# 5. Discriminataing Healthcare System - The Social Determinants of Health Inequlities of autistic adults in Israel

After establishing in the previous chapter autism should be regarded as part of the ‘social position’ of the individual, in this chapter following Solara and Irwin (2010) model an extensive analysis of the sociopolitical context, the Social Determinant of Health Inequalities (SDHI), that influence the health of autistic adults is performed. Because SDHI is an umbrella term that encompass policies and social arrangements that are relevant to all aspects of life, from trade agreements to employment, from public transportation to the judicial system, capturing the full scale of SDHI of autistic adults is impossible in one chapter. Therefore, and because this work observes autistic individuals from a health perspective this chapter focuses on the SDHI that are related healthcare system in Israel.

In the chapter I argue that the current healthcare system in Israel is structurally marginalizing autistic adults. While the previous chapter had demonstrated that on the individual level the collision of the autistic traits with an inaccessible healthcare system is causing barriers to health and marginalizing autistic adults; this chapter shifts the focus to the systemic level and illustrates that current policies, arrangements, and practices are discriminating autistic adults and negatively affecting their health. The chapter begins with analyzing the systemic reasons the barriers to the healthcare system covered in the previous chapter were not addressed. These include the perception of autism as a disease, the invisibility of autistic barriers, and lack of knowledge among professionals. Next the chapter explores mental healthcare policies. First, the section on mental health establishes the extensive need for mental healthcare among autistic adults; then it analyses implications of the current legal situation that exclude autistics from the recently introduced mental healthcare reform; and it ends with analyzing the consequences of not providing autism diagnosis in adulthood within the public healthcare system. The chapter ends with exploring the absence of systemic regulation for the provision of complementary treatments for autistic adults, and its ramifications.

It should mention again at this point before jumping into the analytical sections, that the chapter covers only SDHI that are related to the healthcare system. Many aspects that further marginalize autistic adults in the Israeli sociopolitical context and that were found to be central to autistic adults’ life during the qualitative analysis are not covered. Among these are the absence of structured services for transition to adulthood, lack of community housing, minimal employment support, gaps in the National Insurance Institute stipend procedures and barriers to private insurance market. Furthermore, other issues such as stigma, friendships and relationship in adulthood, challenges in higher education, transportation and serving at the security forces, who were also raised by interviewees will not be covered. Those SDHI should be further investigated in future research as their indirect impact on health is crucial.

## 5.1. Marginalizing perceptions of autism

The last chapter demonstrated variety of barriers to healthcare services autistic adults suffer due incompatible systemic structure. This section attempts to answer why these barriers have never been addressed despite the special traits of autistic adults are widely known for a long period, and even though access to health is an issue that had been extensively discussed. The section argues that although the reasons for overlooking these challenges are complex two main perceptions on autism rooted in the Israeli healthcare system contribute to the negligence of these challenges, and therefore marginalizing autistics. First in concordance with the Medical Model to Disability (MMD) autism is regarded within the healthcare system in Israel as a disease not a disability; therefore, autistics should be habilitated to comply with the neurotypical system and not vis versa. Second, autism is an invisible-unrecognizable disability, therefore, their neurological differences are either considered nonexistence, or mitigations of services that are mostly considered as physical or structural are irrelevant for them. These two perceptions this section claim prevent from moving forward toward an accessible healthcare system, therefore they discriminate autistic adults.

### 5.1.1. Autism is a disease not a disability

The idea that autism is a disease is neither new nor relevant just to Israel as elaborated in the literature review. The notion that it is possible and is needed to cure autism or eliminate autism was the dominant believe among parents and the medical establishment worldwide (Eyal, 2013). This perception is still prevailing despite many in the autism community both autistic advocates, parents and professionals have argued against this perception claiming it has cause negligence of autistics needs and services (Baker, 2011). Yet, this perception has not just delayed the development and investments in services for autistics it also diverted efforts away from mitigation of services, from removing barriers. To understand why defining autism as a disease and trying to cure it is a counter process to accepting it as a disability and trying to eliminate barriers, a careful examination of the interaction between these two perceptions is needed. The explanation given by Ronen Gil, an autistic individual and an advocate, regarding communication differences can assists in this matter:

“Communication is a mutual process. When one side uses ways of communication that are not understandable enough by the other party, there is no communication. When one side dictates that all communication must be only in manners that he wants to communicate, so there isn’t really any communication. If you don’t understand that other manners of communication, different from what you are used to, are possible you will deem those communication manners as deficient. “(Ronen Gil, an autistic individual and an activist)

Although Ronen is describing communication differences his example illustrates accurately the interplay between autism as a disease perception held by administrators and practitioners and autism as a disability that strive to reduce barriers. The disease perception that Ronen criticized is a coercion of the common communication practices on autistic individuals by teaching *them* the “right” unautistic manners. According to this perception if you are not accepting these practices, you deemed as deficient, as someone who have a disease. The disability perception on the other hand, first and foremost recognizes there are two sides to communication and strive to mitigate the gap between them. Thus, the fundamental difference between the perceptions can be summarized to the recognition and acceptance of the other side legitimacy or not. These conflictual approaches that resonate the deviation between the MMD and the SMD, contradict; and holding one, in principle, would mean that the other cannot be hold. But not only on principle these perceptions contradicts, in practice the disease perception often, as the previous chapter exemplify, inflicts barriers and widen the gap between the parties; therefore, it cannot be advanced in parallel to the disability perception that attempt to eliminate barriers.

In the healthcare system in Israel the MMD was fully adopted neglecting almost completely the alternative to mitigate services for autistic individuals. One straightforward example for adopting this perception can be seen by a quick observation on the department of autism goals at the MoH. Among the department responsibilities which are specified at the ministry website (Ministry of Health, Israel, 2021b), five out of ten aims related to early interventions, one to advancing new treatments and diagnosis and one to hospitalization infrastructure. The last three which are not necessarily related to treatment are cultivating collaborations, advancing research and development of training programs. As can be easily seen most efforts are dedicated at promoting and regulating treatment for autistics, mainly autistic children.

Another example for adopting this perception within the ministry of health was raised by Geula, a senior position holder in the ministry of health responsible among other thing on autism. When asked if there are any guidelines to accommodate care for autistic individuals she replied:

“I am not familiar with one… like any other special population here [in the MoH] what happens when a psychotic person come to get medical services? This is not something unique to autistics […] they get around, those who are low functioning usually come with someone, not alone and then you have mitigation. We did not see it as a need” (Geula, a senior position holder in the ministry of health)

Geula who is familiar with the autistic population and eligibility with their needs deem the issue of access to healthcare as irrelevant. She argued those barriers are manageable and easily overcome in the case of non-verbal autistic adults by guardians that mitigate the services. Her comparison of autistic individuals to an individual experiencing a psychotic event exemplify the perception of autism as a disease. In her perception autism is a periodical instance that can dissolved, an instance in which a disabled person can become non-disabled. Coupling Geula’s quote with the fact the Autism department at the MoH is nested in the mental health flank, and that the only service it regulates that relate for autistic adults is hospitalization in mental health institutes further illustrate the perception of autism as a disease hinders the removal of barriers to healthcare services for autistic adults.

The hold of this perception in the establishment is, however, exemplified best by understanding its diffusion to the practitioners’ level. The qualitative inquiry demonstrated the practices professionals working with autistic adopt reflect this perception, as they attempt to teach autistic individuals the neurotypical manners. Among the examples that were mentioned, Anat’s example exactly touch this point. Anat, a mother of an autistic child, a professional working with autistic adults and an activist shared in her interview the practices she use, when discussing her work with an autistic adult who live in the community:

“I try to teach him that he needs to be attentive to gestures and body language, and to turn his attention first to the eyes. This is something they [autistic individuals] often miss. I am illustrating again and again how much of communication is going through these points, that are being missed.” (Anat, a mother of autistic child, a professional working with autistic adults and an activist)

Anat’s explanation, which is corresponding beautifully with Ronen quote, exemplify how the perception of MMD has a stronghold also in the provider level. Anat explained how she taught the autistic adult she is working with, the neurotypical, the ‘right’, manners of communications – be attentive to eye contact and gestures. As Ronen argued, this approach could be coercive as it observes communication from the neurotypical powerful side and subject the autistic individual to its rules. Considering among the aims of the Autism department are promoting treatments and training it is not surprising the MMD perception that is hold by the administrative level penetrated to professionals.

The examples above demonstrate that the perception of autism as a disease that need to be cure or habilitated according to neurotypical standards is dictating the main line of thought in the MoH. It also shows this perception has a strong grip among professionals. Given the MMD is so dominant throughout the organizational levels and considering Ronen’s explanation that one perspective on disability contradicts the other, partially explain why the barriers for healthcare service where not even considered by the MoH. This dichotomic explanation, however, fail to recognize both perceptions of disability might in practice be present side by side. For instance, the Autism Department at the MoH collaborated with this research despite knowing its critical position on the field; or Anat quoted above that in a different part of her interview did mention the importance of mitigating services. Nevertheless, on the models of disability scale when MMD is at one side and SMD in the other, the wight of MMD in the healthcare system in Israel is heavier, thus the perception of autism as a disease is dominating. As such it systemically leading to discrimination and marginalization of autistic adults in the healthcare by preventing the system recognition in their barriers.

### 5.1.2. Autism is an invisible-unrecognizable disability

The second theme that had continuously emerged during the qualitative investigation as a cause for ignoring autistic adults’ barriers at healthcare services was the invisibility of the autistic disability. The notion that is widely spread among the Israel public that when referring to disabilities the meaning is physical disabilities (Feldman & Ben-Moshe, 2006) had been found to be rooted also in the healthcare system. Furthermore, as a direct result of this perception accommodations for disabled individuals are considered structural modifications. While structural modifications might be relevant for autistic adults, for instance with their sensory barriers to healthcare (see chapter 4), alleviating barriers to healthcare services for autistic individuals mean also introducing changes and mitigation in service provision. This idea of providers themselves changing their conduct as a mitigation practice, is not considered under the notion of accommodation for disabled individuals. These two perceptions of disabilities, first that it is relevant to physical disablement and second that it requires only structural modifications have also contributed to the negligence of the barriers of autistic adults, and further marginalizing this population.

