# 2. Literature Review

This research is structured around the multifaceted and entangled issue of inequalities. Consequently, the literature review extends beyond the autism field under investigation, and expands its scope to include the issue of inequalities and the relevant theoretical frameworks I employed to investigate it in the context of autistic adults in Israel.

## 2.1. The evolution of the autism field

In order to understand current processes that can potentially lead to inequalities among autistic people, it is important to briefly review the developments that have occurred in the autism field since autism was first defined as a distinct disorder by [Kanner (1943)](#_ENREF_67). Four major interconnected historical transitions have shaped the autism field and brought it to its current state. The first is the shift to considering autism as a spectrum as opposed to a single condition (American Psychiatric Association, 2013). Second is the fact that the incidence of autism has risen to such an extent that it has been referred to as an epidemic (Fombonne, 2001; Chiarotti & Venerosi, 2020). Third, autism is now attributed to biological mechanisms (Bölte, Girdler, & Marschik, 2019) or is considered a neurological difference (Ortega, 2009). Fourth, it has become represented by influential parents and self-advocacy organizations (Orsini & Smith, 2010), which has played a role in the development of extensive policies concerning various aspects of autism (Dicker & Bennett, 2011). Some of these policy-related aspects include shifts in autism etiology research; changes in classification and diagnosis; the deinstitutionalization process, and the establishment of parent, and later self-advocacy organizations. There is abundant scientific literature, which is briefly reviewed here, that has addressed and analyzed these complex historical and sociological processes.

The first change that is essential to explore is the shift in the discussion about the etiology of autism. Kanner, who first defined autism as a syndrome in the context of the emerging field of child psychiatry (Evans, 2014),[[1]](#footnote-1) attributes the condition to biological processes (Grinker, 2007). Nevertheless, the rise of Freudian psychoanalysis gave rise to the “refrigerator mother theory,” also known as “pathological motherhood” (Eyal, 2010; Bettelheim, 1967 in: Silverman, 2012; Waltz, 2013, pp. 52–67). According to this theory, a mother’s lack of affection gave rise to autism in children. This theory was countered by parents who formed a network, and, based on their accumulated knowledge and expertise about their own children, sought to explore alternative biological explanations for their children’s developmental disorder (Eyal, 2010, pp. 167–172; Eyal, 2013). This network of experts started by Bernard Rimland (1964) and continues to this day, has been performing ongoing research exploring possible etiologies for autism, from environmental exposure (Raz et al., 2017), to biological risk factors (Karimi et al., 2017; Bölte, Girdler, & Marschik, 2019), to genetics (Waye & Cheng, 2018). This research area has grown exponentially with the enactment of the Combating Autism Act in 2006 and later the Autism CARES Act in the United States, which secured approximately $4 billon in total for research and children’s services (Rubinstein, 2010; IACC, 2020; Ne'eman, 2011).

The reasons for enacting these laws were complex and included, among other reasons, the possible connection between the MMR vaccine and, specifically, Thimerosal (mercury), a component of the vaccine, and autism (Wakefield et al. 1998; Offit, 2008); the political connections between autism organizations and influential U.S. senators (Steuernagel, 2005; Baker & Steuernagel, 2009); and, above all, a surge in diagnoses (Baxter et al. 2015; Baio et al., 2018; Segev et al., 2019; Chiarotti & Venerosi, 2020), to the extent that autism has been referred to as an epidemic or a public health emergency (Newschaffer & Curran, 2003). This surge in diagnoses can be attributed to many factors, among which are environmental explanations (Limperopoulos, 2009; Hviid, Melbye, & Pasternak, 2013); increased awareness (Ouellette-Kuntz et al., 2007); the deinstitutionalization process (Eyal, 2010); the change in diagnosis criteria (Croen et al., 2002; King & Bearman, 2009; Eyal, 2010), and others (Matson & Kozlowski, 2011). The shifts in diagnosis criteria, however, are essential to explore, as they expanded the boundaries of autism and reshaped it as a spectrum.

Formally recognized for the first time in the third version of the Diagnostic Statistical Manual (DSM) published in 1981, autism, then called “infantile autism,” was characterized by four major characteristics proposed by Sir Michael Rutter. The next DSM version, III-R published in 1987, was more inclusive and the category Pervasive Developmental Disorders – Not Otherwise Specified (PDD-NOS) was created, which allowed for the inclusion of more individuals to whom the diagnostic criteria did not neatly apply within the diagnostic bracket. Despite the DSM VI being more precise in its wording, it added more categories to PDD, including Asperger syndrome (Grinker, 2007, pp. 103–143). This syndrome, defined by Hans Asperger in 1944, was recognized in 1981 by Lora Wing (1998), and included under the same category individuals with very different phenotypes who nevertheless shared some unique characteristics. The recently published DSM V (American Psychiatric Association, 2013) defined autism as a spectrum and allowed the further expansion of autism; perhaps not surprisingly, the rise in diagnosis continued. Although described here as an almost natural evolution, this expansion included shifts in meanings which were difficult to reconcile with the broader social context, thereby leading to phenomena such as distortions in resource allocation for autistic children (Eyal, 2010; Evans, 2013; Verhoeff, 2013; Verhoeff, 2016).

The psychiatric inclusion of verbal autistic people with high cognitive abilities on the same spectrum was one factor that led to the establishment of the autistic community (Sinclair, 2005). The autistic community, from the beginning, opposed the perception of autism, held by parents and professionals, that autism is a disease and that the biological mechanisms causing it needed to be understood so cures or treatments could be developed to uncover the person “underneath the autism.” In his pathfinding book *Don't Mourn for Us*, Jim Sinclair (2012 [1993]) called for the acceptance of the autistic person and, together with other autistic people (see for example Gardin, 1995), established the notion of autism as a difference (Hacking, 2009). This notion, which eventually evolved into the concept of neurodiversity (Orsini, 2009; Ortega, 2009; Jaarsma & Welin, 2012; Silberman, 2015; Tan, 2018), created a new biological identity that reshaped the field of autism again. The concept of neurodiversity holds that autism, along with other cognitive differences, such as attention deficit hyperactivity disorder (ADHD), are part of normal human diversity, which are marginalized in the current social structure, but should be acknowledged and integrated (Orsini, 2013; Runswick-Cole, 2014; Runswick-Cole, Mallett & Timimi, 2016; Rosqvist, Stenning & Chown, 2020). This view of autistic people as a distinct social group that deserves equal access to public resources is fundamental to this study.

The evolution of the autism field, however, cannot be understood in isolation from the parents of autistic children and the organizations they established. As mentioned above, parents were the ones who spearheaded the rejection of the “pathological mother” etiology (Eyal, 2010). Furthermore, two of the most well-known and widespread treatments for autism – Applied Behavioral Analysis (ABA) therapy[[2]](#footnote-2) and the TEACCH[[3]](#footnote-3) method – which have been practiced since the 1970s, positioned parents as the main therapists of their children and set the stage for parents to claim expertise over treatments as well.[[4]](#footnote-4) It was at parent organization meetings in the early 1990s that autistic people first met and started to form a community (Sinclair, 2005), and some argue that parents were also the ones who claimed their children were different, not deficient, and needed prosthetic environments (Hart, 2014). Above all, it was the advocacy efforts of parent organizations to secure resources for their children that reshaped the material context of the field (Chamak, 2008; Caruso, 2010; Orsini & Smith, 2010; Mishori, 2014; Bosco, 2018; ). These new actors, the “parent-activist-therapist-researchers,” to use [Eyal’s (2010, p. 172)](#_ENREF_46" \o "Eyal, 2010 #45) term,[[5]](#footnote-5) and the organizations they formed (which I discuss later in detail and investigate in my dissertation) played a vital role in shaping the autism field.

Finally, it is essential to recognize the role of the deinstitutionalization process that occurred between the 1970s and the 1990s. As discussed in Eyal’s analysis (2010, 2013), this process, which called for closing down traditional mental institutions and shifting mental health treatment into the community, created the institutional conditions for changing autism diagnosis criteria and the resulting increased prevalence of autism. Additionally, this process enabled the formation of a novel community-oriented approach to services for autistic people (Bagnall & Eyal, 2016). These historical and sociological processes represent just a few of the changes the autism field has experienced since it was first defined, but they are the most essential as the background for this study.

## 2.2. Autism organizations

The complicated field of autism policy which creates the context that determines the social position of autistic people (see a further explanation of this term below in the theoretical framework section 2.6) cannot be understood without close examination of autistic advocacy organizations. As presented above, in Israel and around the world, autism advocacy organizations have shaped and are shaping the autism field (Grinker, 2007; Chamak, 2008; Caruso, 2010; Feinstein, 2010; Orsini & Smith, 2010; Dicker & Bennett, 2011; Rimon-Zarfaty et al., 2020). The oldest organizations were established in the United Kingdom and the United States. The National Autism Society (NAS), which is based in the United Kingdom, was established in 1962 (Hallahan & Murphy, 2014) and the Autism Society of America (ASA) was established in 1965 in the United States (Eyal, 2010).[[6]](#footnote-6) Some years later, in 1974, parents in Israel established their own organization, The Israeli Society for Autistic Children (Alut) (Feinstein, 2010, p. 247; Mishori, 2014). More recently, after the establishment of the autistic community, organizations *of* autistic people have started to form and become important actors in the field of autism (Chamak, 2008; Orsini & Smith, 2010; Raz et al., 2018).

