# 5. Discrimination in the Healthcare System –Social Determinants of Health Inequalities Among Autistic Adults in Israel

In the previous chapter, I established that autism should be regarded as part of the “social position” of an individual. In this chapter, following Solara and Irwin’s (2010) model, I provide an extensive analysis of the sociopolitical context, i.e., the social determinants of health inequalities (SDHIs), that influences the health of autistic adults. SDHIs is an umbrella term that encompasses policies and social arrangements that are relevant to all aspects of life, from trade agreements to employment, from public transportation to the judicial system. With such a broad range of areas having an impact, capturing the full scale of SDHIs affecting autistic adults would be impossible in one chapter. Therefore, and because this work considers autistic individuals from a health perspective, this chapter focuses on those SDHIs that are related to the healthcare system in Israel.

In this chapter, I argue that Israel’s current healthcare system structurally marginalizes autistic adults. In the previous chapter, I demonstrated how, at an individual level, the collision between autistic traits with an inaccessible healthcare system causes barriers to healthcare and marginalizes autistic adults. The focus in this chapter shifts to the systemic level and illustrates that current policies, arrangements, and practices discriminate against autistic adults, thereby negatively affecting their health. The chapter begins with an analysis of the systemic reasons why the barriers to accessing the healthcare system discussed in the previous chapter are not addressed. These include the perception of autism as a disease, how the invisibility of autism creates barriers, and a lack of knowledge among professionals. Next, the chapter explores mental healthcare policies. The section on mental health first establishes the pressing need for mental healthcare among autistic adults; it then analyzes the implications of the current legal situation that excludes autistic individuals from Israel’s recently introduced mental healthcare reforms. This section ends with an analysis of the consequences of not providing a diagnosis of autism in adulthood within the public healthcare system. The chapter then concludes by exploring the absence of systemic regulation for the provision of complementary treatments for autistic adults and the ramifications of this absence.

It should be mentioned again at this point, before delving into the analytical sections, that this chapter covers only those SDHIs that are related to the healthcare system. Many conditions that further marginalize autistic adults in the Israeli sociopolitical context and that were found during the qualitative analysis to be central to autistic adults’ lives are not covered. Among these are the absence of structured services for the transition to adulthood, a lack of community housing, minimal employment support, gaps in the National Insurance Institute stipend procedures, and barriers to the private insurance market. Furthermore, other issues raised by the interviewees, such as stigma, friendships, and relationships in adulthood, as well as challenges in higher education, transportation, and serving in the security forces, will not be covered. These SDHIs should be further investigated as part of any future research in this area, as understanding their indirect impacts on health is crucial.

## 5.1. Marginalizing perceptions of autism

In the previous chapter, I demonstrated that there is a variety of barriers to healthcare services that autistic adults experience due to systemic structures that are incompatible with autism. This section attempts to understand why these barriers have never been addressed, despite the special traits and needs of autistic adults having been widely known for a long period and even though access to healthcare is an issue that has been extensively discussed. The section argues that although the reasons for overlooking these challenges are complex, two main perceptions of autism rooted in the Israeli healthcare system have contributed to the neglect of these challenges and the subsequent marginalization of autistic individuals. First, in accordance with the medical model of disability (MMD), autism is regarded within the healthcare system in Israel as a disease and not a disability; therefore, the system has concluded that autistic individuals should be forced to comply with the neurotypical system and not vice versa. Second, autism is an invisible, unrecognizable disability; therefore, the neurological differences of autistic individuals are either viewed as nonexistent, or, any mitigation of services for their benefit are mostly considered in terms of physical or structural mitigations are irrelevant for them. In this section, I make the claim that these two perceptions prevent the healthcare system from moving forward and becoming accessible, which, thereby discriminates against 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 was elaborated in the literature review. The notion that it is possible and necessary to “cure” or eliminate autism was the dominant belief among parents and the medical establishment worldwide (Eyal, 2013). This perception still prevails despite many in the autism community, including autistic advocates as well as parents and professionals, having argued against this perception, claiming it has resulted in the neglect of services for and the needs of autistic individuals (Baker, 2011). Moreover, this perception has not only delayed the development of and investments in services for autistic individuals, but it has also diverted efforts away from mitigating the difficulties of receiving services by way of removing barriers. To understand why defining autism as a disease and attempting to cure it is a counterproductive process compared with accepting autism 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 autism advocate, regarding communication differences provides insights into this question:

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 a manner in which he wants to communicate, 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 accurately illustrates more broadly the interplay between autism perceived as a disease, a perception commonly held by administrators and practitioners, and autism perceived as a disability, where individuals with the condition strive to overcome barriers. The disease perception that Ronen criticized reflects an attempt to coerce autistic individuals to adopt common communication practices by teaching *them* the “correct” unautistic manners. According to this perception, those who do not accept these “correct” practices, are deemed deficient; in fact, diseased. The disability perception, on the other hand, first and foremost recognizes that there are two sides to communication and strives to mitigate gaps that might arise between them. Thus, the fundamental difference between the perceptions amount to whether or not they recognize and accept the other side’s legitimacy. These conflicting approaches reflect the differences between the MMD and the social model of disability (SMD). Not only are these perceptions contradictory in theory, meaning that holding one position negates the possibility of considering the other, but they are also contradictory in practice. As explored in the previous chapter, the perception of autism as a disease all too often inmposes barriers and widens the gap between the parties. Consequently, it cannot be advanced together with the disability perception, which attempts to eliminate barriers.

The MMD has been fully adopted by the healthcare system in Israel, neglecting almost completely the alternative that would have enabled the mitigation of services for autistic individuals. One straightforward example of how this perception has been adopted can be seen by a quick review of the aims of the Ministry of Health’s (MoH) department of autism. Among the department’s responsibilities, which are listed on the MoH website (Ministry of Health, Israel, 2021b), five out of ten aims relate to early interventions, one to advancing new treatments as well as new methods for diagnosis, and one to hospitalization infrastructure. The remaining three aims, which are not necessarily related to treatment, involve cultivating collaborations, advancing research, and developing training programs. As can be seen, most of the efforts are dedicated to promoting and regulating treatment for autistic individuals, mainly autistic children.

Another example of the adoption of this perception within the MOH was highlighted by Geula, who holds a senior position in the MoH with responsibility for, among other things, 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, who holds a senior position in the Ministry of Health).

Geula, who is familiar with the autistic population and their needs, deems the issue of access to healthcare irrelevant. She argues that those barriers are manageable and easily overcome in the case of non-verbal autistic adults by guardians who mitigate the services. Indeed, her comparison of autistic individuals with an individual experiencing a psychotic event exemplifies the perception of autism as a disease. In her perception, autism is a temporal situation that can be solved, a situation during which a disabled person can become non-disabled. Coupling Geula’s quote with the fact that the autism department at the MoH is nested within the auspices of its mental health services and that the only service it regulates in relation to autistic adults is hospitalization in mental health institutes further illustrate how the perception of autism as a disease hinders the removal of barriers to healthcare services for autistic adults.

The grip this perception has on the healthcare establishment is, however, best exemplified by understanding how it has permeated to the practitioner level. A qualitative inquiry demonstrated that the practices adopted by professionals working with autistic individuals reflect this perception, as they attempt to teach autistic individuals neurotypical manners. Among the numerous examples mentioned, Anat’s touches exactly on this point. Anat, the mother of an autistic child, a professional working with autistic adults, and an activist, shared the practices she uses as she discussed her work with an autistic adult who lives 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, the mother of an autistic child, a professional working with autistic adults, and an activist).

Anat’s explanation, which corresponds beautifully with Ronen’s quote, exemplifies how the MMD perception of autism has a stronghold even at the provider level. Anat explained how she teaches the autistic adult she works with the neurotypical, “correct,” manners of communication, specifically, to be attentive to eye contact and body language. As Ronen argues, this approach could be seen as coercive, as it observes communication from the powerful, neurotypical side and subjects the autistic individual to its rules. Considering that the aims of the autism department include promoting treatments and training, it is not surprising that the MMD perception held at an administrative level has penetrated to the practitioner level.

