# 2. Literature Review

Although this research is structured around the issue inequlities, since inequlities are multifaceted and entangled issue the literature review departs from the field under investigation, the autism field, and will gradually move toward the issue of inequlities and the relevant theoretical framework 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 might led to inequlities among autistics, 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 historical transition that are interconnected have shaped the autism field and brought its current state where autism is considered a spectrum and not a single entity (American Psychiatric Association, 2013); that its incidence had raised (Chiarotti & Venerosi, 2020) to such an extent that is referred to as epidemic (Fombonne, 2001); that it is either attributed to biological mechanism (Bölte, Girdler, & Marschik, 2019) or is considered as a neurological difference (Ortega, 2009); that it is represented by influential parents and self-advocates organizations (Orsini & Smith, 2010); and that there is extensive policy concerning diverse aspects of it (Dicker & Bennett, 2011). Those transitions include the shifts in autism etiology research, the change in classification and diagnosis, the deinstitutionalization process, and the establishment of parent and later self-advocates organizations. Although abundant of scientific literature have addressed and analyzed these historical sociological complex processes the following covers them briefly.

The first change that is essential to explore is the shift in the discussion on 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) attribute it to biological process (Grinker, 2007); nevertheless, the rise of Freudian psychoanalysis has given birth to the theory of the refrigerator mother also known as the ‘pathological motherhood’ (Eyal, 2010; Bettelheim, 1967 in: Silverman, 2012; Waltz, 2013 pp. 52-67). This theory who asserted mothers lack of affection is the reason for the autism of the children evoked a counter process by parents who reclaim their knowledge about their children and formed an expertise network that asked to explore alternative biological explanation for their children developmental disorder (Eyal, 2010, pp. 167-172; Eyal, 2013). This network of experts evoked ongoing research on biological etiologies for autism who started with Bernard Rimland (1964) and continues until today to explore possible etiologies for autism from environmental exposures (R. Raz et al., 2017) to biological risk factors (Karimi, Kamali, Mousavi, & Karahmadi, 2017; Bölte, Girdler, & Marschik, 2019), to genetics (Waye & Cheng, 2018). This research direction has exponentially grown with the enactment of the Combating Autism Act in 2006 and later the Autism CARES Act who secured in total approximately 4 billon USD to research and children services (Rubinstein, 2010; IACC, 2020; Ne'eman, 2011).

The reasons for enacting these acts are complex and includes among others the eligible connection between the MMR vaccine and specifically Thimerosal (mercury) component and autism (Wakefield et al. 1998; Offit, 2008), the political involvement of autism organizations and influential US senators (Baker & Steuernagel, 2009; Steuernagel, 2005), and above all the surge in diagnosis (Baio et al., 2018; Baxter et al. 2015; Chiarotti & Venerosi, 2020; Segev et al., 2019) to an extent autism was referred to as epidemic or a public health emergency (Newschaffer & Curran, 2003). This surge in diagnosis can be attributed to many factors among them environmental factors (Hviid, Melbye, & Pasternak, 2013; Limperopoulos, 2009); raise in awareness (Ouellette-Kuntz et al., 2007) the deinstitutionalization process (Eyal, 2010) the change in diagnosis criteria (King & Bearman, 2009; Croen et al. 2002; Eyal, 2010) and others (Matson & Kozlowski, 2011). The shifts in diagnosis criteria, however, is essential to explore as it 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) for those who could not get the diagnosis was developed, and allowed the inclusion of more individuals under the diagnostic arch. Despite the DSM VI was more precise in wording it added more categories to PDD including Asperger syndrome (Grinker, 2007: pp. 103-143). This syndrome who was defined by Hans Asperger in 1944, got recognition in 1981 by Lora Wing (Wing, 1998), positioned under the same category individuals with very different phenotypes who shared the same unique characteristics. The DSM V (American Psychiatric Association, 2013) who was recently published defined autism as a spectrum and allowed the further expansion of autism and continued the raise in diagnosis. Although described here almost as natural evolution this expansion included shifts in meanings and could not be understood with broader social context such as resources allocation for autistic children (Evans, 2013; Eyal, 2010; Verhoeff, 2013; Verhoeff, 2016).

Allowing the inclusion of verbal autistics with high cognitive abilities under the same umbrella of the spectrum was one of the conditions that allowed the establishment of the autistic community (Sinclair, 2005). The autistic community from its very first steps 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 that expose the person underneath the autism will be developed. At the constitutive work of Jim Sinclair (2012 [1993]) *Don't Mourn for Us* he called for acceptance of the autistic person and set together with other autistics (see for example Gardin, 1995) the notion of autism as a difference (Hacking, 2009). This notion which was later adopted and elaborated to what have become the concept of neurodiversity (Ortega, 2009; Orsini, 2009; Jaarsma & Welin, 2012; Silberman, 2015; Tan, 2018) created a novel biological identity that reshaped again the field of autism. The concept of neurodiversity asserts that autism along other cognitive differences such as attention deficit hyperactivity disorder (ADHD) are part of the human normal diversity, that although being marginalized in the current social structural it should be acknowledged and integrated (Orsini, 2013; Rosqvist, Stenning & Chown, 2020; Runswick-Cole, 2014; Runswick-Cole, Mallett & Timimi, 2016). In the context of this research project, this perception is at the foundation of this work that view autistics as a distinct social group that deserve equal access to public resources.

The evolution of the autism field, however, cannot be understood without parents of autistic children and the organizations they have formed. As mentioned above parents were the ones who launched the rewiring cogwheels of the expertise network that oppose the “pathological mother” etiology in motion (Eyal, 2010). Furthermore, the 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 the parents organization meeting in the early 1990’s that autistics first met and started to form the community (Sinclair, 2005), and some also argue parents were also the ones who claimed their children are different not deficient that need prosthetic environment (Hart, 2014). Above all it was parents’ organizations advocacy efforts to secure resources for their children that have reshaped the material context of the field (Bosco, 2018; Caruso, 2010; Chamak, 2008; Mishori, 2014; Orsini & Smith, 2010). Those new actors, the 'parent-activist-therapist-researchers', to use [Eyal's (2010, p. 172)](#_ENREF_46) phrase,[[5]](#footnote-5) and the organizations they have formed which I discuss later in detail and investigate in my dissertation had a vital role in shaping the autism field.

Finally, it is essential to recognize the part 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 the closing down of old mental institutions and shifting mental health treatment to the community, created the institutional conditions for changing autism diagnosis criteria and the increase in autism prevalence. Additionally, this process enabled the formation of a novel approach regarding services for autistic persons, a community-oriented approach (Bagnall & Eyal, 2016). These historical and sociological processes are just a fraction of the changes which the autism field underwent since it had first been defined, yet those are the most essential to understand as a background for this work.