The best example for this notion centrality within the healthcare system is the 2016 regulations published by the ministry of health as part of the Israeli Equal Rights for People with Disabilities Regulations (Ministry of Health, 2016). These regulations detail in the first and the second attachments all the amendments needed to be introduced within medical provision centers to promote accessibility. Among the variety of mitigations that are required physical changes in passages, doors, bathrooms and many other structures could be found. Nonetheless, not one of the articles is discussing service provision mitigation. These regulations exemplify disability is perceived as physical disability within healthcare system, thus leaving autistic individuals and other invisible disabilities without any answer for their needs. The fact that Geula, a senior position holder at the MoH quoted above said “we did not see it [accommodations] as a need” demonstrating this perception is still prevalent at the ministry corridors.

Similar to the perception of autism is a disease, the invisibility of autistic disabilities can be found also among service providers themselves not only the ministry administration. Rachel, for instance, a deputy head nurse in a tertiary medical center who is also involved in promoting the hospital accessibility explained in her interview the hardship of introducing such changes to the medical personnel:

“There was an initiative […] to start and think about it [accommodating services for people with neurodevelopmental disabilities], talk about it, expose it so later we could succeed to achieve some change. Because as you know changes in this area is very difficult and is divided in to two things. There are the structural changes that is a whole world from wheelchairs, to [headsets for] the deafness, to visual impairment, a huge diversity of disabilities. And there is the awareness the attitude of the staff, the approach, all kind of technics that we can use together to mitigate the services to these [disabled] people according to their needs” (Rachel, a deputy head nurse in a tertiary medical center)

After starting from explaining accommodation of neurodevelopmental disabilities is ‘very difficult’ and recognizing the efforts invested might result only in ‘some’ change, Rachel divided the issue of accessibility in two. Structural changes and service provision changes. Unlike structural changes which becoming a constant environment realm, changes in service provision demands changing perceptions, changing the awareness. The main perception that is needed to be change is that like physical disabilities these individuals could have equal access to healthcare if proper mitigation would be introduced. Only later after the awareness had been raised the attitudes and approaches toward these individuals could be amended. Later in the interview explaining about the programs they have started in the hospital, Rachel said: “We are starting with the awareness of the medical stuff. They, the hospital personnel, not really understand”. This sentence further demonstrates how deep the perception that accommodations are structural and not behavioral is rooted in the healthcare system. This perception is embedded to such an extent that healthcare personnel have difficulties understanding other perceptions are possible.

The invisibility of autistics difficulties was also raised by autistic individuals and their families. Under the mandate of the Israeli accessibility legislations autistics individuals have an exempt card from queues, that allows them to shorten waiting time. The qualitative inquiry demonstrated providers do not accept well this mitigation, thinking it is an unjustifiable privilege. Bar and Tomer, parents of an autistic adult when discussing the unique circumstances autistics need to deal in the Israeli context, reported such attitude from service providers in the airport:

*Bar*: “As I told you we do wait in the queues we are not trying [to shorten them] … I know from my friends that use the card that allows you not to wait in line. It outrages people. In every other country it is unquestionable but here in the state [of Israel] it is something… […] We used it once at the airport and one Israeli [passenger] got really mad at us. Do you remember?”

*Tomer*: “But the people are less interesting me, I more interested in the service providers. Among the service providers it is also not always acceptable.” (Bar and Tomer, parents of an autistic adult)

Trying to avoid hostile responses Bar reported they usually do not to use the disability card they possess to wave queues. Nevertheless, it seems from the one instant they did use it, and from her friends’ experiences there is a reluctance to accept this mitigation, strengthening the argument that autism disability is invisible among the Israeli public. Tomer complement the image by adding that this perception is not just prevalent among the public who need to wait longer but is rooted within service provider’s culture. Although this specific instant discussed an incident in the airport, unfortunately similar experiences are prone to happen in healthcare system given the perceptions in the administrative levels and the provider levels are similar. As the accessibility regulations do not apply in the healthcare system, this kind of incidents have not been mentioned by interviewees.

Smadar, an autistic woman and the mother of three autistic children, complicate the ability to recognize autism as a disability that require amendments even more when describing the invisibility of autism. When asked about the unique experience autistics living in Israel might have she portrayed the following:

"This is an invisible disability, my leg is fine, my hand is fine, I am not sitting on a wheel chair. My son asks ‘if we have difficulties why do have the disabled sign [on our car]? We don’t have wheelchair.’ In the religious education if someone is on a wheelchair or blind or deaf it goes under the category of grace. You need to treat him nice because it is written [on the bible] that you need to treat him nice, but when disability is invisible like in the case of mental or cognitive disability it seems it is elusive all the time. Is it there? Is it not there? I can’t see it, it is not there? Yes? What is happening here? And why he deserves or not deserves?” (Smadar, an autistic woman and the mother of three autistic children)

Smadar who started with marking her disability as not visible explained that her autistic sons who does not know he has a diagnosis of autism but know of his difficulties, could not understood why his difficulties are categorized beneath the same umbrella of people who are physically disabled. Even he does not grasp his difficulties as vivid as those of the individual that sits on a wheelchair. Then after she described the approach to disability in the religious education and framing it as an attitude of grace toward those who do not have or helpless, she turned to the issue of invisible disabilities. In these cases of cognitive or mental disabilities she argued the situation is different. There is eligibly a thin line between disabled and non-disabled, a thin line that the observer drafts and can be crossed easily. Her description emphasis why autism is an invisible disability, it is not just that it is not visually seen, but that some autistic individuals in some circumstances could seem ‘normal’, non-disabled. If autistics in certain times are non-disabled, maybe they do not require or deserve accommodations.

To sum up autistic adults are marginalized at the healthcare system and their barriers are disregarded partially because both at the administrative level and the providers level discriminating perceptions toward autism are prominent. Two major oppressive perceptions were identified. The perception that autism is a disease and as such it should treated, cured or habilitative and not be recognized as a disability that require accommodation; and the perception disability is physical and visible that require only structural accommodations. Invisible disabilities which include in addition to autism other mental and cognitive disabilities and physical disabilities that are not visually shown (See Davis, 2005; Navas et al., 2019) are not recognized. It should be noted, that despite these perceptions are clearly influential in the healthcare system, shift may start to happen. In 2020 the MoH started drafting new service provision regulations, that includes also invisible disabilities. As part of this process the writer of this dissertation together with the advisory committee, were approached to advice the MoH. Another notable example is the introduction of Beit Issie Shapiro’s program for accommodation of services for invisible disabilities to some community medical centers (Nisim, 2020). Furthermore, as mentioned above alongside these discriminating perceptions alternative perceptions are held by individuals within the healthcare system that are trying to promote “some” change, as Rachel quoted above mentioned. Unfortunately, as this section demonstrates the pendulum is still clearly tilled toward discriminating perceptions. These perceptions prevent from introducing mitigations, especially those that require accommodations in services provisions. Thus, as this section argues autistic adults are marginalized within the healthcare system by these perceptions, and they could be regarded as SDHI the political context that define the marginalization of autistic individuals.

## 5.2. Lack of professionals’ knowledge about autistic adults

The interviews had demonstrated that throughout the healthcare system including in professions that autism supposed to be at the core of their specialty including psychiatry, psychology, speech therapy and occupational therapy there is a serious gap in knowledge regarding the autism spectrum and specifically about the mitigations that are needed to provide accessible services to this population. This gap in knowledge is derived by limited number of knowledgeable senior professionals combined with negligence of systemic training on autism and specifically on autistic adults. In addition, the lack of knowledge was found to have implications beyond its interference in reducing barriers, on the provision of unsuited treatments and on service utilization. In the Israeli healthcare system context lack of knowledge is thus marginalizing autistic adults and as the section argues can be regarded as SDHI.

### 5.2.1. The Lack of knowledge

The major gap in knowledge regarding autistic adults was expressed mainly by professionals but also by autistic adults, and their families. The most prominent expression for lack of knowledge among service providers at the healthcare system was that of psychiatrists. Dr. Yair, a psychiatrist working with autistic adults in the community mentioned in his interview during a discussion about the knowledge among psychiatrists:

“If you think of the average resident in psychiatry, there is a very high probability, in adult psychiatry, that a resident will finish his residency without ever seeing a patient with autism. If he saw someone with autism, he didn’t know about it, and if he knew that he sees [an autistic adult] so there was only one patient and there was no discussion about the implication of his autistic aspects” (Dr. Yair, a psychiatrist working with autistic adults in the community)

Despite Pervasive Developmental Disorders (PDD) which autism was included under its category at the previous versions of the DSM, appearing in the latest updated syllabus of psychiatry residency published by the Israeli Medical Association (The scientific committee, The Israeli Medical Association, 2015 p.39) the actual encounter of a resident in psychiatry with autistic adults, as Dr. Yair portrayed it, is very limited. Therefore, the empirical knowledge a resident in psychiatry can acquire on the subject is inadequate. Dr. Yair quote, however, is not just suggesting there is currently no training about autism among adult psychiatrists’ residents that damage the cultivation of future generations, he implied that the knowledge among specialists is also very limited. The fact that a resident can see an autistic adult and not recognized she is autistic without any supervisor directing him, or that he can provide treatment to autistics without proper amendments to the care indicates that knowledge is missing also among the specialists that supposed to educate the next generations. This claim is supported by other psychiatrists interviewed for the research. Dr. Golda, for example, a senior psychatrist working with autistic adults in a residential place testified in her interview that “I did not have any training, not something specific, and I feel it something I could benefit from’“ (Dr. Golda, a psychatrist working with autistic adults).

