# 4. Autistic Adults’ Barriers to Healthcare Services

In research into the social determinants of health (SDH), autism is categorized as a health outcome. As explored in my Introduction, my research adopts the analytical framework of the social model of disability (SMD) and asserts that autism is a socially constructed disability. According to this perspective and by adopting appropriate social mitigations, individuals with autism could participate equally in society. To support this research standpoint, in this chapter I will seek to describe and analyze the barriers to healthcare services faced by adults with autism in Israel; furthermore, I will claim that the elimination of these barriers will allow adults with autism to gain equal access to healthcare services. Much like inequalities that result from cultural differences, which the Ministry of Health (MoH) in Israel has decided to combat with cultural and linguistic adaptations (Cultural and Linguistic Adaptation and Accessibility in the Health System, 2011), in this chapter I make the claim that by undertaking neurological adaptations, inequalities between autistic and neurotypical[[1]](#footnote-1) individuals in the healthcare services could be reduced. Illustrating how these barriers to adults with autism can be lifted will allow autism to be recategorized in light of the SMD as part of the ‘social position’ of the individual in the SDH framework and not as a health outcome. This chapter will also set the ground for the analysis in the subsequent chapter, which utilizes autism as a social position to investigate the social determinants of health inequalities (SDHI) facing adults with autism in Israel.

To claim autism is a social disability, the chapter focuses on the unique traits of autism and explores the collision between these qualities and the common practices in the healthcare system. From this position, the chapter argues that, as with gender oppression, which is social marginalization structured around an innate biological quality – sex (Manandhar et al., 2018), marginalization of individuals with autism is based on their intrinsic neurological differences when they encounter unsuitable, oppressive social structures. Illustrating that it is the social constructs that are marginalizing and not the biological difference itself will highlight that autism is a social position. For this purpose, three intrinsic traits that were found in the qualitative investigation to be the conflictual core causing barriers to the healthcare system are explored: communication difficulties, the need for familiarity as a manifestation of repetitive behaviors, and sensory differences. Each trait is meticulously analyzed and examples of strategies for structural changes to eliminate it as a barrier are presented. Quantitative findings that are relevant to each specific theme are also explored. To understand the importance of addressing these barriers and to complete the analysis from an SDH point of view, although not the focus of this research, the implications of these barriers on the health of individuals with autism is illustrated. Furthermore, the mechanisms by which these implications affect health are analyzed.

According to the DSM criteria (APA, 2013), communication difficulties and repetitive behaviors are essential traits for a diagnosis of autism. Sensory differences, which can manifest either as hypersensitivity or low reactivity to stimuli, are considered to be a sub-criterion for the repetitive interest major criteria, but these differences are known to be very prevalent among individuals with autism (Crane, Goddard & Pring, 2009). Together, these three qualities constitute the unique intrinsic traits of individuals with autism, and all were found to affect autistic individuals’ access to the healthcare system in distinct and diverse ways. These qualities, as will be explored, have been found to affect accessibility in two settings during an encounter with the medical system. Unsurprisingly, these settings are during the intimate interaction with a service provider and during the bureaucratic process to get to see the service provider. This distinction is crucial as each conflictual encounter should be addressed by different policies: one that equips providers with the tools to manage the barrier, the other that establishes an accessible administrative structure. Despite these settings having different policy implications, this chapter is organized according to the different aspects that were identified to be influential during these encounters and not the settings themselves, as many barriers affect both settings.

## 4.1. Communication differences as a barrier to healthcare

Communication differences were raised by various interviewers as a major barrier to accessing healthcare services. These differences included: a distinct rationale for communication, difficulties in expression, longer processing time, alternative communication manners, concretization of the message, and difficulties in asking for assistance. It should be noted that these communication differences are easily understood when discussing nonverbal autistic individuals, yet they are also profound in verbal individuals who communicate in an autistic fashion, as will be discussed.

### 4.1.1. Distinct rationale for communication

Communication as a concept is usually simplified as the ability to exchange messages. However, the analysis of the qualitative interviews demonstrates that to fully comprehend the communication difficulties an adult with autism faces when encountering the healthcare system, the concept of communication must be broken into pieces and then explained piece by piece. Ronen Gil, an individual with autism and a well-known advocate for autistics, described very accurately several basic concepts about the communication process when explaining his own perception of autism:

“We have also a different manner to communicate, and here I want to say that ‘it is not a deficiency but difference’, our natural way to communicate is different. And when I say our natural manner of communication, I talk about everything that is related to communication. I talk about how is it best to communicate? Why even communicate? What are the motives for communication? How to communicate in efficient way, ok?” (Ronen Gil, an autistic individual and an activist.)

Ronen, in his decisive style, began his explanation by deconstructing the communication process and asserting that autistic individuals are not deficient but different. To explain his position, he first dismantled the idea that communication differences are merely based on the different means of exchanging information. According to him, this difference also includes the motives for and the setting in which communication is taking place. Although in this statement Ronen was not referring directly to an encounter with the healthcare system, when opening these dimensions of communication to observation and criticism there is a need to challenge this encounter. For example, the known setting of a physician’s office or a hospital as a place to discuss illness should be challenged. While the neurotypical society understands that a clinic is the setting in which you explain to a stranger with a professional title what is disturbing you and you ask for their help, to an individual with autism this setting might be considered to be a playground, or worse, as a place in which painful intrusions to the body, called examinations, are held, with no real rationale for them. Why, for instance, can a residential place that has the potential to be a more welcoming and trust-building setting than a socially imposed one, not be the place where an autistic individual shares their difficulties with a stranger that society refers to as a doctor? Ronen’s description mandates us to begin examining the differences in communication between autistic individuals and neurotypical society by rethinking the basics of what is socially accepted.

The setting is not the only dimension of communication that needs to be explored; the goals of communication, Ronen asserted, should be questioned as well. Is it possible that when seeking assistance, the goal of an autistic individual is different to the one that is assumed by healthcare service providers? Numerous instances were raised during the interviews of discrepancies between autistic individuals’ need for help and the actual assistance that was offered to them. These included behavioral interventions that were offered to an autistic adult, that all he needed was a key to ensure he could not be locked in the laundry room by mistake (Bar and Tomer, parents of an autistic adult); and sleeping pills that were prescribed to suppress anxiety while traveling to the employment center (Dr. Efron, psychiatrist), when a different means of transportation could be much more helpful. The most obvious example, however, of the discrepancy between the goal of communication that is assigned by an autistic individual and a provider, was described by Jude, an autistic individual who is the mother of an adult autistic son and an activist:

“I need that someone direct me. I need help to understand what is wrong. When I am coming to the doctor and say there is something wrong […] Help me find what is wrong. […] You as a doctor expect that I will give you symptoms and you, he…, ‘wonderful I will give you a medication according to the symptoms’. I cannot give you symptoms, I need you to help me find, you are the doctor […] the distrust in professionals that was created along the years is still combined with expectations…” (Jude, an autistic individual, the mother of an adult autistic son, and an activist.)

In this quote, Jude described a situation in which her goal of communication was completely different than the socially accepted one. Her goal was to understand how she feels different, what is unusual with her body; on the other hand, the doctor, as is socially accepted, was asking about the unusual, about symptoms, to find the cause of these symptoms and treat it. This discrepancy in the goal of communication can result in misunderstanding, frustration, and disbelief between the two parties involved. Echoing Ronen’s assertion that any analysis of communication should include an understanding of the motive for the communication, Jude’s situation exemplifies that even when there is an awareness of the different goals, the autistic individual who is the service recipient is expected to align with society and not vice versa.

Mitigating these differences is possible, yet it requires flexibility and the will to make the necessary adaptations. First, although thought to be intuitive and socially accepted, the incentives and motives for reaching out for assistance should be clarified. Following such clarification, amendments to services could be introduced, or a patient could be referred to a relevant service provider that can meet the specific goal. In Jude’s case, an attentive physician could try to explore with her what is different with her body or refer her to an alternative therapist for this exploration. The setting for the encounter could also be reconsidered. Options such as home visits by a family physician, or home hospitalization, should be offered and discussed with autistic adults as an alternative for their care. Dr. Golda, a psychiatrist working with autistic adults, argued exactly that when discussing the tendency following the Mental Health Reform to move mental health visits to a community setting:

“It is better to see these autistics in their environment, where they live. Not to take them to the clinic which is an unfamiliar place that takes them out from their routine. On its own it can inflict serious stress.” (Dr. Golda, a psychiatrist working with autistic adults.)

By questioning the community clinic as the best solution for the examination and treatment of adults with autism, Dr. Golda de facto problematized the setting of the communication. According to her observations, an obligation to arrive at an unfamiliar setting is itself a stressor, which can also affect the examination. Thus, a neurodiverse-accessible healthcare system would have to reconsider and negotiate the exact goal of a healthcare encounter and allow changes in the setting of the encounter. Given that these barriers to communication could be mitigated by structural accommodations strengthens the argument that autism is a socially constructed disability that should be regarded as part of the social position of an individual.

A neurodiverse-accessible healthcare system would also have to consider the manner of communication. The following sections deconstruct different aspects of the manner of communication that can create barriers for individuals with autism.

### 4.1.2. Difficulties in expression

Diverse interviewees, including adults with autism, parents of adults with autism, and healthcare professionals, raised the issue of the difficulty autistic adults have in expressing themselves. Given that communication difficulties are integral to a diagnosis of autism, this is not a surprising finding; however, if these difficulties are disregarded and not properly addressed, they can become a real barrier to services and a threat to health. Bat-el, for instance, an advocacy lawyer working with the autism community, described the importance of this issue for nonverbal autistic adults:

“One of the subjects we discuss is early detection. We, if we have something that hurt us, we will say. They [autistic adults] will not say. Especially those who are nonverbal. We won’t know that she feels pressure in her breast for a week, or for six months. We won’t know we need to do something… we need to consider proactive procedures that are not invasive as much as possible. It is not easy for physicians to understand what the autistic person has, because he is not telling his symptoms; and a lot of the things are being missed” (Bat-el, an advocacy lawyer who works with the autism community.)