## 2.2. Autism organizations

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

The literature regarding these organization is diverse, yet the three prominent questions are explored: the influence of these organizations on policy, their influence on knowledge production (or both combined), and the differences between the organizations operating in the field. The influence on the policy arena can be found, for example, at Dicker and Bennett (2011) who examined the influence of these organizations on policies regarding children with disabilities in the US, and Baker and Steuernagel (2009) who argued 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 it is used by these organizations in the autism field and in the policy arena. And Eyal (2010; 2013) have discussed their influential role in forming constructing alternative knowledge.

The third type of literature on autism organizations, that I elaborate about as it deals with representation claims that are relevant to my analysis, explores the differences between the organizations operating in the field. The first and most common deviation is between organization *for* autistics of parents, and organizations *of* autistics (Bertilsdotter Rosqvist, Brownlow & O'Dell, 2015; Chamak, 2008; Orsini & Smith, 2010; Raz et al., 2018). Although advocating for the same population their claims are different (Chamak, 2008) and the type of knowledge the employ is different (Orsini & Smith, 2010). However, this is not the only difference between these organizations. A. Raz and colleagues (2018) argued there are different representational claims on the autism functionality spectrum and while some claim for representation the “low functioning” (or Kanner’s autism) autistics other claim to represent the “high functioning” (or Asperger syndrome). In addition, they have recognized among these organizations some represent a more inclusive approach in accordance with the social model of disability (SMD) and others request to accommodate the “affected” autistic to society 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 are different in their activity and structure. This is well represented at the difference between the ASA in the US and NAS in the UK. While the former chose to deal exclusively with advocacy the latter is both advocacy and supplier of services (Eyal, 2010; see also Rimon-Zarfaty et al., 2020 on Israel). These four organizational axes *of* or *for*, low or High (functioning), SMD or MMD, and advocacy or supplier have evoked ethical discussions (Jongsma & Schicktanz, 2020; Jongsma, Spaeth, & Schicktanz, 2017; McCoy, Liu, Lutz & Sisti, 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. A. Raz and colleagues (2018) briefly describe the chronological establishment of the four main organizations operating in Israel. Alut the first and oldest parent organization was established in 1974 (Mishori, 2014; Feinstein, 2010) to promote services for autistic children. Effie the Israeli Asperger Association was founded in 2001 also by parents to give voice and promote services for “high functioning” autistics who were overlooked by Alut. Next in 2006 the autism community of Israel, ACI, the first and only organization *of* autistics was officially founded, although it has not registered as one until today. Finally, following an internal dispute in Alut regarding the organization’s position on integration and inclusion group of parents decided to establish Yozmot HaShiluv (“Integration Initiative”) which was later renamed as Mishtalvim BaRezef (Integration of the Spectrum) (A. Raz et al., 2018; Rimon-Zarfaty et al., 2020). These four organizations who currently operate in Israel represent the deviation of the autistic community on three axes the *of* or *for*, low or High, and SMD or MMD. Alut was identified by Rimon-Zarfaty et al (2020) on the supplier-advocacy axis both as supplier and an advocacy organization. Despite the other organizations have not been scientifically analyzed on this axis Effie like Alut is both a supplier and an advocacy organization (Effie Asperger Israel, 2020), albeit in much smaller scales than Alut, and ACI and Mishtalvim BaRezef only focus on advocacy. At the last chapter of this dissertation project I delve into these axes and demonstrate how they articulate in my findings.

Although the direct involvement of these organizations, and specifically Alut who is the oldest organization operating in the field, in setting policy agenda had not been meticulously investigated there are recognitions at the scientific literature of the prominent influence of Alut on autism policy. Shulman (2000) mentions Alut not only as the sole provider of housing for autistic adults, but she also described the intimate collaboration between Alut and the Ministry of Education in forming an information center of autism in the beginning of the 1990’s - MILA. In addition, Mishori (2014: pp. 175-206) described the role of Alut in advancing the service for autistics 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 autistics and the first residential facility for autistic adults, by working closely with the Ministry of Health (MoH). In the last chapter of this dissertation, I delve into Alut’s policy involvement and demonstrate it indeed was and is comprehensive, yet it transformed throughout the years.

### 2.2.2. Health social movements

Autism organizations, however, should be understood in the broader context of health social movements (HSMs) sometimes also referred to as patient organizations. Referring to this scholarly is necessary as it allows to utilize insights on issues such as the consequences of these organizations actions and representation in health policy. On the three domains of HSM identified by Brown and Zavestoski (2004): “(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: 53; Epstein, 2008: p.506; see also Orsini & Smith, 2010: pp. 40-42). Nevertheless, their actions and implication on the third domain, inequlities, cannot be disregarded in the context of this research.

Epstein (1996: p.352) in the conclusion of his constitutive book *Impure Science* who delve into the Aids movement and its effect on knowledge production mentioned 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, have still not been explored, especially not the impact of HSMs on the discrimination of marginalized communities (Epstein, 2008: p.526). This lacuna resulted both because the consequences of HSMs actions in the policy field are usually discounted (Epstein, 2008: p.519-521; see also Klawiter, 2004) and because in HSMs research and more broadly in social movement research the intersectional perspective who request to explore multiple marginalization is neglected (Watkins-Liu, 2018; Wojnicka, 2019; see section 2.6 for elaboration on the intersectionality theoretical framework).

Among those who did explore HSM from an intersectional perspective Watkins-Hayes (2014) review on the influence of intersectionality on the AIDS movement summarized that this approach has raised the interaction of HIV with marginalize social positions beyond gay men, who was vastly explore in the literature, to include other marginalized groups such as women or people of color. Furthermore, it allowed exploring the forms of power that is transmitted through risk and politics. At the autism literature Decoteau (2017) have explored the significance role the interaction of race and Somali nationality with autism have had in forming dedicated organization for Somali autistic who could argue for better services.

I intend to follow 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 these HSM policy activity on inequlities. Yet, as I explain below on 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 research in HSM literature who walk this path. Nevertheless, in social movement literature few studies have adopted this approach among them Hunt (2018). Investigating the SlutWalk she illustrated how the provocative strategy which was led by privileged white women discriminated 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 HSM world describe similar analytical process I adopt in the last chapter.

## 2.3. Autism policy

As mentioned above autism organization have shaped the autism policy field, yet the borders of this field should be specified. Autism whether it defined as a neurological difference or as a developmental disorder, alters the individuals needs throughout the entire life and almost in every aspect of life. Therefore, autism policy comprises of policies that relate to every step throughout an autistic individual 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; Gotham et al., 2015; Wright, Brooks, D'Astous, & Grandin, 2013). In addition, to the temporal or developmental relevant policies, autism policy also affects and is affected by cross ages 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 on this framework below) all these policies issues are affecting autistics health, along with healthcare system related policies, and create the sociopolitical context in which autistic individuals live. It should be stressed that as any other policy issue autism policies are contextualized and articulate within the sociopolitical structure relevant to each country, nevertheless, as the fundamental needs of autistics are the same policies in one context can be relevant to other contexts. Owing to the rising recognition that these policies immensely influence autistics lives recently there is a growing interest in depicting and analyze their influence (AIMS-2-TRAILS, 2021; Debra et al., 2021; Zeidan et al., 2019).