The examples above demonstrate that the perception of autism as a disease that must be cured or rehabilitated in accordance with neurotypical standards is dictating the main line of thinking in the MoH. They also show that this perception has a powerful sway among professionals. That potential barriers to accessing healthcare service are not even considered by the MoH is not entirely surprising, given that the MMD is so dominant throughout the organizational levels, and considering Ronen’s explanation that one perspective of disability contradicts the other. This dichotomic explanation, however, fails to recognize that, in practice, both perceptions of disability might be present, in parallel. For example, the autism department at the MoH collaborated with this research despite knowing its critical position with regard to MoH action in the field, while Anat, in a different part of her interview, did mention the importance of mitigating services. Nevertheless, on a scale of the models of disability, with MMD on one side and SMD on the other, the weight of the MMD in the Israeli healthcare system is far greater; consequently, the perception of autism as a disease is dominant. As such, this leads to the systemic discrimination and marginalization of autistic adults in healthcare settings by preventing the system from recognizing the barriers they face.

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

The second theme that emerged repeatedly throughout the qualitative investigation as being a cause for the neglect of barriers facing autistic adults’ access to healthcare services was the invisibility of autism as a disability. Widespread among the Israeli public is the notion that “disabilities” refer to physical disabilities (Feldman & Ben-Moshe, 2006), which has been shown to also be rooted in the healthcare system here. Furthermore, as a direct result of this perception, any accommodations for disabled individuals are considered to involve physical, structural modifications. While structural modifications might be relevant for some autistic adults, for example, in relation to their sensory barriers to healthcare (see Chapter 4), alleviating barriers to healthcare services for autistic individuals also means introducing changes and mitigation in service provision. This idea of providers themselves changing their conduct as a mitigation practice is not considered part of the concept of accommodation for disabled individuals. These two perceptions of disability, first that it applies only to physical disabilities and, second, that it requires only physical, structural modifications, have also contributed to the neglect in addressing the barriers to healthcare facing autistic adults, thus further marginalizing this population.

The best example for the centrality of the notion within the healthcare system that disabilities refer to physical disabilities is the set of regulations published in 2016 by the MoH as part of the Israeli Equal Rights for People with Disabilities Regulations (Ministry of Health, 2016). These regulations detail in their first and second amendments all the elements that must be introduced within medical provision centers to promote accessibility. Among the various mitigations required are physical changes to corridors, doors, bathrooms, and many other structures. However, not one of the regulations refers to the mitigation of service provision. These regulations exemplify how disability is perceived to be a physical disability within the healthcare system, thus leaving autistic individuals and those with other invisible disabilities without any consideration of their needs. The fact that Geula, who holds a senior position at the MoH and is quoted above as saying “we did not see it [accommodations] as a need,” demonstrates how this perception remains prevalent within the ministry’s corridors of power.

Similar to the perception that autism is a disease, is the sense that autistic disabilities are invisible. This attitude can be found among service providers themselves, as well as at the administrative level at the MoH. Rachel, for example, a deputy head nurse in a tertiary medical center who is also involved in promoting the hospital’s accessibility program, explained in her interview the challenge for medical personnel of introducing such changes:

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 in achieving some change. Because as you know, changes in this area is very difficult and is divided into two things. There are the structural changes that are a whole world from wheelchairs, to [headsets for] the deafness, to visual impairment, a huge diversity of disabilities. And there is the awareness about the attitude of the staff, the approach, all kind of techniques 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 by explaining that the accommodation of neurodevelopmental disabilities is “very difficult” and recognizing any efforts invested might only result in “some” changes, Rachel divided the issue of accessibility into two components: structural changes and service provision changes. Unlike structural changes, which represent a constant environmental change, changes in service provision require a change in staff perceptions, a change in their awareness. The main perception that must be instilled is that, as with physical disabilities, neurodiverse individuals could have equal access to healthcare if proper mitigation measures were to be introduced. Only later, once awareness had been increased, could the attitudes and approaches toward these individuals be amended. Later in the interview, explaining about the programs they have introduced in the hospital, Rachel said: “We are starting with the awareness of the medical staff. They, the hospital personnel, don’t really understand.” Her observation further demonstrates how deeply rooted in the healthcare system is the perception that accommodations are structural and not behavioral, to such an extent that even healthcare personnel have difficulty understanding that other perceptions are possible.

Autistic individuals and their families also raised the difficulties engendered by this invisibility of their autism. Under the mandate of the Israeli accessibility legislation, autistic individuals are entitled to a card that exempts them from waiting on lines allowing them to reduce their waiting time. The qualitative inquiry demonstrated that providers do not readily accept this mitigation, believing it to be an unjustifiable privilege. Bar and Tomer, the parents of an autistic adult, discussing the unique circumstances autistic individuals must deal with in the Israeli context, reported on their experience with service providers at an airport:

*Bar*: “As I told you, we do wait in the lines, we are not trying [to shorten them] … I know from my friends who 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 to 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).

In an attempt to avoid hostile responses, Bar reported that they usually do not use the disability card to waive standing on lines. Nevertheless, it seems from the one instance when they did use it, and from their friends’ experiences, that there is a reluctance by the public to accept this mitigation, strengthening the argument that autism as a disability is invisible among the Israeli public. Tomer expanded on this, noting that this perception is not only prevalent among the public who may need to wait longer, but is also rooted within the service provider culture. Although this specific example refers to an incident in an airport, unfortunately, similar experiences are prone to occur in the healthcare system, given that the perceptions at both the administrative and the provider levels are comparable. As the accessibility regulations do not apply in the healthcare system, these types of incidents were not mentioned by the interviewees.

When describing the invisibility of autism and the unique experiences of autistic individuals in Israel, Smadar, an autistic woman and the mother of three autistic children, eloquently demonstrates how difficult it is to recognize autism as a disability that requires legal attention:

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 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 [in 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 by describing her disability as being not visible, explained that her autistic son, who does not know he has a diagnosis of autism but knows of his difficulties, could not understand why his difficulties come under the same umbrella as those of people who are physically disabled. Even he does not consider his difficulties to be as great as those of someone confined to a wheelchair. Then, after Smadar described the approach to disability in religious education, framing it as an attitude of grace toward those who have a disability or are helpless, she turned to the issue of invisible disabilities. In the case of cognitive or mental disabilities, she argued, the situation is different. There is clearly a line, albeit thin, between disabled and non-disabled, one that is observable and crossed easily. Smadar’s description emphasizes why autism is an invisible disability; not only is it simply not visible, but, in some cases, autistic individuals may appear to “normal” or non-disabled. The logical consequence of this is that if at certain times autistic individuals appear non-disabled, perhaps they do not require or deserve any special accommodations.

To summarize, autistic adults are marginalized within the healthcare system and the barriers to their access are disregarded, partially because discriminatory perceptions towards autism are prominent both at the administrative and the provider level. Two major oppressive perceptions were identified: 1) the perception that autism is a disease and, as such, it should treated, cured, or rehabilitated, and thus not be recognized as a disability that requires accommodation, and 2), the perception that only a disability that is physical and visible requires structural accommodations. Other mental and cognitive disabilities, as well as physical disabilities that cannot be seen are, like autism, invisible and unrecognized (see Davis, 2005; Navas et al., 2019). It should be noted, however, that while these perceptions have certainly been influential in Israel’s healthcare system, shifts may be starting to occur. In 2020, the MoH began to draft new service provision regulations that also cover invisible disabilities. As part of this process, my PhD advisory committee and myself were approached to advise the MoH. Another notable example is the introduction of Beit Issie Shapiro’s program for the accommodation of services for invisible disabilities in some community medical centers (Nisim, 2020). Furthermore, as mentioned above, alongside these discriminatory perceptions, alternative perceptions can be held by individuals within the healthcare system who are trying to promote “some” change, as Rachel, quoted above, mentioned. Unfortunately, as this section demonstrates, the pendulum is still clearly tilted toward discriminatory perceptions and practices. These perceptions prevent mitigations from being introduced, especially those that require accommodations in service provisions. Thus, as this section argues, autistic adults continue to be marginalized within the healthcare system as a result of these perceptions, which could be regarded as SDHIs in the political context that defines the marginalization of autistic individuals.