The diverse literature on these organizations typically focuses on three major issues: the influence of these organizations on policy, their influence on knowledge production (or both combined), and the differences between organizations operating in the field. Dicker and Bennett (2011) examined the influence of these organizations on policies regarding children with disabilities in the United States, and Baker and Steuernagel (2009) argued that their representatives should be regarded as policy entrepreneurs. Orsini and Smith (2010) and Baker (2013) explored the utilization of knowledge and type of knowledge that is used by these organizations in the autism field and in the policy arena, while Eyal (2010; 2013) discussed their influential role in forming alternative knowledge.

The third type of literature on autism organizations explores the differences between the organizations operating in the field. This is relevant to my analysis because it deals with representation claims. The first and most common difference is between organizations *for* autistic people of parents, and organizations *of* autistic people (Chamak, 2008; Orsini & Smith, 2010; Bertilsdotter Rosqvist, Brownlow & O'Dell, 2015; Raz et al., 2018). Although advocating for the same population, their claims are different (Chamak, 2008) and the type of knowledge they employ is different (Orsini & Smith, 2010). However, this is not the only difference between these organizations. Raz et al. (2018) argued there are different representational claims on the autism functionality spectrum, and, while some claim to represent the “low functioning” (or Kanner’s autism) autistic people, others claim to represent people presenting with “high functioning” autism (or Asperger syndrome, for example). In addition, they have recognized that, among these organizations, some represent a more inclusive approach in accordance with the social model of disability (SMD), and others seek to accommodate the “affected” autistic community in line with the medical model of disability (MMD) (see also Jongsma, Spaeth, & Schicktanz, 2017; on the theoretical models of disability see below under the theoretical framework). Finally, these organizations also differ in terms of their activity and structure, as can be clearly seen in the differences between the ASA in the United States and NAS in the United Kingdom. While the former chose to deal exclusively with advocacy, the latter is both an advocacy group and a service provider (Eyal, 2010; see also Rimon-Zarfaty et al., 2020 on Israel). These four organizational axes: *of* vs. *for*, low vs. high functioning; SMD vs. MMD, and advocacy group vs. supplier, have been the source of ethical discussions (Spaeth, & Schicktanz, 2017; Jongsma & Schicktanz, 2020; Jongsma, et al., 2020) and organizational insights (Rimon-Zarfaty et al., 2020).

### 2.2.1. Autism organizations in Israel

In Israel, like in other places, autism organizations were established as part of the development of the field. Raz et al. (2018) briefly describe the chronological establishment of the four main organizations operating in Israel. Alut, the first parent organization, was established in 1974 (Feinstein, 2010; Mishori, 2014) to promote services for autistic children. Effie, the Israeli Asperger Association was founded in 2001, also by parents, to give a voice to and promote services for “high functioning” autistic people who were overlooked by Alut. Next, in 2006, the autism community of Israel, ACI, the first and only organization *of* autistic people, was officially founded, although it has still not formally registered. Finally, following an internal dispute within Alut regarding the organization’s position on integration and inclusion, a group of parents decided to establish *Yozmot HaShiluv* (Integration Initiative), later renamed *Mishtalvim BaRezef* (Integration of the Spectrum) (Raz et al., 2018; Rimon-Zarfaty et al., 2020). These four organizations, currently operating in Israel, represent the differences in the autistic community on three axes: the *of* vs. *for*, low vs. high, and SMD vs. MMD axes. Alut was identified by Rimon-Zarfaty et al. (2020) on the supplier vs. advocacy axis both as a supplier and an advocacy organization. Despite the other organizations not having been scientifically analyzed on this axis, Effie, like Alut, is both a supplier and an advocacy organization (Effie Asperger Israel, 2020), albeit on a much smaller scale than Alut. ACI and Mishtalvim BaRezef focus only on advocacy. In the last chapter of this dissertation, I delve into these axes and demonstrate how they are reflected in my findings.

Although the direct involvement of these organizations, and specifically Alut, the oldest organization operating in the field, in setting the policy agenda has not been thoroughly investigated, the scientific literature does recognize the prominent influence of Alut on autism policy. Shulman (2000) mentions Alut, not only as the sole provider of housing for autistic adults, but also for its close collaboration with the Ministry of Education in forming an information center for autism at the beginning of the 1990s – MILA. In addition, Mishori (2014, pp. 175–206) described the role of Alut in advancing services for autistic people in Israel. She illustrated how Alut’s involvement set an alternative treatment agenda to the one promoted by the psychiatric establishment, and how the organization established the first school for autistic people and the first residential facility for autistic adults, working closely with the Ministry of Health (MoH). In the last chapter of this dissertation, I delve into Alut’s policy involvement and demonstrate that while it has been transformed over the years, Alut indeed was and continues to be a dominant organization.

### 2.2.2. Health social movements

Autism organizations, sometimes also referred to as patient organizations, must also be understood in the broader context of health social movements (HSMs). Reference to this scholarly tradition is essential, as it provides insights on issues such as the consequences of these organizations’ actions and representation in health policy. The three domains of HSM identified by Brown and Zavestoski (2004) are: “(a) access to, or provision of, health-care services; (b) disease, illness experience, disability and contested illness; and (c) health inequality and inequity based on race, ethnicity, gender, class and/or sexuality.” Autism organizations could be classified as operating both on the access and disease domains while blurring the boundaries between them (Brown & Zavestoski, 2004, p. 53; Epstein, 2008, p.506; see also Orsini & Smith, 2010, pp. 40–42). Nevertheless, their actions and implications of these actions on the third domain, inequalities, cannot be disregarded in the context of this study.

Epstein (1996, p.352), in the conclusion of his seminal book *Impure Science*, which examines the AIDS movement and its effect on knowledge production, mentions that, “The fact that various dimensions of social hierarchy […] crisscross and intertwine with the politics of expertise complicates the story.” This “complication,” as he argued a decade later, has still not been adequately explored, especially in terms of the impact of HSMs on the discrimination of marginalized communities (Epstein, 2008, p.526). This lacuna has emerged both because the consequences of HSMs’ actions in the policy field are usually discounted (Klawiter, 2004; Epstein, 2008, pp.519–521) and because HSM research and, more broadly, social movement research, have tended to neglect the intersectional perspective, which focuses on multiple levels of marginalization (Watkins-Liu, 2018; Wojnicka, 2019; see section 2.6 for an elaboration on the intersectionality theoretical framework).

Among those who have explored HSMs from an intersectional perspective, Watkins-Hayes’ (2014) review of the influence of intersectionality on the AIDS movement summarized that this approach has analyzed the intersection of HIV with marginalized social positions, beyond gay men, who are very well-represented in the literature, to include other marginalized groups, such as women or people of color. Furthermore, it allowed for the examination of the forms of power that are transmitted through risk and politics. Decoteau (2017) has explored the significant role the interaction of race, Somali nationality, and autism has had in forming dedicated organizations for Somali autistic people who advocate for better services.

I intend to draw on these scholars’ work and explore the connection between the limits of representation in HSM (van de Bovenkamp & Vollaard, 2018) from an intersectional perspective, and the consequences of HSM policy activity on inequalities. Yet, as I explain below in the theoretical section, my focus will not be on the HSM of the marginalized, but of the privileged. To my knowledge, this is the first study in HSM literature to take this approach. Nevertheless, in social movement literature, a few studies, such as that of Hunt (2018), have adopted this approach. Investigating the SlutWalk, she illustrated how the provocative strategy led by privileged white women discriminated against marginalized group of women, especially those who come from religious communities, such as Muslim women, by preventing their participation and diverting attention away from their protests and needs. This example, despite not being from the HSM world, describes a similar analytical process I adopt in the last chapter.

## 2.3. Autism policy

As mentioned above, autism organizations have shaped the autism policy field, but have not successfully demarcated the parameters of the field. Autism, whether it is defined as a neurological difference or as a developmental disorder, affects the individual’s needs throughout their entire life and in almost every aspect of life. Therefore, autism policy comprises policies that relate to every step of an autistic individual’s life, from screening, diagnosis, early interventions, and education, among other issues, in childhood (Feinberg & Vacca, 2000), to employment, residential arrangements, and community services, among other issues, in adulthood (Clark, Scharaschkin, & Xu, 2009; Wright, Brooks, D'Astous, & Grandin, 2013; Gotham et al., 2015;). In addition to age-related or developmentally relevant policies, autism policy also affects, and is affected, by cross-age policies, such as rights and anti-discrimination laws, autism research funding, and residual effects on families and the community. From a social determinants of health (SDH) perspective (see explanation of this framework below), all these policy issues, along with healthcare-system-related policies, affect autistic people’s health and contribute to the formation of the sociopolitical context in which autistic individuals live. It should be stressed that, like any other policy issue, autism policies are contextualized and articulated within the sociopolitical structure relevant to each country; nevertheless, as the fundamental needs of autistic people are the same everywhere, policies in one context can be relevant to other contexts. Owing to the growing recognition that these policies have an immense influence on the lives of autistic people, recently there has been increasing interest in identifying and analyzing their influence (Zeidan et al., 2019; AIMS-2-TRAILS, 2021; Debra et al., 2021).