One of the major issues discussed in relation to autism policy is the definition or classification of autism. As mentioned above there are continues 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 medical problem. This discussion is crucial to policy as this verity of definitions can lead in different sociopolitical contexts to different access to services and accommodation of needs (Baker, 2011; Jaarsma & Welin, 2012; Mishori, 2014; Orsini, 2013; Orsini & Smith, 2010; Runswick-Cole, 2014; Steuernagel, 2005). While this issue also clearly influences autism policy in Israel (Mishori, 2014; Comptroller annual report 2012), I avoid discussing these classification implications directly within the Israel system and argue following the first chapter that autism should be regarded as a distinct social group (see below theoretical framework).

Another major issue that is often discussed regarding autism policy is the uneven weight policies regarding autistic children get in comparison to policies regarding autistic adults. Many scholars have demonstrated and argued that autism policy and research is focused on autistic children leaving the needs of the exponentially growing autistic adults’ 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 and others for example (2012b; see also Office of Autism Research Coordination, 2012) have reported only 2% of funded research regarding autism spectrum disorder (ASD) was directed towards autistic adults needs; and other have shown there is an agreement within the community this gap should be narrowed (Pellicano, Dinsmore, & Charman, 2014; Warren et al., 2012). In Israel only handful of studies explored the autistic adults’ population needs or relevant policies most in regard to employment (Gal, Landes, & Katz, 2015; Garar-Bashir, Rivkin, & Lef, 2014; Nizan-Weisman et al., 2019; Ran, 1999), one regarding the conflictual engagement with service providers (Schneid, 2018; Schneid & Raz, 2019), and one on social outcomes (Beenstock, Pinto & Rimmerman, 2021). Only Drori (2015) have attempted to specify the need of adults with Asperger syndrome more broadly as part of a new program development. The National Autism Research Center of Israel established 2015 with the support of the Ministry of Science and Technology of Israel also aim in promoting research mainly on diagnosis and medical treatments (The National Autism Research Center of Israel, 2021) pinpointing the governmental inclination toward children 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 parents organizations in autism policy construction have clearly affected this uneven notice. This research project requested to narrow this research gap and investigated the sociopolitical context that affect autistic adult’s lives in Israel.

### 2.2.1. Autism adult policy

On the temporal axis, policies regarding autistic adults should reflect the specific needs of this population, which clearly different from those of children. Two major issues particularly concern the autism community and policy makers living arrangement (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014; Dudley et al., 2019; Krauss, Seltzer, & Jacobson, 2005; Lee et al., 2020) and employment (Chen, Leader, Sung, & Leahy, 2015; Gal, Landes, & Katz, 2015; Gotham et at., 2015; Harrington, 2021; Lorenc et al., 2018; Nicholas et al., 2018; Nizan-Weisman et al., 2019; Roux et al., 2013; Targett & Wehman, 2008; Taylor & Seltzer, 2011) which can be either within the community or provide a more secluded protective environment (Mandell, 2017). In addition, autism adult policy is directed to answer more specific needs of autistic adults as the need for structural services for the transition period from childhood to adulthood (Wehman et al., 2014; Wei, Wagner, Hudson, Yu, & Shattuck, 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 accommodation in the 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. As everyone autistic adults are also aging and their needs and specific policies needed to address them transform once again (Elichaoffa, 2015; Happé & Charlton, 2012; Piven, Rabins, & Autism-in-Older Adults Working Group, 2011; Roestorf, Howlin & Bowler, 2021; Waldron, Coyle, & Kramer, 2021).

In addition to these policies, along the years and with aging this population, autistic adults encounter the healthcare system and specific policies directed to address their health needs are essential. As this research investigation is nested within the healthcare system, health policies will be further explored below (see section 2.4) and were investigated as part of this research (at the second analytical chapter). Nevertheless, it should be stressed again that from a SDH perspective all the policy issues mentioned above also directly affect the wellbeing and health of autistic adults (see for example Harkey, 2017 and Fleming, Fairweather, & Leahy, 2013 on the effect of employment on mental health; and Dudley et al., 2019 on residential arrangement and its effects on needs). In the last chapter of this dissertation, I explore the formation of residential arrangement policy in Israel, from this perspective, it is also considered a health-related issue.

### 2.2.2. Autism policy in Israel

As autism policies address many aspects of life diverse official bodies are involved in its formation including the legislative authorities and different ministries and institutions of the executive authorities. In Israel the construction of specific policies regarding autistic children started in the 70’s. The first landmark was 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. It mandated maximum inclusion of disabled children in the regular school system and demanded the provision of 3 hours a week of paramedical services provided today by the Sick Funds (SFs).[[8]](#footnote-8) Two years later in 1990 the MILA center for autism knowledge was established with the corporation 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, US, were formally indorsed (Shulman, 2000). In 1998 two law amendments had been passed that greatly influenced autistic children. First the 19’s amendment in the National Insurance Law that mandated autistic children will be entitled for 100% monthly children disability stipend (today the stipend sums to 2,608 NIS [800USD]) thought the National Insurance Institute (NII) according to their diagnosis alone and regardless to their needs (National Insurance Law, 1995; The High Court of Justice 7879/06, 2006). The second amendment was at the National Health Insurance Law (NHIL) that mandated the provision of additional 14 weekly hours of allied 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 in the autistic spectrum, 2009). It can be concluded that autistic children should receive according to the law suitable educational services, a monthly stipend and additional allied healthcare services to support their development.

For autistic adults the first landmark was the opening of a residential place for autistics in 1988 called Ofarim Village by Alut. I explain in detail at fourth chapter about the circumstances that led for the village establishment (see also Mishori, 2014), but it followed by the opening of additional residential facilities called in Israel “house for life”. The responsibility to supervise these houses shifted following a government decision in 1999 form the responsibility of the (MoH) to a new unit established within the Rehabilitative Services and Disassociated Youth Department in 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 was divided between the Housing department and the Community department who are responsible for the provision of services to all disabilities according to type of service and not according to disability title (Rimon-Grinshpan et al., 2019). At the last decade following a shift to more community-oriented services and the expansion of the spectrum, additional less seclusive residential opportunities were established including satellite apartments, and supported living apartments (Rimon-Grinshpan et al., 2019). In addition to the residential facilities along the years more services for autistic adults where established. The first additional services were employment centers for autistics called Meital (Shulman, 2000) and later other services were founded including rehabilitative afternoon care facilities, vacation resorts and more.[[9]](#footnote-9) While the number of autistics who are enrolled in community services and less seclusive residential options grew about five time in the decade between 2009-2019, the absolute number of autistics using these services is still relatively small (Rimon-Grinshpan et al., 2019). Furthermore, from the age of 18 autistic individuals can receive from the NII disability stipend, if they have additional mental or physical disability as autism is not considered as a possible diagnosis that entitle disability, and they have been recognized by the institute medical committee as having reduced functional abilities (Israel State Comptroller, 2012).