Limited training about autism was reported among other professions as well. For example, Kfir a clinical psycologist working with autistic adults, shared that in his academic studies: “we didn’t touch this subject so much” (Kfir, a psycologist working with autistic adults) and Tze’ela, a rehabilitative psychologist working with autistic adults had the same impression saying that she had “no exposure whatsoever” to autism. Given the lack of knowledge among psychiatrists and psychologists it is not surprising the knowledge among primary healthcare providers is also limited. Dr. Mor, a family physician working with autistic adults described similar gaps in training and knowledge:

“I can tell you that in the training we learned about it [autism] in relation to child psychiatry […] I think we are not being prepared in anyway to treat special populations. When I started working with autistics I searched for information and thus far the best material I have you [the interviewer] sent me” (Dr. Mor, a family physician)

Dr. Mor similarly to former interviewers quoted above, described limited exposure to autism. She did mention a short introduction to autism in child psychiatry, which is crucial; yet as autistic advocates have been arguing for long time the focus on children diverted research and practices away from the needs of adults (see Ne'eman, 2011, and additional elaboration at the literature review). Dr. Mor’s additional annotation regarding the lack of preparation to treat special populations emphasis this argument of autistic adults even further as they are the ones who could have benefit from such preparations along other disabled individuals. Dr. Mor’s lack of knowledge as she state was not limited to her training. When she did make an effort to learn more about the autistic adult population and primary care, she found limited information emphasizing the current healthcare system negligence of the field.

Not only professionals mentioned their limited knowledge regarding autistic adults. The unfamiliarity of healthcare professionals with autistic adults did not go unnoticed by autistic adults, guardians and caretakers of autistic adults who utilize healthcare services. Smadar, for instant, an autistic woman and the mother of three autistic children shared her experience with unknowledgeable professionals:

“Today I have a family physician […] that opposes the idea that I am on the spectrum [… and] my psychiatrist at the Sick Fund […] I am the one who taught her what is autism” (Smadar, an autistic woman and the mother of three autistic children).

Smadar portrayed her encounter with unknowledgeable professionals and complement the recipient side. Additional observation in her statement reveals two responses the lack of knowledge among providers can evoke. One is complete dismissal of the diagnosis corresponding with the perception of disability is visible as discussed above, and the other is openness to learn from the patient. The spectrum of responses that was mentioned in the interviews was broader; nevertheless, its importance is in what it demonstrates. Without any systemic alignment regarding the needed knowledge for professionals the the services autistic adults receive might greatly differ from one provider to the other.

The survey who was conducted among autistic adults and guardians of autistic adults, in counter to the qualitative findings demonstrated responders agreed that on average professionals are trained to a satisfactory degree to answer autistic adults needs. Three questions measured the knowledge of professionals. The first questions measured the degree of agreement in the comprehensiveness of professional’s knowledge and included sub-questions regarding family physicians, psychiatrists, and psychologists. The second question was directed to individuals who were treated at the mental health system in the year prior to their completion of the questioner. The question measured the degree of agreement in the comprehensiveness of the mental health professional’s knowledge. The third relevant question was a yes/no question that asked responders if they have difficulties finding a family physician that is trained enough and able to answer their needs. The degree of agreement in the comprehensiveness of professional’s knowledge about autistic adults was measured in all relevant questions in 1 to 4 scale when 1 is the least agreement and 4 most agreement.

The degree of agreement regarding the comprehensiveness of the knowledge of family physicians, psychiatrists and psychologists was 2.96, 2.81, and 2.81 respectively. Among the responders that have utilized community mental health services (n=51, 54.8% from 93 responders), the degree of agreement in the comprehensiveness of the mental health professional’s knowledge was 2.77. Despite the agreement the comprehensiveness of family physician’s knowledge was found to be higher than the average, 30% of responders (n=31, out of 93) reported they are having difficulties finding a primary care physician that have enough training to answer their needs. These finding imply that among service recipients the majority are satisfied from the knowledge of their providers regarding autism.

Three explanations could account for the gap between the centrality of the theme in the qualitative investigation and quantitative findings. The first is the selection of interviewees that are “good informants” for the qualitative part. Those interviewees most likely possess more than the average knowledge about autism than the average person and might have a different, more accurate, impression on what is considered enough knowledge. Moreover, the quantitative results should be interpreted carefully because the degree scale might be partially biased, as other qualities such as trust in the healthcare system could divert the result. Finally, the results are an impression of the service recipients and their families of the professionals’ expertise and not an objective quantification of their actual knowledge. In the qualitative analysis, however, this theme was also prominent among the professionals who were interviewed. Considering finding from the international literature who reported gaps in knowledge among professionals (Zerbo, Massolo, Qian & Croen, 2015) an assumption could be made that the situation in Israel is no different. This discrepancy, however, deserve further exploration of professionals’ knowledge about autism in future research.

It should be noted despite the extensive lack of knowledge among professional that some efforts are being done both by the MoH and the academia to reduce these gaps. Dr. Rotem, for instance, a psychatrist working with autistic adults mentioned in her interview that:

“[Lately I heard that] an approval was given to run a course at the continuing education program […] 100 hours on autism for psychiatrists, family physicians, and other healthcare professionals that hold at least a second degree. […] The idea from what I understand is to develop a social network among the people who went through the course, and that will probably treat autistic adults in the future” (Dr. Rotem, a psychatrist working with autistic adults)

The course Dr. Rotem’s mentioned which is running since 2019 is an essential first step toward enhancing the knowledge of professionals about autism in adulthood. The syllabus published online (Portuguese, 2021) reveilles a crucial overview on neurodevelopmental diagnoses and a sample of the most urgent issues the initiators realized needed to be covered. If indeed the course will also succeed establishing a network of knowledge this is an additional benefit of the course that can assist in further developing the field. Yet, one national course given to professionals who actively look for relevant information that is intended to explore all neurodevelopmental diagnosis might be a too little given the expected increase in the number of autistic adults.

In summary this section has demonstrated there are vast gaps in the knowledge of professionals regarding autistic adults across disciplines. These gaps are a result of lack of knowledge among senior professionals that treat autistic adults without regarding their uniqueness, and absence of structured training on the subject for future professionals’ generations. Despite the prominence of this theme in the qualitative phase, in the quantitative phase on average this gap in knowledge was not identified by the service recipients who ranked the professional knowledge as suitable for their needs. This section, thus, argues that the absence in training and body of knowledge regarding this population, is part of the sociopolitical context that structurally marginalizing the autistic adults’ population. The next part of this section will briefly explore additional implication of this knowledge gap.

### 5.2.2. Implications of the gaps in knowledge

The importance of training healthcare professionals about autism spectrum in adulthood is not derived just from the possibility that some professionals will treat autistic adults better than others. The lack of knowledge about autism has additional implications. First, as the previous chapter demonstrates lack of knowledge among professionals can result in barriers to healthcare services. Professionals who are not familiar with the unique manners of communication autistic adult utilize, or that are not taking in considerations autistics sensory difference can inflict serious barriers. In addition, the qualitative investigation demonstrated lack of knowledge on autistic adults can have implications beyond providing unaccommodated care. As knowledge about autistic adults includes many additional aspects of care beyond the prism of accessibility, not having knowledge about this population can result in unsuitable treatment. Moreover, the absence of knowledgeable professionals on autistic adults is diverting autistic adults and their caregivers to look for professionals who specialized in autistic children. A practice that can unfortunately harm the health of autistic adults. The next chapter on inequalities between autistic adults will discuss another implication of this circumstance, the reliance on private services.

#### Unsuitable treatment

The lack of knowledge regarding autism among health professionals and specifically mental health professionals can result in providing irrelevant and in some cases even harming treatments. Barak and Shlomi, autistic adult couple who were interviewed together express their confusing experience with health professionals who are unfamiliar with the autism spectrum:

*Shlomi*: “In regard to psychologists and psychiatrists in no circumstances someone who is not an expert in autism should treat someone with autism. Psychologists all they learned in their lives is irrelevant to the manner autistics think and act […] You take someone with autism and you put him in treatment of psychologist he will end up crazy […] The psychologist says you should do one two three, you should do…”

*Barak*: “you are starting to do it, you don’t succeed, you fail, and you starting to get crazy. Why can’t I do it? You are told what you need to do the whole time and it suits completely different [mental] system. When you try to do it anyhow it causes you bad feelings.”

(Barak and Shlomi, autistic adult couple)

Barak and Shlomi express their explicit negative opinion regarding the treatment of autistic individuals by mental health professionals who are unknowledgeable about autism. They describe a completely different psychological system that corresponds adversely to the practices common in neurotypical psychology. Barak’s description of repeated failures following unsuited guidance by a psychologist demonstrates Shlomi’s point that being treated by untrained health professional could have disastrous results. Additional examples that were raised in the interviews, emphasis the different mental interpretation autistic adults require when going through treatment, an interpretation that cannot be provided by therapists that are unfamiliar with the autism spectrum (on unique aspects of diagnosing mental health disorders in autistic adults see Portuguese, 2019). To understand the absurd of this circumstances better, it is easier to imagine what would be the systemic response if a practitioner that do not understand nothing about type 1 diabetes or Attention Deficit Hyperactivity Disorder (ADHD) would treat patients who have these disabilities – it would be seen as unreasonable practice. In addition to mental healthcare services other medical issues that are require specific attention in autistic adults had been raised by interviewees and are known in the literature, such as gastroenterological diseases (Buie et al.,2010) and sleep disorders (Lugo et al., 2020). Hence, it can be concluded that the systemic negligence of the training regarding autistic adults is a practice that directly harm these individuals’ health and marginalizing them in comparison to neurotypicals.