One of the major issues discussed in relation to autism policy is the definition or classification of autism. As mentioned above, there are continuous tensions within the autism community on how autism should be defined: as a neurological difference; as a mental health disorder; as a developmental disorder; or as a medical problem. This discussion is crucial to policy, as this variety of definitions can lead, in different sociopolitical contexts, to different access to services and accommodation of needs (Steuernagel, 2005; Orsini & Smith, 2010; Baker, 2011; Jaarsma & Welin, 2012; Orsini, 2013; Mishori, 2014; Runswick-Cole, 2014). While this issue also clearly influences autism policy in Israel (State Comptroller Annual Report, 2012; Mishori, 2014), rather than discussing the implications of these classifications directly within the Israeli system, I argue that autistic people should be regarded as belonging to a distinct social group (see theoretical framework below).

Another major issue often discussed regarding autism policy is the uneven weight given to policies concerning autistic children in comparison to policies concerning autistic adults. Many scholars have argued and demonstrated that autism policy and research are focused on autistic children, leaving the needs of the exponentially growing autistic adult population with no proper exploration of their needs, not enough policies that address them, and insufficient funding (Ne’eman, 2011; Wright, Brooks, D'Astous, & Grandin, 2013). Shattuck et al. (2012b), for example (see also Office of Autism Research Coordination, 2012), have reported that only 2% of funded research regarding autism spectrum disorder (ASD) was directed toward autistic adult needs; and others have shown there is agreement within the community that this gap should be narrowed (Warren et al., 2012; Pellicano, Dinsmore, & Charman, 2014). In Israel, only a handful of studies have explored the autistic adult population’s needs or relevant policies, and most of those have focused on employment (Ran, 1999; Garar-Bashir, Rivkin, & Lef, 2014; Gal, Landes, & Katz, 2015; Nizan-Weisman et al., 2019), as well as one regarding the conflictual engagement with service providers (Schneid, 2018; Schneid & Raz, 2019), and another on social outcomes (Beenstock, Pinto & Rimmerman, 2021). Only Drori (2015) has attempted to specify the needs of adults with Asperger syndrome more broadly as part of a new program development. The National Autism Research Center of Israel, established in 2015 with the support of the Ministry of Science and Technology of Israel, also aims to promote research mainly on diagnosis and medical treatments (The National Autism Research Center of Israel, 2021), further demonstrating the governmental inclination toward children’s needs and research.[[7]](#footnote-7) The reasons for neglecting the research and needs of autistic adults are complex, yet as Ne’eman ([2011](#_ENREF_92)) argued, the influential role of parent organizations in autism policy creation has clearly been a factor. This project tries to narrow this research gap and investigates the sociopolitical context that affect the lives of autistic adult in Israel.

### 2.2.1. Adult autism policy

Policies regarding autistic adults should reflect the specific needs of this population, which are clearly different from those of children. Two major issues in particular concern the autism community and policy makers. These are living arrangements (Krauss, Seltzer, & Jacobson, 2005; Anderson et al., 2014; Dudley et al., 2019; Lee et al., 2020), and employment (Targett & Wehman, 2008; Taylor & Seltzer, 2011; Roux et al., 2013; Chen, Leader, Sung, & Leahy, 2015; Gal, Landes, & Katz, 2015; Nizan-Weisman et al., 2019; Harrington, 2021) which can be either within the community or provided in a more isolated or sheltered environment (Mandell, 2017). In addition, adult autism policy is directed at answering the more specific needs of autistic adults, particularly in light of the need for: structural services for the transition period from childhood to adulthood (Wehman et al., 2014; Wei et al., 2015); accessible postsecondary education (Hurewitz & Berger, 2008; Shattuck et al., 2012a; Sims, 2015; Taylor, Henninger, & Mailick, 2015); assistance in community participation (Bureau of Autism Services, 2011c); accommodation in public transportation and in physical space (Lubin & Feeley, 2016; Wilson et al., 2021); policies that address social life and leisure needs (Drori, 2015; Eaves & Ho, 2008; Strunz et al., 2017); and more. Like everyone else, autistic adults also age and their needs and the specific policies for addressing them must be readjusted as they reach old age (Piven, Rabins, & Autism-in-Older Adults Working Group, 2011; Happé & Charlton, 2012; Elichaoffa, 2015; Roestorf, Howlin & Bowler, 2021; Waldron, Coyle, & Kramer, 2021).

As this investigation is positioned within the field of the healthcare system, health policies are further explored below (see section 2.4) and were investigated as part of this research (in the Chapter 2 analysis). Nevertheless, it should be stressed again that, from an SDH perspective, all the policy issues mentioned above also directly affect the wellbeing and health of autistic adults (see for example Fleming, Fairweather, & Leahy, 2013 and Harkey, 2017 on the effect of employment on mental health; and Dudley et al., 2019 on residential arrangements and their effects on needs). In the last chapter of this dissertation, I explore the formation of residential arrangement policy in Israel, from the SDH perspective, as this is also considered a health-related issue.

### 2.2.2. Autism policy in Israel

As autism policies must address countless aspects of life, diverse official bodies are involved in their formation, including the legislative authorities and different ministries and institutions associated with the executive authorities. In Israel, specific policies regarding autistic children started being developed in the 1970s. The first landmark came in 1978, when the first school for autistic children *Yachdav* (Together) was established with the collaboration of the Ministry of Education and the municipality of Tel Aviv (Mishori, 2014). In 1988, the Special Education Law was enacted, mandating maximum inclusion of disabled children in the regular school system and the provision of three hours a week of paramedical services for each autistic child, provided today by the Israeli sick funds (SFs).[[8]](#footnote-8) Two years later, in 1990, the MILA center for autism knowledge was established with the cooperation of the Ministry of Education (MoE) and, in 1996, the center was broadened, as close connections with members from the TEACCH program in North Carolina in the United States were formally established (Shulman, 2000). In 1998, two legislative amendments were passed that had a major impact on autistic children. First, Amendment 19 to the National Insurance Law that mandated that autistic children would be entitled to 100% of the monthly childhood disability stipend (today the stipend amounts to NIS 2,608 [$800 USD ]) through the National Insurance Institute (NII), based on their diagnosis alone, regardless of their needs (National Insurance Law, 1995; The High Court of Justice 7879/06, 2006). The second amendment was to the National Health Insurance Law (NHIL), mandating the provision of an additional 14 weekly hours of related healthcare services called advancement health therapies (*Tipul Briuti Mekadem*), provided until the age of seven by the SFs (National Health Insurance Law, 1994; Provision of Services in Child Development for Children on the Autistic Spectrum, 2009). Based on these policies, autistic children are legally entitled to suitable educational services, a monthly stipend, and additional related healthcare services to support and advance their development.

For autistic adults, the first landmark was the opening by Alut of a residential facility for them in 1988 called Ofarim Village. In Chapter 4, I explain in detail the circumstances that led to the establishment of the village (see also Mishori, 2014). This was followed by the opening of additional residential facilities called “houses for life” in Israel. The responsibility for supervising these houses shifted, following a government decision in 1999, from the MoH to a new unit established within the Rehabilitative Services and Disassociated Youth Department at the Ministry of Social Affairs and Social Services (MSASS), which later became the Autism Department. In 2017, the Disability Administration was established, and the responsibilities of the Autism Department were divided between the Housing Department and the Community Department, which are responsible for the provision of services catering for all disabilities according to the type of service and not according to the disability (Rimon-Grinshpan et al., 2019). In the last decade, following a shift to more community-oriented services and the expansion of the spectrum, additional, less isolated residential opportunities have been established, including satellite apartments and supported living apartments (Rimon-Grinshpan et al., 2019). In addition to the residential facilities, over the years, more services for autistic adults have been established. The first additional services were employment centers for autistic people called *Meital* (Shulman, 2000). Later, other services were established, including rehabilitative afternoon care facilities, vacation resorts, and more.[[9]](#footnote-9) While the number of autistic people enrolled in community services and less isolated residential options grew by about five times in the decade between 2009–2019, the absolute number of autistic people using these services is still relatively small (Rimon-Grinshpan et al., 2019). Furthermore, a diagnosis of autism does not automatically entitle an adult to disability stipends; if diagnosed from the age of 18, autistic individuals are eligible for the NII disability stipend only if they have additional mental or physical disabilities, and have been recognized by the NII’s medical committee as having reduced functional abilities (Israel State Comptroller, 2012).

Two very important policy landmarks from the last decade should be mentioned. First, following an advocacy effort by parent organizations and, owing to the rise in the incidence of autism, an autism-specific bill was presented to the Knesset in 2013, calling for additional resources for autism, while regulating services (Rehabilitation, Development, and Integration of People with Autism in the Community, 2013). Although the bill has not been enacted yet, and has been radically amended, as I discuss in the last chapter, it marks a novel policy approach to autism. The second landmark is the formation of an autism coordination committee in 2013 that was supposed to submit its recommendations in 2014 (Vagshal, 2013). This committee, which was established following a report by the State Comptroller Office (Israel State Comptroller, 2012), assisted with the further expansion of funds dedicated to autistic people and laid the foundation for later discussions, for example, on the issue of functionality (Rimon-Grinshpan et al., 2019; see also Chapter 3).