Two policy landmarks from the last decade to important should be mentioned. The first, following an advocacy effort by parents’ organizations and due to the rise in incidence in autism, an autism specific bill was presented to the Knesset in 2013 calling to secure 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 been radically amended as I present 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 who was established after a report by the State Comptroller Office (Israel State Comptroller, 2012) assisted to further expand the funds dedicated to autistics and set the foundation for later discussion for instance on the issue of functionality (Rimon-Grinshpan et al., 2019; see also at the third chapter).

A transverse policy issue that also tremendously affect autistic adults in Israel is the legal status of disability rights. In 1998 the Equal Rights for People with Disabilities Law have been passed (Equal Rights for People with Disabilities Law, 1998). Along with administrative decisions as the establishment of Commission for Equal Rights of Persons with Disabilities under the ministry of Justice, the law provide the first legal anti-discrimination foundation that recognize the equal rights of people with disabilities in Isreal, similar to other laws passed around the world (Avrami & Rimmermann, 2005).The law marked the beginning of a gradual change in the legal recognition in this marginalized population rights, including the right for 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 being another milestone for people with disabilities among them autistics, 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 was in 2016. Amendment 18 to the Legal Capacity and Guardianship Law of 1962 was enacted and allowed autistic adults alternative less restrictive legal arrangement than guardianship such as supported decision-making and continuous power of attorney who have a potential to greatly affect the independence of autistic adults (Davies, Werner & Sinai, 2017).

Finally, since 1995 healthcare service are provided by the power of NHIL for Israeli citizens. The services and treatments the national insurance covers appear under the Health Basket (HB), which is decided by the Basket Committee of the MoH.8 As mentioned above currently the HB mandate treatment for children under the age of 7, 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 for autistic individuals, including mental health services, institutionalization in mental health departments 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, is multifaceted provided by multiple authorities and had been going through major changes over the past 30 years. In this research project I thoroughly examined both health related policies and the construction process of the residential arrangement policies; these issues have not been investigated in Israel.

## 2.4. Autistics and the healthcare system

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

### 2.4.1. Health related needs

The health care needs of autistics adults are higher from those of the neurotypical[[11]](#footnote-11) population. Research had shown that autistic adults have higher rates and risk for seizure disorder, gastrointestinal disorders, thyroid disorders, auto immune diseases, hypertension, obesity, prediabetes and diabetes, hyperlipidemia, cardiac arrhythmias, asthma, allergies, osteoporosis, bone fractures, and parkinsonism than non-autistics. Although the specific rates change from one cohort to another and with age and sex there is a clearly high prevalence of chronic health conditions among autistics (Cawthorpe, 2017; Croen et al., 2015; DaWalt et al., 2021; Hand et al., 2020; Fortuna et al., 2015; Neumeyer et al., 2015; Saqr et al., 2018; Tint et al., 2021; Starkstein et al., 2015; Weir, Allison, Warrier & Baron-Cohen, 2021; Wise, Smith & Rabins, 2017; Weiss et al., 2018). It should be noted, however, that among adults with ASD some diseases are found in lower rates including sexual transmitted diseases, infectious diseases, along with lower rates of tobacco use, and alcohol misuse (Hand et al., 2020; Fortuna et al., 2015). Given the high rates of medical conditions it is hardly surprising research have found higher utilization rates of healthcare among autistic adults in comparison to unautistic population including higher rates of primary healthcare visits, neurology and gastrointestinal specialists, hospitalization (DaWalt et al., 2021; Vohra, Madhavan & Sambamoorthi, 2017; Weiss et al., 2018; Zerbo et al., 2019), hospitalization length (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 autistics also have significantly elevated rates of mental health co-morbidities. Depression, anxiety, ADHD, personality disorders, suicidality, psychotic disorders, and bipolar disorders all were found to be more prevalent among autistic in compare with the typical developing population, with rates ranging from double risk to 12 time the risk in certain condition and cohorts (Buck et al., 2014; Croen et al., 2015; Fortuna et al., 2015; Ghaziuddin, Ghaziuddin, & Greden, 2002; Hand et al., 2020; Saqr et al., 2018; Tint et al., 2021; see reviews Hossain et al., 2020 and Lai et al., 2019). As a result, higher rates of psychiatric drugs use were found among autistic adults (Buck et al., 2014; Kohane et al., 2012; Saqr et al., 2018; Zerbo et al., 2019) and higher utilization of mental health care services (DaWalt et al., 2021; Weiss et al., 2018; Zerbo et al., 2019) and emergency department visits for psychiatric reasons (Vohra, Madhavan, & Sambamoorthi, 2016; Weiss et al., 2018). In Israel only Drori (2015) who surveyed 80 autistic adults diagnosed with Asperger syndrome as part of the founding of assisted community leaving for this population, reported 62.5% had at least one more psychiatric diagnosis, and 40% were using psychiatric medicines. In addition to mental health utilization, the mental health care system as the regulator of autism diagnosis should address the issue 'the lost' autistic adults that were misdiagnosed or not-diagnosed in childhood (Lai & Baron-Cohen, 2015). This diagnosis procedure in adulthood requires additional specialization (T. Epstein, 2019; Huang, Arnold, Foley, & Trollor, 2020).

Beyond medical care and mental health care service 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 , 2016; Bishop-Fitzpatrick, Bureau of Autism Services, 2011a; Cummins, Pellicano, & Crane, 2020; Minshew & Eack, 2013; Ke, Whalon, & Yun, 2018; Lorenc et al., 2018; Skaletski, Chakraborty, & Travers, 2021; Taylor et al., 2012; Tincani & Bondy, 2016). However, because the coverage of these services by health insurance is diverse and changes between countries and within countries there is limited data about their utilization. Zerbo and colleagues (2019) who used data from a insurer that covers these services demonstrated higher rates of additional services specifically speech therapy and occupational and physical therapy among autistic adults, in comparison to 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 high health needs and 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 their encounters with the healthcare system will be further expand in the coming years.

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

Despite the high needs to healthcare services of autistic adults, this population experience significant barriers to healthcare services. The scientific literature usually divides these barriers according to one of three domains it is affected by, either patient or autism-related barriers, provider-related barriers, or systemic barriers (Calleja, Islam, Kingsley, & McDonald, 2020; Nicolaidis et al., 2015; Raymaker et al., 2017; Walsh, Lydon, O’Dowd & O’Connor, 2020). As my investigation request to analyze autistic adults from the perspective of SDH (see extended explanation at section 2.6) I treat the autism-related barriers as a unique characteristic that define the group disability while the provider and system barriers are considered as part of the sociopolitical context which determine healthcare services accessibility. This sub-section explores the autism-related barriers the next explore the SDH.