Bat-el described how the difficulty that nonverbal autistic individuals have in expressing pain or symptoms can affect the ability of the physician to find a problem and treat it. She, together with others who advocate for autistic adults, suggested that given these circumstances a proactive approach that searches for treatable diseases should take place, so long as it is not too invasive. This proactive approach, which can be framed as an investigative approach to examination similar to that enacted in pediatrics, as Dr. Mor, a family physician working with autistic adults claimed in her interview she is using, is a form of mitigation that should be available for all adults with autism.

In the case of nonverbal adults with autism, it is intuitively understood how their difficulty in expressing themselves can be a barrier to services. Unfortunately, many other individuals with disabilities, such as patients with progressive Alzheimer’s disease, suffer from the same barrier. Nevertheless, it became evident throughout the current research that this is also a problem for verbal autistics who are conversant and actively participate in the community. Bruce, for instance, an adult with autism and an activist in the field of autism, shared his experience in the physician’s office, recalling:

“Physicians that I went to see throughout the years, at least some of them were very impatience, very. It is easy to silence me, very easy. So I don’t tell them what I think, but the thing is I feel I am trying, sometimes I really try, and they aggressively made me shut my mouth […] especially when you are on the spectrum and it takes you longer to explain yourself, so you won’t explain yourself good enough. So for meetings with physicians, it might be better that someone that know how to explain, be with them [with autistic adults], to summaries in a manner physicians understand. I think it happened to me twice this year that it really felt like the physicians are yelling at me as if I were impudent, but why? was I rude? I tried to explain my opinion” (Bruce, an autistic adult and an activist in the autism field.)

Bruce, who lives independently in his parents’ house, takes care of his mother, and has been employed in the past, described a distressing experience in the physician’s office. He noted that due to his difficulty in explaining himself and his slower processing time, physicians silenced him and were reluctant to hear what he had to say. Considering anamnesis is an essential component of the clinical process, the inability of a patient to express themselves, especially in a stressful and impatient setting, could be a major barrier to care. Bruce suggests that a mitigator should join the intimate meeting with a physician, to try and explain the issues raised by an autistic individual in a manner the physician understands. Bruce’s statement encompasses much more than just the difficulty to express oneself clearly, and later I will return to his quote; however, his statement highlights the fact that the difficulty in expressing oneself is not limited to nonverbal individuals with autism but is experienced by most autistic individuals.

Difficulty in expression clearly qualifies as a barrier to accessing healthcare services. Those who endorse the medical model of disability (MMD) will easily transfer responsibility to the side that has difficulty in expressing their opinion, that is, the individual with autism. However, it should be acknowledged that difficulties in expression viewed from the opposite direction are in fact a difficulty of the provider to understand. From this perspective, an SMD perspective, this barrier is socially constructed and can therefore be lifted by mitigating between the two sides of the communication end. It should be noted at this point that this barrier is also very relevant to the bureaucratic process. Difficulties in expression can manifest, for instance, when scheduling an appointment and may result in unwanted outcomes. The options for mitigation outlined by Bat-el, Dr. Mor, and Bruce are examples, among others, that can be enacted to remove or at least reduce this barrier for individuals with autism. Understanding that one of the core traits of autism is mostly a result of social construction of the system further strengthens the claim that autism is, along with other disabilities, part of the social position of an individual.

### 4.1.3. Longer processing time

Bruce, an autistic individual and an activist, cited above, pointed in his quote to another issue that accompanies the autistic communication experience: extended processing time. Although he coupled it with his difficulty to express himself, he added the time component to the equation, saying that with autism it “takes you longer”. Longer processing time was raised as a separate issue by several interviewees. Hila, the sister of two autistic adults and a guardian of one of them, explained when discussing her brother’s nocturnal enuresis:

“I don’t know, you cannot talk to him about it, he… speaks very slowly and mostly on his thought, he has thoughts, but he is not really explaining what.” (Hila, the sister of two autistic adults.)

Hila, echoing Bruce’s experience in the physician’s office, described not only a difficulty to express thoughts but also a slower pace of engagement. Considering that she, as his sister, finds it difficult to communicate with her brother given his slower pace of engagement, in a medical setting where the clock is always ticking, slower processing time can be a real barrier.

This barrier on its own, however, can be easily mitigated. Allowing extra time for engagement and explaining to providers the importance of patience as a mitigating tool is all that is required. Tiferet, a secretary in a psychiatric clinic that cares for adults with autism, shared her experience:

“They [autistic adults] are probably stuck, and then they need a lot of guidance and explanations, and repeat all kind of things again and again, they really, really need accommodation […] I repeat many times on explanations, trying to simplify, clarify, write it down […], it requires a lot of patience as much as I can, I am not getting angry, I am not losing my temper” (Tiferet, a secretary in a psychiatric clinic that cares for adults with autism.)

Tiferet, in her description, did not just repeat the claim that adults with autism have difficulties in understanding and a longer processing time, she also portrayed what this type of communication requires from her, the provider. Mitigating the bureaucratic process, in Tiferet’s case, demands that when an autistic individual is ‘stuck’, there must be a willingness to repeat explanations to guide them and above all a lot of patience.

The examples above clarify that it is not just the lack of words or the difficulty to express one’s own thoughts that hamper an autistic adult’s communication with a service provider; the time frame required to process the situation and respond also serves as a barrier to communication. Given that the healthcare system operates on a tight schedule, whether in a doctor’s office where she has 10 minutes for a patient, at a pharmacy with a long queue, or on the phone when trying to schedule an appointment, it is not surprising that adults with autism find healthcare services inaccessible. Rushing care while on a tight schedule is a barrier for adults with autism to access healthcare services. This barrier could be lifted by a structural arrangement that allows individuals with autism extra time with a healthcare provider, together with an explanation to providers that patience is not just an expression of empathy but a service requirement, without which care could be reduced. Eliminating longer processing time as a barrier will allow adults with autism more equal access to healthcare services; as such, this example once again demonstrates how social structures discriminate against those with autism and that autism should qualify as a social position.

### 4.1.4. Alternative communication manners

At this point, it is clear that communication mishaps are an integral part of autistic adults’ encounters with the healthcare system. However, these mishaps not only occur due to difficulties in individuals’ expression or long processing times but also partially because of a failure to recognize and acknowledge the alternative communication manners that adults with autism utilize. Alternative manners could be different means of communication or alternative roots of communication. While different means of communications, such as augmentative and alternative communication (AAC) or written communication are visible, different roots of communication may be easily overlooked if not actively searched for. Ronen Gil, an adult with autism and an activist, in his interview when discussing the meaning of different communication, referred to an accurate example that Jim Sinclair, one of the founders of the autistic community, gave in one of his articles:

“Let’s say that you don’t know there is sign language of deaf people, you even don’t know there an option for this kind of language to be exist. And you walk the street, and you meet two deaf persons talking in sign language. You will see there a lot of things, a theater performance, impulsive and stereotype behaviors, you will see many types of things. One thing you won’t see there is communication. And this is the main thing that happens there.” (Ronen Gil, an autistic individual, and an activist.)

In this example, Ronen illustrated how easily an alternative means of communication can be missed. This example also shows that being unaware of a manner of communication does not mean it is not there, while interpreting it with the limited tools one has might result not just in taking the wrong meaning but in a degrading explanation. Whether it is sign language; the higher and lower tones used when speaking Chinese, that Rachel, a deputy head nurse in a tertiary medical center mentioned in her interview; the clicking sounds of Bantu languages (Bostoen & Sands, 2009); or the alternative roots of communication adults with autism utilize, differences in communication manners should be actively searched for.

Although most physicians and healthcare service providers are educated to adopt the MMD and would therefore claim no common manners of communication is equal to no communication at all, some professionals interviewed for this research recognized the importance of searching for alternative communication manners. Dr. Mor, for example, a family physician working with autistic adults in a residential facility pointed in her interview to a different type of communication that must be searched for when looking for expressions of distress:

“I think yes, it should be based on alertness of whoever is with them, alertness of their caregivers. Behavioral change, mood change, appetite, even if those are not obvious things like fever, dyspnea, or restless […] and then when you guide the caregivers to keep notice of these things, so there is a question if they will not overwhelm me with every small change. Now many, many of the changes are changes in behavior that is part of the autism or part of the medications or relate to the category of psychiatry.” (Dr. Mor, a family physician working with autistic adults.)

Dr. Mor adopts an empathic and critical stance, which actively looks for any sign of communication. It is clear from her words that she is not sure exactly what those signs of communication are, but she does agree that those signs are there, even in nonverbal individuals with autism. From her description, greater alertness and attention is needed to any sign of change that might mean communication, including behavioral, mood, and physical changes. In addition, Dr. Mor recognized that the search for communication is a quest for each and every individual with autism that will demand close collaboration with the immediate caregivers and many mistakes in the process as communication be relevant to other spheres in an autistic adult’s life; nevertheless, she asserts that this is essential.

Dr. Mor was not alone in recognizing the importance of understanding the alternative manners of communication used by individuals with autism. Rachel, a deputy head nurse in a tertiary medical center who is also involved in promoting the hospital’s accessibility, explained in her interview about a new approach the hospital is attempting. Together with residential places and organizations that take care of people with autism and cognitively impaired individuals in hospital surroundings, they created a form known as the traffic light form. This form should introduce the autistic adult to the hospital team upon arrival. Holding the form, Rachel said:

“I will explain the rationale [of using the traffic light form], when a patient arrives from an institution with some kind of disability, he has needs we are not aware of. We don’t know them, we don’t know how to make the services accessible, we don’t know how to communicate. We are not always refer to the person accompany the person as a figure to consult with […] these individuals will go through a slightly different route then the ordinary patient because they can’t wait, because noise bothers them [… the from will include] type of communication, action that could be made to ease the treatment operations, what helps the patient to relax, special words, needs, special equipment, functioning level, things that he or she likes, what makes him feel safe […]” (Rachel, a deputy head nurse in a tertiary medical center.)