## 5.2. Lack of knowledge among healthcare professionals about autistic adults

The interviews demonstrated that throughout the healthcare system, including in professions where autism is supposed to be a core element of their specialty, such as psychiatry, psychology, speech therapy, and occupational therapy, there is a serious knowledge gap with regard to the autism spectrum in general and specifically about the mitigations needed to provide accessible services to this population. This gap in knowledge arises due to the limited number of knowledgeable senior professionals combined with the lack of systemic training about autism and autistic adults in particular. In addition, this lack of knowledge was found to have implications beyond acting as an obstacle to reducing barriers to access; for example, on the provision of unsuitable treatments and on service utilization. In the context of the Israeli healthcare system, this lack of knowledge marginalizes autistic adults and, as this section argues, can be regarded as an 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 of a lack of knowledge among service providers in the healthcare system came from psychiatrists. Dr. Yair, a psychiatrist working with autistic adults in the community, mentioned the following in his interview during a discussion about the knowledge of autism 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 (PDDs), among which autism was included in 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 encounters a resident in psychiatry has with autistic adults, as Dr. Yair described, can be very limited. Therefore, the empirical knowledge a resident in psychiatry can acquire on the subject is inadequate. Dr. Yair’s quote, however, does not suggest only that there is currently no specific training about autism among adult psychiatry residents and that this lacuna further impairs the education of future generations; he also implied that knowledge about autism among specialists is very limited. The fact that a resident can see an autistic adult and not recognize that he or she is autistic unless being advised of this fact by a supervisor, or that a resident can treat an autistic individual without proper adjustments to their care, indicates that knowledge is also lacking among the specialists who are charged with caring for this generation of autistic individuals and with educating the next generation of professionals. This claim is supported by other psychiatrists interviewed for this research. Dr. Golda, for example, a senior psychiatrist working with autistic adults in a residential setting, admitted in her interview that “I did not have any training, not something specific, and I feel it was something I could have benefitted from.” (Dr. Golda, a psychiatrist working with autistic adults).

Limited training about autism was also reported among other professions. For example, Kfir, a clinical psychologist working with autistic adults, shared that in his academic studies: “we didn’t touch this subject so much” (Kfir, a psychologist working with autistic adults). Tze’ela, a rehabilitative psychologist working with autistic adults echoed Kfir’s remarks, saying that she had “no exposure whatsoever” to autism. Given this lack of knowledge among psychiatrists and psychologists, it is not surprising that 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 any way 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, like the other interviewees quoted above, described her limited exposure to autism. She did mention a short introduction to autism as part of her child psychiatry education, which is indeed crucial; however, as autistic advocates have been arguing for a long time, this focus on children with autism diverts research and practice away from the needs of autistic adults (see Ne’eman, 2011 and further elaboration in the literature review). Dr. Mor’s comment regarding the lack of preparation to treat special populations emphasizes this line of argument regarding autistic adults, as they are the very individuals who could benefit from such preparation, along with other disabled individuals. Dr. Mor’s lack of knowledge was, as she stated, not limited to her training. When she did try to learn more about the autistic adult population and primary care, she found limited information, highlighting the current healthcare system’s neglect of the field.

It was not only healthcare professionals who mentioned their limited knowledge about autistic adults, as autistic adults themselves or the guardians and caretakers of autistic adults who use healthcare services were acutely aware of healthcare professionals’ unfamiliarity with autistic adults. Smadar, for example, an autistic woman and the mother of three autistic children, shared her experience with professionals lacking knowledge about autism:

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

Smadar’s description of her encounter with professionals who lack knowledge provides evidence from the side of the healthcare recipient. Additional observations in her statement reveal two opposing responses the lack of knowledge among providers can evoke. One is complete dismissal of the diagnosis of autism, corresponding with the perception of disability as being only those conditions that are visible, as discussed above; the other is that some practitioners actually express an openness to learn from their patients. The spectrum of responses obtained during the interviews was broader. What is important in the range of responses is what it represents for autistic adults, as in the absence of any systemic agreement as to the knowledge professionals should have about autism, the services autistic adults receive might differ markedly from one provider to another.

The survey that was conducted among autistic adults and guardians of autistic adults, in contrast to the findings of the qualitative study, demonstrated that the responders agreed that, on average, professionals are trained to a satisfactory degree to address the needs of autistic adults. Three questions measured the knowledge of professionals. The first measured the degree of agreement about the comprehensiveness of professionals’ knowledge and included sub-questions about family physicians, psychiatrists, and psychologists. The second question was directed to individuals who had been treated in the mental health system in the year prior to their completion of the questionnaire. The question measured the degree of agreement about the comprehensiveness of mental health professionals’ knowledge. The third question was a yes/no question that asked participants if they had experienced difficulties in finding a family physician who was sufficiently trained and able to meet their needs. The degree of agreement in the comprehensiveness of professionals’ knowledge about autistic adults was measured in these questions using a 1 to 4 scale, where 1 is the least agreement and 4 the 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 respondents who had utilized community mental health services (n=51/93, 54.8%), the degree of agreement about the comprehensiveness of mental health professionals’ knowledge was 2.77. Despite the agreement that the comprehensiveness of family physicians’ knowledge was found to be greater than average, 30% of respondents (n=31/93) reported having difficulties in finding a primary care physician who had sufficient training to meet their needs. These findings imply that the majority of service recipients are satisfied with the level of knowledge of their healthcare providers with regard to autism.

Three explanations could account for the gap between the centrality of the theme in the qualitative investigation and that of the quantitative findings. The first is the selection of interviewees who were “good informants” for the qualitative investigation. These interviewees most likely possess more knowledge about autism than the average person and could have a different, more accurate, impression of what is considered sufficient knowledge. Second, the quantitative results should be interpreted with care, because they may be partially biased, as other factors such as trust in the healthcare system could affect participants’ responses. Third, the results are the subjective impression of the service recipients and their families in relation to the professionals’ expertise and not an objective quantification of their actual knowledge. In the qualitative analysis, however, this theme regarding experts’ knowledge was also prominent among the professionals who were interviewed. Considering the finding from the international literature of reported gaps in knowledge about autism among professionals (Zerbo, Massolo, Qian & Croen, 2015), the assumption could be made that the situation in Israel is no different. This discrepancy, however, suggests further exploration of professionals’ knowledge about autism is warranted in any future research.

It should be noted that despite the lack of extensive knowledge among healthcare professionals, some efforts are being made both by the MoH and by academia to reduce these knowledge gaps. Dr. Rotem, for instance, a psychiatrist 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 who 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 psychiatrist working with autistic adults).

The course Dr. Rotem mentioned, which has been running since 2019, is an essential first step toward enhancing the knowledge of healthcare professionals in relation to adult autism. The syllabus has been published online (Portuguese, 2021) and provides a crucial overview of neurodevelopmental diagnoses and a sample of the most urgent issues the course directors realized needed to be addressed. If the course does, in fact, also succeed in establishing a network of knowledgeable professionals, then this is an additional benefit that will assist in developing the field further. However, one national course aimed at professionals already actively seeking more information and that is intended to explore all neurodevelopmental diagnoses might be insufficient given the anticipated increase in the number of autistic adults.

In summary, this section has demonstrated there are vast gaps in the knowledge of healthcare professionals regarding autistic adults across multiple disciplines. These gaps are the result of a lack of knowledge among senior healthcare professionals, who treat autistic adults without regard for their uniqueness, and an absence of structured training on the subject for future generations of healthcare professionals. Despite the prominence of this theme in the qualitative phase, during the quantitative phase, this gap in knowledge tended not to be identified by the service recipients, who ranked the level of professional knowledge they had encountered as suitable for their needs. This section, therefore, argues that the absence of training and the insufficient body of evidence regarding this population forms part of the sociopolitical context that structurally marginalizes the autistic adult population. Next, I will briefly explore the additional implications of this knowledge gap.