A related policy issue, which also had a considerable impact on autistic adults in Israel, is the legal status of disability rights. In 1998, the Equal Rights for People with Disabilities Law was passed (Equal Rights for People with Disabilities Law, 1998), which is similar to other laws passed around the world (Avrami & Rimmermann, 2005). Along with administrative decisions, such as the establishment of the Commission for Equal Rights of Persons with Disabilities under the Ministry of Justice, this law provides the first legal basis for anti-discrimination policies against autistic people, as it recognizes the equal rights of people with disabilities in Israel. The law marked the beginning of a gradual change in the legal recognition of the rights of this marginalized population, including the right to accessible public services. This change, however, is still incomplete (Mor, 2019). In 2012, the United Nations Convention on the Rights of Persons with Disabilities (The United Nations, 2006) was approved by the Israeli government, becoming yet another milestone for people with disabilities, among them autistic people, as it recognized their legal right to live independently in the community (Commission for Equal Rights of Persons with Disabilities, 2021). The most recent policy change came in 2016, with the enactment of Amendment 18 to the Legal Capacity and Guardianship Law of 1962, allowing autistic adults alternative, less restrictive legal arrangements than guardianship, such as supported decision-making and continuous power of attorney. This change has the potential to greatly enhance the independence of autistic adults (Davies, Werner & Sinai, 2017).

Finally, since 1995, healthcare service have been provided by the NHIL for Israeli citizens. The services and treatments that the national insurance covers appear under the Health Services Basket (HB), which is determined by the Health Services Basket Committee of the MoH.8 As mentioned above, currently, the HB mandates treatment for children under the age of seven; for autistic adults, however, there are no specific services available through the NHIL. Nevertheless, the SFs are responsible for the provision of other healthcare services that are relevant to autistic individuals, including mental health services, institutionalization in mental health facilities and, of course, other medical services (Bin Nun, Berlovitz, & Shani, 2005; Elroy, Samuel, Elmakias & Rosen, 2017).[[10]](#footnote-10) Autism policy in Israel, which was briefly described above, is multifaceted, provided by multiple authorities, and has undergone major changes over the past 30 years. In this study, I thoroughly examine both health-related policies and the construction process of the residential arrangement policies. This research represents the first time these issues have been investigated in Israel.

## 2.4. Autistic people and the healthcare system

This section delves into the scientific literature concerning the central determinant I investigated – the healthcare system. I start by exploring the healthcare needs and healthcare-related determinants, including individual and systemic barriers, that affect autistic adults’ health and conclude with the implications of not meeting these needs, and imposing these accessibility barriers on the autistic adult population.

### 2.4.1. Health related needs

The healthcare needs of autistic adults are greater than those of the neurotypical[[11]](#footnote-11) population. Research has shown that autistic adults are at a higher risk than the general population for seizure disorders, gastrointestinal disorders, thyroid disorders, autoimmune diseases, hypertension, obesity, prediabetes and diabetes, hyperlipidemia, cardiac arrhythmias, asthma, allergies, osteoporosis, bone fractures, and parkinsonism. Although the specific rates vary from one cohort to another and according to age and sex, chronic health conditions among autistic people are clearly highly prevalent (Croen et al., 2015; Starkstein et al., 2015; Cawthorpe, 2017; Wise, Smith & Rabins, 2017; Saqr et al., 2018; Weiss et al., 2018; Hand et al., 2020; DaWalt et al., 2021; Tint et al., 2021; Weir, Allison, Warrier & Baron-Cohen, 2021). It should be noted, however, that among adults with ASD, some diseases are found at lower rates, including sexually transmitted diseases, infectious diseases, along with lower rates of tobacco use and alcohol misuse (Fortuna et al., 2015; Hand et al., 2020). Given the high rates of medical conditions, it is hardly surprising that research has uncovered higher rates of healthcare utilization among autistic adults in comparison with the general population, including higher rates of primary healthcare visits; neurology and gastrointestinal specialists; hospitalization (Vohra, Madhavan & Sambamoorthi, 2017; Weiss et al., 2018; Zerbo et al., 2019; DaWalt et al., 2021); hospitalization duration (Lokhandwala, Khanna & West-Strum, 2011), and emergency department visits, mainly due to epilepsy (Vohra, Madhavan, & Sambamoorthi, 2016; Vohra, Madhavan & Sambamoorthi, 2017; Weiss et al., 2018).

The scientific literature also demonstrates beyond doubt that autistic people also have significantly elevated rates of mental health comorbidities. Depression, anxiety, ADHD, personality disorders, suicidality, psychotic disorders, and bipolar disorders were all found to be more prevalent among autistic people compared to the typical developing population, with rates ranging from double the risk to 12 times the risk in certain conditions and among certain cohorts (Ghaziuddin, Ghaziuddin, & Greden, 2002; Buck et al., 2014; Croen et al., 2015; Fortuna et al., 2015; Saqr et al., 2018; Lai et al., 2019; Hand et al., 2020; Hossain et al., 2020). As a result, higher rates of psychiatric drug use were found among autistic adults (Kohane et al., 2012; Buck et al., 2014; Saqr et al., 2018; Zerbo et al., 2019); higher utilization rates of mental health care services (Weiss et al., 2018; Zerbo et al., 2019; DaWalt et al., 2021), and emergency department visits for psychiatric reasons (Vohra, Madhavan, & Sambamoorthi, 2016; Weiss et al., 2018). In Israel, Drori (2015), who surveyed 80 autistic adults diagnosed with Asperger syndrome as part of the founding of assisted community living for this population, reported that 62.5% had at least one or more psychiatric diagnoses, and 40% were using psychiatric medicines. In addition to mental health utilization, the mental health care system as the regulator of autism diagnosis needs to address the issue of “lost” autistic adults who were misdiagnosed or undiagnosed in childhood (Lai & Baron-Cohen, 2015). This diagnosis procedure in adulthood requires additional specialization (Epstein, 2019; Huang et al., 2020).

Beyond medical care and mental healthcare services, it is clear from the literature that autistic adults need additional allied health services. These services include occupational therapy, physical therapy, speech therapy, community-based interventions, behavioral therapy, social and life skills development, and more (Bishop-Fitzpatrick, Bureau of Autism Services, 2011a; Taylor et al., 2012; Minshew & Eack, 2013; Bishop-Fitzpatrick, 2016; Tincani & Bondy, 2016; Ke, Whalon, & Yun, 2018; Lorenc et al., 2018; Cummins, Pellicano, & Crane, 2020; Skaletski, Chakraborty, & Travers, 2021). However, because the coverage of these services by health insurance is diverse and varies between and within countries, there is limited data concerning their utilization. Zerbo et al. (2019), who used data from an insurer that covers these services, demonstrated higher rates of additional services – specifically, speech therapy, occupational, and physical therapy – among autistic adults, as compared with the neurotypical population and a cohort of adults with ADHD (see also Defense-Netrval & Fernandes, 2016 on the high utilization despite the shortage in Sao Paulo, Brazil). Considering these elevated health needs, the high utilization of healthcare services, together with the rise in the absolute number of autistic adults, and the fact that this population is aging, it can be concluded that their encounters with the healthcare system will grow even more in the coming years.

### 2.4.2. Accessibility barriers to healthcare services: autism-related barriers

Despite autistic adults having high needs related to healthcare services, this population experiences significant barriers to access to healthcare services. The scientific literature usually divides these barriers into one of three domains: patient or autism-related barriers; provider-related barriers, or systemic barriers ( Calleja, Islam, Kingsley, & McDonald, 2020; Walsh, Lydon, O’Dowd & O’Connor, 2020). As my investigation is an analysis of autistic adults from the perspective of SDH (see extended explanation in section 2.6), I treat the autism-related barriers as a unique characteristic that defines the group disability, while the provider and system barriers are considered as part of the sociopolitical context which determines healthcare services’ accessibility. This subsection explores the autism-related barriers; the next explores the SDH.

Among the autism-related barriers identified in the literature are communication difficulties, sensory difficulties, emotional distress when accessing the healthcare system, the need for consistency, atypical non-verbal communication, slow processing speed, and challenges with organization ( Nicolaidis et al., 2015; Dern & Sappok, 2016; Raymaker et al., 2017; Mason et al., 2019; Calleja et al., 2020; Doherty et al., 2020; Walsh et al., 2020). However, only communication difficulties and sensory difficulties, which are articulated in diverse forms, were identified by all studies as a barrier to access, while others appeared in only some studies. It should be noted that since communication involves both parties, communication difficulties can be articulated as an autism-related barrier, a provider barrier, or both (see for example Nicolaidis et al., 2015). I classify communication as an intrinsic autism barrier, not to minimize professional responsibility, but to stress that the autistic population should be treated as a separate social group. To emphasize this claim, I further investigated the barriers faced by autistic adults to healthcare services. However, as no study has been conducted in Israel, and to my knowledge, apart from one study conducted in Germany (Dern & Sappok, 2016), all existing studies have examined barriers faced by autistic adults in English-speaking countries, this research also provides a novel perspective on this issue from a unique context.