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

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

The sociopolitical context that affects autistic adults’ accessibility for healthcare services can generally divided into provider-related barriers and system barriers. The most common barrier in relation to provider barriers was lack of knowledge regarding autistics which was reported both in physical services and mental health services (Adams, Young, 2020; Mason et al., 2019; Nicolaidis et al., 2015; Raymaker et al., 2017; Walsh, Lydon, O’Dowd & O’Connor, 2020). Several studies that examined knowledge of providers on autism found that in majority of disciplines and settings the knowledge level was between fair to poor (Corden, Brewer & Cage, 2021; Dooren, McPherson, & Lennox, 2016; McCormack et al., 2020; Zerbo, Massolo, Qian & Croen, 2015). In Israel, however, Atun-Einy and Ben-Sasson (2018) who conducted a knowledge survey among pediatric allied healthcare professionals found adequate knowledge about autism, a finding that might imply different trends in Israel. In addition to lack of knowledge, providers poor flexibility, unwillingness to accommodate services and perceived stigma were mentioned as barriers to healthcare services (Corden, Brewer & Cage, 2021; Nicolaidis et al., 2015; Walsh, Lydon, O’Dowd & O’Connor, 2020).

The systemic barriers to healthcare services for autistic adults that were identified in previous research include financial and insurance issues, time and resources constrains, inflexibility and complexity of the healthcare system, lack of designated support for autistic adults, specific issue with scheduling appointments, and issues with continuity of care (Dern & Sappok, 2016; Mason et al., 2019; Nicolaidis et al., 2015; Raymaker et al., 2017; Walsh, Lydon, O’Dowd & O’Connor, 2020). In mental healthcare specific barriers were mentioned including unavailability of services, long waiting lists, luck of funding, and not meeting inclusion criteria for services (see review by Corden, Brewer & Cage, 2021). Although the issue of accessibility was hardly explored from a policy perspective, recently Debra and colleagues (2021) have analyzed the organizational and structural barriers for mental healthcare services of individuals with intellectual and developmental disabilities including ASD in the US and concluded current provision structure place the burden of integrating mental health services with the unique care needs of autism on the individual instead of the system. Furthermore, Zeidan and colleagues (2019) who conducted policy analysis in Quebec, Canada mentioned several gaps including access issues to family physician and allied health services, problems with continuity of care, and one size service that should fit all, among others. This gaps were found despite initiating 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 both aimed at the autistic individual side and providers sides (see review by Walsh, O’Connor, Walsh, & Lydon, 2021), and formal guidelines (NCCMH, 2012; Nicolaidis, Kripke & Raymaker 2014; Sullivan, 2011) from different countries have tried to address some of the barriers of autistic adults with considerable improvement. Unfortunately, in Israel the providers and system accessibility barriers of autistic adults were not 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 extended healthcare needs of autistic adults and their individual and systemic barriers to healthcare services, various health outcomes of this population have found to be reduced in comparison to those of non-autistic population. Several studies have shown increase mortality rates among autistics as well as lower age at passing (Hirvikoski et al., 2018; Hwang et al., 2019; Woolfenden et al., 2012). Other studies have shown autistic adults have poorer quality of life (QoL) and health related QoL than their non-autistic equivalents (Braden et al., 2021; Kamio, Inada, & Koyama, 2013; Khanna, Jariwala-Parikh, West-Strum & Mahabaleshwarkar, 2014 Roestorf, Howlin, & Bowler, 2021) with a clear association between QoL and co-morbidities (Leader et al., 2021; Roestorf, Howlin, & Bowler, 2021). Moreover, several studies have shown autistic adults report higher unmet health and mental health needs than non-autistics (Doherty et al., 2020; Nicolaidis et al., 2013). At the care provision setting it had been shown chemical or physical restraints are often used in emergency department visits os autistic adults ranging from 23% of visits of autistic adults (Lunsky et al., 2015) to up to 50% of visits (Tint et al., 2019). Finally, from a public health perspective healthcare inaccessibility and unmet needs translates to higher healthcare expenditure (Vohra et al., 2017; Zerbo et al., 2019) and high public expenditure on autistics (Buescher et al.,2014; Knapp, Romeo, & Beecham, 2009). Although the implications of barriers of accessibility to healthcare services were not the main concern of this research I discuss in this work, for the first time in Israel, mechanisms by which barriers impact health. Furthermore, these implications demonstrate inequalities between autistic adults and non-autistics articulate in several measurable health outcomes.

## 2.5. Inequalities between autistics

As presented above autistic adults are found to be discriminated both due to incompatible service on the individual level and due to marginalizing sociopolitical context. This discrimination results in reduction in diverse health outcomes in comparison to neurotypicals; thus, they can be considered as suffering from discrimination and health inequlities. Nevertheless, as health inequalities are defined as the unacceptable, avoidable unequal healthcare access, quality, and outcomes (Braveman, 2006; Whitehead, 1991) and in the case of autism it is referred to as the “unequal access to diagnosis, treatment, and services related to ASD” (Singh & Bunyak, 2019) leaving the investigation of inequlities without exploring between autistic inequlities, will leave the central issue this project request to investigate, inequlities, only partially explored. This section explores between autistic inequlities which is a prevalent phenomenon that affect individuals around the world and in Israel. This section will end with discussing the mechanism that contribute to inequlities.

### 2.5.1. Between-Autistic Inequalities around the world

Mainly in the US but in other countries as well, inequalities have been illustrated between autistic children and autistic adults from diverse groups. The literature on inequalities in autism is roughly divided in to two: inequalities in the age of diagnosis and inequalities in access to services. The interest in the age of diagnosis is mainly because abilities in adulthood is attributed to early interventions that are 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 (Baio et al., 2018; Liptak et al., 2008; Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009; Shattuck et al., 2009; Stein et al., 2012); different Socio-Economic Status (SES) groups (Durkin et al., 2010; Fountain, King, & Bearman, 2011; Jo et al., 2015; P. Thomas et al., 2012; see Daniels & Mandell, 2014 review on disparities of age of diagnosis); between immigrants and non-immigrants families (Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012) and between rural and urban communities (Antezana et al., 2017). Limited access to services, which is this research focus, had been found to be associated in several studies to race (Habayeb, Dababnah, John & Rich, 2020; Liptak et al., 2008; Magaña, Lopez, Aguinaga, & Morton, 2013; Magaña et al., 2012; Montes & Halterman, 2011; Zuckerman et al., 2017); SES (Al-Farsi et al., 2013; Bilaver, Cushing & Cutler, 2016; Irvin et al., 2012; Lin & Yu, 2016); lower parental education and living in nonmetropolitan area (K. C. Thomas, Ellis, McLaurin, Daniels, & Morrissey, 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 noticed that most studies explored inequlities quantitively to show disparities, while only few explored them qualitatively to understand mechanism that cause these inequlities (Singh & Bunyak, 2019), which I will explore later.