### 5.2.2. Implications of the knowledge gap

The importance of training healthcare professionals about autism spectrum in adulthood is not just a function of 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, a lack of knowledge among professionals can result in barriers to healthcare services for autistic adults. Professionals who are not familiar with the unique manners of communication that autistic adult utilize, or who do not take into consideration the sensory differences autistic adults may experience, can create major barriers to access. In addition, the qualitative investigation demonstrated that a lack of knowledge in relation to autistic adults can have implications beyond providing undifferentiated 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 healthcare professionals’ knowledge about autistic adults is diverting autistic adults and their caregivers to look for alternative practitioners specializing, or purporting to specialize in autistic children. This practice can, unfortunately, harm the health of autistic adults if they turn to the services of unqualified people. The next chapter, about the inequalities faced by autistic adults, will discuss another implication of this situation, namely, the reliance on private services.

#### Unsuitable treatment

The lack of knowledge regarding autism among health professionals and, specifically, mental health professionals can result in the provision of unnecessary and in some cases even harmful treatments. Barak and Shlomi, a couple who are both autistic adults and who were interviewed together, describe their confusing experiences 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 opinions regarding the treatment of autistic individuals by mental health professionals who are lacking in knowledge about autism. They describe a having completely different psychological system that reacts adversely to the practices commonly used in neurotypical psychology. Barak’s description of repeated failures following unsuitable guidance by a psychologist illustrates Shlomi’s point that being treated by an untrained health professional could have disastrous results. Additional examples that were mentioned during the interviews emphasize the different mental interpretations autistic adults require when undergoing treatment, interpretations that cannot be provided by therapists who are unfamiliar with the autism spectrum (or the unique aspects of diagnosing mental health disorders in autistic adults, see Portuguese, 2019). To better understand the absurdity of this situation, it is easier to imagine what the systemic response would be if a practitioner that understood nothing about type 1 diabetes or attention deficit hyperactivity disorder (ADHD) attempted to treat patients who had these conditions – it would be seen as unreasonable practice. In addition to mental healthcare services, other medical issues that require specific attention in autistic adults were raised by interviewees and are reported in the literature, such as gastroenterological problems (Buie et al., 2010) and sleep disorders (Lugo et al., 2020). Hence, it can be concluded that the systemic neglect of specific training with regard to the treatment of autistic adults directly harms these individuals’ health and marginalizes them in comparison with neurotypical individuals.

#### Turning to child therapists for treatment and care

The qualitative analysis showed that the lack of knowledge among adult therapists causes another marginalizing practice. In the absence of alternatives and given the enormous lack in knowledge and the need for relief, autistic individuals and their caregivers are turning to child therapists for help. Ben, a professional working with autistic adults and the 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 has a child psychiatrist that is treating autistic children. So, we took our resident there and we paid 900 NIS for first aid.” (Ben, the director of a program focused on autistic adults).

Although child therapists are also partially trained in adult psychiatry, the need to choose either a therapist who is familiar with autism or a therapist who is familiar with adult care, because there are none available who combine these disciplines, 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, adults with autism turning to child therapists, which results from the absence of knowledge among health professionals, inevitably results in suboptimal care for autistic individuals and negatively affects their health. This practice, although not formally encouraged, is the result of the continuous systemic neglect of the autism in adulthood field. It should be noted that although this practice might seem similar to using a pediatrician in adulthood (see Chapter 4), the rationale underlining each of these practices is different. While one practice aims to reduce barriers by returning to the same place that is familiar to the autistic adult, the other not only not reduces the familiarity barrier, but also further marginalizes the autistic individual by providing suboptimal care. What these practices have in common, however, is that both involve child practitioners, highlighting that the autism field in Israel is no different than the global autism field, in the sense that in both contexts, autistic adults have been neglected.

To conclude, this section has demonstrated the lack of knowledge regarding autistic adults across disciplines and throughout different levels of expertise. Despite some nascent efforts to close this knowledge gap having been made in recent years, there remains systemic neglect of this field. In addition to being an impediment to overcoming barriers to healthcare services, this lack of knowledge has 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 few knowledgeable adult therapists are available, autistic adults and their caregivers have to resort to using the services of child therapists. These findings clearly demonstrate that the lack of knowledge among professionals caused by the systemic neglect of the field is another sociopolitical determinant that marginalizes autistic adults in Israel and harms their health. This SDHI further discriminates against the social position of autistic individuals in Israel and must be addressed.

## 5.3. Marginalizing mental healthcare policies

As has 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 in Israel has never been explored, this section begins by demonstrating the significant role mental health plays in the life of autistic adults in Israel. It then turns to explore the ability of autistic adults to access mental health services within the current public system. While the previous section focused on how increasing practitioners’ knowledge could act as a mitigator of marginalization and how the system was not performing its role by providing this knowledge, 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 autistic adults from accessing the services they need and is limiting the development of the system’s capacity to treat autistic adults. The policy that is preventing adults from obtaining a diagnosis of autism in the public healthcare system deprives unrecognized autistic individuals of the personal and systemic recognition of their difference, which is necessary to obtain access to any services. Thus, this section claims that the current mental healthcare policies in Israel represent another SDHI that marginalizes autistic adults in Israel.

### 5.3.1. The need for mental healthcare services

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

Multiple examples of the need for mental healthcare were demonstrated by diverse stakeholders during the interviews. 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 needs of the adults who are under her supervision:

Despite it not being 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 adult.).

According to Pazit, 80% of the autistic adults who fall under her responsibility require mental healthcare services. The emotional relief was needed to such an extent that, although it was contrary to their initial agenda and is not being funded by the Ministry of Labor, Social Affairs and Social Services (MOLSA), which subsidizes the program, the program team decided to invest in mental health treatments. Bina, a manager at a residential home for autistic adults who need more assistance with their daily activities given their cognitive abilities and the comprehensiveness of their autistic traits, depicted a 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 health maintenance fund” (Bina, a manager at a residential home for autistic adults).

Bina described how, at the other end of the spectrum, for those individuals with lower cognitive and functional abilities, the need for psychiatric care is considerable. Furthermore, she explained, as Pazit did before her, that this 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 from the survey findings. Among the respondents, 91% (n=112) of autistic adults and their guardians alike answered that they had been treated or diagnosed with an additional mental health disability, while 54.4% answered that they had two or more additional mental health disabilities. In addition, among those who replied about whether they had ever received mental healthcare in the community, 54.8% testified they had. In comparison with the general population (Elroee, Rozen, Elmakaias & Samuel, 2017), these findings indicate an almost three-times higher occurrence of having experienced mental distress among autistic adults (26% vs. 91%), as well as higher utilization of mental health services among autistic adults (36% vs. 54.8%). Considering both the quantitative and qualitative findings, the need for mental health services among autistic individuals in Israel is substantial and clearly not less than the needs of their neurotypical counterparts. As the quotes above demonstrate, however, despite the importance of providing autistic adults with access to mental health services, most of the mental healthcare services are paid for by organizations themselves or privately. The next part of this section explains this unreasonable phenomenon.