In her explanation, Rachel reveals several principles that led to the development of the traffic light form. First, people with neurodevelopmental disabilities can communicate in their own way. Second, each patient has a distinct way of communicating and distinct preferences. As such, a medical team cannot a priori know or be familiar with every one of these. Finally, it recognizes there is a need to be attentive to these preferences and communication manners, to enable disabled individuals access to an alternative care process that is mitigated for their needs. I will return to this form later, as it encapsulates many more aspects that are relevant for mitigating the healthcare system. Here, however, it demonstrates that the quest for alternative manners of communication need not always be performed by healthcare service providers, but without their recognition and active request for these manners of communication during the care process these important alternatives would be left out and barriers to autistic individuals accessing the healthcare system will remain.

In terms of means of communication, the most apparent example for the need to accept and respect alternative means of communication arose during the advisory committee work. While most members could use either spoken or written communication, two committee members asked me to communicate with them using just one of these means. One committee member did not manage well with written communication and asked that all communication be conducted using audial means. To enable his participation, I read out entire sets of written text for him, including the research questionnaires and a summary of the research. He then told me his comments, which I transcribed to a written form that I then read back to him so that he could make any further comments. While this process demanded a major investment of time spent on the phone, it was necessary to enable his participation. Choosing not to respect his request would have excluded him from participating in this research. Conversely, the other committee member asked me to communicate with her only via written communication. Taking a phone call, for instance, or asking her to rush her comments on the final report, was not an option. The accepted, unwritten social convention that a phone call represents an urgent issue did not apply in her case. Other means of communication, such as AAC, also exist and must be considered and respected if an individual asks for them to be used (see, for instance: Iacono, Trembath, & Erickson 2016; Levi, 2019). Although this example are not directly from the healthcare services realm, its implication for the healthcare system are obvious. For instance, sending a form for written follow-up to an autistic individual who does not manage well with written communication, in practice means sending him with empty hands. Not respecting an autistic adult’s AAC when trying to schedule a follow-up appointment from the secretary’s office would mean that no appointment will be scheduled. Thus, it can be claimed that not recognizing alternative means of communication and allowing their use acts as a barrier to accessing healthcare services.

To sum up, an important aspect of the communication barrier faced by adults with autism during their encounter with the healthcare system is the reluctance of providers to acknowledge the alternative manners of communication that adults with autism use. The qualitative inquiry demonstrated that some healthcare providers recognize the need to look for alternative manners of communication and invest some effort in discovering them. Means of communication, despite being continuously developed and widely used by individuals with autism, are not always welcome in healthcare settings. Refusing to acknowledge these distinct communication manners, especially different means of communications, marginalizes adults with autism and deprives them of equal access to healthcare services. This example further strengthens the claim that autism is a component of the social position that is marginalize in the current context of the Israeli healthcare system.

### 4.1.5. Concretization of the message

The difficulties in communicating with a healthcare provider, however, extend beyond the interruption in the basic exchange of messages between the two or more parties involved. Even when communication is being performed using neurotypical manners, misunderstandings can easily arise and manifest as a barrier to healthcare. This barrier is often referred to in the scientific literature as a ‘language barrier’, which can result in a misunderstanding of a healthcare provider’s requests or instructions and affects many types of patient populations, such as immigrants (in Israel see: Fleischman, Willen, Davidovitch & Mor, 2015; in relation to autism see: St. Amant, 2018); nevertheless, the language barriers faced by autistic individuals are articulated differently. Many adults with autism that communicate in a neurotypical manner do understand the words that are being said to them, but they might understand them literally instead of with their socially attached interpretation. Barak, an autistic individual interviewed together with his partner, Shlomi, who is also autistic, gave a fabulous example of what literalization or concretization of language might mean when he explained his experience in school prior to his diagnosis:

*Barak*: “for example you did something [at school] and they [the teachers] are mad at you, so you ask: ‘what have I done?’ So you won’t do it again, and they tell you that ‘you know [what you have done]’, but it contradicts! If you knew you wouldn’t ask. Years later, Shlomi explained that other children ask this not because they really don’t know what they have done but… what have you explained? [to Shlomi]”

*Shlomi*: “so they… it is like they are like troublemaker, as if they are trying to… how can I explain it’

Barak: ‘never mind… something else […] from my experience with myself and with other autistics I saw a complete different understanding of stuff and behavior” (Barak and Shlomi, an adult couple who are both autistic.)

Although it is not health-related, this example uses a very common scenario that is probably familiar to most readers and demonstrates that the literal translation and the socially accepted translation could have opposite meanings. The phrase ‘what have I done?’ can be said literally, with the intention of discovering the answer, or as an act of trying to play innocent. Confusion between these two meanings, as Barak shared, can be harmful in a school setting. What is striking in this example is that mainly Barak, but also Shlomi, who was the interpreter of the situation in the past, struggle to explain the alternative definition in the interview. Both, when they hear the question, understand it literally. Barak ends by generalizing his experience to other instances and to other individuals with autism. The qualitative inquiry established that in relation to the healthcare system he is totally correct.

Among the other examples that were raised during this research, the example that Naomi, a social worker working on a program for autistic young adults, shared when discussing the setbacks of available psychiatric care, showed the importance of recognizing:

“Someone very, very emotionally overwhelmed, two hours ago she wrote in Facebook she doesn’t want to live in this world anymore, that she hates everyone, and she is not going to talk to anyone for a week. Two weeks earlier [before that event happened] we had to stop her physically from going to an orgy, this is the level of risk of that girl. Now she never hurt herself and we weren’t afraid she would do so, but there was something very, very intense. And he [the psychiatrist] sits in front of her, talk to her like a retarded child: ‘how do you feel? You are studying? Wonderful. What do you study?’ And he asks, ‘how do you feel?’ [and she answers] ‘fine’. Two hours earlier she was... ‘*now* I am fine, two hours earlier I was not fine, in that very moment I am feeling fine.’ We know how to question her, and it is like I need to mitigate her all the time” (Naomi, a social worker at a residential home for autistic adults; emphasis by the author.)

Naomi, who understood the language comprehension difficulties of the autistic woman she was escorting to the psychiatrist, explained how the manner by which the psychiatrist interviewed her could completely change his risk assessment. Asking ‘how do you feel’ was understood by that woman to mean the present tense, without any regard to her recent history, two hours earlier, of profound emotional distress and the expression of suicidal thoughts. This example illustrates that without paying special attention to the wording used during a conversation with an autistic adult, language can become a serious barrier to healthcare services. Moreover, Naomi’s final remark, that she must continually mitigate the autistic woman who is under her responsibility, suggests that this language barrier can be overcome if providers are taught to recognize such barriers.

Finally, it should be stressed that being concrete and literal works both ways. Individuals with autism, when they speak, might say directly what they think, disregarding any consequences that being honest might have on their surroundings. An example of such direct speech was mentioned by Cohav, an autistic woman, in her interview. Talking about her employment experience, she explained her difficulties in maintaining her position:

“My manager was diagnosed with a serious illness, everybody said ‘yes he will return’, and I said, ‘no way, he will die’, and he died. But saying it out loud, burned me [a Hebrew expression that means terminated my chances], and I told them […] the whole truth, the horrible truth. It is not accepted. You need to learn to play the game. Now I do not fight I am keeping silence. It will take me time to learn the issue of small talk conversations” (Cochav, an adult female with autism.)

Although Cohav’s example is taken from her work experience, it illustrates how a small talk conversation can create a negative atmosphere and even have consequences for the autistic individual’s reality. In a healthcare setting, a practitioner that is not familiar with the literal understanding experienced by autistic individuals may find them rude and offensive. In a calm environment, this may just result in a lack of empathy and motivation to provide care; however, in a stressful environment, such as is often found in healthcare settings such as emergency departments, this could result in a reluctance to give assistance or even deteriorate to violence. Although an instance like this did not come up in the interviews, Bruce, the autistic adult quoted above regarding his difficulty to express himself, mentioned that “it really felt like the physicians are yelling at me as if I were impudent, but why? was I rude? I tried to explain my opinion”. It is possible that, although he was just trying to express his opinion, his decisiveness and direct approach made him sound rude.

Whether this is the correct interpretation of this instance or not, the concretization of language is a barrier to autistic adults’ access to healthcare services that is affecting all levels of care and should be considered when promoting access for autistic individuals. This language difference can be mitigated by an external translator, similar to those provided for people who use sign language, or by teaching providers to manage such differences in an empathetic way. Furthermore, as written language is also open to interpretation, language concretization can be a barrier to healthcare services even in indirect ways (an example of possible misinterpretation due to concretization of written language can be found in appendix 4.1). Therefore, medical documents should be modified to be suitable for neurodiverse individuals. Above all, this section clarifies that there is a need to recognize autistic individuals as a distinct group that have specific language sensitivities, which can pose a barrier to their access to healthcare services. Recognizing autistic individuals as a distinct group further strengthens the claim that autism is part of an individual’s social position.

### 4.1.6. Asking for assistance

Autistic adults encounter another major barrier related to their communication abilities when trying to access medical services. This barrier results from a small yet important part of managing the healthcare system, which is the need to ask for assistance, to self-advocate, when utilizing services. While the scientific literature mainly discusses self-advocacy in relation to a patient’s encounter with their provider (Wiltshire, Cronin, Sarto, & Brown, 2006), the qualitative analysis made it clear that the bureaucratic process in itself, and not solely the encounter with the provider, is a major barrier for autistic individuals because it demands a great deal of self-advocacy. Navigating the healthcare system without a proactive engagement with the people working in it often means not obtaining the service that is needed. Dr. Yair, a psychiatrist who works with autistic adults in the community, when asked about the non-psychiatric health-related care of adults with autism, said:

“The ability of these people [autistic individuals] to execute their rights or to use services, is very low, because they are really bad in speaking to other people, and in self-advocacy so… so they don’t know how to utilize medical services […] what makes the difference is the parameters of how much your parents, your family, knows to ask or utilize, and how intense is yours or their distress [from the situation]. Someone who is not distressed, and which doesn’t know how to utilize [services] will not come [to the clinic]” (Dr. Yair, a psychiatrist who works with autistic adults in the community.)