#### Turning to child therapists

The qualitative analysis showed the lack of knowledge among adult therapists cause another marginalizing practice. In the absence of alternatives given the enormous lack in knowledge and the need for relief, individuals and caregivers are turning to child therapists. Ben a professional working with autistic adults, and a head of a program for autistic adults explained:

“When we had a major difficulty [with one of our autistic participants], there is a medical center nearby that have a child psychiatrist that is treating autistic children. So, we took our resident there and we paid 900 NIS for first aid.” (Ben, a director of a program focused on autistic adults)

Although child therapists are partially trained also in adult psychiatry the need to choose either a therapist that is familiar with autism or a therapist that is familiar with adult care, because there are none available that combines both is unreasonable. The famous saying in pediatrics that “children are not small adults” works both ways as autistic adults are not large autistic children. Thus, this solution which result due to the absence of knowledge among health professionals inevitably result in suboptimal care for autistic individuals and negatively affect their health. This practice although not formally encouraged is a result of systemically continues negligence of the autism in adulthood field. It should be noted that although this practice might seem similar to using pediatrician in adulthood (see chapter 4), the rational underlining both practices is different. While one aims at reducing barriers by going to the same place that is familiar to the autistic adult, the other not only not reduce the familiarity barrier but also further marginalize the autistic individual by providing suboptimal care. What this practices, however, have in comment is that both involve child practitioners, stressing that the autism field in Israel is not different then the global autism field, in the sense that it also had been neglected autistic adults.

To conclude, this section demonstrated the absence of knowledge regarding autistic adults across disciplines and throughout different levels of expertise. Despite some efforts to close this gap in knowledge have been started to be promoted in recent years, there is still systemically negligence of this field. In addition, to being a setback for overcoming barriers to healthcare services this lack of knowledge have been shown to cause to additional marginalizing practices. First, knowledge about the unique treatment approaches these individuals require is not applied, especially in mental healthcare. Second, as knowledgeable adult therapist are not available, autistic adults and caregivers need to use the services of child therapists. These findings clearly demonstrate that lack of knowledge among professionals caused by systemic negligence of the fields is another sociopolitical determinant that marginalize autistic adults in Israel an harm their health. This SDHI further discriminate the social position of autism in Israel and should be addressed.

## 5.3. Marginalizing mental healthcare policies

As have been explored in the literature review autistic adults need extensive mental healthcare services (see for example Nylander et al., 2018). As the need for mental healthcare for autistic adults have never been explored in Israel, this section begins by demonstrating the significant role of mental health in autistic adults’ life in Israel. It then turns to explore the ability of autistic adults to utilize mental health services within the current public system. While the previous section focused on practitioners’ knowledge as the mitigator of marginalization, and the role of the system was for not providing this knowledge systemically, this section argues that current health policies are directly marginalizing autistic adults. The policy that excludes autism from the recently introduced mental health reform is preventing from autistic adults needed services and is limiting the development of the system capacity to treat autistic adults. The policy that prevents from adults obtaining a diagnosis of autism in the public healthcare system, deprive unrecognized autistics the personal and systemic recognition in their difference, which is needed to obtain any services. In other words, the section claims current mental healthcare policies in Israel are another SDHI that marginalize autistic adults in Israel.

### 5.3.1. The need for mental healthcare services

A great need for mental and emotional care for autistic adults was demonstrated across the spectrum. Both autistic adults with cognitive disability or dominant autistic traits who live in institutions and individuals with high cognitive abilities who live in the community have demonstrated high need for mental healthcare.

Multiple examples for the need for mental healthcare was demonstrated at the interviews by diverse stakeholders. Pazit, for instance, a social worker working with autistic adults in a dedicated program for adults with normal to high cognitive abilities who wish to live in the community shared the need of the adults that are under her supervision:

“In spite it is not funded by the ministry of social affairs we are paying for it [mental healthcare services]. We cannot forgo the emotional therapy. This is something you just can’t waive… 80% of our guys need it, you cannot give up on it. We tried to at the beginning [of the program], it was even part of our agenda but… we are referring them to the community” (Pazit, a social worker working with autistic adults)

According to Pazit 80% of the autistic adults that are under her responsibility need mental healthcare services. The emotional relief was needed to such an extent that although it was against their initial agenda and it is not being funded by Ministry of Labor, Social Affairs and Social Services (MOLSA) which subsidize the program, they had decided to invest in mental health treatments. Bina, a manager at a residential place for autistic adults who need more assistance at their daily activities giving their cognitive abilities and the comprehensiveness of their autistic traits depicted similar image:

“Those are individuals who use psychiatric medicines for years. The psychiatrists who are being employed by the organization running the residential place, are coming every two weeks and are available to us for 24/7. They are funded by us not the Sick Funds. (Bina, a manager at a residential place for autistic adults)

Bina described that on the other side of the spectrum for individuals with lower cognitive and functional abilities the need for psychiatric care is also considerable. Furthermore, she explained, as Pazit before her, that the care is needed to such an extent that the operating organization is funding the mental healthcare.

The need for mental health services was also evident at the survey’s findings. Among the responders, autistic adults, and guardians a like (n=112) 91% have marked that they were ever treated or diagnosed with additional mental health disability, and 54.4% have marked two or more additional mental health disability. In addition, among those who replied whether they ever received mental health care at the community 54.8% have testified they have. In comparison with the general population (Elroee, Rozen, Elmakaias & Samuel, 2017) the findings indicate almost triple ever feeling mental distress among autistic adults (26% vs. 91%); and higher utilization of mental health services among autistic adults (36% vs 54.8%). Considering the quantitative and qualitative findings the need for mental health services among autistic individuals in Israel is substantial and clearly not reduced than the needs of their parallels in the world. As the quotes above demonstrate despite its importance most of the mental healthcare services are paid by organization or privately. The next part of this section explains this unreasonable phenomenon.

### 5.3.2. The Mental Health Reform - Excluding Autism, Marginalizing Autistic Adults

Despite the evident need for mental healthcare services that had been establish in the previous sub-section autistic adults who reside in residential facilities, leaving in the community in programs of MOLSA or with family members, are not entitled to publicly covered mental healthcare services. It is not just the enormous need for mental healthcare services that caused the organizations mentioned above to look for service in the private market it is the discriminating policy that its effects are covered in this sub-section that brought them there. This situation is a result of the exemption of autism diagnosis from the mental health reform which was introduced in July 2015. The mental health reform had three main goals: to transfer the responsibility of mental health care from the MoH to the Sick Funds; to reduce stigma by integrating mental health care with non-mental health care in the primary setting; and to enhance the quality the accessibility and the availability of mental healthcare services (Ministry of Health Israel, 2021b). Nevertheless, and in oppose to all other diagnoses appear at the DSM (APA, 2013), individuals diagnosed with autism are not entitled for mental health services under the current reform based on their autism diagnosis. The immediate consequence of this was described accurately by Dr. Efron, a psychiatrist working with autistic adults in a hospital and the community:

“The Ministry of Health together with the Ministry of Justice had declared autism is not a mental health issue. Thus, the Sick Funds are not providing services. The services are available only privately. This is an abuse. Abuse of hostels for autistics, and especially an abuse for individuals that their children are residing not in hostels but at home.” (Dr. Efron, a psychiatrist working with autistic adults)

Dr. Efron defined the decision exclude autism from the mental health reform as an abuse. Echoing the descriptions of Pazit and Bina from the previous part, Dr. Efrom criticized the policy decision and described unavoidable private payments for mental health care of residential facilities, and individuals. Diverting the entire mental health care to the private sector necessarily discriminating autistic individuals from less affluent families and causing inequalities between autistic adults as will be discussed in the next chapter extensively; however, this practice also has ramification on the quality of mental healthcare. In residential facilities although private mental healthcare services are usually mandate by MOLSA as part of the operating contract (Establishing a providers’ set for operating housing facilities "houses for life" for the population on the autism spectrum, 2021), given some of the organizations operating residential facilities are for profit companies the quality of the services might not be a priority and adversely effect the health of autistic adults. For autistic individuals who reside in the community among those who can pay for private mental healthcare services, the decision to maintain continues treatments might come on the expense of other needs, or the quality of the service.

It should be stressed at this point, that autistic individuals are entitled to receive public mental healthcare service for additional psychiatric diagnosis as any other resident in Israel who has public healthcare insurance. Nonetheless, this arrangement has two intrinsic flaws. First, services are not provided most of the time by practitioners who are familiar with autism diagnosis as the previous section covers, which can adversely affect the mental health of treated individuals. Second, the decision that only if additional psychiatric diagnosis is given to an autistic individual, he or she will be entitled to mental healthcare services deem that only extreme cases will be given assistance. Autistic individuals who need assistance in their day to day lives given the stressful life events they experience (Fuld, 2018) and who are not categorized under other formal mental diagnosis, will be not entitled to any services. Pazit’s and Bina’s quotes above, exemplify that the daily challenges not major additional psychiatric diagnosis is the assistance that is usually needed. Moreover, this policy decision might unintentionally encourage practitioners, autistic individuals, and caregiver to look for additional psychiatric diagnosis even if are not warranted just to allow access to services.

The policy decision to exempt autism from the mental health reform had been shown to have three additional consequences. First, it creates a legal situation were autistic individuals need to choose between mental health diagnosis and autism diagnosis; second, it prevents from developing a capacity among mental healthcare provider to treat this populations; and third, it harms the continuity of care between body and mind the mental healthcare reform was set to improve.