### 5.3.2. Mental health reform – excluding autism, marginalizing autistic adults

Despite the evident need for mental healthcare services as described above, autistic adults living in residential facilities, in the community as part of a MOLSA program, or with family members are not entitled to publicly provided mental healthcare services. It is not only the enormous need for mental healthcare services that causes the organizations mentioned above to seek such services in the private sector but also discriminatory policies that bring them to this, the effects of which are covered in this sub-section. This situation is a result of the exclusion of a diagnosis of autism from the mental health reforms introduced in July 2015. These mental health reforms had three main goals: to transfer responsibility for mental healthcare from the MoH to the health maintenance funds; to reduce stigma by integrating mental healthcare with non-mental healthcare in the primary care setting; and to enhance the quality, accessibility, and availability of mental healthcare services (Ministry of Health Israel, 2021b). Nevertheless, and unlike all other diagnoses included in the DSM (APA, 2013), individuals diagnosed with autism are not entitled to mental health services under the current reforms, based on their autism diagnosis. The immediate consequence of this was accurately described by Dr. Efron, a psychiatrist working with autistic adults in a hospital and in the community:

The Ministry of Health, together with the Ministry of Justice, declared autism is not a mental health issue. Thus, the health maintenance 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 to exclude autism from the mental health reforms as an abuse. Echoing the descriptions from Pazit and Bina in the previous section, Dr. Efron criticized the policy decision and described how it led to unavoidable private payments by residential facilities and individuals for mental healthcare. Diverting all mental healthcare to the private sector clearly discriminates against autistic individuals from less affluent families and leads to inequalities between autistic adults, as will be discussed in detail in the next chapter. However, this practice also has ramifications on the quality of mental healthcare. In residential facilities, although private mental healthcare services are usually mandated by MOLSA as part of the operating contract (establishing a providers’ network for operating housing facilities “houses for life” for the population on the autism spectrum, 2021), given that some of the organizations operating these residential facilities are for-profit companies, the quality of the services might not be a priority, which could adversely affect the health of autistic adults. For autistic individuals who reside in the community, among those who can afford to pay for private mental healthcare services, the decision to continue receiving such care might come at the expense of other needs or the quality of the service.

It should be stressed at this point that autistic individuals are as entitled to receive public mental healthcare services for any additional psychiatric diagnosis as any other citizen in Israel who has public healthcare insurance. Nonetheless, this arrangement has two intrinsic flaws. First, mental healthcare services are generally not provided by practitioners who are familiar with autism, as outlined in the previous section, which can adversely affect the mental health of treated individuals. Second, the decision that an autistic individual will only be entitled to mental healthcare services if she or he has an additional psychiatric diagnosis means that only extreme cases will receive assistance. Autistic individuals who need assistance in their day-to-day lives due to the stressful life events they experience (Fuld, 2018) and who are not diagnosed with any other formal mental health diagnosis are not entitled to any services. Pazit’s and Bina’s statements above exemplify that it is these daily challenges, and not a major additional psychiatric diagnosis, for which assistance is usually needed. Moreover, this policy decision might unintentionally encourage practitioners, autistic individuals, and caregivers to seek an additional psychiatric diagnosis even if it is not warranted, just to gain access to services.

The policy decision to exclude autism from the mental health reforms has three additional consequences. First, it creates a legal situation where autistic individuals must choose between a mental health diagnosis and an autism diagnosis; second, it prevents the development of capacity among mental healthcare providers to treat this population; and third, it harms the continuity of care between body and mind that the mental healthcare reforms were intended to improve.

Excluding autism from the mental healthcare reforms also prevents autistic adults from accessing rehabilitation services provided under the Community Rehabilitation of Persons with Mental Health Disability Law (2000). Under this law, individuals with mental disabilities are entitled to a basket of rehabilitation services in addition to the mental healthcare services provided by the health maintenance funds. Autistic adults’ rehabilitation services, on the other hand, such as supported employment and residential facilities, are provided by MOLSA; up until 2017, by the autism department and, since then, by the Disability Administration (Shalom, 2017). These two routes for rehabilitation services provide different services and have different availability, thus creating a dilemma for autistic individuals and their caregivers as to whether they want to be diagnosed with autism or with a mental disability. Hila, a sister of two autistic adults, 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 has two brothers on the autistic spectrum, described her sister’s resistance to seeking a diagnosis of autism for the older brother. Her sister understood, following the experience the family had with the younger brother, that a diagnosis of autism would deprive the older brother of the rehabilitation services that are provided by the Community Rehabilitation of Persons with Mental Health Disability Law (2000); therefore, she preferred him not to receive a diagnosis of autism. The sister’s refusal, about which she later changed her mind, deprived her brother from receiving care appropriate for his needs. This example illustrates the impossible choice individuals and families are faced with given the current policy that excludes autism from the mental health reforms: either choosing to seek a diagnosis of autism and receiving suitable care according to the diagnosis, or not seeking the diagnosis and being entitled to a basket of services including mental healthcare that might be more suitable or needed, especially for individuals who live in the community. It should be noted that in childhood, this dilemma is reversed. Until the age of 18 years, a diagnosis of autism results in a larger stipend from the National Insurance Institute (NII) and additional treatments that are unavailable for most mental health disabilities, thus making a diagnosis of autism preferable.

The second negative implication of excluding adult autism from the mental health reforms is that it prevents training for mental health practitioners who work for the health maintenance funds about autistic adults. Despite the evident lack of knowledge among mental healthcare providers discussed above and the anticipated increase in the number of autistic adults, because autism is excluded from the reforms, there is a disincentive for the health maintenance funds that provide the services to promote training among their employees. Pazit, a social worker in a program dedicated to autistic adults, described a meeting with a representative of the local mental health clinic that illustrates the catch-22 situation the health maintenance funds must handle:

The health maintenance 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 reforms].” She tries. She told me: “I can’t bring a training session on autism, and I can’t send my workers to a training session.” (Pazit, a social worker working with autistic adults).

Pazit’s quote begins by describing the inability of the local mental health service provider to address the treatment needs of the adults attending the program Pazit works at, given the untrained therapists working in the clinic. The explanation the health maintenance fund representative gave to Pazit was that despite recognizing the urgent need for training, they are unable to provide it because autism was excluded from the mental health reforms. According to the representative, they are not allowed to conduct training in the clinic, nor are they allowed to send someone elsewhere for specialized training in the subject. This paradoxical situation, which prevents efforts to enhance the knowledge of practitioners working in the system, is another harmful consequence of excluding autism from the mental health reforms. Considering that a lack of knowledge was identified above as an SDHI, this unfortunate outcome of excluding autism from the mental health reforms has huge implications for the health of autistic adults.

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

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 home for autistic adults).

Considering autistic adults’ extensive use of psychiatric drugs, Bina criticized the disconnect between the family physician and the psychiatrist the mental health reform policy had imposed. In her criticism, she raised some important questions regarding the need for supervision of the continuous use of psychiatric drugs that could not be properly performed if there is an active separation between body and mind. The closing sentence of her statement that relates to “active managed medicine” emphasizes the importance of integrated care beyond the specific case of psychiatric drugs. Actively managed medicine could, for example, take into consideration the physical and mental changes that accompany major life events, such as the 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 has caused is not only counter to the mental healthcare goals but also has implications for the health of autistic adults.

Despite the inherent policy failures of the mental healthcare reforms covered above, the reforms had at least one positive outcome for autistic adults. Following the inclusion of the reforms, Keshet Clinic, in Tel HaShomer Medical Center, located in the center of Israel, which specializes in the care of individuals with developmental disabilities, including autism, received formal approval from the MoH as a specialized service. Obtaining approval as a specialized service means that any autistic adult with a dual diagnosis of autism and any additional mental health disability can apply to his or her health maintenance 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 health maintenance 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 shift from exclusively private and expensive services to a publicly funded model, where the health maintenance funds can authorize specialized services for autistic adults with any additional mental disability diagnosis. Contrary to the negative implications the reforms had for inequalities among autistic adults, this instance represents a positive shift following the reforms toward a more equal provision of services. It should be stressed that only autistic individuals with an additional mental health diagnosis can receive a referral to the clinic and, as discussed earlier, this has implications for health. From the interviews, it appears that the recognition of this specialized service has also increased the awareness among professionals of the need for specialized care for autistic adults. Dr. Yair, a psychiatrist working with autistic adults in the community, mentioned that since the reforms were implemented, autistic adults are being referred to Keshet Clinic by “residential facilities, employment programs […] by their family physician or the psychiatrist at the health maintenance fund.” Dr. Yair’s statement demonstrates the additional benefit that recognizing the clinic as a specialized service has had in raising awareness regarding the unique needs of autistic individuals.