Dr. Yair, speaking from his experience with autistic adults, declared very bluntly what he thinks prevents adults with autism from obtaining health services. Pointing to autistic adults’ communication difficulties and their ability to advocate for themselves, he argued that the severity of the situation and the abilities of the family to self-advocate is what dictates healthcare service utilization. Dr. Yair’s observation was echoed by other interviewees. Sigal, for instance, a mother of a young, autistic female adult and an activist in the autism field, discussed her ability to leave her daughter at home alone beyond short periods of time, because something might happen:

“They [autistic individuals] don’t know to ask for help. She can recite that she can ask for help na na na, but practically she will not do it.” (Sigal, mother of an autistic adult and an activist.)

Although pointing to a different situation in which help may be needed, this scenario demonstrates that even in a known environment, asking for assistance can be a barrier. Sigal’s description encapsulates an additional hurdle of this barrier. In her view, although her daughter comprehends that she may need to ask for assistance, she would not. Thus, attempts to train autistic self-advocacy as the sole strategy to address this barrier, without reciprocal efforts to mitigate the system, may be ineffective.

Omer, another individual with autism interviewed for this study, also described a scenario in which he did not ask for help despite needing it. In one of his former jobs, his co-workers would frequently scare him, for a joke. It got to the point where he accidently spilled hot coffee on himself and received slight injuries. In an attempt to understand this situation, I asked:

*Interviewer*: “Was there someone you could talk to [about the things that bothered you in the workplace]?”

*Omer*: “I did not know who it was”

*Interviewer*: “Ho… you didn’t know who it was?

*Omer*: “No”

*Interviewer*: “During the whole…so you just went there day after day, and there wasn’t a supervisor? Or someone above you?”

*Omer*: “There was the warehouse director, and I spoke with him, but it didn’t help” (Omer, an adult with autism.)

Omer’s replies to my questions further strengthens the notion that self-advocacy represents a considerable barrier. Omer encountered this barrier despite experiencing considerable difficulties in the workplace, and despite the fact that he was autistic having been disclosed to his superiors and colleagues. Our short exchange on the topic demonstrates two additional aspects that must be considered regarding this barrier. First, having a known supervisory figure does not necessarily mean to an autistic individual having an address to express needs. Only when specifically asked about a supervisor did Omer reply that he had someone, but this did not come up when he was asked about a person he could have expressed his distress to. Second, although not explicitly stated, Omer’s brief description illustrates that his conversation with the supervisor was more of a report than an explicit attempt to solve the issue. This signifies that an ability to express a need might not be sufficient, as this need must be heard by someone who can take further action in relation to it.

The ability to self-advocate is essential to be able to utilize the service required in the realm of the Israeli healthcare system. Having difficulties with this ability can create a genuine barrier for adults with autism. This qualitative analysis illustrates that addressing this barrier should include, in addition to efforts to develop this ability, a counterpart solution that includes a point person who is sensitive to autistic individuals’ inability to express their needs and who is prepared to advocate for autistic individuals. The fact that the need to self-advocate during the bureaucratic process necessary to obtain medical services has not, to my knowledge, previously been reported as a barrier to healthcare services, provides further support for the claim that individuals with autism represent a distinct social group that suffers from unique barriers to accessing healthcare services.

This section has tried to illustrate how one of the core traits of autism – communication differences – can be a considerable barrier to healthcare for adults with autism. To overcome this barrier, communication must be dismantled and understood in a multifaceted manner. The setting in which the communication is taking place needs to be questioned and altered accordingly; the goal of the communication must be clarified to both parties; preparation or mitigation by external helper should be considered to overcome difficulties in expressing oneself; additional time and patience should be devoted for any interaction with healthcare providers; alternative communication means and manners should be recognized, investigated, and accepted; the concept of concretization of language should be familiar to all service providers and be taken into consideration, both when communicating a message and when receiving one; finally, it should be recognized that in the Israeli healthcare system structure currently, many of the seemingly small bureaucratic procedures demand self-advocacy, which is a challenge for autistic individuals and thus represents another barrier to services. This section has further demonstrated that, with the right approach and structural changes, and by providing suppliers with the correct tools, these communication barriers can be overcome. By illustrating that these barriers are a result of an inaccessible healthcare system that marginalizes adults with autism, I have supported the claim in this chapter that autism is a distinct social category and should be analyzed as such in the context of SDH.

## 4.2. The need for certainty and familiarity

This section claims that the need for certainty and familiarity, which is one of the manifestations of repetitive behaviors, serves as a barrier to healthcare services for adults with autism. Furthermore, it asserts that this barrier, if properly addressed, could in many cases be minimized, and services could become much more accessible. Together, both claims further support the chapter claim that autism represents a unique social position that is being marginalized in the current structure of the healthcare system in Israel.

While communication differences might intuitively be understood to cause difficulties in a healthcare system setting, the reason why repetitive behaviors, which are considered one of the fundamental characteristics of autism according to formal diagnosis guidelines, can be a barrier to healthcare services should be explained. Understanding it in its most simplistic manner, which comes from observing the manifestation of this characteristic, that is, doing the same thing again and again, misses the reason for such behaviors. A dominant theme that emerged in the qualitative analysis has illustrated that in addition to being a manifestation of limited interests or structure of thought, repetitive behaviors serve the need to maintain certainty by returning to familiar circumstances. Unfortunately, most individuals’ encounters with the healthcare system often involve unfamiliar situations and are saturated with uncertainties, whether the encounter takes place during an unusual examination or during hospitalization. The conflict that emerges between the need for certainty and the uncertain conditions can cause a barrier and have long-term ramifications.

The need for certainty and the usage of repetitive behaviors to maintain such certainty arose in the interviews mostly as coping techniques of parents when their adult child experienced difficulty when encountering the system. One example that repeatedly emerged in the interviews was the practice of visiting a known pediatrician in adulthood instead of going to a new family physician. During the conversation about healthcare services, Bar and Tomer, parents of a 24-years-old autistic adult, mentioned that:

*Tomer*: “If we are talking on healthcare systems, we are trying, trying as much as we can to go to places where they know us, that they are familiar with him. So they won’t be things entirely new.”

*Bar*: “Until recently we went to his pediatrician, until he retired”

*Tomer*: ‘Until he retired, it was the same pediatrician, he [our autistic adult son] knew him and he felt comfortable with him’ (Bar and Tomer, parents of an autistic individual.)

Bar and Tomer not only stated they still take their son to a pediatrician but also revealed the reason they continued to attend his office: the familiarity with the place. This familiarity, according to their description, works both ways. The physician and their office staff are familiar with their son, thus avoiding any inconvenience, while their son is familiar with the place and feels comfortable there. Among the interviewees, the oldest autistic adult that still went to his pediatrician was Carmit and Tuvia’s son, who was 34 years old.

Following the qualitative analysis, to understand the scope of this phenomenon a question was added to the survey about the frequency of replacing the family physician. Among the responders, (n=102) 20.6% stated they were still visiting their pediatrician. The age range of this group was 19 to 30 years (average 23 years). Of those who still visited their pediatrician, 71.4% were verbal and answered the survey themselves. These quantitative findings indicate that a fifth of the population visit their pediatrician in adulthood, most likely because they prefer to preserve the familiarity of their healthcare provider rather than search for a suitable adult alternative. The age range of this population indicates that this practice continues into individuals’ thirties, and the fact that the majority who still engage in this practice answered the questionnaire themselves implies it is not related to a relative convenience practice to avoid stigma, but to a genuine need to maintain familiarity.

The technique of using familiar places was not limited to seeking continuous care from a pediatrician throughout adulthood. For instance, later in the conversation, Bar further elaborated on their coping strategy within the healthcare system:

*Bar*: “Lately I developed this something, everything that he does in routine works well with him. So even if blood tests are not needed, I take him every year at the summer to do blood test so he would have a … [routine].”

*Tomer*: “When he had to go through examinations before starting his national service, I went through two infirmaries in three rounds, and in each round, I had to convince him for at least half an hour. At one of the rounds the time frame for conducting the examination had passed, after 10 am they are not sending blood tests, and we had to go and come back in a different day.” (Bar and Tomer, parents of an autistic individual.)

Bar’s description of her practice to take her son for an annual blood examination, even if not medically indicated, highlights the importance of routine when utilizing healthcare services. While this practice is well known with autistic individuals in other spheres of life (on the use of repetition with autistics, see Lequia, Machalicek, & Rispoli, 2012), it has not been recognized as a barrier to accessing healthcare services (Mason et al., 2019; Walsh, Lydon, O’Dowd, & O’Connor, 2020), despite its anecdotal use in intervention programs at healthcare service settings (Walsh, O’Connor, Walsh, & Lydon, 2021). Although her practice raises questions about risks and benefits to their son, her partner’s description of going back and forth several times for blood examinations and each time needing to go through a lengthy process of explanation illustrates the importance of such practices. It exemplifies that unfamiliarity could really be a barrier, as not everyone would agree to lengthy and repeated visits to the infirmary just for blood tests. Moreover, the quote emphasizes that with proper arrangements that allow for provision of care in the same place and time this barrier could be alleviated. Unfortunately, according to some interviewees, among them Noa, a mother of an autistic adult individual and an activist in the autism field, this practice is not always available because the sick funds look out for their own financial interests before the needs of autistic individual.