Although inequlities between autistic adults have not been studied extensively in health-related literature (Bishop-Fitzpatrick & Kind, 2017; Singh & Bunyak, 2019) this population access to services as post-secondary education and employment had been explored. Eilenberg, Paff, Harrison and Long, (2019) in the recent review they have published note disparities between SES classes and between different ethnic groups in access to transition programs, higher education, employment, independent living arrangement and social participation in favor for high SES and white ethnicity (see for example: Griffin et al., 2014; Kirby, 2016; Shattuck et al., 2012a; Wei et al., 2015). In addition to these disparities research have found geographical variation in the US in participation in vocational rehabilitation programs (Roux, Rast & Shattuck, 2020) and recently also in the eligibility to supplementary security income (Anderson et al., 2021). Health-related inequlities were found by Taylor and Henninger (2015) who reported more unmet service needs among ethnic minority. Benevides, Carretta, Rust and Shea (2021) have recently demonstrated ethnic inequlities in the likelihood to have full-dual eligible for both Medicare and Medicaid between white autistics and black, Asian/Pacific Islander or Hispanic autistic with specific variation across ages. Their findings indicate clear inequlities in eligibility for public health services. Another group that has recently been reported as suffering from excessive health accessibility barriers and poorer health is autistic from the LGBTQ[[12]](#footnote-12) community, who reported 35% of providers decline treating them (Hall et al., 2020). This community must be specifically regarded in the case of autism as gender identity formation is unique and alternative genders are more prevalent among autistics (George & Stokes, 2017; Glidden et al., 2016). To sum up, inequlities between autistic adults based on SES, ethnicity, and geographical location have been demonstrated in the literature, despite that in comparison to children this issue has yet been extensively explored.

### 2.5.2. Between-Autistic Inequalities in Israel

In Israel inequalities in diagnosis had been documented in several studies. [Meiri et al. (2011)](#_ENREF_84) mentioned 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 (Abiri, 2013; M. Davidovitch, Hemo, Manning-Courtney, & Fombonne, 2013; Gal et al., 2012; Kerub et al., 2018; Raz, Weisskopf, Davidovitch, Pinto, & Levine, 2014; Segev et al., 2019) specifically in the southern Israel (Kerub et al., 2018; Kerub et al., 2021). Inequalities in diagnosis were also shown between non-Ultra-Orthodox Jews and Ultra-Orthodox Jews (M. Davidovitch et al., 2013; Raz et al., 2014; Segev et al., 2019); between SES groups with higher prevalence in high-income families (Abiri, 2013; M. Davidovitch et al., 2013; Kamer et al., 2004; Kerub et al., 2018; Segev et al., 2019); between different familial origin with higher prevalence of autism in families from European and American origin; between the center and the periphery; and between immigrants and natives Israelis (Abiri, 2013; Kamer et al., 2004; Kerub et al., 2018).

To my knowledge no systematic study has been done on inequalities in services access or provision to autistic children or adults in Israel. However, R. [Raz et al. (2013)](#_ENREF_105) mention higher enrolment in secluded special education schools of children from lower SES and from Ultraorthodox families, while other children are mostly enrolled in more inclusive setups. Furthermore, [Lubetzky, Shvarts, Merrick, Vardi, and Galil (2004)](#_ENREF_75) study on the usage of developmental rehabilitation services for different 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) stated that educational services for autistic children are not provided equally in Israel. Therefore, it can be concluded with much confidence that inequalities in services for autistic person are present. Beenstock, Pinto & Rimmerman (2021) are the only scholars who examined young adults from the national registry of the NII. Albeit the limitations of this dataset that as mentioned above does not include autistics who were not recognized by the NII, their analysis show opposite trends in adulthood than the one observed among autistic children in Israel. According to their discussion SES and residency in the periphery was not associate with lower participation in adulthood in employment, civil volunteering, or tertiary education. Moreover, they did report higher rates of employment among Arab autistic and lower rates of volunteering among Ultraorthodox Jews (the data is not presented). Apart from their publication, that its additional limitations will be discussed later, no other research investigated inequlities between autistic adults in Israel.

### 2.5.3. Investigating Inequalities in Autism – Unique Concerns

There are two unique aspects to inequalities among autistics. The first is gender inequlities and specifically inequlities between men and women, and the latter is inequalities between autistic persons with and without Intellectual Disability (ID) or what is sometimes referred to as low or high functional abilities. Inequalities between men and women have been long studied in health related issues (e.g. Heise et al., 2019); yet in the case of autism where women are not just discriminated because of their gender but because they constitute also a numeric minority with men/women ratios raging from 3:1 to 6:1 (e.g. Globally: Chiarotti & Venerosi, 2020; Elsabbagh et al., 2012; In Israel: M. Davidovitch et al., 2013; Raz et al., 2014; Segev et al., 2019) articulation of inequalities could be different than in other health issue. There are several questions this unique instance of gender inequlities evokes from the question whether these men/women ratios are a result of inequlities in diagnosis process (Bargiela, Steward & Mandy, 2016 ; [Constantino & Charman, 2012](#_ENREF_33); Gesi et al., 2021; Hiller, Young & Weber, 2016) or biological difference (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” are evoked (Barnbaum, 2008); these questions are of course coupled with social discrimination questions (Bargiela et al., 2016; Milner, McIntosh, Colvert & Happé, 2019) and they translate to health outcomes inequalities (DaWalt et al., 2021; Kirby et al., 2019; Tint & Weiss, 2018). From all these important avenues of investigation, social discrimination are the focus of this study given SDH perspective this research adopts.

The second special consideration is inequalities between autistic persons with and without ID. Although these inequlities are less reported in the literature, possibly owing to minimal representation of autistic individuals with ID in research conducted in recent years (Russell et al., 2019), they had also been demonstrated. Vogan et al. (2014), for example, showed inequalities in caregivers' burden 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 persons and reported those without ID were less likely to receive services. This aspect also explored in the research (See also Daniels & Mandell, 2014 on delay diagnosis, and Zeidan et al., 2019 on the identification of this gap in services in Quebec).

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

This research project, however, request to move beyond the description of inequlities to understanding the mechanism that influence them. Although to acquire such understanding qualitative perspective is needed, the discussion section of most quantitative research dealing with inequlities regarding autistic adult is rich with explanations that are infer from the findings. These explanations are important to explore as they signify the discourse of the reasons for inequlities within the field. Among these explanations are lack of awareness among disadvantage communities (Abiri, 2013; Daniels & Mandell, 2014; MSASS, 2013; Segev et al., 2019), perception of autism (Segev et al., 2019; Sell, Giarelli, Blum, Hanlon & Levy, 2012; Zuckerman et al., 2014), and access to resources (Segev et al., 2019; Zuckerman et al., 2014). These explanations correspond with some of discourses on inequlities in healthcare more broadly (Avni, 2016).

In addition to those assertation some studies have tried to explore the reason for inequlities between autistics quantitatively. Fountain and Bearman (2011) demonstrated the effect of immigration policies on autism diagnosis and argued those policies are contributing to inequlities. King & Bearman (2011) demonstrate how community resources interlink with individual resources and affecting diagnosis. In Israel Kerub and colleagues (2021) analysis of diagnosis of autistic children in the Bedouin community who broke down the diagnosis process into different phases from screening to obtaining diagnosis, demonstrates the exact phases, for example lost to follow up, that creates the inequlities and suggest those should be tackled.