Although the reforms might have positively affected the mental healthcare provided to some autistic adults, it seems its implications have not reached most of the autism community. Many autistic adults and their relatives who were interviewed for the qualitative study knew very little about the reforms. This included Shira, an autistic adult, who when asked “did you ever hear about the mental reform?” answered: “from you”; Omer, an autistic adult, who answered: “I didn’t know about this reform”; and Gefen, the 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 didn’t go into the details.” Furthermore, the quantitative findings demonstrate that the mental health reforms did not have any impact on autistic individuals. Among the participants who responded to the questions about the mental health reforms (n=90), 60% stated that they did not know about the reforms. Furthermore, for the questions that dealt with the influence of the reforms on the quality, availability, and continuity of care, 66.1% chose not to answer or answered that the reforms were irrelevant to them. Among those respondents who did answer about the quality, availability, and continuity of care (n=36), which was measured on a scale of 1 to 5, with 1 being much worse than before the reform, 3 no change, and 5 considerable improvement, it seems there was minimal change, if any, as a result of the reforms. The results showed a slight increase in the quality of care (mean = 3.21; standard deviation (SD) = 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 respondents answered that they were treated in the mental healthcare system; thus these data do not indicate a low level of use of mental healthcare services but the irrelevancy of the mental health reforms.

In summation, the exclusion of autism from the mental health reforms has resulted in several policy failures in the provision of mental healthcare for autistic adults. These failures include the diversion of mental healthcare provision to the private sector; not providing emotional assistance for stressful life events; the danger of over-diagnosis of additional psychiatric disabilities; the need to choose between different rehabilitation services, i.e., those that are dedicated to autistic adults or those that are provided for individuals with mental disabilities; setbacks in the ability to promote autism training; and detachment between the care for body and mind. Nevertheless, the reforms enabled the recognition for the first time of a mental healthcare clinic dedicated to treating autistic adults. It can be concluded that, despite having little positive impact on the health of autistic individuals, the policy decision to exclude autism from the mental health reforms has resulted in policy failures that individually, let alone combined, further marginalize autistic adults and harm their health. As part of the sociopolitical context of autistic adults, this policy decision can be considered as an SDHI that deprives autistic adults of the equal access to services they need and thus further discriminates against them.

### 5.3.3. Diagnosis of autism in adulthood

Another policy failure that was raised by many interviewees and that was directly related to mental health is the diagnosis of autism in adulthood. Unlike any of the other diagnoses that constitute the DSM 5 (APA, 2013), this research revealed that after the age of 18 years, an adult cannot receive a diagnosis of autism in the public healthcare system. If there is a suspicion that an adult individual is on the autistic spectrum, he or she can choose one of two options. They can either search for a private specialist and pay out of their own pocket, or, alternatively, they can obtain a special authorization to seek a diagnosis at a center authorized by MOLSA that is designated to reaffirm a diagnosis of autism for autistic adolescents who turn 18 and apply for these services.

In addition to the basic health right to have an accurate diagnosis, and before delving into the systemic failures caused by the current policy to exclude a diagnosis of autism from the public healthcare system, it is essential to emphasize the personal importance of a diagnosis to autistic individuals. The most notable effect receiving a diagnosis had in those who were not diagnosed in childhood, especially for individuals with normal or high cognitive abilities and their families, was a sense of relief. Smadar, an autistic woman and the mother of three autistic children, who was diagnosed following her children’s diagnosis, expresses 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 moving description of her emotions creates an impression of removing a heavy burden from her shoulders, similar to what many autistic individuals and their relatives described in their interviews. The sudden landing after floating for their entire life between diagnoses and experts was coupled with a sense of belonging and unaccustomed understanding. Preventing diagnosis in adulthood, therefore, means keeping individuals and their families in a dark fog and a state of continuous searching.

Not allowing a diagnosis of autism in the public healthcare system also has serious implications for the health of autistic adults. First, as has been extensively discussed above and in the previous chapter, autistic individuals require appropriate care and accommodation. Not having a diagnosis of autism means preventing autistic adults from accessing mitigated care and causes serious, direct harm to their health. Second, a diagnosis is the preliminary criterion necessary to be able to access services provided by MOLSA and other governmental authorities for autistic adults, services that are unavailable to individuals without a diagnosis. Tze’ela, a psychologist working with autistic adults, briefly summarized the importance of a diagnosis:

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 a diagnosis of autism as a port of entry to a variety of services that are unavailable to those who are not diagnosed. It is crucial to briefly discuss the last point Tze’ela raised, about the autism community. The door to the autistic community, the community of individuals on the autism spectrum, is often open for individuals who have not been formally diagnosed with autism. This is because members of this community usually recognize alternative diagnosis methods, such as peer acceptance; therefore the community is also accessible also to those without a formal diagnosis. 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 relationships courses, often does demand a formal diagnosis as a condition of entry. Thus, diagnosis is important both for personal relief and as an “entry key” to the variety of services that do exist.

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

It should be stressed that many individuals from across the autism spectrum are misdiagnosed in childhood, especially in underprivileged communities, as covered in the literature review under the section on inequalities. Dr. Yair, a psychiatrist working with autistic adults in the community and who offers private services for the diagnosis of autism, described the individuals who generally arrive at 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 portrayed two types of individuals on the autistic spectrum that might require services more than others on the spectrum. It does not mean that all those who are not included in these categories do not need a diagnosis, but that they approach less frequently to ask for assistance. What Dr. Yair’s argument clarifies, however, is that diagnosis in adulthood is needed for individuals from across the spectrum.

Text

Description automatically generatedNot providing the diagnosis of autism as part of the public healthcare system causes two additional problems: broadening the inequalities among autistic individuals and minimal regulation of the diagnosis process. Diagnosis of autism in adulthood is extremely expensive due to the complexity of the process, which includes comprehensive testing by practiced professionals (Epstein, 2019). The image of the transaction below (Image 5.1), which 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)

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

The second systemic problem of not providing a diagnosis of adult autism through the public healthcare system is that standardization of the diagnosis process has been introduced only recently, resulting in minimal regulation of this process. In 2013, following a comptroller’s report that found differences between the MOLSA, the NII, and the MoH routes to diagnosis of autism in children, the MoH convened a committee that created clear standards for the diagnosis of autism in children (Diagnosis of children on the autism spectrum, 2013). However, similar standards for adults were not introduced until December 2020 (Diagnosis of autism spectrum in adults, 2020), leaving the field unregulated. Geula, who holds a senior position at the MoH and 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 mandates [services] until the age of 18, afterwards there is no obligation […] there are 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, who holds a senior position at the MoH.).

Geula acknowledged during her interview that there is an issue with the diagnosis of autistic adults. She highlighted 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 similar to those that exist for diagnosis in children. Although Geula’s last point has recently materialized, preventing the diagnosis of autism under the public system has delayed the standardization of the field and left it unregulated. At the beginning of the quote, it should be noted that Geula argued that the gaps in diagnosis between children and adults are a result of the limited services designated for autistic adults in the law. I will return to this argument in the next chapter, given that its counter explanation, which asserts services are not developed because there are not enough autistic adults diagnosed, is central in explaining inequalities between autistic adults.

Considering that until recently there were no guidelines for or standardization of diagnosis, it is not surprising that some interviewees shared negative experiences of the diagnosis process. Cohav, for instance, an autistic adult who, after obtaining a diagnosis privately, approached MOLSA’s diagnosis center because she wanted to be entitled to services, shared 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 at length her distressing experience in the diagnosis center that conducts reevaluations for MOLSA of autism diagnoses in individuals aged 18 years and older. In her statement above, which represents just a fraction of her detailed description, two problems are conspicuous. First, the setting in which the clinic operates is clearly unsuitable for the purpose of diagnosis of autism. Visiting a prisoner detention center can be stressful for anyone, let alone someone who is there to have a reevaluation of their diagnosis of autism. The second problem is the obvious lack of knowledge of both the psychologist and the psychiatrist regarding autism and, specifically, the diagnosis process. The degrading discussion regarding her autism that Cohav outlines is clearly inappropriate and unprofessional. The incident Cohav describes thus exemplifies the consequences of having no standardized diagnosis process for autistic adults and strengthens the need for it to be included in the public health system along with any other diagnosis.