Accommodating the uncertain and unfamiliar environment of the healthcare system can be achieved using another technique: early preparation and prior introduction. The qualitative inquiry revealed that this technique is utilized by diverse stakeholders. Tali, the grandmother and guardian of a nonverbal autistic adult who was residing at home, explained the significant effect a simple explanation could have:

“I went two days before we had the appointment, and I defined the problem [the expected difficulties during the examination]. The radiology institute made a great issue from getting him into the CT machine […] The kid [her adult grandson] heard the simple instructions at the institute, climbed the machine, laid down still, but really he was more precise than us […] ten minutes and the radiologist and the other doctor who was inside, because they [at the institute] heard he is autistic [and thought additional help from anesthesiologist will be required], were astonished” (Tali, a grandmother and the guardian of an autistic adult.)

Tali’s grandson, despite being considered difficult as an autistic individual and requiring extra personnel and attention, accomplished the CT examination effortlessly following a mitigating explanation and surprised all parties involved. Tali’s example also demonstrates the value of preparation for medical providers. In this case, it allowed them to plan for the arrival of her grandson and to reduce possible stigmas they might have had on autistics. Although it cannot be guaranteed that such an intervention will be successful each time with every autistic individual, the simplicity of this measure and the fact it was mentioned repeatedly demands that it should be attempted. Moreover, it illustrates that the barrier of unfamiliarity can be mitigated.

The importance of the practice of preparation to enhance autistic adults’ certainty and familiarity with medical procedures was greatly reinforced by a counter example raised by Einat, an autistic woman, an activist in the autism field, and the mother of an autistic individual, who was part of the research advisory committee. During a discussion on the importance of preparation, she recalled an instance her son experienced before having a gastroscopy examination. In an attempt to ease the examination, she explained to her son almost all stages of the expected procedure, following the explanations she received from the attending physician. This explanation included the entire process, from the injection of the sedative to the insertion of the camera through the oral cavity. When her son arrived, he sat in the examination chair and was about to go through the procedure; he was then asked to insert a protective plastic into his mouth. Although he had agreed to the examination, and he understood what was about to happen next, he refused to insert the protective plastic, which was not part of the original sequence of events explained to him. Due to the incomplete explanation that missed just one stage of the procedure, the entire examination was almost canceled. Fortunately, despite involving brief distress that included an awful attitude from the physician, after additional reassurance from his mother he agreed to proceed (Einat, personal communication, July 18th, 2021).

Einat’s example illustrates that unfamiliarity can be a real barrier to healthcare services. The fact that such a ‘small’ fraction of the examination was not well communicated in advance meant the entire examination was jeopardized, emphasizing the significance of an exact and detailed explanation for an autistic adult’s ability to participate in a medical process. Proper preparation, as Einat tried to do with her son, could eliminate this barrier and allow equal access to the healthcare system for individuals with autism.

Shlomi, an autistic individual, interviewed together with his partner, when asked what could be done to improve healthcare services, emphasized that accurate preparation was also important in relation to the bureaucratic process:

“I need to understand what exactly is the problem and what is going to happen with me. A detailed technical information on the problem and the solution. What are the next steps? […] In case there is no other option but meeting the doctor. A photo of the doctor, of the room he is treating, of the place [the infirmary] will be much better to someone that is arriving to a new location. […] If I don’t know how the place looks like and how to arrive and it makes me anxious. If I had a video system of what happens or even pictures it will give me a much better access” (Shlomi, an autistic individual.)

To gain access to healthcare services, Shlomi argued, means for autistic individuals knowing what problem they have, what they are expected to go through next, and then comprehending what these next steps will include and will look like. In addition to this assertion that sums up previous interviewees’ quotes, above, he argued that an accessible system would also prepare him for the process until the medical procedure itself, from illustrating the room in which the examination is intended to take place to the route to get to this room. Framing it as an access issue, Shlomi’s quote confirms that unfamiliarity and the need for certainty are barriers for autistic adults to access healthcare services. His practical suggestions on how to alleviate this barrier demonstrate that this is a socially constructed barrier that, with suitable practices and mitigation, could be removed.

To conclude, autistic adults’ need for certainty and familiarity with the medical system, procedures, and bureaucratic processes is a barrier to their access to healthcare services. For an unfamiliar and often unexpected environment such as the healthcare system to alleviate this barrier, two practices should be and are utilized. The first is returning to a familiar and known environment. The second is the use of preparation and a detailed explanation of what is about to happen. An accessible system would have such procedures embedded, to alleviate this barrier, for example suitable forms that explain in detail what one should expect when going into medical procedure (for an example of an unsuitable explanation form see appendix 4.2). Considering that this is a structural barrier for adults with autism that can be relatively easily eliminated, it further supports the claim that autism is a socially constructed disability and is part of the social position of an individual. It also illustrates that in the current context, this social position is being marginalized.

## 4.3. Sensory differences

Sensory differences, although not considered one of the main characteristics of autism, are recognized as part of the formal diagnosis minor criteria and are known to be prevalent among individuals with autism (Robertson & Baron-Cohen, 2017). This section argues these differences, which can manifest as hypersensitivity or reduced stimulation, mean that the current Israeli healthcare system structure creates barriers to autistic adults in two ways. First, sensory overload within healthcare settings can cause autistic adults to experience anxiety and an overwhelming sensation, to the extent that it prevents them from seeking services. Second, hyperstimulation or low sensations of pain or symptoms can result in an incorrect diagnosis. The following section explores the manifestation of these sensory differences in the healthcare system and illustrates that they do not have to be a barrier if proper accommodations in the system are introduced. Together, these arguments add another plank to the overall argument of this chapter, that autism is a distinct social category that is being discriminated against in the current Israeli healthcare system.

### 4.3.1. Sensory overload

Sensory overload was identified as a barrier to healthcare services. Diverse interviewees described waiting areas as sensory overwhelming places. The combination of fluorescent lights that flicker and a noisy and often smelly environment makes the waiting area unbearable for adults with autism. Jude, an autistic adult, a mother of an autistic adult, and an activist in the autism field, mentioned waiting areas as a guanine difficulty during her interactions with the healthcare system:

“The other thing is accessibility at the waiting area. We discussed that if I don’t have a scheduled appointment I need to sit and wait. This is a nightmare. I don’t speak about this that everyone coughs in your face. Ok. Everyone speaks out loud, speaking in their phones and yelling, hearing music out loud. And the fluorescent lights, which you probably heard already from everyone [interviewed for the research], it is a nightmare, these fluorescent lights. […] I sometimes prefer going to a private clinic, pay out of my pocket. I am a member of a sick fund, [but I prefer] to come, pay, get into the doctor office, receive what I need, one-two and get out. And not sit and wait in the queue at the sick fund clinic” (Jude, an autistic adult, a mother of an autistic adult, and an activist at the autism field.)

Jude described her experience in the waiting area as a nightmare. This nightmare is caused by the fluorescent lights and the noises surrounding her, which are unbearable for her. Jude not only framed this issue as an access issue identifying sensory overload as a barrier to the healthcare system from the initial sentence of the quote but also explained that waiting areas prevent her access to such an extent that, despite having public insurance, she seeks alternatives in the private sector to avoid this obstacle. Her choice demonstrates that the overwhelming experience in waiting areas is an avoidable barrier that can be mitigated by changing these settings to be a more suitable sensory environment. In the current system, only those who have capital to invest could have access to such accessible services.

Rachel, a deputy head nurse in a tertiary medical center and who is also involved in promoting hospital accessibility, was not only aware of the stress that waiting areas can cause but also suggested a similar solution to the one Jude uses:

“Maybe the hospital needs to devote a different place to treat those [autistic] patients not within all the chaos and the crowd and the mess of the emergency department […] They might need a different place quieter, calmer” (Rachel, a deputy head nurse in a tertiary medical center, who is also involved in promoting hospital accessibility.)

Rachel, affirming autistic adults’ difficulties in crowded and noisy areas, suggested dedicating a place within the emergency department for autistic adults to wait and receive treatment. Unlike Jude’s solution, which separates services that are accessible for autistic individuals from those used by neurotypical individuals, Rachel’s solution is an inclusive one that demands dedicated areas within the system to accommodate the needs of autistic adults. Earlier in the chapter, Rachel was quoted regarding the traffic light form. Describing this form, she also mentioned the possible difficulties in waiting areas and that those who experience this difficulty could be directed to a slightly different, more accessible treatment root in the emergency department. These are mitigation measures that Rachel is suggesting, while stressing that although the solution to this barrier has yet to be decided, it could be overcome with the correct structural changes.

Another alternative to address the barrier waiting areas pose to autistic adults was suggested by Smadar, an autistic woman and the mother of three autistic children. Talking about her struggles within the healthcare system, Smadar shared her experience of a wait to see a gynecologist:

“I didn’t have an appointment and it was really crowded that day, and I accept it, I am not alone [others need to schedule urgent appointments]. But I need to sit four hours in the waiting area with the fluorescent [lights] I almost pulled out all my hair. Now you can say that I need to get in [to the doctor] first, but maybe the woman next to me has more medically urgent issue, so if it is possible that I won’t wait at the crowded waiting room that has no windows, and the secretary will send me a message five minutes before my turn, and I will wait in the park that is located nearby and come, that could have been very helpful to bear this waiting. (Smadar, an autistic woman and the mother of three autistic children.)

Smadar, echoing the difficulties Jude had mentioned regarding fluorescent lights and crowded waiting areas, also describes an unbearable situation. Unlike Jude, and taking into consideration the limits of the public healthcare system, she suggested a different approach to overcome the waiting area barrier – to allow autistic individuals to wait outside and inform them when their appointment time has arrived. Mitigating services using this technique could be easily implemented, yet in the current neurodiverse-inaccessible healthcare system structure, this mitigation is not widely available.

The qualitative inquiry demonstrated that sensory overwhelming conditions, which often exist in waiting areas, are a barrier to autistic adults accessing healthcare services. The interviewees suggested several strategies to overcome this unbearable barrier, some of which could be easily applied within the system. These examples affirm that individuals with autism represent a distinct social group that, with the correct structural changes, could have equal access to services.