Exempting autism from the mental healthcare reform also prevent from autistic adults to get rehabilitative services by the power of the Community Rehabilitation of Persons with Mental Health Disability Law (2000). Under this law individuals with mental disabilities are entitled to a basket of rehabilitative services in addition to mental healthcare services provided by the Sick Funds. Autistic adults’ rehabilitative services such as supported employment and residential facilities on the other hand are provided by MOLSA, until 2017 by the autism department and since then by the Disability Administration (Shalom, 2017). These two routes of rehabilitative services give different verity of services and have different availability, thus, putting autistic individuals and their caregivers in dilemma whether they want to be diagnosed with autism, or whether they prefer to be marked with mental disability. Hila, a sister of two autistic adults, described in her interview such a dilemma when discussing her brothers’ diagnosis:

“My second brother was not formally diagnosed with PDD. He is 31 and one of his doctors wanted to categorize him under this diagnosis [autism]. But my sister opposed it so he will get rehabilitative services from the rehabilitative act” (Hila, a sister of two autistic adults)

Hila who have two brothers on the autistic spectrum, portrayed her sister resistant to get a diagnosis of autism for the older brother. Because her sister understood following the experience the family had with the younger brother that diagnosis of autism will deprive the older brother from rehabilitative services that are provided by the Community Rehabilitation of Persons with Mental Health Disability Law (2000) she preferred he will not get the diagnosis. The sister refusal, which was later revoked, deprived her brother from suited care for his needs. This example illustrates the impossible choice individuals and families are facing given the current policy that exclude autism from the mental health reform. Either choosing to be diagnosed with autism and get suited care according to the uniqueness of the diagnosis, or not getting the diagnosis and be entitled to a basket of services including mental health care that might be more suited especially for individuals who live in the community. It should be noted that in childhood this dilemma is reverse. Until the age of 18 diagnosis of autism provides a larger stipend from National Insurance Institute (NII) and additional treatments that are unavailable for most mental health disabilities; thus, making autism diagnosis preferable.

The second, negative implication of excluding autism from the mental health reform is prevention of training on autistic adults for mental health practitioner who work in the Sick Funds. Despite the evident lack of knowledge among mental healthcare providers that is covered above and the rise in the number of autistic adults, because autism is excluded from the reform there is a negative incentive for the Sick Funds who provide the services to promote training among their workers. Pazit, a social worker in a program dedicated for autistic adults described in her interview a meeting with a representative of the local mental health clinic that talks about the catch-22 the Sick Funds need to handle:

“The Sick Fund representative told us ‘We are helpless, your guys apply to the clinic and not the psychiatrists and not the emotional therapists have training in autism. Even if we ask for training in autism we will not be given one because it was exempt [from the reform]’ She tries. She told me: ‘I can’t bring a training on autism, and I can’t send my workers to a training’” (Pazit, a social worker working with autistic adults)

Pazit quote starts with describing the inability of the local mental health service provider to answer the treatment needs of the adults attending the program pazit works at, given the untrained therapists working in the clinic. The explanation the representative of the Sick Fund gave to Pazit was that despite they are recognizing the urgent need for training they are unable to answer it because autism was excluded from the mental health reform. According to the representative they are not allowed to conduct a training in the clinic, nor they allowed to send someone to specialize in the subject somewhere else. This paradoxical situation that prevents efforts to enhance the knowledge of practitioners working in the system is another harmful consequence of excluding autism from the mental health reform. Considering lack of knowledge was identified above as a SDHI, this unfortunate result of autism exemption from the mental health reform has vast implications on autistic adults’ health.

Finally, this policy decision contradicts the second goal of the reform to reduce stigma by integrating mental health care with non-mental health care. The exclusion of autism from the mental healthcare reform who caused the privatization of mental healthcare services for autistic adults, distant mental healthcare away from primary healthcare. Bina, a manager at a residential place for autistic adults who is quoted above regarding her residents’ mental healthcare needs, described this consequence accurately:

“The interface between the family physician and the psychiatrist is practically nonexistent. And these are people [the residents] who take psychiatric medicines in crazy amounts, for years […] No one had stopped for a second to ask ‘Do we need to check their liver functions? Maybe we need to check this, or to do that? You reach to the age of 50 so we need to do one two three, and maybe revise your treatment.’ We are running here protective medical care that is responsive to illnesses and not one that is actively managed.” (Bina, a manager at a residential place for autistic adults)

Considering the extensive use of psychiatric drugs, Bina criticized the detachment between the family physician and the psychiatrist the mental health reform policy had enforced. In her criticism she raised some important questions regarding the need for supervision over continuous use of psychiatric drugs that could not be properly execute if there is an active separation between body and mind. The closing sentence of the quote that relate to ‘active managed medicine’ emphasis the importance of integrated care beyond the specific case of psychiatric drugs. Actively managed medicine could, for example, take in consideration the physical and mental changes that accompany life events such as loss of a relative or that can appear with age around menopause or the development of dementia. The detachment between body and mind that this policy decision had caused, not only counter the mental healthcare goals but have implications on health of autistics adults.

Despite the inherent policy failures of the mental healthcare reform covered above the reform had at least one positive effects on autistic adults. Following the inclusion of the reform Keshet clinic in Tel HaShomer Medical Center, located in the center of Israel, who specialize in care for individuals with developmental disabilities including autism got a formal approval from the MoH as a specialized service. Getting the approval of a specialized service means that any autistic adult with a dual diagnosis of autism and additional mental health disability can apply to his or her Sick Fund and be referred to the clinic. Tze'ela, a psychologist working with autistic adults explained:

“People who previously paid for the service at Keshet clinic privately, while each treatment cost them a decent amount of money, could now be funded by the Sick Funds using form 17[[1]](#footnote-1) .It sounds great, but it included dealing with difficult bureaucratic procedures.” (Tze'ela, a psychologist working with autistic adults)

Tze’ela described a shifting from exclusively private and expensive services to a public funded model where the Sick Funds can authorize the specialized service for autistic adults with additional mental disability diagnosis. In oppose to the negative implication the reform had on inequalities between autistic adults, this instance represents a positive shift following the reform toward a more equal provision of services. It should be stressed that only autistics with additional mental health diagnosis can receive referrals to the clinic, and as discussed earlier this has implications on health. From the interviews it appears that the recognition in this specialized service had also increased the awareness of professionals for the need to specialized care to autistic adults. Dr. Yair, a psychiatrist working with autistic adults in the community mentioned that since the reform initiation autistics are being referred to Keshet clinic by “residential facilities, employment programs […] by their family physician or the psychiatrist at the Sick Fund “(Dr. Yair, a psychiatrist working with autistic adults in the community). Dr. Yair’s annotation demonstrating the additive importance of recognizing the clinic as specialized service in raising the awareness regarding the unique needs of autistic individuals.

Although the reform might positively affect the mental healthcare provided to some autistic adults, it seems its implications had not penetrated to most of the autism community. Many autistic adults and relatives that were interviewed to at the qualitative part knew very little about the reform. Whether it is Shira, an autistic adult who were asked “did you ever heard about the mental reform?” and answered: “from you” (Shira, an autistic adult); Omer, an autistic adult who answered: “I didn’t know about this reform” (Omer, an autistic adult); Or Gefen, a mother of an autistic adult and an activist who answered: “I heard… I heard there is a reform. I heard about advantages and disadvantages but did went into details” (Gefen, a mother of an autistic adult and an activist). Furthermore, the quantitative findings demonstrate that the mental health reform did not have any implications on autistic individuals. Among the participants who responded to the questions on the mental health reform (n=90) 60% marked they did not know about the reform. Furthermore, on the questions that dealt with the reform influence on quality, availability and continuity of care 66.1% chose not to answer or marked that the reform is irrelevant to them. Among those who did answer about the quality, availability and continuity of care (n=36), who were measure in a scale of 1 to 5, were 1 marked much worse than before the reform, 3 no change, and 5 considerable improvement, it seems there was minimal change to the reform if any. The result shows a slight increase in the quality of care (Mean 3.21, Standard Deviation: 0.875), no effect on the availability of care (2.92, SD:0.929), and no effect on the continuity of care (3.03, SD: 0.753). It should be mentioned that 54.8% of responders marked they were treated in the mental healthcare system, thus this data does not indicate low utilization of mental healthcare services but irrelevancy of the mental health reform.

To sum up the exclusion of autism from the mental health reform causes several policy failures in the provision of mental healthcare for autistic adults. These failures include the diversion of mental healthcare provision to the private market; not providing emotional assistance for stressful life events; the danger for over diagnosis of additional psychiatric disabilities; the need to choose between different rehabilitation services or those that dedicated for autistic adults or those that are provided for individuals with mental disabilities; setbacks in the ability to promote autism training; and detachment between body and mind care. Nevertheless, the reform enabled recognizing for the first time an ambulatory mental healthcare clinic dedicated for autistic adults. It can be concluded that despite it had little positive affect on the health of autistic individuals, the policy decision to exclude autism from the mental health reform caused policy failures that each alone let alone combined further marginalizing autistic adults and harm their health. Being part of the sociopolitical context of autistic adults, this policy decision can be accounted as SDHI that deprives autistic adults from equal access to services they need and further discriminate them.

### 5.3.3. Diagnosis of autism in adulthood

Another policy failure that was raised by many interviewees and that directly related to the mental health is diagnosis of autism in adulthood. Unlike any other diagnoses that constitute the DSM 5 (APA, 2013), the research revealed that an adult after the age of 18 cannot get diagnosis of autism in the public healthcare system. If there is a suspicion that an individual adult is on the autistic spectrum, he or she can choose one of two options. Either search for private diagnostician and pay from their own pocket, or alternatively get a special authorization to go through diagnosis at the centers authorized by MOLSA that are designate to reaffirms autism diagnosis for autistics adolescents who became 18 and apply for services under this ministry.

In addition to the basic health right to get an accurate diagnosis, and before delving into the system failures caused by the current policy to exclude diagnosis of autism from the public healthcare system, it is essential to emphasize the personal importance of the diagnosis to autistic individuals. The most notable effect getting a diagnosis had especially on individuals with normal or high cognitive abilities and their families, who were not diagnosed in childhood was a sense of relief. Smadar, an autistic woman and the mother of three autistic children, who were diagnosed following her children diagnosis express this feeling vividly:

“It [the diagnosis] was a little bit scary at the beginning but I felt an enormous sense of relief, it was like I swam my entire life and finally I got to a safe haven […] It felt like you are walking in a matrix with no solid ground under your feet, and suddenly you are told: ‘here, you got to the seashore, you got home.’ I suddenly met people like me and spoke to them and felt that I am talking with people that understands what I am talking about” (Smadar, an autistic woman and the mother of three autistic children)

Smadar’s beautiful description of her emotions creates an impression of removing a heavy burden from her shoulders that many of autistic individuals and their relatives have described in their interviews. The sudden landing after floating the entire life between diagnoses and experts was coupled with a sense of belonging and unfamiliar understanding. Preventing diagnosis in adulthood, therefore, means keeping individuals and their families in a dark fog and continues search.