Lastly, the quantitative findings are also indicative of the pressing need for diagnosis in adulthood. Of 85 respondents who had received a formal diagnosis and knew their estimated age at the time of their diagnosis, 21 (24.7%; of all 112 respondents, 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 who were diagnosed after the age of 18 than among those whose guardians answered for them (25.8% vs. 11.1%, respectively; 15/58 and 6/54, respectively). This finding strengthens Dr. Yair’s claim (see above) that those who seek diagnosis in adulthood are high-functioning autistic individuals who do not manage in their normal adult lives. Furthermore, 14 (12.5%) of the total 112 respondents answered that they had not received a formal diagnosis, all of whom were autistic individuals. These individuals were included in the analysis to avoid exclusion of autistic individuals from lower socioeconomic classes who cannot afford to obtain a diagnosis, considering the current policy regarding diagnosis. These data illustrate the importance of allowing the diagnosis of autism in adulthood to be included as part of the public healthcare system.

To conclude, according to the current policy in Israel, the diagnosis of autism in adulthood is not publicly funded. This policy, in addition to preventing individuals from exercising their basic right to be diagnosed, has both personal and public implications. On the personal level, not receiving a diagnosis might leave the undiagnosed autistic individual in an unending quest to understand their difference and prevent her or him from obtaining the access to appropriate services and the autism community. At a population level, not having a publicly funded system for diagnosis de facto enables only those who have the resources to do so to obtain a diagnosis, and leaves this practice unregulated, which, in turn, results in unprofessional and sometimes harmful services. The survey findings illustrate the extent of the diagnosis-in-adulthood phenomenon, highlighting that this is an issue that cannot be neglected. The findings above exemplify the diverse ways in which not providing a diagnosis for autism in adulthood can harm autistic adults, both individually and collectively. Thus, it can be argued that this “un-policy” realm, which is part of the sociopolitical context of autistic adults in Israel, further marginalizes them and reduces autistic adults’ social position.

## 5.4. Complementary treatments

Until the age of 18 years, following a 1998 amendment of the National Health Insurance Law (1994), autistic children and adolescents are entitled to receive three paramedical services termed “advanced medical treatments” (in Hebrew: טיפול בריאותי מקדם - Tipul Briuti Mekadem) from their health maintenance fund. Upon turning 18, this right is revoked and, as covered above, other policies that mandate the 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 these services beyond the age of 18 was actually instrumental and not based on evidence. Furthermore, it argues that these services are needed throughout an individual’s life and that preventing autistic individuals from accessing them interferes with their ability to live independently in the community. Thus, the lack of these services marginalizes autistic individuals. Finally, the section briefly discusses the effect that neglecting this arena has had at the population level.

The position of this section, that autistic individuals have a right to live independently in the community, stems from the United Nations Convention on the Rights of Persons with Disabilities, which 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” (United Nations, 2006). Thus, as will be shown in this section, additional paramedical services are not warranted to gain equal access to healthcare but to progress toward equal participation in the community. This section, therefore, differs from the previous ones, as although the services discussed are situated within the healthcare system, their provision does not directly affect health. Community participation is a proxy for other SDHs, such as employment, housing, and others, that have been proven to affect health. Without the discussed services, full participation in the community will not be possible, thus, these policy cases should also be considered SDHIs.

The common belief among some professionals and officials who work with autistic individuals is that additional paramedical services have no benefit in adulthood; thus, providing them throughout adulthood would be unreasonable in terms of resources. Geula, who holds a senior position at the MoH, when asked about the needs of autistic adults, 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, who holds a senior position at the MoH).

Geula openly stated that complementary paramedical services are required less in adulthood. Although she recognized some assistance is needed in adulthood, for example, in social capabilities and mental health, she was also aware that these services are not currently widely available for autistic individuals. Her words, which resonate, together with the long-term neglect of research and services for autistic adults (see the literature review), demonstrate the common belief that after turning 18 the development of autistic adults ceases and there is no incentive to invest in further services for them. However, as other interviewees explained, these services are not available for adults due to procedural decisions made during the policy construction process and not because of evidence that shows these services to be irrelevant. Noa, the mother of an autistic adult and an activist, who was involved in the amendment of the National Health Insurance Law in 1998 that mandates these services, explained that:

It [the amendment of the national insurance law to include paramedical services for autistic children] began from a lawsuit, then it went through the health maintenance 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, the mother of an autistic adult and an activist).

Noa explained that the 1998 amendment to the law that allowed autistic children to receive paramedical treatments was accepted only after a struggle for the rights of autistic children to be equal 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 for which the parents of autistic children could claim they had similar needs. Those who promoted the amendment realized that expanding it beyond the age of 18 would be very difficult because it would demand a novel decision that might affect the entire disability community and not just autistic individuals. Noa’s explanation, therefore, indicates the claim that 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 made at that time is the reason services are available until the age of 18 and not beyond.

Moreover, contrary to the common perception held among staff at the MoH, the qualitative inquiry demonstrated that autistic adults, their relatives, and professionals who work with autistic adults consider paramedical services to also be essential 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 out the need for paramedical treatments as the “hottest,” most prominent problem facing autistic adults, Bat-el explained that denying autistic adults these services means denying them development in their adulthood. While occupational centers provided by MOLSA are intended to fill autistic adults’ time with productive activities, they do not aim to promote the daily capacities of autistic adults, nor do they aim to expand autistic adults’ knowledge. Paramedical services are therefore necessary to assist an individual in their self-development throughout their adult life. Bat-el, who was referring to individuals who require comprehensive assistance, added that in residential facilities, the MOLSA requirement for paramedical treatment is also very minimal, leaving the autistic adult with no actual prospect of future development.

The need for paramedical services, however, is not limited to non-verbal autistic adults or to those who also have cognitive disabilities. Diverse interviewees stressed the need for paramedical services to be provided for autistic individuals across the spectrum. An outstanding example of this need came up in Jude’s interview. Jude, an autistic adult, the mother of an autistic adult, and an activist in the autism field, who lives at Israel’s periphery and runs a private business, 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, the mother of an autistic adult, and an activist in the autism field).

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

In addition to exemplifying the need across the spectrum, Jude’s case demonstrates two important issues regarding paramedical services that were also stressed by other interviewees. First, paramedical services should be available throughout an individual’s life and should be suited to the individual’s changing needs. In Jude’s example, it was only when her son began high school that the need for mitigation of this social interaction became apparent. During adulthood, different needs may emerge that require mitigation in certain scenarios. These include, for example, helping with executive functioning when starting a new job, or assisting with personal relationships; therefore, services should be tailored to the individual and should be flexible enough to assist with the most urgent needs. The second issue that Jude’s case raises is that neglecting paramedical services creates inequalities among autistic adults. While Jude was fortunate enough to have the resources to pay for someone to come with her to her son’s high school, others who did not have these resources would have no assistance. Therefore, not providing autistic adults with publicly funded additional complementary services that will respond to their changing needs in effect diverts those from higher socioeconomic classes to the private sector and creates inequalities among autistic adults.

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

The survey included dedicated questions about additional paramedical services for autistic adults. The first question, adopted from the needs assessment survey of the 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. Of those who answered this question (n=89), 64% marked three or more services that they do not receive but need to receive or that they receive but they need more of. 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 for the needs for additional services). These findings further indicate that the common assumption prevalent among policymakers in the MoH, that autistic adults do not genuinely need additional paramedical services, is without basis. The fact that almost two thirds of responders answered that they or their relative need three or more services indicates the current policies that prevent autistic adults from obtaining additional complementary services leave autistic adults’ needs unaddressed and prevent their self-development and full participation in the community.