### 2.4.3. The sociopolitical context of healthcare provision for autistic adults

The sociopolitical context that affects accessibility to healthcare services for autistic adults can generally be divided into provider-related barriers and system barriers. The most common barrier in relation to provider barriers was a lack of knowledge regarding autistic people, which was reported both in physical services and mental health services (Mason et al., 2019; Adams & Young, 2020; Walsh et al., 2020). Several studies examining the knowledge of providers about autism found that, in the majority of disciplines and settings, the knowledge level was between fair to poor (Zerbo et al., 2015; Dooren, McPherson, & Lennox, 2016; McCormack et al., 2020; Corden, Brewer & Cage, 2021). In Israel, however, Atun-Einy and Ben-Sasson (2018), who conducted a survey of knowledge among pediatric healthcare professionals, found adequate knowledge about autism, a finding that might imply that Israel experiences different trends. In addition to lack of knowledge, poor flexibility on the part of providers, unwillingness to accommodate services, and perceived stigma were mentioned as barriers to healthcare services (Nicolaidis et al., 2015; Walsh et al., 2020; Corden, Brewer & Cage, 2021).

The systemic barriers to healthcare services for autistic adults that were identified in previous studies include financial and insurance issues, time and resources constraints, inflexibility and complexity of the healthcare system, lack of designated support for autistic adults, specific issues with scheduling appointments, and issues with continuity of care (Nicolaidis et al., 2015; Dern & Sappok, 2016; Raymaker et al., 2017; Mason et al., 2019; Walsh et al., 2020). In mental healthcare, specific barriers were mentioned, including unavailability of services, long waiting lists, lack of funding, and not meeting inclusion criteria for services (see review by Corden, Brewer & Cage, 2021). Although the issue of accessibility has hardly been explored from a policy perspective, recently Debra et al. (2021) analyzed the organizational and structural barriers to mental healthcare services for individuals with intellectual and developmental disabilities, including ASD, in the United States and concluded that the current provision structure places the burden of integrating mental health services with the unique care needs of autism on the individual instead of on the system. Furthermore, Zeidan et al. (2019), who conducted a policy analysis in Quebec, mentioned several gaps, including issues with access to family physicians and allied health services, problems with continuity of care, and a one-size-fits-all service culture, among others. These gaps were found despite that introduction of a program in 2017 that had an exclusive section focused on autistic adults. It should be noted that different regulations (Parkin et al., 2018), interventions aimed both at the autistic individuals and providers (see review by Walsh, O’Connor, Walsh, & Lydon, 2021), and formal guidelines in different countries (Sullivan, 2011; NCCMH, 2012; Nicolaidis, Kripke & Raymaker 2014) have tried to address some of the barriers faced by autistic adults with considerable success. Unfortunately, in Israel, the providers and system accessibility barriers faced by autistic adults have not been explored, and, apart from one program implemented by a non-profit organization (Nisim, 2020), no guidelines or policies for addressing these barriers are currently in place.

### 2.4.4. Implication of unmet needs

As a direct result of the extensive healthcare needs of autistic adults and the individual and systemic barriers to healthcare services they face, various health outcomes in this population have been found to be poorer in comparison to those in the general population. Several studies have shown increased mortality rates among autistic people, as well the likelihood of dying at a younger age (Woolfenden et al., 2012; Hirvikoski et al., 2018; Hwang et al., 2019). Other studies have shown autistic adults have a poorer quality of life (QoL) and health-related-QoL than their neurotypical equivalents (Kamio, Inada, & Koyama, 2013; Khanna et al., 2014; Braden et al., 2021; Howlin, & Bowler, 2021) with a clear association between QoL and comorbidities (Leader et al., 2021; Roestorf, Howlin, & Bowler, 2021). Moreover, several studies have shown that autistic adults report higher unmet health and mental health needs than do neurotypical people (Nicolaidis et al., 2013; Doherty et al., 2020). In the care provision setting, it has been shown that chemical or physical restraints are often used on autistic adults in emergency department visits, ranging from 23% of visits (Lunsky et al., 2015) to up to 50% of visits by autistic adults (Tint et al., 2019). Finally, from a public health perspective, healthcare inaccessibility and unmet needs translate to higher healthcare expenditures (Vohra et al., 2017; Zerbo et al., 2019) and high public expenditure on autistic people (Knapp, Romeo, & Beecham, 2009; Buescher et al., 2014). Although the implications of barriers of accessibility to healthcare services are not the main concern of this study, I discuss here, for the first time in Israel, mechanisms by which barriers negatively impact health. Furthermore, these implications demonstrate inequalities between autistic adults and neurotypical people which are reflected in several measurable health outcomes.

## 2.5. Inequalities between autistic people

As discussed above, autistic adults have been found to be discriminated against both in terms of the provision of incompatible services at the individual level and on account of the marginalizing sociopolitical context. This discrimination results in a reduction in various health outcomes in comparison to neurotypical people. Health inequalities have been defined as unacceptable and avoidable unequal access, quality, and outcomes in terms of healthcare (Whitehead, 1991; Braveman, 2006) and, in the case of autism, the definition can be extended to the “unequal access to diagnosis, treatment, and services related to ASD” (Singh & Bunyak, 2019). This section explores the health inequalities faced by autistic people in Israel and the world more generally and will conclude by discussing the mechanisms that contribute to inequalities.

### 2.5.1. Intra-Autistic inequalities around the world

Inequalities that exist between autistic children and autistic adults from various groups have been discussed in the literature, mainly in the United States, but in other countries as well. The literature on inequalities within autism can be roughly divided into two categories: inequalities in the age of diagnosis and inequalities in access to services. The interest in the age of diagnosis is important because the development of abilities in adulthood is attributed to early interventions that can be provided only after diagnosis. Disparities in age of diagnosis and enrollment in the mental health system was demonstrated between children with ASD from different ethnic groups: white non-Hispanic, Black, Hispanic, and Asian (Mandell et al., 2002; Mandell et al., 2007; Liptak et al., 2008; Mandell et al., 2009; Shattuck et al., 2009; Stein et al., 2012; Baio et al., 2018); different socioeconomic status (SES) groups (Durkin et al., 2010; Fountain, King, & Bearman, 2011; Thomas et al., 2012; Jo et al., 2015; see Daniels & Mandell, 2014 review on disparities of age of diagnosis); between immigrant and non-immigrant families (Valicenti-McDermott et al., 2012); and between rural and urban communities (Antezana et al., 2017). Limited access to services, which is the focus of this study, has been found to be associated with race in several studies (Liptak et al., 2008; Montes & Halterman, 2011; Magaña et al., 2012; Lopez, Aguinaga, & Morton, 2013; Magaña, Zuckerman et al., 2017; Habayeb et al., 2020); SES (Irvin et al., 2012; Al-Farsi et al., 2013; Bilaver, Cushing & Cutler, 2016; Lin & Yu, 2016); lower parental education; and living in nonmetropolitan areas (Thomas et al., 2007; see also Baum, 2007). Finally, disparities between SES groups and ethnic groups are evident also in children’s treatment outcomes (Fountain, Winter, & Bearman, 2012). It should be noted that most studies explored inequalities quantitively to show disparities, while only a few explored them qualitatively to understand the mechanisms behind these inequalities (Singh & Bunyak, 2019), as I do in my study.

Although inequalities between autistic adults have not been studied extensively in health-related literature (Bishop-Fitzpatrick & Kind, 2017; Singh & Bunyak, 2019) this population’s access to services, such as post-secondary education and employment, have been explored. Eilenberg et al., (2019), in a recent review, note disparities between SES classes and between different ethnic groups in access to transition programs, higher education, employment, independent living arrangements, and social participation in favor of autistic people of high SES and white ethnicity (see for example: Shattuck et al., 2012a; Griffin et al., 2014; Wei et al., 2015; Kirby, 2016). In addition to these disparities, research has found geographical variations in the United States in terms of participation in vocational rehabilitation programs (Roux, Rast & Shattuck, 2020) and, recently, also in eligibility for supplementary security income (Anderson et al., 2021). Health-related inequalities were found by Taylor and Henninger (2015), who reported more unmet service needs among ethnic minorities. Benevides et al. (2021) recently demonstrated ethnic inequalities with specific variations across ages in terms of eligibility for full dual Medicare and Medicaid coverage between white autistic people and black, Asian/Pacific Islander or Hispanic autistic people. Their findings indicate clear inequalities in eligibility for public health services. Another group that has recently been reported as suffering from excessive barriers to healthcare and poorer health is autistic people from the LGBTQ[[12]](#footnote-12) community, who reported that 35% of providers declined them treatment (Hall et al., 2020). This community must be especially considered in the case of autism, as the gender identity formation of autistic people is unique, and alternative genders are more prevalent among autistic people (Glidden et al., 2016; George & Stokes, 2017). In summation, inequalities between autistic adults based on SES, ethnicity, and geographical location have been demonstrated in the literature, whereas this issue in the case of children has yet to be extensively explored.