Yet not allowing diagnosis in the public healthcare system have additional serious implications on autistic adults’ health. First, as been extensively discussed above and in the previous chapter autistic individuals require suited care and accommodations. Not having a title of autism means preventing autistic adults mitigated care and a serious direct harm on their health. Second, diagnosis is the preliminary criteria for services supplied by MOLSA and other governmental authorities for autistic adults, services that are prevented from individuals without diagnosis. Tze'ela, a psychologist working with autistic adults, summarized the importance of diagnosis briefly:

“Diagnosis for individuals on the spectrum, for adults and I assume that also for children, is a very important landmark. Life is really splitting to before and after, when the after holds all kind of options. Whether it is residential arrangements, or employment, or rehabilitation, or connection to the autism community and all it has to offer,” (Tze'ela, a psychologist working with autistic adults)

Tze’ela recapped in these few sentences the importance of autism diagnosis as a port of entry to a verity of services that are prevented from those who are not diagnosed. It is crucial to briefly delay on the last point Tze’ela raised about the autism community. The door to the autistics’ community, the community of individuals on the autism spectrum is often open for individuals that are not formally diagnosed with autism. Because members in this community usually recognized alternative diagnosis methods such as peer acceptance, the community is accessible also to those who are not formally diagnosed. The autism community, however, which also includes parents’ organizations that provide additional services for autistic adults and their families, such as support groups or personal relation courses often do demand formal diagnosis as an entry key. Thus, diagnosis is important both to personal relief, and as an entry key to the verity of services that do exist.

This entry key has an additional implication on the collective level. Not having the diagnosis means not being formally considered and measured as part of the autistic community. Therefore, the main damage that it inflicts by preventing services is on autistic adults that would not be counted in formal measurements, making this discrimination invisible and harder to account for. In this regard this policy is further marginalizing the social position of autism as it prevents from its members to be recognized as part of it, and from the full scale of autistic needs to be recognized by the authorities.

It should be stressed that individuals from across the spectrum are misdiagnosed in childhood, especially in underprivilege communities as covered in the literature review under the section of inequalities. Dr. Yair a psychiatrist working with autistic adults in the community and conducts private diagnosis of autism described the individuals that are usually arrive to his clinic for this purpose:

“We are talking on two categories it is either you have a marginal functional abilities or mild cognitive disability, and you are not getting along in the facilities you suppose to [for people with cognitive disabilities], or you are high functioning, and you are not getting along in the ordinary adulthood life.” (Dr. Yair, a psychiatrist working with autistic adults in the community)

Dr. Yair de facto portrayed two types of individuals on the autistic spectrum that might require suited services more than others on the spectrum. It does not mean that all those who are not included in these categories do not need the diagnosis, but that they approach less to ask for assistance. What Dr. Yair’s argument, however, clarifies is that diagnosis in adulthood is needed for individuals from across the spectrum.

Not providing autism diagnosis as part of the public healthcare system cause two additional problems: broadening inequalities between autistic individuals and minimal regulation of the diagnosis process. Diagnosis of autism is extremely expensive due to the complexity of the process in adulthood that includes comprehensive testing by practiced professionals (Epstein, T., 2019). The image of the transaction below (Image 5.1), who was taken by Cochav, an autistic adult who was interviewed for the research and was diagnosed in adulthood, tells the whole story.

Image 5.1: Transaction approval of payment for diagnosis

(Cochav, an autistic adult, personal communication)

5800 NIS (1800$) is what Cohav had paid for her diagnosis, a sum higher in 500 NIS (155$) than the minimum monthly wage in Israel (Minimum Wage, 2021). Although the sums vary between clinics this amount, if is not covered by the public system, clearly nurture the inequalities in diagnosis that are evident in childhood, especially between autistics from different socioeconomic classes. The alternative pathway for diagnosis thought the centers authorized by MOLSA is usually not available. As these centers are designated to reaffirm diagnosis and evaluate functioning of autism to adolescents who apply for services by MOLSA in their adulthood (Tilovich Levi & Niger, 2019) usually they do not provide novel diagnosis even for individuals who applies for services from MOLSA. Only those who do not have financial resources, have a recommendation from their local social worker, and get special authorization from a regional supervisor will get the right to receive novel diagnosis.

The second systemic problem of not providing diagnosis of autism trough the public healthcare system is that standardization of the diagnosis process has been introduced just recently resulting in minimal regulations of this process. In 2013 following the comptroller report who found differences between MOLSA the NII and MoH to diagnosis of autism in children, the MoH convened a committee that created clear standard for diagnosis of autism in children (Diagnosis of children on the autism spectrum, 2013). However, similar standards for adults have not been introduced until December 2020 (Diagnosis of autism spectrum in adults, 2020) leaving the field unregulated. Geula, a senior position holder at the ministry of health, who was interviewed before the introduction of the recent regulations testified on this subject:

“With adults it is more difficult [to find someone to diagnose], it is easier to recruit for children […] This is why we are trying to study the issue of diagnosis in adulthood, which is really problematic […] The law mandate [services] until the age of 18, afterwards there is no obligation […] there is great difficulties, there are not enough experts, there are not enough centers […] Several years ago we published an update of the director general regulations for diagnosis of autistic children, we [at the MoH] intend to convene a similar committee on the issue of diagnosis of adults. We want to update the tools” (Geula, a senior position holder at the ministry of health)

Geula acknowledged in her interview there is an issue with diagnosis of autistic adults. She depicted three points that should be addressed to overcome this problem: enhance the capacity of healthcare professionals to diagnose autism, establish or recognize more centers for diagnosis, and develop guidelines for diagnosis like those which exist for diagnosis of children. Although Geula’s last point have recently been materialized preventing diagnosis of autism under the public system have delayed the standardization of the field and left it unregulated. At the beginning of the quote, it should be noted Geula argued the gaps in diagnosis between children and adults are a result of the limited services designated for autistic adults by the law. I will return to this argument in the next chapter given its counter explanation that asserts services are not developed because there are not enough autistic adults diagnosed is central in explaining inequalities between autistic adults.

Considering there were no guideline or standardization of diagnosis until recently it is not surprising some interviewees shared negative experience of the diagnosis process. Cohav, for instance, an autistic adult who approached MOLSA’s diagnosis center, after she got private diagnosis because she wanted to be entitled for services shred her terrible experience:

“The clinic who won the tender is the clinic in Abu Kabir detention center […] you get there, and there are prisoner, like OZ, police officers with guns. […] The psychologist come and she says now we need to ask you if you are retarded, you know what is retarded, you are not retarded […] She told me ‘I am not sure if I will sign you the papers, you are not convincing.’ And then the psychiatrist arrives […he says] ‘OK, I know nothing about autism, what are you doing here?’ The last time he read about autism was in his psychiatry exam, he did it 20 years before our meeting. […]” (Cohav, an autistic adult)

Cohav described in length her distressing experience in the diagnosis center that conducts the reevaluation of the diagnosis at the age 18 for MOLSA. In the part quoted above, which is just a fraction of her detailed description, two problems are conspicuous. First, the setting the clinic operates is clearly unsuited for the purpose of diagnosis of autism. Visiting to a detention center could be stressful for anyone let alone someone who supposed to get reevaluation of his diagnosis. Second, the obvious lack of knowledge of the psychologist and the psychiatrist regarding autism and specifically the diagnosis process. The degrading discussion regarding her autism she portrayed is clearly unsuited and is not professional. Cohav incident exemplify the consequences of unstandardized diagnosis process for autistic adults and strengthen the need to include it in the public health system like any other diagnosis.

Lastly, the quantitative findings are also indicative of the great need for diagnosis in adulthood. Out of 85 responders who had formal diagnosis and knew the estimated age of diagnosis, 21 (24.7%, out of the 112 total responders - 18.7%) were diagnosed after turning 18. It should be noted that among autistic individuals who answered the survey themselves there was a higher percentage of diagnosis after the age 18, than among guardians who answered for their families 25.8% vs. 11.1%, respectively (15 out of 58 and 6 out of 54, respectively). This finding strengthens Dr. Yair’s claim (see above) that those who seek diagnosis in adulthood are high functioning autistic that do not get on in normal adult lives. Furthermore, 14 out of the total 112 (12.5%) responders marked they do not have formal diagnosis, all of them autistic individuals. These individuals were included in the analysis to avoid exclusion of autistics from lower socioeconomic classes that cannot afford diagnosis, considering the current policy regarding diagnosis. This data combined illustrates the importance of allowing diagnosis of autism in adulthood as part of the public healthcare system.

To conclude, according to the current policy in Israel autism diagnosis in adulthood is not publicly funded. This policy, in addition to preventing individuals from their basic right to be diagnosed have both personal and public implications. On the personal level not getting a diagnosis might leave the undiagnosed autistic individual in a continues quest to understand his difference and prevents him or her from getting the access key to services and the autism community. On the population level not having public funded diagnosis de facto enable only those who have resources to get a diagnosis and leaves this practice unregulated, which in turn result in unprofessional sometimes offensive services. The survey finding illustrates the extent of the diagnosis-in-adulthood phenomenon, stressing it is not an issue that can be neglected. The findings above exemplify diverse avenues in which not providing diagnosis for autism in adulthood harm autistic adults individually and collectively. Thus, it can be argued this un-policy realm which is part of the sociopolitical context of autistic adults in Israel further marginalize them and belittle autism social position.