### 4.3.2. Hypersensitivity or reduced stimulation

The second barrier adults with autism face in the current Israeli healthcare system that relates to their sensory differences manifests during their encounter with health practitioners. It became evident during the qualitative inquiry that the sensation of pain or the interpretation of sensory stimuli as pain in autistic adults differs from that experienced by neurotypical individuals. Given that pain is a marker of disease that deserves to be addressed, experiencing it or not experiencing it in uncommon circumstances can lead to inappropriate diagnosis and treatment. While sensory experiences may vary from one individual to another, the fact that many clinicians are unaware that sensory differences are common in the autistic population and do not respect autistic individuals self-reporting of pain is causing a barrier to equal quality of care. Sigal, the mother of an autistic adult woman and an activist in the autism field, shared an experience she had with her daughter, who was suffering from pain in her pelvic area:

“We arrived at an anus specialist because she was… she had days that she could not sit from the pain she had. He didn’t find anything. He told me ‘Miss everything is fine, maybe it is something emotional’. You understand, it is like they are not looking. If I was not looking the information myself and concluded [like he said] it is something emotional… And I am speaking about my child’s quality of life, our quality of life because the yelling that were going around the house […] They know she has the diagnosis [of autism] they know she has sensory sensitivities, in a very high levels, so they just say she feels it stronger than the ordinary person… and I need to go and search” (Sigal, the mother of an autistic adult and an activist.)

Sigal’s daughter’s physician, who could not find any objective cause for her pain, concluded it was psychosomatic pain given her daughter’s diagnosis of autism. Sending her away with no solution, as Sigal testifies, seriously affected the entire family’s quality of life, especially her daughter, who suffered tremendously. Not accepting this physician’s opinion, Sigal described later in the interview how she found a specialist who discovered the cause of the pain, an autoimmune disease of the vagina that usually manifests differently and therefore was not even considered. Sigal’s daughter’s case illustrates how incorrect perceptions of autism, coupled with ignorance about the sensory differences experienced by individuals with autism, act as a barrier to quality healthcare services. Mitigating this barrier requires above all an acknowledgment of these sensory differences, not stigmatizing pain as an emotional manifestation, and having a willingness to explore uncommon manifestations of diseases.

Another example was conveyed by Jude, an autistic woman who is the mother of an adult autistic son and an activist in the autism field, who was also quoted above. When discussing her and her son’s experiences with physicians, she focused on the sensory differences, as for her this represented a major barrier:

“The measurement of pain. ‘Yes… 1 to 10 how much that hurts you?’ What does it mean between 1 to 10? My 1 and your 1 is not the same, my 10 and your 10 is not the same […] I really like to pet, my son can stand it. It hurts him. It physically hurts him. You will ask him 1 to 10 he will say 11. On the other hand, I walked around with a broken arm for a month, and it didn’t hurt. It was uncomfortable. What is pain?” (Jude, an autistic individual, a mother of an adult autistic son, and an activist.)

Jude, as an autistic woman who seeks the literal meaning (see above, article 4.1.5) of the pain scale, could not understand how such different experiences of pain could be measured so subjectively. She explained that in her and her son’s case, this measurement is completely inaccurate, giving two extreme examples: petting, which can cause serious pain to her son, and on the other hand, a fracture that caused her minimal inconvenience. Finishing with the question ‘what is pain?’, Jude challenged the idea that subjective reports of pain could be used when examining autistic individuals. In other words, a reliance on the pain scale that is commonly used with neurotypical individuals to determine health issues in autistic adults could result in an incorrect impression and diagnosis. The fact that clinicians are unaware of this difference is a barrier to healthcare for individuals with autism.

To sum up, the sensory differences possessed by autistic adults can cause serious barriers to healthcare, either by causing overwhelming sensory experiences or through the misunderstanding and misinterpretation of their symptoms by healthcare providers. The barrier caused by overwhelming sensory experiences commonly manifests in waiting areas or in noisy, crowded environments such as the emergency department. This barrier can be mitigated relatively easily and accommodated using a range of structural changes. The barrier relating to different experiences of symptoms such as pain demands an expansion of knowledge and enhancing the acceptance of this difference among clinicians. This section has illustrated how the sensory differences that are prevalent among individuals with autism can act as a barrier to healthcare services; a barrier that can be diminished by the introduction of systemic changes. Thus, this section contributes to the chapter argument by adding another way in which adults with autism, as a distinct social group, are suffering from barriers and are structurally marginalized by the healthcare system in Israel.

## 4.4. Barriers to healthcare services facing autistic adults, in numbers

To further understand the extent of the barriers faced by the autistic population and following the sequential exploratory design to mixed methods of this research, several questions that directly explored the barriers to healthcare facing autistic adults were included in the survey. As mentioned in the Methodology chapter, a lingual adapted, contextualized version of the barriers to healthcare short questionnaire developed by Raymaker and colleges (2017) was included. In addition, two questions exploring specific barriers to mental healthcare services and additional services were included. The term ‘additional paramedical services’ is an inclusive definition that refers to paramedical services, including occupational therapies, speech therapies, and others.

Among the individuals who replied to the adapted questionnaire (n=94), 74.4% identified four or more barriers to healthcare services, while 42.5% identified 10 or more (see table 4.4). The barriers that were identified by at least 50% of responders were: 1) Difficulties with filling in paperwork (67.7%); 2) difficulties in understanding the work process of the healthcare system (61.7%); 3) difficulties in scheduling appointments (58.5%); 4) difficulties being in a waiting area (56.3%); 5) difficulties translating physicians requests to actions (53.2%); and 6) difficulties in following examination and treatment continuation (53.2%) (see table 4.5 for additional details).

In the two questions about additional barriers, three choices among the twelve available choices specifically touched on the encounter between an autistic individual with the healthcare system: 1) Bureaucratic difficulties, 2) scheduling difficulties, and 3) communication difficulties. Other choices were related to other dimensions of marginalization (such as cultural barriers) or broader systemic issues (such as a lack of providers). Among the responders who answered regarding psychiatric services (n=100), 26.0% identified bureaucratic difficulties, 25.0% identified scheduling difficulties, and 8% identified communication difficulties as barriers to healthcare. Among the responders who answered the question regarding additional services (n=84), 20.2%, 15.4%, and 9.5% identified these issues as constituting difficulties (see table 4.6 for additional details).

These results separately and combined indicate that adults with autism suffer from major barriers to healthcare services in Israel. Both bureaucratic barriers and barriers that manifest during the encounter with the provider were found in more than 60% of the population, signifying that both of these processes are marginalizing adults with autism. These results strengthen the notion that the communication and sensory barriers that arose as major themes in the qualitative analysis are indeed significant barriers for this population. Furthermore, Raymaker and colleagues (2017), as part of their research, tried to identify a cutoff that differentiated autistic adults from those with other disabilities, based on the number of barriers individuals suffer from. When using their questionnaire, a cutoff of 4 barriers out of 18 was argued to be differentiating. In this research ,almost 75% of responders identified four or more barriers, while more than 40% identified ten or more barriers. These results indicate that while four barriers could be differentiating between individuals with autism and other people with a disability, a large proportion of the autistic population is deprived of access to healthcare to a much greater extent. These quantitative findings support the claim that adults with autism represent a distinct social group that is being deprived of equal access to healthcare services in Israel.

|  |  |
| --- | --- |
| Table 4.4: Number of barriers to healthcare services |  |
| No. of barriers | N (94) | Percentage | Cumulative percentage |
| 1-3 barriers | 24 | 25.5% | 25.5% |
| 4-9 barriers | 30 | 31.9% | 57.4% |
| 10 or more barriers | 40 | 42.5% | 100% |

|  |
| --- |
| Table 4.5 Barriers to healthcare services |
|  | N (94) | Percentage |
| Fear, anxiety, embarrassment, or frustration  | 38 | 40.4% |
| Trouble following up on care | 50 | 53.2% |
| Difficulty understanding how to translate medical information into concrete steps  | 50 | 53.2% |
| Understanding the healthcare system | 58 | 61.7% |
| Difficulties in scheduling appointments | 55 | 58.5% |
| Problems filling out paperwork | 63 | 67.0% |
| Behaviors are misinterpreted | 35 | 37.2% |
| Providers do not take communications seriously | 23 | 24.4% |
| Difficulties finding a suitable healthcare provider | 20 | 21.2% |
| Providers do not discuss health decisions  | 22 | 23.4% |
| Communication with the healthcare provider | 34 | 36.1% |
| Difficulties identifying pain and/or other physical symptoms | 35 | 37.2% |
| Difficulties reporting pain and/or other physical symptoms | 43 | 45.7% |
| Sensory discomfort | 42 | 44.6% |
| Difficulties in commuting to healthcare facilities | 38 | 40.4% |
| Inadequate social, family, or caregiver support  | 10 | 10.6% |
| Difficulties handling the waiting areas | 53 | 56.3% |
| Providers do not mitigate the servicesǂ | 38 | 40.4% |
| Difficulties finding a family physician ǂǂ | 28 | 29.7% |

ǂ This question was not included in the original short questionnaire of Raymaker et al. (2017). Following a discussion with the advisory committee a decision was made to include a broader question regarding mitigation.

ǂǂ In the Israeli healthcare system the family physician is usually the coordinator of care. A decision was made to include a separate question regarding family physicians as question 8, which refers to healthcare providers could have been understood as referring to other providers.