### 2.5.2. Intra-autistic inequalities in Israel

In Israel, inequalities in diagnosis have been documented in several studies. [Meiri et al. (2011)](#_ENREF_84) discusses inequalities in diagnosis between Jews and Bedouin Arabs in the south of Israel. Their conclusions correspond with data from other epidemiological studies that demonstrated disparities in diagnosis between Jews and Arabs (Gal et al., 2012; Abiri, 2013; Davidovitch et al., 2013; Raz et al., 2014; Kerub et al., 2018; Segev et al., 2019), specifically in southern Israel (Kerub et al., 2018; Kerub et al., 2021). Inequalities in diagnosis were also found between non-ultra-Orthodox Jews and ultra-Orthodox Jews (Davidovitch et al., 2013; Raz et al., 2014; Segev et al., 2019); between SES groups, with a higher prevalence in high-income families (Kamer et al., 2004; Abiri, 2013; Davidovitch et al., 2013; Kerub et al., 2018; Segev et al., 2019); between those from different family origins, with a higher prevalence in families from European and American origin; between the center and the periphery; and between immigrants and native Israelis (Kamer et al., 2004; Abiri, 2013; Kerub et al., 2018).

To my knowledge, no systematic study has been performed on inequalities in access to services or provisions to autistic children or adults in Israel. However, [Raz et al. (2013)](#_ENREF_105) mention higher enrollment in secluded special education schools of children from lower SES and from ultra-Orthodox families, while other children are mostly enrolled in more inclusive settings. Furthermore, [Lubetzky et al.’s (2004)](#_ENREF_75" \o "Lubetzky, 2004 #70) study on the use of developmental rehabilitation services for diverse mental disorders found disparities between Jews and Arabs; [Naon and Keib (2012)](#_ENREF_91) have demonstrated differences between geographical districts in out-of-home residential arrangements; and [Shulman (2000)](#_ENREF_116) found that educational services for autistic children are not provided equally in Israel. Therefore, it can be confidently concluded that there are inequalities in service delivery for autistic people of different groups in Israel. Beenstock, Pinto & Rimmerman (2021) are the only scholars who examined young adults from the national registry of the NII. Although the limitation of this dataset is that, as mentioned above, it does not include autistic people who are not recognized by the NII, their analysis shows opposite trends in adulthood from those observed among autistic children in Israel. According to their discussion, SES and residency in the periphery were not associated with lower participation in adulthood in employment, civil volunteering, or tertiary education. Moreover, they did report higher rates of employment among Arab autistic people and lower rates of volunteering among ultra-Orthodox Jews (the data is not presented). Apart from their publication, additional limitations of which are discussed later, no other study exists investigating inequalities between autistic adults in Israel.

### 2.5.3. Investigating inequalities in autism – Unique concerns

There are two unique aspects to inequalities among autistic people. The first aspect refers to gender inequalities and, specifically, inequalities between men and women, and the second is inequalities between autistic people with and without intellectual disabilities (ID), or what is sometimes referred to as low or high functional abilities. Inequalities between men and women have been studied for a long time in health-related issues (e.g., Heise et al., 2019). In the case of autism, women are not just discriminated against because of their gender, but because they also constitute a numeric minority among autistic people, with the male/female ratio ranging from 3:1 to 6:1 (see Elsabbagh et al. [2012] and Chiarotti & Venerosi [2020] for the global view and Davidovitch et al. [2013], Raz et al., [2014] and Segev et al. [2019] for the Israeli view). There are several questions which arise from the issue of gender inequality, from the question of whether these male/female ratios are a result of inequalities in the diagnosis process ([Constantino & Charman, 2012](#_ENREF_33" \o "Constantino, 2012 #35); Bargiela, Steward & Mandy, 2016; Hiller, Young & Weber, 2016; Gesi et al., 2021) or biological differences (Ferri, Abel & Brodkin, 2018; Lundström, 2021). If, indeed, it can be attributed to biology, ethical questions regarding fetus sex selection for parents who wish their second child be “normal” arise (Barnbaum, 2008). These questions are, of course, coupled with social discrimination questions (Bargiela et al., 2016; Milner et al., 2019) and they translate to health outcomes inequalities (Tint & Weiss, 2018; Kirby et al., 2019; DaWalt et al., 2021). Among all these important avenues of investigation, social discrimination is the focus of this study given the SDH perspective this research adopts.

The second special consideration is inequalities that exist between autistic people with and without ID. These inequalities are less reported in the literature, possibly owing to a minimal representation of autistic individuals with ID in research conducted in recent years (Russell et al., 2019), but some useful studies do exist. Vogan et al. (2014), for example, demonstrated inequalities in caregiver burdens between parents of autistic young adults with and without ID, and Taylor and Henninger (2015) used the category of ID in their study on unmet needs of autistic people, reporting that those without ID were less likely to receive services. This aspect is explored in this study too (see also Daniels & Mandell, 2014 on delay diagnosis, and Zeidan et al., 2019 on the identification of service gaps in Quebec).

### 2.5.4. Mechanisms that contribute to the creation of inequalities

This research project, however, moves beyond the description of inequalities to understanding the mechanisms that give rise to them. To acquire such an understanding, a qualitative perspective is needed. The discussion sections of most quantitative research dealing with inequalities regarding autistic adult are rich with explanations inferred from the findings. These explanations are important to explore, as they reflect the discourses that exist surrounding the origins of inequalities within the field. Among these explanations are a lack of awareness among disadvantaged communities (Abiri, 2013; MSASS, 2013; Daniels & Mandell, 2014; Segev et al., 2019); perceptions of autism (Sell et al. 2012; Zuckerman et al., 2014; Segev et al., 2019), and access to resources (Zuckerman et al., 2014; Segev et al., 2019). These explanations correspond with some discourses on inequalities in healthcare more broadly (Avni, 2016).

In addition to these avenues of research, some studies have tried to explore the reasons for inequalities between autistic people quantitatively. Fountain and Bearman (2011) demonstrated the effect of immigration policies on autism diagnosis and argued that policies in this area are contributing to inequalities. King & Bearman (2011) demonstrate how community resources combine with individual resources in affecting diagnosis. In Israel, Kerub et al. (2021) provide an analysis of the diagnosis of autistic children in the Bedouin community. They break down the diagnosis into different phases, from screening to obtaining the diagnosis and demonstrate the exact phases; for example failure to follow up, where inequalities emerge and provide recommendations for tackling them.

Singh and Bunyak (2019), who conducted a literature review of qualitative research that analyzed inequalities among autistic people, described several mechanisms that contribute to inequalities. These include barriers that were identified by quantitative researchers, such as a lack of information available to families and a corresponding lack of awareness, and mental health and disability stigmas that correspond with perceptions about autism (see also Khanlou et al., 2017; Rivard et al., 2019; Habayeb et al., 2020). Other mechanisms include poverty as a driver of inequalities. Autism services are costly, require money for transportation, and are inflexible, which prohibits low-income workers from accessing services. Other factors include language use and cultural beliefs (see also Fong, Lee & Iarocci, 2021); structural barriers, including a lack of training in ASD diagnosis and interventions (see also Rivard et al., 2019; Fong, Lee & Iarocci, 2021); racism on the part of providers; fractured healthcare systems (see also Fong, Lee & Iarocci, 2021); and broader policy issues, such as immigration policies and anti-bilingual policies. In Israel, Manor-Binyamini and Shoshana (2018), who conducted qualitative research interviewing mothers of autistic Bedouin children, also mentioned cultural barriers, lack of knowledge of professionals, lack of suitable services, and language barriers (see also St. Amant et al., 2018; Fong, Lee & Iarocci, 2021) as sources of marginalization in the autistic Bedouin community.

Other studies analyzed policies, and argued that they contribute to inequalities in service provision (Caruso, 2010; Shulman, 2000). Yet some go a step further and argue that actors who created the policies, in this case autism organizations, have contributed to the development of inequalities between autistic people (Ne'eman, 2011; [Caruso 2010)](#_ENREF_30). While many factors contribute to inequalities between autistic children, there are studies examining inequalities among autistic adults. In the following chapters, I explore both the political discourses about inequalities among autistic adults and, following the arguments of Ne'eman (2011) and [Caruso (2010)](#_ENREF_30), I illustrate the contribution of autism organizations to inequalities among autistic adults through the promotion of discriminatory policies.

## 2.6. Theoretical framework

To investigate inequalities in the case of autistic adults. I utilize three theoretical frameworks: social determinants of health, the social model of disability, and intersectionality. The following sections explain these frameworks and describe how I utilize them in the research.

### 2.6.1. Social determinants of health

As this research project is structured around the question of health inequalities, I have decided to adopt one of the most utilized frameworks to investigate this phenomenon from a public health perspective and one that was also adopted by the World Health Organization (WHO) – the framework of the social determinants of health (SDH). The WHO defines SDH as: “the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems” (WHO, 2021b). This definition is widely accepted and scientifically established. These “forces”, which are often portrayed using the well-known diagram produced by Göran & Whitehead (1991) (see Figure 2.1) influence health inequalities between and within countries (Marmot, Friel, Bell, Houweling, & Taylor, 2008).