Singh and Bunyak (2019) who conducted a literature review of qualitative research that analyzed inequlities between autistics described several mechanisms that contribute to inequlities. These include barriers that were identified by quantitative researcher as lack of information that is needed to be acquired by the family, corresponding with the lack of awareness; and mental health and disability stigma that correspond with perceptions on autism (See also Habayeb et al., 2020; Khanlou et al., 2017; Rivard et al., 2019). Other mechanisms include poverty as a mitigator of inequlities, in a system that autism services are costly, require money for transportation and are inflexible which makes it impossible to correspond with low-income work schedule; culture that articulates in the language use and cultural beliefs (see also Fong, Lee & Iarocci, 2021); and structural barriers including lack of training in ASD diagnosis (See also Fong, Lee & Iarocci, 2021; Rivard et al., 2019) and interventions, racism of providers, fractured health care system (see also Fong, Lee & Iarocci, 2021), and broader policies as immigration policies and anti-bilingual policies. In Israel Manor-Binyamini and Shoshana (2018) who conducted qualitative research interviewing mother 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 mediators of marginalization of the autistic Bedouin community.

Other studies analyzed policies and argued those are contributing to inequalities in services provision (Caruso, 2010; Shulman, 2000). Yet some go a step further and argue the actors who constructed the policies, in the case of autism autistic organizations, have contributed to inequlities between autistics (Ne'eman, 2011; [Caruso 2010)](#_ENREF_30). While many factors are contributing to inequalities between autistic children, almost no study examined inequlities between autistic adults. In the following chapters I explore both the political discourse about inequlities between autistic adults, and following the argument of Ne'eman’s (2011) and [Caruso (2010)](#_ENREF_30) I illustrate the contribution of autism organizations to inequalities between autistic adults trough promoting discriminating policies.

## 2.6. Theoretical framework

To investigate inequlities in the case of autistic adults I utilize three theoretical frameworks: social determinants of health, the social model of disability and intersectionality. The following 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 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 known diagram of Göran & Whitehead (1991: see below image 1.1) influence health inequalities between and within countries (Marmot, Friel, Bell, Houweling, & Taylor, 2008).

Image 2.1

(Göran & Whitehead, 1991)

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

Although Göran & Whitehead (1991) diagram or similar ones are widely utilized until today, the WHO Commission of the SDH have recognized Graham’s (2004) contribution and adopted hers and other scholars’ observations in the conceptual framework for SDH published in 2010 (Solar & Irwin, 2010). This conceptual framework further developed Graham’s argument on SDHI and differentiate between the s*ocioeconomic position* that I refer to as social position(see footnote 3 at the introduction) of an individual that is affected for instance from the individual’s gender or education, and the *socioeconomic and political context* that influence both the social position and the distribution of resources, for instance through policies. These two factors in turn affect the intermediary determinants that result in health inequity (see diagram below image 1.2). One of the important distinctions this conceptual framework allows is between the biological factors of the individual which appear in the older model as constitutional factor (image 1.1 inner circle) and their social manifestation (image 1.2 socioeconomic position). Sex, for instance, which is an inherent biological characteristic of an individual which clearly affect her or his health has also social aspect represented by the gender which influence her or his access to resources and therefore also influence some would argue considerately more the individual’s health.

Image .2

(Solar & Irwin, 2010)

Yet, even the evolved framework that do allow inclusion of the individual’s social realm in the analysis of SDHI characterize autism and other disabilities as an intermediary determinant either under Behavioral and Biological Factors or under Psychological Factors (see right square at image 1.2). As such autism using this SDH conceptual framework should be studied as a health outcome of SDHI - the illness that is measured for establishing unequal distribution of health. For example, as association between exposure to air pollution in pregnancy and autism was observed (Volk, Lurmann, Penfold, Hertz-Picciotto & McConnell, 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 a SDH as it elevates the prevalence of autism. This perception of disability and specifically autism is widely accepted in SDH research (???). Disability, thus, according to this framework is a synonym for health outcome.

This health outcome, as the upper arrows in the image (1.2) illustrate, can affect the social position of the individual but it is not considered as an integral component of this position. Put differently, in this model a case of someone who suffered injury in car accident and will have to use a wheel chair for the rest of his life will take in consideration he might lose his job and as consequence his social position could shift; however, the policies that will dictate whether his employer be obliged to install a lift in the work place to accommodate his changing needs are regarded as constant that influence the social position and not as SDHI to be investigated. Hence, this framework which adopts the perception that a disease or more accurately a disability is an outcome not a SDHI does not allow exploring autism, and to further extant disabilities, as an inherent social category that is an integral part of the social position of an individual.

Considering disability as a health outcome adopts the medical model of disability (MMD), that asserts disability is 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 additional elaboration on the theoretical framework below). Emerson and others (2011) have pointed to this gap in SDH scholarly and called for the adoption of the SMD within 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 allow exploration of the interplay between disability and marginality within the SDH framework, and the sociopolitical context that affect the health of people with disability. Despite some scholars have adopted this position (See for instance: Mithen, Aitken, Ziersch, & Kavanagh, 2015; Liang et al., 2012; Milner et al., 2019; Emerson et al., 2014; Emerson, 2021; Siddiqua, 2020) most SDH scholarly still regard disability using the MMD model.

Another gap in the SDH literature is the failure to accommodate the complex interaction between marginalities. As Hankivsky and Christoffersen (2008; see also McGibbon & McPherson, 2011) have identified accurately while SDH scholarly have identified and demonstrated time and time again the influence of one determinant on health it often misses the complex combined effects of multiple determinants. Socioeconomic status, for example, is well establish as a SDH, yet its interaction when combined other axes of marginalization such as ethnicity or gender or (dis)ability or the three combined is often neglected. They argue for the use of intersectionality analytical framework that examine the interactions between these axes within the framework of SDH could assist narrowing this gap. Among the possibilities of utilizing intersectionality, which I further elaborate about below, is the ability to explore the experience of multiple marginalization and expose the interdependence between discriminating social structures.

In my research I utilized SDH framework to examine the socioeconomic political context that deprive autistic adults from equal access to needed services in Israel. In other words, I embrace Emerson and other (2011) argument that disability should be studied as a social position within SDH research and following Graham’s differentiating definitions for SDH, I request to investigate the SDHI that determine autistic adults’ social position. Employing SDH framework in that manner request to further narrow the gap in SDH literature that conceive disability as a social position and not a health outcome, especially regarding autistic adults that to my knowledge have not been explored in that manner. Moreover, as this research concern with inequlities I adopt the position of Hankivsky and Christoffersen (2008), and I utilize intersectionality to further examine the implications of SDHI on different social groups within the autistic community. Observing SDHI in that manner was never conducted to my knowledge regarding autistic adults.