The survey results also stress the need for these services, by illustrating the extent of use of these services provided by the private sector. For the question regarding the barriers to additional paramedical services, among the responders (n=80), 21% identified 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 means of payment for complementary services provided, for which responders could choose more than one answer from several available. Among the responders (n=80), 80% answered that they used private funding either by paying out of pocket or via private insurance, while 76% responded that they received public funding for the services, which was provided either by health maintenance funds, MOLSA, or the NII. Collectively, these results demonstrate the indirect effect the current policies have on diverting individuals to the private sector. Although 76% of responders do receive publicly funded paramedical services, probably through the programs they attend, these are clearly not sufficient, as 80% of responders also utilize private funding to cover the remaining expenses for services they need. Furthermore, as current policies prevent almost all public funding of additional services, it is not surprising that service costs were identified by one fifth of responders as being a barrier to these services.

In summation, the findings from both the qualitative and quantitative inquiries clearly indicate 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 either historically or by most of stakeholders operating in the field. There is wide recognition within the autism community that additional paramedical services are needed throughout an autistic individual’s life. These services should be individualized and flexible enough to accommodate the changing needs of the adult throughout his or her life and to allow them to lead an independent life in the community. Moreover, at the population level, this section demonstrates that the current absence of paramedical services in the relevant policy diverts autistic individuals and their relatives to the private sector and therefore creates inequalities among autistic individuals based on their financial situation. The current sociopolitical context that this section reveals and which denies autistic adults equal access to much-needed complementary services is preventing these individuals from fully participating in the community. Preventing participation clearly affects other SDHs, thus, enabling labeling this policy gap as a SDHI that further marginalizes this population.

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| 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 the Bureau of Autism Services (2011) or were suggested by committee members or stakeholders who reviewed the questionnaire.

## 5.5. Conclusions

To conclude, this chapter analyzed the SDHIs that influence the social position of autistic adults in Israel. Focusing on the healthcare system, the chapter argues that autistic adults are marginalized in the Israeli healthcare system due to perceptions held by individuals within the system, ignorance regarding autism, and discriminatory policy decisions. These sociopolitical circumstances negatively affect the health of autistic individuals and their ability to participate fully in the community; they also have harmful implications for the autistic community collectively.

The chapter first explored the mechanisms that prevent the introduction of regulations to reduce the barriers to accessing the healthcare system, covered in the previous chapter. These mechanisms include two perceptions regarding autism that contradict the policy of mitigation. One is that autism is a disease that requires treatment and not modifications to the system. The other is that the only disabilities that require structural modifications are physical disabilities. Autism, which is an “invisible” disability, does not fit into this definition, therefore, it is not perceived as requiring service accommodations. The chapter illustrates that these perceptions have a foothold throughout the system, from the administrative level to the practitioners on the ground. These perceptions are accompanied by alternative perceptions that do recognize the need for treating adults with autism as a social group that requires specific mitigation. The dominance of the notion of autism as a disease, however, limits the introduction of mitigations for autistic adults in the healthcare system. Therefore, this can be considered an SDHI or, in other words, 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 healthcare professionals regarding autism. Throughout the system and across disciplines, professionals themselves, autistic adults, and their caregivers have reported gaps in practitioners’ knowledge. This lack of knowledge was attributed to unfamiliarity with autism among senior professionals, combined with the absence of structured training on the subject for future generations of healthcare professionals. In addition to impeding the introduction of measures to overcome barriers to the healthcare system, this lack of knowledge was found to be marginalizing autistic adults, as they are provided with unsuitable care, especially mental healthcare, and because there is an absence of alternatives, which diverts them to child therapists who do have knowledge about autism. This section concludes that discrimination against the autistic adult population in the healthcare system is aggravated by the ignorance of professionals and the neglect 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 unaddressed were identified during the qualitative research. The first is the exclusion of autistic adults from the mental healthcare reforms, the second is the inability to obtain a publicly funded diagnosis of autism in adulthood, and the third is the absence of publicly provided additional paramedical services for autistic adults. After establishing both qualitatively and quantitatively that there is a great need for mental healthcare services for autistic adults in Israel, a need that has also been reported in the literature from other countries, it is argued that the exclusion of autism from the mental healthcare reforms discriminates against autistic adults in several ways. The lack of publicly funded services discriminates against autistic adults from lower socioeconomic groups and reduces the quality of mental healthcare; by allowing treatment only for autistic individuals with a dual diagnosis with an additional mental disability, this decision prevents autistic adults from getting much-needed assistance for their daily challenges; for individuals with additional mental disabilities it also means they must choose between suitable services for autism or for mental disabilities, which might be more widely available and diverse; it hampers efforts to promote knowledge about autism by not providing funding for training about autism; and, finally, it contradicts the goal of the mental healthcare reforms, as it creates further separation between the autistic individual’s physical and mental care. These discriminatory processes, which derive from the policy decision to exclude autism from the mental healthcare reforms, further marginalize autistic adults and harm their mental healthcare; thus, they can be regarded as another SDHI.

The inability to be diagnosed with autism in adulthood in the public healthcare system also marginalizes autistic adults. On a personal level, it denies autistic adults their fundamental right to know their diagnosis, and it leaves them on a continuous quest regarding their difference. Furthermore, not allowing publicly funded diagnosis in adulthood is denying autistic individuals access to the services that are available for this population, both public services and the additional assistance that is provided by the autism community. On a population level, this decision creates disparities among autistic adults in favor of those who come from an affluent background; also, because this decision left this practice completely unregulated until recently, it harmed even those who were diagnosed. Finally, this decision interferes with the expansion of the autistic community as it deprives some individuals of their ability to be formally recognized as part of it. Having no policy in relation to the gatekeeper of services is therefore another SDHI faced by autistic adults in Israel.

Finally, the termination of the right to obtain additional complementary services for autistic adults upon reaching the age of 18 years was identified as another SDHI. Although these services do not directly affect health, their absence clearly restricts the ability of autistic individuals to continue their development throughout adulthood and to fully participate in the community. The quantitative findings clearly indicate that most autistic adults need three or more such services, unlike the commonly held belief among healthcare professionals and MoH officials. Thus, the policy decision to end additional paramedical services at the age of 18, which constitutes part of autistic adults’ sociopolitical context in Israel, further discriminates against this population.

To sum up, the sociopolitical context of the healthcare system in Israel marginalizes autistic adults in many ways. This analysis, which is the first to be conducted in Israel, is important first and foremost in that it identifies health policy issues that should be urgently addressed by policymakers and the autism community. In addition to the practical significance of this chapter, this analysis demonstrates the need to understand autism as a social position that allows an examination of the relevant SDHIs. Being an autistic adult in Israel does not mean just having a unique neurological structure, or even having barriers to healthcare that resemble those faced by autistic individuals elsewhere, such as in the United States. It means autistic individuals are deprived of their right to be diagnosed, that they do not deserve mental healthcare services for the difficulties they experience as an autistic person, they are defined as having a disease or not having a disability, they are treated by practitioners who do not recognize their uniqueness, and they do not have access to the additional services they need. This situation, while it might exist elsewhere, is far from necessary or inevitable. As these circumstances directly and indirectly dictate health outcomes, it is crucial to recognize them if we wish to understand the health inequities faced by autistic adults and how to reduce these inequities.

1. Form 17 is a payment voucher or a letter of financial obligation that constitutes an official authorization given by the health maintenance fund to use services provided by facilities that are not part of the health maintenance fund provision centers (see footnote in Yonatan-Leus, Strauss & Cooper-Kazaz, 2021). This form is used to secure the financial agreement between the health maintenance fund and the actual provider. Tel HaShomer medical center is a government-owned center, therefore, this form must be obtained prior to accessing services at Keshet Clinic. [↑](#footnote-ref-1)