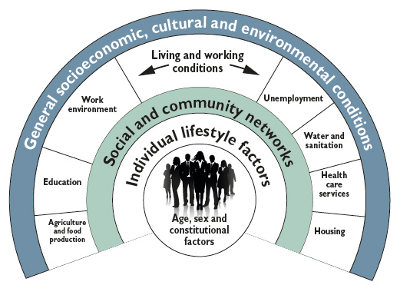


Figure 2.1

(Göran & Whitehead, 1991)

This definition of the SDH, however, as Graham (2004) has accurately identified, combines two distinct factors that affect health inequalities. The first are the determinants themselves and the second is their unequal distribution within and among countries. She, thus, differentiates between research that explores the SDH, for example, measuring *the effect of employment* or unemployment on health outcomes, and research on the Social Determinants of Health Inequality (SDHI) that seeks to explore the *unequal access* to health-supportive employment.

Although Göran & Whitehead’s (1991) diagram, or similar ones, are widely utilized to this day, the WHO Commission of the SDH have recognized Graham’s (2004) contribution and incorporated her and other scholars’ observations into the conceptual framework for SDH published in 2010 (Solar & Irwin, 2010). This conceptual framework further developed Graham’s argument on SDHI and differentiates between the s*ocioeconomic position* (that I refer to as a social position– see footnote 3 in the Introduction) of an individual that is affected, for example, by the individual’s gender or education, and the *socioeconomic and political context* that influences both the social position and the distribution of resources, for example, through policies. These two factors, in turn, affect the intermediary determinants that result in health inequities (see Figure 2.3 below). An important distinction that this conceptual framework allows for is that existing between the biological factors of the individual, which appear in the older model of autism as constitutional factors (Figure 2.1 inner circle), and their social manifestations (Figure 2.2, socioeconomic position). Sex, for example, which is an inherent biological characteristic of an individual with clear health effects, on also has social aspects related to gender which influences access to resources and, therefore, some would argue, also influences, the individual’s health considerably more.

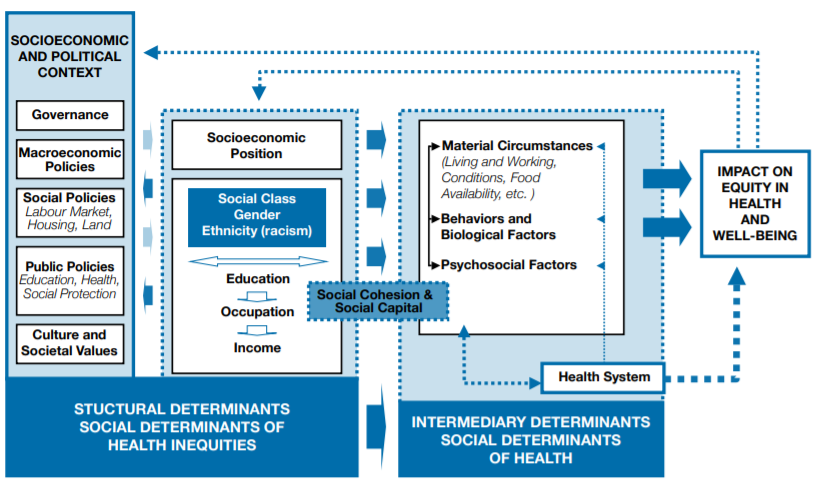


Figure 2.2

(Solar & Irwin, 2010)

Yet, even the revised framework that does include an individual’s social realm in the analysis of SDHI, characterizes autism and other disabilities as an intermediary determinant either under Behavioral and Biological Factors or under Psychological Factors (see right square in Figure 2.2). Using this SDH conceptual framework, autism should be studied as a health outcome of SDHI – an illness that is measured for establishing unequal distribution of health. For example, as an association between exposure to air pollution in pregnancy and autism has been observed (Volk et al., 2013), and exposure to air pollution in pregnancy disproportionately affects women from lower social positions (Woodruff, Parker, Kyle & Schoendorf, 2003), it can be claimed that air pollution is an SDH as it elevates the prevalence of autism. This perception of disability, and specifically autism, is widely accepted in SDH research (???). Disability, according to this framework is a synonym for health outcome.

This health outcome, as the upper arrows in Figure 2.2 illustrate, can affect the social position of the individual, but it is not considered an integral component of this position. Put differently, in this model, someone who has suffered an injury in a car accident and is then confined to a wheelchair for the remainder of their life may lose their job and, as a consequence, their social position could change. However, the policies that dictate whether their employer is obligated to install an elevator in the workplace to accommodate their changing needs are regarded as a constant that influences the social position and not the SDHI to be investigated. Hence, this framework, which adopts the perception that a disease or, more accurately, a disability, is an outcome or not a SDHI, does not allow autism, and to a greater extent, disabilities, to be examined as inherent social categories that are integral parts of the social position of an individual.

Considering disability as a health outcome adopts the medical model of disability (MMD­) that views disability as an inherent flaw in the individual. However, as the scholar who developed the social model of disability (SMD) argues, disability can also be perceived as a construct of disabling social structures that prevent the individual from equal participation in society and equal access to social resources (see theoretical framework below). Emerson et al. (2011) have pointed to this gap in the SDH scholarly literature and called for the adoption of the SMD within the SDH framework. Adopting this approach has multiple implications, among them regarding disability as an additional axis that affects the social position of the individual, which then allows for an allows exploration of the association between disability and marginality within the SDH framework, as well as the sociopolitical context that affects the health of people with disabilities. Despite some scholars having adopted this position (see Liang et al., 2012; Emerson et al., 2014; Mithen et al., 2015; Milner et al., 2019; Siddiqua, 2020; Emerson, 2021) most SDH scholarly work still discusses disability using the MMD model.

Another gap in the SDH literature is the failure to accommodate the complex interactions between marginalities. As Hankivsky and Christoffersen (2008) have accurately identified, while SDH scholarship can consistently identify and demonstrate the influence of one determinant on health, it often misses the complex combined effects of multiple determinants (see also McGibbon & McPherson, 2011). Socioeconomic status, for example, is well established as an SDH, yet its interaction with other axes of marginalization, such as ethnicity, gender, or (dis)ability (or the three combined) is often neglected. They argue for the use of intersectionality as an analytical framework that examines the interactions between these axes within the framework of SDH in order to narrow this gap. Among the possibilities for utilizing intersectionality, about which I further elaborate below, is that it facilitates the examination of the experience of multiple marginalization and expose the interdependence between discriminating social structures.

In my research, I utilized the SDH framework to examine the socioeconomic political context that deprives autistic adults of equal access to the services they need in Israel. In essence, I embrace the argument of Emerson et al. (2011) that disability should be studied as a social position within SDH research and, following Graham’s differentiating definitions for SDH, I investigate the SDHI that determine autistic adults’ social positions. Employing the SDH framework in this manner further narrows the gap in SDH literature that currently conceives of disability as a social position and not as a health outcome, especially regarding autistic adults, an issue, which, to my knowledge, has not been explored in this way. Moreover, as this research focuses on inequalities, I adopt the position of Hankivsky and Christoffersen (2008), and utilize intersectionality to further examine the implications of SDHI on different social groups within the autistic community. To my knowledge, this is the first study observing SDHI with respect to autistic adults in this way.

### 2.6.2. The social model of disability

Although discrimination and prejudice against people with disabilities have existed throughout history (Stiker, 2019), it was the social changes brought on by industrialization that demanded the conceptualization of disability as the result of an intrinsic individual impairment that needed repair. The creation of a labor market that required workers that were physically able resulted in families not being able to stand the burden of care of the disabled. To shift the care away from the family and onto society, disability needed to be defined as a medical problem. This definition gave rise to the creation of individualist medical interventions for “repairing” disabilities and the establishment of isolated institutions for the disabled who could not take part in creating a capitalist society. While the practices and attitudes towards people with disabilities that this definition referred to those with disabilities as people in need of repair, called the medical model of disability (MMD) in the scientific literature, have changed over the years and in different contexts ranging from euthanasia (Gallagher, 2001) to robotic prothesis (Bertolini, 2015), it is still the most widely accepted model of disability today, especially in the health sciences (Oliver & Barns, 2012, pp.11–31; Barnes, 2020).

First identified by Oliver in 1981, the social model of disability (SMD) tried to draw attention away from the perception of disability as an individual impairment and focus on the structures that transform the individual impairment into a disability. This model, which became prominent during the 1980s and 1990s following a struggle on the part of the disability community, asserts that disability results from social structures that limit the participation of individuals with impairments (Barnes, 2020). To understand this perception, the most illustrative, and intuitive example, which is often used, is the access to public resources of individuals who are dependent on wheelchairs to move. In a society that does not mandate the installation of ramps or elevators, these individuals will be disabled and their access to public resources, such as public bathrooms, doctors’ offices, hospitals, public transportation, office buildings, or municipal structures would be limited. However, if public policies are put in place and physical mediators are installed, their disability would be eliminated or mitigated, and they would gain the ability to participate as equals in society. Therefore, this model claims it is not the wheelchair or the paralysis of a person’s lower limbs that makes the individual disabled, but, rather, the social incompetence to accommodate the unique needs of the wheelchair user is disabling. A similar rationale can be applied to any disability, including autism. Because it is the social structures that are the disabling factors and those structures are constructed by society, disability can be transformed.

