducting multiple comparisons on the same dataset might have introduced a statistical bias – the Family-Wise Error Rate of type 1 error. Given the limited number of entries, I have not introduced a Bonferroni correction. Therefore, the statistical findings should be interpreted as being eligible for additional risk for type 1 errors. Finally, despite the qualitative data collection being conducted prior to the COVID-19 virus pandemic, the survey was disseminated mostly after the outbreak. This could distort the survey findings, as individuals might have considered their changing needs following the outbreak when answering the survey. As in Israel these needs changed dramatically, given the long curfews and the shutdown of essential services, the survey findings might not reflect needs in routine times. Although the research findings should be interpretated in the context of these limitations, the validity and generalizability of the research findings are nonetheless compelling.

## 8.6. Closing remarks

This dissertation project utilized the case of autistic adults in Israel to examine health inequalities, their manifestations and their formation. Exposing all the pieces that make up the puzzle of health inequalities, and the struggle to eliminate them is a Sisyphean process. My work should be understood as another small, but important piece of this puzzle.

My attempt to dismantle different levels of oppression from individual barriers to the systemic oppressive perceptions and marginalizing policies; from the marginalized within the marginalized to the limiting discourses of their marginalization; from the privileged representatives who were oppressed by a neglectful system to their own discriminatory actions in the policy field; from employing neurotypical marginalizing research practices to trying to overcome them by means of participatory research only to realize this practice is also discriminating – all these efforts have led me to the conclusion that what we need to do is urgently scale up our efforts. As long the oppressive social axes continue to exist, inequalities will keep manifesting themselves in different forms. Therefore, we should strive to not only expose them but to eliminate them, or they will continue to dog our path.

A world free from oppression is unimaginable but a first step could be internalizing the lessons on communication practices autistic people have tried to teach me. Communication is different between neurotypical and neurodiverse individuals. However, if we wish to communicate and advance from the point we are currently, the powerful partners in the conversation need first to stop coercing the disadvantaged, and then both sides must try to draw closer to the other. This process is true on the individual level, as well as on the social level. Failing this, the powerful will always dominate the conversation, or society, to serve their own interests.

1. An example of another health inequalities issue in Israel, can be found in the discussion on closing the gap in infant mortality between women from different socioeconomic classes in Israel (Avarbuh, Perez & Avni, 2020, p.34). This discussion ignores access to birth control that is not funded by the state (Orshalimy, Forthcoming) which marginalizes women from low socioeconomic classes and misses important possible avenues of intervention. [↑](#footnote-ref-1)
2. Recently, these arguments were widely used regarding the management of the Coronavirus in the ultra-Orthodox community (Malahi, Malach & Friedman, 2020) and regarding the surge in violence within the Arab community (Rivlin, 2020). [↑](#footnote-ref-2)
3. I use the term neurotypicalism, as it represents the main system of oppression I investigate in this dissertation. This term should be conceived as a sub-category of ableism. [↑](#footnote-ref-3)
4. For example, on the neurotypicality axis, autistic people which are on the far left are affected differently from the same SDHI than neurotypicals as I show in Chapter 2; on the gender axis, women who are systemically oppressed are affected differently from current patriarchal marital religious arrangements than men. [↑](#footnote-ref-4)
5. The ideas for this section and specifically the term “bridging research” were constructed together with Iris Schneid, an autistic doctoral student in the department of Sociology and Anthropology at the Ben- Gurion University of the Negev, as part of our joint presentation on participatory research for the autistic convention in Tel Hai Collage. [↑](#footnote-ref-5)
6. This is not to say that all autistic people included in the committee were from a good socioeconomic level. On the contrary, owing to their disability, some would be considered from among the lowest socioeconomic classes. Nevertheless, the background of all is a middle-upper class background that allowed them to acquire social and cultural capital. [↑](#footnote-ref-6)