## 5.4. Complementary treatments

Until the age of 18, following a 1998 amendment at The National Health Insurance Law (1994), autistic children and adolescents are entitled to receive three paramedical services termed “advancing medical treatments” (in Hebrew: טיפול בריאותי מקדם - Tipul Briuti Mekadem) from their Sick Fund. When turning 18 this right is revoked and as covered above other policies that mandate provision of similar services for people with mental disabilities such as the Community Rehabilitation of Persons with Mental Health Disability Law (2000) exclude autistic individuals. This section demonstrates that despite the accepted belief within the healthcare system that these services are not needed in adulthood the decision not to expand theses services beyond the age of 18 was instrumental and not based on evidence. Furthermore, it argues that these services are needed throughout the life span and preventing them from autistic individuals interfere with their ability to live independently in the community. Thus, the lack of these services is marginalizing autistic individuals. Finally, the section briefly discusses the influence neglecting this arena have created in the population level.

The standpoint of this section that autistic individuals have a right to live independently in the community stem from the United Nations Convention on the Rights of Persons with Disabilities who was approved by the Israeli government in 2012 (Commission for Equal Rights of Persons with Disabilities, 2021). The convention states that disability is a result of “barriers that hinder full and effective participation in society on an equal basis with others” (The United Nations, 2006). Thus, additional paramedical services as will be shown in this section are not warranted to get equal access to health but to progress toward equal participation in community. This section, therefore, differs from the previous ones as although the services discussed are situated within the healthcare system, their provision is not directly affecting health. Community participation is a proxy for other SDH such as employment, housing, and others, that were proven to affect health. Without the discussed services full participation in community will not be possible, thus, these policy case should also be considered SDHI,

The common belief among some professionals and officials who work with autistics is that additional paramedical services have no benefit in adulthood; thus, providing them throughout adulthood will be unreasonable in terms of resources. Geula, a senior position holder at the ministry of health, who was asked on autistic adults’ needs disclosed in her interview this common belief:

“Occupational therapy and speech therapy is less needed at the older ages. We are usually focused on providing this care until the age of 18 […] In the older age what is needed is assistance in the social capabilities and mental healthcare” (Geula, a senior position holder at the ministry of health)

Geula, openly said that complementary paramedical services are less needed in adulthood. Although she recognized some assistant is needed in adulthood in social capabilities and mental health, she also aware these services are not currently widely available for autistic individuals. Her words which resonate the long-lasting negligence of research and services for autistic adults (see literature review) demonstrate the common belief that after turning 18 the development of autistic adults is stopped and there is no incentive to invest in it. But as interviewees explained these services are not available for adults due to procedural decisions during the policy construction process not based on evidence that show these services are irrelevant. Noa, a mother of an autistic adult and an activist, who was involved in the amendment of the National Health Insurance Law in 1998 who mandate those services explained:

“It [the amendment of the national insurance law to include paramedical services for autistic children] began form a lawsuit, then it went through the Sick Funds in different forms. What we argued is that the autistic children also have somatic disorders like children with developmental somatic disorders and we succeeded changing the law […] After the age of 18, a decision like that would mean a change for all disabilities not just for autistics, and this is a very hard to struggle for.” (Noa, a mother of an autistic adult and an activist)

Noa, explained that the 1998 amendment in the law that allowed autistic children to receive paramedical treatments was accepted after struggle to equal the rights of autistic children to those of children with developmental somatic disorders. In other words, this change was made possible because there was a prior decision to allow paramedical services for children with somatic disorders that parents of autistic children could claim they have similar needs. Those who promoted the amendment realized that expanding it beyond the age of 18 would be very hard because it would demand a novel decision that might affect the entire disability community and not just autistic individuals. Noa’s explanation, thus, indicates the claim these services are irrelevant for adults based on the current policy is not supported by the history of the law. An instrumental-political decision the advocates who promoted the amendment had made at that time is the reason services are available until the age of 18 and not beyond.

Moreover, in oppose to the common perception at the MoH the qualitative inquiry has demonstrated autistic adults, relatives of adults and professionals think paramedical services are essential also in adulthood. Bat-el, an advocacy lawyer who works with the autism community explained in her interview how profound the problem is:

“The hottest topic regarding [autistic] adults is that there are no paramedical treatments available above the age of 18 […] People at the autism community had realized that in the occupational centers after they [the autistic adults] finish the education system they don’t learn anything […] In hostels you have one position for paramedical therapist, I can’t remember if it is full-time position or part-time, maybe 75% of a position, for 24 residents…” (Bat-el, an advocacy lawyer who works with the autism community)

Starting with setting the need for paramedical treatments as the “hottest” most prominent problem of autistic adults, Bat-el explained that preventing these services from autistic adults means preventing them development in their adulthood. While occupational centers provided by MOLSA intend to fill the time with productive activity, they do not aim to promote the autistic adult daily capacities, nor they aim to expand the adult knowledge. Paramedical services are, thus, necessary to allow the individual assistance in his self-development throughout adult life. Bat-el, who referred to individuals who require comprehensive assistance adds that in residential facilities MOLSA’s requirement for paramedical treatment is also very minimal, leaving the autistic adult with no actual prospect for future development.

The need for paramedical services, however, is not limited to non-verbal autistic adults or to those who also have cognitive disability. Diverse interviewees have stressed the need for paramedical services to autistic individuals across the spectrum. An outstanding example to this need had come up in Jude’s Interview. Jude, an autistic adult, a mother of an autistic adult, and an activist at the autism field, who live in the Israel periphery and have a private bussiness shared that:

“If there was someone that could sit with me and assist to analyze situations, and things that happens… When he [my son] have started high school, I went with a lawyer to school. I needed someone from outside to speak with them [the teachers]. I paid a lawyer to come all the way here [as I am living in the periphery], paid for his time, so he could come with me to meetings in the school. It was crazy, crazy. You are sitting in meetings and the teachers are lying in your face […] there are a lot of situations that I am stuck, I do not understand what they want from my life” (Jude, an autistic adult, a mother of an autistic adult, and an activist at the autism field)

Jude’s experience speaks for itself. Despite leaving an independent life and running a business, in certain situations Jude’s ability to understand the social interaction is limited. Her need, as she explained, is for someone that could help her analyze situations, someone that could mitigate the new scenarios she faced. This need cannot be addressed under the current policies where no complementary services are available for autistic adults. A psychologist, a speech therapist or a service coordinator could assist Jude in this instance and also provide her with additional tools for future interactions. Unfortunately, in the current policy situation, she needs to hire a lawyer on her own expense to cope with a situation neurotypical adult would not find challenging. In that sense the absent of additional paramedical services prevented Jude from full participation in community.

In addition to exemplifying the need across the spectrum, Jude’s case demonstrates two important issues regarding paramedical services who were also stressed by other interviewees. First, paramedical services should be available throughout the life span and should be suited to the individual’s changing needs. In Jude’s example only when her son began high school the need for mitigation of this social interaction became apparent. As during adulthood different needs may emerge from mitigation in certain scenarios, to help with executive functioning when starting a new work, to assistance in personal relationship, services should be tailored to the individual and should be flexible so they could assist with the most urgent needs. The second, issue that Jude’s case raises is that neglecting paramedical services creates inequalities between autistic adults. While Jude was lucky enough to have the resources to pay for someone to come with her to her son’s high school, other who do not have these resources would have no assistance. Therefore, not providing autistic adults with public funded additional complementary services that will answer their changing needs, in effect diverting those from higher socioeconomic classes to the private market and creates inequalities between autistic adults.

The importance of complementary service throughout the life span is further strengthen by scrutinization of programs available for autistic adults. Roim Rahock (רואים רחוק, literal translation: See Far) a program for autistic adults who want to serve in the IDF in positions that are suited for the autism spectrum strength, suggests for the adults that join the program emotional therapy, speech therapy, occupational therapies, and other treatments as part of the program (Roim Rahock Program, 2021). Similarly, Ariel University who runs a program for autistic adults have mitigation services and workshops for developing self-abilities (A program to integrate high functioning students on the autistic spectrum, 2021). These programs and others who are partially funded by the state, recognize the need for additional complementary services to allow autistic adults capabilities that will help them succeed; hence, they provide these services as part of the program to their attendees. Furthermore, the qualitative inquiry demonstrated that organizations or employers who are not dedicated for autistic adults might mandate additional services to allow the participation of autistic adults in their environment as they understand these services are necessary to overcome difficulties that might emerge throughout the participation process.

The survey included dedicated questions on additional paramedical services for autistic adults. The first question adopted from the needs assessment survey from PA (Bureau of Autism Services, 2011) asked the responders to mark one of five categories for each service: Receiving the service; Receiving but needs more; Receiving but does not need; Not receiving, but needs; and Not receiving. From those who answered this question (n=89) 64% marked three services or more they are not receiving, but needs or receiving but needs more. Among the list of additional services social counseling (45%), communication assistance (40.4%), sexual counseling (38.2%), speech therapy (31.5%) and occupational therapies (31.4%) were the most needed services (See table 5.1 below for the needs of additional services). These findings further indicates that the common assumption prevalent among policy makers in the MoH that autistic adults do not genuinely need additional paramedical services do not hold. The fact that almost two third of responders marked they or their relative needs three or more services indicates current policies that prevent autistic adults from getting additional complementary services leave autistic adults needs unanswered, and prevent them self-development and full participation in community.

The survey results also stress the need for these services, by illustrating the extent of these service utilization at the private market. At the question regarding the barriers for additional paramedical services among the responders (n=80) 21% marked service costs as a barrier, making it the most prominent barrier together with bureaucratic barriers (See chapter 4 table 4.3 for additional barriers). The survey also included a question regarding the mean of payment for complementary services provided, which responders could choose more than one answer from several available. Among the responders (n=80), 80% marked they used private funding either by pay out of their pocket or by private insurance; and 76% marked they had public funding for the services that were provided either by Sick Funds, MOLSA or the NII. Combined these results demonstrate the indirect effect current policies have on diverting individuals to the private market. Although 76% of responders do get publicly funded paramedical services probably through programs they attend, those are clearly not sufficient as 80% utilize private funding to cover remaining expanses for services they need. Furthermore, as current policies prevent almost entirely publicly funded additional services it is not surprising services costs was marked by fifth of responders as a barrier to these services.