It is important to note that this model does not claim that impairment does not exist; on the contrary, according to the model, it is the intrinsic biological difference that causes specific social needs which, if not mitigated by social structures, disable individuals. Therefore, it also does not oppose individual medical or rehabilitative interventions, as long as they are not further disabling or disempowering to disabled individuals, as they often, unfortunately, are (Barnes, 2020). This position regarding impairment was criticized by Shakespeare (2006) and other scholars (Shakespeare & Watson, 2010; Broyer & Finkelstein, 2016) who claimed that deeming impairment a biological construct and disability a social one creates an impossible distinction, since both impairment and disability inflict harm on individuals and because some impairments limit the participation of an individual. Therefore, he calls also for the socialization of impairment, not just disability. The neurodiversity movement, mentioned above, adopts this perspective, as it argues that autism, and other neurological differences, are part of human variation, and not an impairment that should be repaired (Ortega, 2009; Orsini, 2013).

Despite this model being absent from most health research and SDH research, as I mentioned above, I utilize the SMD as it facilitates the conceptualization of the social structures that disable autistic people in our societies. From the perspective of SDH, these structures are the SDHI that deprive autistic individuals of resources. In contrast to other social positions, however, using the SMD allows these resources to be defined as the resources needed for full participation in society, not just public resources. Using the wheelchair example, the lack of policies mandating ramps and elevators are SDHI if adopting the SMD, despite not being relevant to other social positions. Although the debate about the social construction of impairment is integral to the use of the concept of neurodiversity that I adopt, this study does not delve further into this issue further, as it focuses, like the “classic” SMD, on the availability or lack thereof of material resources for the autistic population.

### 2.6.3. Intersectionality

Intersectionality research focuses on the complex relations between social actors’ multi-dimensional identity and the manifestations of those complexities in the social reality. Crenshaw, (1991) who coined the term intersectionality, illustrates in her study how social identities which are usually understood as separate entities must be examined as one. In her research, she demonstrates that the identities of women and of people of color in the United States intersect in the realities of women of color. Referring to other scholars (e.g. Hooks, 1984, p.44). Crenshaw demonstrates that black women face distinct challenges in the judiciary system and that their experiences are unique. Drawing on Crenshaw, many scholars have studied identities using the intersectional framework to demonstrate the unique qualitative experiences of individuals’ intersected identities, including: race and gender (Shields, 2008); age and homosexuality (Cronin & King, 2010); and class and religion (Ortbals & Rincker, 2009). In recent years, following the development of the intersectionality approach (Cho, Crenshaw & McCall, 2013), researchers from diverse disciplines have utilized the analytical framework in the health systems research field (Dhamoon & Hankivsky, 2011; López & Gadsden, 2016; Young et al., 2020; Lapalme, Haines-Saah & Frohlich, 2020); disability studies (Ben-Moshe & Magana, 2014), and public policy (Hankivsky & Cormier, 2011; Hankivsky & Jordan-Zachery, 2019).

In addition to encompassing the complex qualitative experiences of individuals with multiple marginalities, intersectionality also allows for the exploration of the co-existence of privilege and marginality in a single social actor’s identity (Dhamoon & Hankivsky, 2011; Watkins-Liu, 2018; Wojnicka, 2019). Utilizing intersectionality in this manner sheds light on the intertwined systems of oppression and the techniques applied by the elite to preserve power. On example is the way racism, ableism, and the patriarchy interact to secure white male domination (Whitesel, 2017). Nevertheless, as Walby, Armstrong and Strid (2012) discuss in their critical analysis of the intersectionality literature, very few authors explore privileged actors.

In my research, I utilize the analytical framework of intersectionality both to understand the multiple marginalization of autistic people from oppressed groups and to investigate the mechanisms that generate inequalities. While the first line of investigation is straightforward, as the experiences of those with multiple marginalities can be directly captured, the issue of the mechanisms that lead inequalities is more complex and may require more elucidation. To explore the mechanisms that contribute to the creation of inequalities or, in other words, the presumably unconscious techniques of the hegemony to preserve dominancy, I examine the intersected identity of disability, or, more specifically in the context of this study, parents of disabled individuals with privileged identities within representative organizations. I further investigate whether those identities affected the policy creation process and follow the effect of these policies on inequalities. This process, which links identity, policy and its outcomes, provides insights into the mechanisms of power preservation. This analytical mode further allows me to address another scholarly gap identified by Walby, Armstrong and Strid (2012, p.229) between structural inequalities and political projects that conserve them which are “[separate issues] as well as having relationship with each other.”

## 2.7. Summary

This dissertation analyzes the inequalities in the case study of autistic adults in Israel. I described above the central processes that influenced the creation of the autism field, and central aspects relevant for this research regarding autism organizations. I further describe autism policy and depict both policy concerning autistic adults and the autism policy in general in the Israeli context. I next delve into the healthcare system, which is the main determinant I explored in my research, and depict health needs, healthcare service utilization, individual and systemic accessibility barriers to healthcare services, and the implication of all the above on diverse health outcomes of autistic adults. The last topic, which clearly situates autistic people in a marginalized position compared to neurotypical people, begins the description of inequalities in this specific case. Yet, as I explain, these are not the only inequalities that should be explored in relation to this population. Therefore, the last descriptive section describes inequalities between autistic children and adults both in Israel and other countries, and briefly discusses the mechanisms that cause them. I conclude this literature review by explaining the theoretical frameworks I utilize in this project and describing how I apply them.

1. The development of the field of child psychiatry was made possible thanks to the institutionalization process coupled with the Mental Hygiene Movement– also known as the Child Guidance Movement. The movement was developed in the context of eugenic notions prevalent at the beginning of the 20th century. It called for tracing mentally ill and mentally disabled children and “controlling” their development in schools and institutions. Some psychiatrists in Israel in the 1930s also implemented mental hygiene ideas (Zalashik & Davidovitch, 2009). Assembling the “abnormal children” under one roof enabled a categorization of children’s mental pathologies for the first time (Waltz, 2013). [↑](#footnote-ref-1)
2. ABA therapy was introduced in the early 1960s by Ole Ivar Lovaas, who was influenced by behavioral psychology theory. It was among the first suggested treatments for autism that was widely adopted. ABA therapy is based on breaking down a complex task into sub-tasks and giving positive (and in the past negative) reinforcements to alter behaviors (Waltz, 2013). This treatment is still one of the most recommended treatments for autism (See Dillenburger, McKerr, & Jordan, 2014). [↑](#footnote-ref-2)
3. In 1972, Eric Schopler, together with Gray Mesidov, established the TEACCH ([Waltz, 2013](#_ENREF_136)) method that is based on visual learning and environment modification. It was the first statewide program in the United States. The program was implemented in North Carolina, both in school settings and in regional centers. [↑](#footnote-ref-3)
4. Today, there are a great number of treatments created by parents of autistic children. For example, the Son-Ride therapy, which drew its inspiration from the New Age psychology, was developed by parents of an autistic child (Eyal, 2010; Waltz, 2013). [↑](#footnote-ref-4)
5. Waltz (2013, pp. 116–124) also recognizes the importance of those actors, although she differentiates between the parent-researcher and the parent-therapist. [↑](#footnote-ref-5)
6. The Autism Society of America (ASA) was first called the American National Society for Autistic Children (NSAC) and only later became the Autism Society of America (ASA). [↑](#footnote-ref-6)
7. Despite the National Autism Research Center of Israel’s emphasis on children, it should be noted that, together with the leaders of the center, we have tried to promote research regarding autistic adults’ needs in Israel. [↑](#footnote-ref-7)
8. In Israel, four sick funds (SFs) are responsible for the provision of most healthcare services mandated by the NHIL. Some services, however, such as public health services, are provided directly by the Ministry of Health (Bin Nun, Berlovitz & Shani, 2005; Clarfield et al., 2017) [↑](#footnote-ref-8)
9. Community services are provided by Ministry of Labor, Social Affairs and Social Services (MOLSA), previously called MSASS. They include supportive family centers, transition programs from school to employment, inclusion in National Service and the IDF, programs for young adults, rehabilitative care centers, and several employment programs (Rimon-Grinshpan et al., 2019). [↑](#footnote-ref-9)
10. Mental health services were under the full responsibility of the MoH according to the third addition to NHI law. In 2012, the health minister launched the “Mental Health Reform,” which was fully implemented in 2015 and shifted the responsibility for mental health provision to the SFs. [↑](#footnote-ref-10)
11. Neurotypical is an alternative term for an individual with common neurological function, the “normal”. This term is used by the autistic community (Rosqvist, Stenning & Chown, 2020). [↑](#footnote-ref-11)
12. Lesbian, Gay, Bisexual, Transexual, and Queer. [↑](#footnote-ref-12)