\*Unlike the system in the United States, the Israeli healthcare system is public. Thus, we decided to forfeit the question regarding payment for health services as a barrier to health generally. We referred to socioeconomical barriers in other questions.

|  |  |  |
| --- | --- | --- |
| Table 4.6 Barriers to services |  |  |
|  | Psychiatric services a (n=100) | Additional services a(n=84) |
| Transportation  | 7 (7%) | 13 (15.4%) |
| Scheduling | 25 (25%) | 13 (15.4%) |
| Costs | 24 (24%) | 17 (20.2%) |
| Cultural or lingual inaccessibility | 2 (2%) | 2 (2.3%) |
| There are no service providers | 10 (10%) | 12 (14.2%) |
| Few service providers | 18 (18%) | 15 (17.8%) |
| Communication difficulties | 8 (8%) | 8 (9.5%) |
| Service providers are not treating individuals on the autism spectrum | 16 (16%) | 11 (13.0%) |
| Bureaucratic difficulties | 26 (26%) | 17 (20.2%) |
| Gender inaccessibility | 0% | 1 (1.1%) |
| Service provider specializes only in children with autism | 14 (14%) | 9 (10.7%) |
| No barriers | 23 (23%) | 13 (15.4%) |
| Irrelevant | 17 (17%) | 15 (17.8%) |

a presented as absolute number (percentage)

## 4.5. The implications of the barriers to healthcare services

This section aims to portray the implications of the barriers mentioned above for the health of adults with autism. While the four previous sections were aimed at grounding the major argument of this chapter, which is that autism should be considered as part of an individual’s social position based on the distinct marginalization of the condition, this section completes the analysis from an SDH point of view and demonstrates that this marginalization is affecting people’s health. Furthermore, despite the fact that the initial goal of this research did not include identifying or quantifying these consequences, they emerged as a significant theme during the qualitative investigation and should therefore be explored. Lastly, as this was participatory research that approached the field from a critical stance and wished to influence it, this section is required to explain to policymakers that ignoring the barriers mentioned above will have ramifications on this population and beyond.

The qualitative investigation illustrated that barriers to the healthcare of adults with autism can directly and indirectly influence the health of this population. Although barriers to healthcare services could intuitively seem to be linked to health outcomes, this link does require elucidation. Most often this link is investigated quantitatively, as discussed in the literature review, by demonstrating disparities between the health outcomes of autistic compared with neurotypical individuals. The qualitative research conducted here cannot answer this research question; however, it did uncover three mechanisms by which health barriers are linked to health outcomes in the Israeli context. First, these barriers can lead to incompatible treatment provision that can result in adverse health outcomes; second, because these barriers can inflict an additional burden on autistic adults and their families when seeking healthcare services, this can discourage them from seeking care, which can directly affect their health; and, third, unsuitable services that trigger anxiety and resistance in the autistic individual can translate to the use of force being necessary to provide the treatment needed, a practice that is known to harm health (Castle & Engberg, 2009; Rakhmatullina, Taub, & Jacob, 2013). It is essential to understand these mechanisms, as they can be addressed directly by policymakers and they should be utilized as a proxy measurement of health outcomes when introducing programs to alleviate barriers, in the case of this distinct population.

### 4.5.1. Unsuitable care

Unsurprisingly, one of the major themes that emerged in the qualitative investigation regarding the implications of barriers to healthcare was inappropriate care. Adults with autism, their family members, and relevant professionals, although not physicians, reported encountering cases of unsuitable treatment. Hila, for instance, the sister of two adults with autism and the guardian of one of them, described her brother’s experience at the ophthalmologist:

“He had… he complained about a problem in his eyes, and my father succeeded persuade him to go to the ophthalmologist […] my brother did not let the doctor to examine his eye, so it was left without any solution. […] He was afraid and he just didn’t let him examine the eye. […] Because he is young there were no major health issues that came up, but I am sure that when he will be older they [the doctors] will be very helpless dealing with him” (Hila, the sister of two autistic adults.)

Hila, who shared during an earlier part of her interview that she lost her mother, who had a mental illness, due to incompliance with her heart medication, talked about her brother’s difficulties to go through with an eye examination. Hila started by describing her brother’s reluctance to reach out for assistance despite having complaints. Although in this instance he was convinced to go, following his father’s efforts, the qualitative inquiry has demonstrated this is not always the case with autistic individuals. When he got to the ophthalmologist’s office he refused to be examined and went home with no solution to his eye complaint. According to his sister, his anxiety, his fear, of the examination were the reasons for his refusal. These feelings could, however, have been addressed if better mitigation of the service offered was in place; for example, if he had been introduced earlier to the office, the physician, and the equipment. This instance, Hila stressed, is just a preface of what is about to come in her brother’s future; she expressed her worries that his aging will unavoidably be accompanied by additional, more serious illness. According to Hila, if measures are not introduced to mitigate health services it will be impossible to treat him. Considering her mother’s early death, she is afraid illnesses in later life will result in major health consequences.

Another example was raised during the interview with Bina, a manager at a residential facility for adults with autism, who discussed the need to mitigate healthcare for the residents in the hostel she manages:

“We have a resident he is forty-one years old, and we noticed he had trouble sitting, we noticed that he sits in a strange position […] We went to the family physician, and she didn’t see any problem, but we asked for referral his neurologist who works in a major hospital. They did bone scintigraphy but found nothing significant that will explain the pain. I asked the resident’s mother to take him to an orthopedic doctor using her private insurance […] He immediately asked for a CT of the lumbar area, and last week we got the results of five disks eruptions and a tumor between L3 and L4. Why am I telling you about it? Because we wouldn’t found it if we didn’t insist. Maybe in two years from now […] How is he not suffering from the pain? How come he doesn’t scream? I don’t know. You have no one to talk to.

You just see that from September in few months he had changed, something happened. This whole thing of mitigated medicine it is essential, a duty, there are going to be more autistics and those who are at their youth today will sometime be older” (Bina, a manager at a residential facility for adults with autism.)

Bina’s detailed description exemplifies the dire consequences that uninformed physicians who are ill-equipped to communicate with autistic adults could have on their health. A similar case could occur with a non-autistic adult, as misdiagnosis is a known phenomenon, yet as the scientific literature comparing health outcomes demonstrates, and from Bina’s depiction, this is not the case. Communication difficulties coupled with a probable lack of awareness to insensitivity to pain and misrecognition of alternative communication manners have caused treating physicians to miss evolving illnesses. This signifies, as Bina emphasizes, the importance of mitigating services.

The barriers to adults with autism accessing healthcare services unfortunately impacts these individuals’ health on a daily basis, first and foremost because they do not receive the appropriate care, as neurotypical individuals do. To used Bina’s words, it is a ‘duty’ to develop ways to mitigate these services. Not only because other autistic individuals’ serious illness may be mistreated but also because this population of adults with autism is aging, and sickness will inevitably become more prevalent. To conclude, barriers to healthcare services negatively affect the health of adults with autism by preventing them from receiving appropriate treatment for their illness.

### 4.5.2. Avoidance of care

Another important mechanism by which barriers to healthcare services influence health outcomes is the avoidance of care. Despite being an indirect effect of the unsuitable and often unpleasant experience of the healthcare system, it has major ramifications for health. Repeatedly mentioned by diverse stakeholders, avoiding interactions with the healthcare system altogether is a strategy utilized both by autistic individuals and by guardians, who anticipate a dire experience when encountering the system. One such example was expressed by Carmit, the mother of an autistic adult, when she described her experience of the healthcare system:

“We are avoiding taking him to the doctor. He complained, for a long time now, that his stomach hurts, and we are acting like criminals. Because we know that if he will need an ultrasound examination, because his doctor will probably send him, he will not collaborate. He won’t be calm. And then they will start with us, looking at us like we are the big criminals. So, we spare it from ourselves for many years, and it is not good, it is not ok, it is wrong.” (Carmit, the mother of an autistic individual.)

Carmit testified that she is avoiding taking her son to the doctor as she anticipated a prolonged and distressing experience with him. Although she repeatedly makes amends on herself and her partner’s behavior, calling themselves criminals, she explained that this experience will be harsh given her son’s lack of cooperation. Her choice of wording, when carefully analyzed, also concealed the attitude she previously experienced from the system toward her son’s noncompliance. Instead of trying to mitigate their services or identify the barriers for her son, the system’s representatives were looking at her as being the one responsible for these difficulties. Having carried this responsibility for the system’s misconduct for more than 34 years, Carmit and her partner decided to avoid it. As a result, their son did not get proper care. It should be noted that, given that caregivers of autistic adults who reside in the community are getting older, along with their children, and their children’s encounters with the healthcare system are expected to expand, given their age, if healthcare services remain inaccessible this will result in further avoidance.

Dr. Yair, a psychiatrist working with autistic adults in the community, also discussed the issue of avoidance. Although many autistic individuals reported that they avoided care, among them Ronen Gil, an autistic adult and activist, who bluntly stated: “I avoid reaching out to this [healthcare] system”, or Bruce, another autistic adult and activist, who said “there is no doubt they [the providers] is causing me to hesitate [whether or not to approach the system]”, and their voice should be heard, Dr Yair’s observation is also important as it sheds lights on the relationship between avoidance and barriers to healthcare services. Discussing the interaction of autistic adults with the system, he said:

“Yes, and there are many that don’t want to go to the doctor at all… It is hard to say what is the origin of this phobia, this specific type of phobia […] a lot of them had raised as children in what I imagine is a struggle against the normal environment, that the system expresses different types of dissatisfaction, lack of acceptance and pushing them into treatment […] Individuals that the system had impose them all kind of stuff. So this could be… I mean that all these interactions can cause many complexities in receiving help.” (Dr. Yair, a psychiatrist working with autistic adults in the community.)

Dr. Yair, who framed avoidance of care as a phobia, is connecting the dots between barriers and avoidance. His observation that the autistic experience is seeded with ‘struggle[s] against the environment’ and recognizing that these struggles and the systemic dissatisfaction that can cause avoidance is essential to understanding this link. In the context of this section, the healthcare system, which is imposing additional barriers to care on autistic individuals, is refeeding the experience of a struggle. Coupling this struggle with the practice of ‘blaming the victim’ that Carmit described above, it is clear these barriers are actively causing avoidance of care. Dr. Yair adds to this struggle another implication of unsuitable services, discussed below (see sub-section 4.5.3 ‘Using force’); namely, coercion to receive treatment. He asserts that the compulsion of treatment also reinforces the negative experience, ‘the phobia’, resulting in the avoidance of care.