### 2.6.2. The social model of disability

Although discrimination and prejudice of people with disability existed throughout the history of humanity (Stiker, 2019) it was the social changes that followed industrialization that demanded the conceptualization of disability as result of an intrinsic individual impairment that need fixing. The creation of labor market that required workers that are physically able with supportive family could not stand the burden of care. To shift the care away from the family to society disability need 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 secluded institutions for the disabled who could not take part in the construction of the capitalist society. While the practices and attitudes toward people with disabilities this definition which is termed in the scientific literature the medical model of disability (MMD), have produced have changed along the years and context from euthanasia (Gallagher, 2001) to robotic prothesis (Bertolini, 2015), it is still the widely accepted model to disability today, especially in health sciences (Oliver & Barns, 2012 p.11-31; Barnes, 2020).

First termed by Mike Oliver in 1981 the social model of disability (SMD) wanted to drew attention away from the individualistic perception of disability that result from intrinsic impairment to the structures that transforms the intrinsic individual impairment to disability. This model that became prominent during the 80’s and 90’s following the struggle of the disability community asserts that disability results form 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 that are dependent in wheelchairs to move. In a society that do not mandate ramps or elevators to be installed these individuals will be disabled and their access to public resources such as public bathrooms, their doctor office, hospitals, public transportation, their office building, or the municipality would be limited. However, if public policies will be put in place and physical mediators will be installed their disability will be eliminated, and their will gain the ability to participate as equals in society. Therefore, this model claims it is not the wheelchair or the paralysis of lower limbs that makes the individual disabled but the social incompetence to accommodate his unique needs that is disabling. Similar rationale can be applied to any disability including autism. Because it is the social structures are the disabling factors and those structures are constructed by society disability can be transformed.

It is important to note that this model do not claim impairment does not exist, on the contrary according to the model it is the intrinsic biological difference that construct the social need that is not mitigated by social structures. Therefore, it also does not oppose to medical or rehabilitative individual interventions as long as they are not further disabling or disempowering disabled individuals as they often do (Barnes, 2020). This standpoint regarding impairment was critique by Shakespeare (2006) and others scholars (Shakespeare & Watson, 2010; Broyer & Finkelstein, 2016) who claimed that deeming impairment as a biological construct and disability as a social one creates an impossible distinction, since both inflicting harm on individuals and because some impairments limit themselves 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 autism and other neurological differences are part of human variation not an impairment that should be habilitated (Ortega, 2009; Orsini, 2013).

Despite this model is alienated from most health research and SDH research, as I mentioned above, I request to utilize the SMD as it allows conceptualization of the social structures that dis/able autistics in our societies. From the perspective of SDH these structures are the SDHI that deprive autistic individuals from resources. In counter to other social positions, however, using the SMD allows me to define these resources as the needed resources for full participation in society not just public resources. Using the wheelchair example, the lack of policies that mandate 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 usage of neurodiversity concept, that I adopt, this work does not further discuss this issue as it focuses like the “classic” SMD on material resources available or not available 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 claimed the term intersectionality illustrated in her study how social identities which are usually understood as sperate entities had to be examined as one. In her research she demonstrated that the identities of women and of people of color in the United States intersects in the realities of women of color. Following other scholars (e.g. Hooks, 1984 p.44) Crenshaw demonstrated that black women face distinct challenges at the judiciary system and that their experiences are unique. Continuing the footsteps of Crenshaw’s many scholars have studied identities using the intersectional framework to demonstrate the unique qualitative experiences of individuals intersected identities (for instance: race and gender Shields, 2008; age and homosexuality: Cronin & King, 2010; including class and religion Ortbals & Rincker, 2009). In recent years, following the field development (Cho, Crenshaw & McCall, 2013) researchers from diverse disciplines have utilized the analytical framework including in the health systems research field (López & Gadsden, 2016; Dhamoon & Hankivsky, 2011; 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 experience of individuals with multiple marginalities intersectionality also allow exploration of privilege and marginality co-existence in a singular social actor’s identity (Dhamoon & Hankivsky, 2011; see also Wojnicka ,2019; Watkins-Liu, 2018). Utilizing intersectionality in that manner sheds light on the interwind systems of oppression and the technics applied by the elite to preserve power. For instance, the manner racism, ableism, and the patriarchy interlink to secure white men domination (Whitesel, 2017). Nevertheless, as Walby, Armstrong and Strid (2012) discuss on their critical analysis of intersectionality literature very few authors go through this path and explore privileged actors.

In my research I utilize the analytical framework of intersectionality both to understand the multiple marginalization of autistic from oppressed groups and to investigate using this framework the mechanism that reproduce inequlities. While the first line of investigation is straight forward as the experiences of those with multiple marginalities can be directly captures, the latter might need elucidation. To explore mechanism that contributes to creation of inequalities or in other words the presumably unconscious technics of the hegemony to preserve dominancy I examine the crisscross identity of disability, or more accurate in the context of this work parents of disabled individuals, with privileged identities within representative organizations. I further investigate whether those identities affected the policy construction process and follows the effect of these policies on inequlities. This process which connects identity, policy and it outcomes provides insight to mechanism of power preservation. This analytical path further allows to mitigate 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 project analyses the inequlities in the case study of autistic adults in Israel. I described above central processes that influenced the creation of the autism field, and central aspects relevant for this research regarding autism organizations. I further specify autism policy and depict both autistic adults’ policy and autism policy articulation 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 situate autistics in a marginalized position in compare to neurotypicals, starts the description of inequlities in this specific case. Yet as I explain these are not the only inequlities that should be explored in relation to this population. Therefore, the last descriptive section depicts inequlities between autistic children and adults both in Israel and other countries, and briefly discuss the mechanism that cause them. I finish this literature review with explaining the theoretical frameworks I utilize in this project and description of the manner I exploit them.

1. The development of the child psychiatry field was possible due to the institutionalization process enhanced by the Mental Hygiene Movement also known as the Child Guidance Movement. The movement was developed on the platform of eugenic notions prevalent at the beginning of the 20th century. It called for tracing the 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). The ‘abnormal children’ who were assembled under one roof enabled for the first time categorization of children’s mental pathologies (Waltz, 2013). [↑](#footnote-ref-1)
2. ABA therapy was introduced in the early 1960’s by Ole Ivar Lovaas who was influenced behavioral psychology theory. It was among the first suggested treatments for autism that was vastly adopted. ABA therapy is based on breaking down a complex task to sub-tasks and give positive (and in the past negative) enforcements to alter the behavior (Waltz, 2013). This treatment is considered until today one of the most recommended treatments for autism (See for instance 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 U.S. The program had been executed in North Carolina both in school settings and in regional centers. [↑](#footnote-ref-3)
4. Today there are a great deal 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 recognize the importance of those actors although she differentiates between the parent-researcher to 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 inclination toward 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 service, however, 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 include also supportive family centers, programs of transition 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 lunched 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 to 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)