To sum up both the findings from the qualitative and quantitative inquiries clearly indicates that autistic adults need additional paramedical services. The common belief that these services are mostly needed in childhood following the current policy mandate, is not supported historically and not by most of stakeholders operating in the field. There is wide recognition within the autism community that additional paramedical services are needed throughout the lifespan. These services should be individualized and flexible enough to accommodate the changing needs of the adult throughout his or her life and to allow independent life in the community. Moreover, on the population level this section demonstrates that the current absence in the policy divert autistics and their relatives to the private marked and therefore create inequalities between autistic based on financial capabilities. The current sociopolitical context this section revile which prevents autistic adults equal access to needed complementary services, is preventing these individuals full participation in community. Preventing participation clearly affect other SDH, thus, enabling labeling this policy gap as a SDHI that further marginalize this population.

|  |
| --- |
| Table 5.1 – Needs for additional paramedical services; n=89\* |
|  | Receiving the service  | Receiving but needs more | Receiving but does not need | Not receiving but needs | Not receiving | Do not know |
| Speech therapy | 5 (5.6%) | 4 (4.5%) | 1 (1.1%) | 24 (27%) | 38 (42.7%) | 17 (19.1%) |
| Communication assistance | 8 (9.0%) | 5 (5.6%) | 1 (1.1%) | 31 (34.8%) | 24 (27.0%) | 20 (22.5%) |
| Occupational therapy | 7 (7.9%) | 5 (5.6%) | 1 (1.1%) | 23 (25.8%) | 35 (39.3%) | 18 (20.2%) |
| Physical Therapy | 7 (7.9%) | 1 (1.1%) | 0 (0%) | 16 (18.0%) | 46 (51.7%) | 19 (21.3%) |
| Social Skills Training | 23 (25.8%) | 12 (13.5%) | 0 (0%) | 28 (31.5%) | 12 (13.5%) | 14 (15.7%) |
| Mobile Therapy | 7 (7.9%) | 2 (2.2%) | 1 (1.1%) | 10 (11.2%) | 53 (59.6%) | 16 (18.0%) |
| Case Management | 10 (11.2%) | 2 (2.2%) | 0 (0%) | 17 (19.1%) | 34 (38.2%) | 26 (29.2%) |
| Behavioral treatments (ABA\CBT) | 10 (11.2%) | 3 (3.4%) | 1 (1.1%) | 23 (25.8%) | 31 (34.8%) | 21 (23.6%) |
| Couples counseling | 2 (2.2%) | 2 (2.2%) | 1 (1.1%) | 18 (20.2%) | 48 (53.9%) | 18 (20.2%) |
| Sexual counseling | 3 (3.4%) | 3 (3.4%) | 0 (0%) | 31 (34.8%) | 34 (38.2%) | 18 (20.2%) |
| Family counseling | 5 (5.6%) | 2 (2.2%) | 0 (0%) | 10 (11.2%) | 20 (22.4%) | 52 (58.4%) |
| Drug and Alcohol Counseling | 0 (0%) | 0 (0%) | 1(1.1%) | 4 (4.5%) | 67 (75.3%) | 17 (19.1%) |
| Holiday relief  | 12 (13.5%) | 4 (4.5%) | 0 (0%) | 19 (21.3%) | 37 (41.6%) | 17 (19.1%) |
| Support Groups | 11 (12.4%) | 5 (5.6%) | 1(1.1%) | 22 (24.7%) | 30 (33.7%) | 20 (22.5%) |
| Transitional Planning | 11 (12.4%) | 4 (4.5%) | 1(1.1%) | 21 (23.6%) | 30 (33.7%) | 22 (24.7%) |
| Support in Employment  | 33 (37.1%) | 9 (10.1%) | 0 (0%) | 22 (24.7%) | 12 (13.5%) | 13 (14.6%) |
| Adult daycare | 8 (9.0%) | 0 (0%) | 0 (0%) | 10 (11.2%) | 48 (53.9%) | 23 (25.9%) |

\*The different categories were either adopted from Bureau of Autism Services (2011) or were suggested by committee members or stakeholders that reviewed the questionnaire.

## 5.5. Conclusions

To conclude this chapter requested to analyze the SDHI that influence the social position of autistic adults in Israel. Focusing on the healthcare system the chapter argues that autistic adults are marginalized at the Israeli healthcare system due perceptions hold by individuals within the system, ignorance regarding autism, and discriminating policy decisions. These sociopolitical circumstances negatively affect the autistic individual health and ability to participate in the community and have harmful implications also on the autistic collective.

The chapter first explored the mechanism that prevent from introducing regulations to reduce the barriers to the healthcare system which are covered in the previous chapter. These mechanisms include two perceptions regarding autism that contradict the idea of mitigation. One is that autism is a disease that require treatment not modifications. The other is that disabilities that require structural modifications are physical disabilities. Autism which is an “invisible” disability does not fit into this definition, therefore, it is not require service accommodations. The chapter illustrates that these perceptions have a foothold through the system from the administrative level to the practitioners on ground. These perceptions are accompanied by alternative perceptions that do recognize the need for treating autism as a social group that require specific mitigation. The dominancy of the former, however, limits the introduction of mitigations for autistic adults in the healthcare system; therefore, it can be accounted as a SDHI, or in other word a part of the Israeli sociopolitical context that is marginalizing this population.

The second mechanism that was recognized as preventing the introduction of mitigations for autistic adults is the lack of knowledge among professionals regarding autism. Throughout the system and across disciplines professionals themselves, autistic adults and their caregiver have reported gaps in practitioners’ knowledge. This lack of knowledge was identified to result from unfamiliarity with autism among senior professionals combined with absence of structured training on the subject for next generations. In addition to setting back the introduction of measurements to overcome barriers to the healthcare system, the lack in knowledge was found to be marginalizing autistic adults by providing them unsuitable care, especially mental healthcare, and by in the absence of alternatives diverting them to child therapists that do have knowledge about autism. Discrimination of the autistic adults’ population in the healthcare system the section conclude is aggravated by the ignorance of professionals and the negligence of this field of knowledge by health authorities.

In addition to marginalizing autistic adults by preventing the introduction of mitigation to healthcare services three major gaps in current policy that leave autistic adults needs unanswered were identified in the qualitative research. The first is the exclusion from the mental healthcare reform, the second is the inability to get public funded diagnosis of autism in adulthood, and the third is the absence of public provided additional paramedical services for autistic adults. After establishing both qualitatively and quantitatively there is a great need for mental healthcare services for autistic adults in Israel like the need that have been reported in the literature in other countries, it is argued that the exemption of autism from the mental healthcare reform discriminates autistic adults on several bases. By preventing public funded services it discriminates autistic adults from lower socioeconomic groups and tamper the quality of mental healthcare; by allowing treatment only for autistics with dual diagnosis this decision prevents autistic adults from getting needed assistance for their daily challenges; for individuals with additional mental disability it also mandates to choose between suitable services for autistics or services for mental disabilities which might be more available and varied; it tampers with efforts to promote knowledge about autism by preventing refunds on training about autism; and finally it contradicts the mental healthcare reform goal as it further separate between the autistic individual physical and mental care. These discriminative processes that are derived from the policy decision to exclude autism from the mental healthcare reform further marginalize autistic adults and harm their mental healthcare; thus, it can be regarded as another SDHI.

The inability to be diagnose with autism in adulthood at the public healthcare system also marginalize autistic adults. On the personal level, it prevents from autistic adults a basic right to know their diagnosis, and it leaves them in the continues quest regarding their difference. Furthermore, not allowing public diagnosis in adulthood is preventing from autistics the entry key to the services that are available for this population both public services and additional assistance that is provided by the autism community. On the population level this decision creates disparities between autistic adults in favor of autistic from affluent background; and because this decision left this practice completely unregulated until recently it harmed even those who were diagnosed. Finally, this decision interferes with expending the autistic community as it deprives from some individuals their ability to be formally recognized as part of it. Having no-policy in relation to the gatekeeper of services is therefore another SDHI of autistic adults in Israel.

Finally, the termination of the right to get additional complementary services for autistic adults at the age of 18 was identified as another SDHI. Although these services do not directly affect health, their absences clearly harm the ability of autistic individuals to continue their development in adulthood and to be able to fully participate in the community. The quantitative findings clearly indicate that most autistic adults need 3 services or more, unlike the common believe among professionals and the officials at MoH. Thus, the policy decision to stop additional paramedical services at the age of 18 which constitute part of autistic adults’ sociopolitical context in Israel, further discriminating this population.

To sum up, the sociopolitical context of the healthcare system in Israel is marginalizing autistic adults in many aspects. This analysis who is the first to be conducted in Israel is important first and foremost to identify health policy issues that should be addressed by policy makers and the autism community. In addition to the practical significant of this chapter, this analysis demonstrates the need to understand autism as a social position that allows examination of the SDHI. Being an autistic adult in Israel does not mean just having unique neurological structure, or even having barriers to healthcare that are resemble to those that autistic individuals in the US have; it means you are deprived of your right to be diagnosed, you do not deserve mental healthcare service for your difficulties as autistic person, you are being defined as having a disease or not having a disability, you are not being treated by practitioners who recognize your uniqueness, and you do not have access to additional service you need. While this could be the case of autistics also in other contexts this is not obligatory. As these circumstances dictates directly and indirectly health outcomes, it is crucial to recognize them if we wish to understand health inequities autistic adults suffer from and reduce them.

1. Form 17 is a payment voucher or a letter of financial obligation that constitute as an official authorization given by the Sick Fund to use services given by facilities who are not part of the Sick Fund provision centers (see footnote at Yonatan-Leus, Strauss & Cooper-Kazaz, 2021). This form is given to secure the financial agreement between the Sick Fund and the actual provider. Tel HaShomer medical center is a government owned center, therefore, there is a need to get this form prior to getting services in Keshet clinic. [↑](#footnote-ref-1)