Together, these examples demonstrate that avoidance of care is a serious implication of the barriers to healthcare services facing adults with autism. Considering that when an autistic individual who usually avoids care does seek assistance in a serious situation, she or he will encounter further barriers, this results in a vicious cycle of inaccessible healthcare services that reaches the point of being irrelevant for the autistic adult. Although avoidance is not relevant only for adults with autism, nor is it the first time it has been linked with barriers to healthcare services (Kannan & Veazie, 2014; Taber, Leyva, & Persoskie, 2015), its ramifications for health mandate this issue should be targeted as part of any future effort to improve services for adults with autism.

### 4.5.3. Using force

One of the worst implications of unsuitable healthcare services for autistic adults is the need to use force to treat them. In cases where treatment is required, to mediate the resistance of the autistic patient force is sometimes applied, either in the form of physical or pharmacological restraint. During the qualitative inquiry, some unfortunate examples were described. Dr. Efron, a psychiatrist working with autistic adults, analyzed the experience of one of his autistic patients during a medical procedure she required following a self-inflicted hand fracture; his analysis demonstrates the health and moral implications of the use of force:

“After she went through the operation that she needed, she had to stay in the hospital, and she was tied […] it is not good she was tied for a week. Really not good. It is not good morally, but it is not really intrest me; however, from the aspect of what happens afterwards [after the long period of being tied], dealing with the implications [of this practice]. But, what can I say, can they deal with anything like this? […] I don’t expect that they do” (Dr. Efron, a psychiatrist working with autistic adults.)

Dr. Efron, who during an earlier part of the interview told me that he used his personal connections to ensure this patient received the operation she needed, expressed his frustration at the fact she was tied to her bed for an entire week. He raised two reasons why this act was wrong. The first was the moral issue. The morality of tying a patient to a bed to make them go through a procedure they need, while removing their bodily autonomy, has long been debated (Gastmans & Milisen, 2006; Mohr, 2010). Although Dr. Efron dismissed this argument by trying to focus on the practicality, the moral implications of such practices should be taken into consideration and discussed both in relation to autistic individuals’ marginalized position in society and in the context of the barriers to healthcare services covered above. Dr. Efron’s second argument was that this practice of restraint has implications for the autistic patient. In a separate part of his interview, he explained that the implications of restraints are on the autistic individual’s wellbeing and their mental health. Despite arguing against the use of restraint, he concluded in his closing sentence that this practice is inevitable, and he would not expect treatment to be any different. His finale suggests that while the implications of the barriers are no-doubly harmful to health and should be changed, the barriers to healthcare services that lead to these implications are transparent.

The relationship between the existence of unsuitable healthcare services and the use of force was illustrated by Carmit and Tuvia, the parents of an autistic adult. Talking about their son’s experiences with the medical system, they illustrated how a pharmacological restraint could be avoided when a different attitude to treatment was enacted:

“Dental treatment we are doing only privately, and only under anesthesia. Why we need to put him to sleep? If we had laughing gas or different attitude so you won’t have to put his to sleep. Anesthesia is not the healthiest thing, you know, but otherwise no one will accept treating him.” (Tuvia, the father of an autistic individual.)

Tuvia depicts a grim situation in which dental care could be performed only under anesthesia. Although this practice is subsidized by the state for autistic individuals and other individuals with disabilities following an MoH regulation from 2002 (General Anesthesia for Dental Care, 2002), as Tuvia mentions this practice is not ideal. Anesthesia, which is used to restrain the autistic adult for the period of care, can have complications and should only be used if there is no other option. Tuvia and Carmit continued to explain their position and gave an example of an alternative their son’s childhood dentist had utilized:

*Tuvia*: “The physician laughed at me: ‘this is easy, let me, you think I can’t handle with it?’ ‘Leave the teeth I want to play on your teeth like a piano would you let me?’, and of course he let him play on his teeth and examine them […]”

*Carmit*: “He had an attitude, and the moment he had approach our son collaborated”

*Tuvia*: “So there are solutions”

*Carmit*: “It is just that no one is ready to make an effort. Or know how to do it” (Carmit and Tuvia, parents of an autistic individual.)

Tuvia and Carmit described their son’s childhood dentist, who had retired. His attitude, which involved games and music alongside treatment, made cooperation possible. Instead of pharmacological restraint he utilized alternative practices of communication that enabled participation. Both Tuvia and Carmit agreed that a different approach in adulthood is possible as well, and that anesthesia is not unavoidable; nevertheless, according to them, the current medical establishment is either reluctant to try or does not know how to utilize alternate approaches. This instance illustrates that physical or pharmacological restraints, although prevalent and broadly accepted, are not a mandatory practice. Lifting barriers could help to reduce their use and minimize their implications for health, as intervention programs have shown (Sturmey, 2018).

To sum up, current barriers to accessing the healthcare service have major implications for the health of adults with autism. Thus, they can be classified as determinants of health inequalities. The serious consequences of the barriers presented in the previous sections mandate urgent notice by policymakers and position holders within the healthcare system. Receiving unsuitable care, avoiding care due to maltreatment, and the use of force in cases where treatment could not be avoided are three distinct mechanisms by which these barriers can affect autistic individuals’ health. These mechanisms, especially avoidance and the use of force, should be addressed separately and could be used to monitor intervention programs designed to reduce barriers to healthcare experienced by adults with autism.

## 4.6. Conclusions

This chapter aimed to demonstrate that autism should be regarded as a ‘social position’ within the SDH framework, instead of a health outcome as it usually is. By illustrating that adults with autism suffer from distinct barriers to accessing the healthcare system in Israel that can be mitigated through the use of structural and systemic adaptations, the chapter established that autism is a socially constructed disability. Being a socially constructed disability, as the SMD asserts, allows to address autism as a distinct social group that forms part of the individual’s social position. Although this argument is not novel (see for instance Jaarsma & Welin, 2012), SDH scholars have generally failed to adopt this position regarding autism and disability more broadly; thus, making this analysis was crucial for the analytical work in this dissertation.

In addition to closing the gap in the SDH literature, this argument is essential for practical reasons. The medical establishment, specifically in Israel, has yet to recognize autism as a social group of reference; therefore, it has overlooked the marginalization of this population within the healthcare system. From a practical perspective, the analysis proposed in this chapter requests that individuals with autism be regarded as a social group, so the efforts made to reduce discrimination against this group within the healthcare system should be performed under the umbrella of reducing inequalities, similar to the efforts invested to reduce culturally discriminating practices. Furthermore, this high-resolution analysis allows an understanding of the distinct barriers this population encounters in the Israeli healthcare system. It also proposes practical measures for overcoming these barriers, which were mentioned by a diverse range of stakeholders.

Three intrinsic characteristics of autism were raised as creating barriers: communication difficulties, repetitive behaviors, and sensory differences. Communication difficulties unsurprisingly involve difficulties in expression; nevertheless, as has been demonstrated, other factors can also affect the communication difficulties experienced by adults with autism. These include discrepancies in the perceptions around the settings and the goals of the communication, longer processing times during an interaction, the use of alternative means and manners of communication that are not recognized, understanding messages too literally, and specific difficulties in self-advocacy and reaching out for assistance. Repetitive behaviors manifest as the need for certainty and familiarly when utilizing healthcare services. Not recognizing the need for a proper and detailed explanation of the medical process, or the need for prior introduction to a facility or a procedure, can act as a major barrier to accessing healthcare services. Finally, the role of sensory differences as a barrier to healthcare service was analyzed. Manifesting as either oversensitivity or insensitivity, this difference can affect both the ability of clinicians and autistic adults themselves to understand their symptoms and obtain the correct diagnosis, as well as affecting the ability to wait in the overstimulating spaces often found in the healthcare system. While most of these barriers have been recognized in the scientific literature (Walsh, Lydon, O’Dowd, & O’Connor, 2020), other barriers, such as concretization of language and the lack of self-advocacy, were first mentioned in this work. This research is the first to explore all of these barriers in Israel.

The quantitative findings from the survey strengthen the qualitative analysis. By showing that more than 70% of responders experienced four or more barriers, a number that was found to differentiate between individuals with autism and those with other disabilities, it demonstrates that this population could be regarded as a distinct group despite its heterogeneity. The findings further indicate that more than 40% of this population face even greater challenges, as they encounter ten or more barriers, highlighting the magnitude of this problem. While the qualitative inquiry demonstrated that barriers could manifest both in the encounter with the provider and the bureaucracy, the quantitative findings indicated that a large proportion of the barriers are involved in the process to access services in the first place, thus indicating that structural mitigation efforts should not neglect the bureaucratic aspect.

To complete the analysis from an SDH perspective, this chapter demonstrates that these barriers have serious health implications. However, by using the distinct perspective of the qualitative inquiry allowed not only the health implications to be depicted but also the main mechanisms via which they operate. These mechanisms include the provision of unsuitable care, avoidance of contact with healthcare services, and the need to use force, either physical or pharmacological, to provide the necessary treatment. Understanding the mechanisms that marginalize this group are also crucial from a practical point of view, as they could be used either as a distinct target of intervention or as an outcome measurement for programs to reduce barriers.

Considering the anticipated surge in the number of individuals with autism and the fact that autistic traits are lifelong, these barriers are expected to affect a growing number of individuals. Accepting the existence of these barriers and introducing structural changes is urgently needed, as the implications of these barriers are profound for the health of the autistic population. These structural changes should include a variety of mitigation strategies, some of which, as this chapter has illustrated, are already utilized by various stakeholders. In addition, direct confrontation of the mechanisms that affect health outcomes is needed. Above all, these changes should result in adults with autism being perceived as a distinct social group who deserve equal healthcare services, in light of the National Health Insurance Law (1994) principles.

## Appendix 4.1



This form, which was used by a genetic counseling center, includes many unclear points. Some issues might also confuse neurotypical individuals. For instance, including all the mutation names within the form could confuse someone who does not have a medical background. The second to last sentence of the form, which reads “These results are a statistical calculation based on the information you provide us and known medical research”, could easily confuse an autistic individual. If read literally, the meaning could be that all of the above is irrelevant, as it is just a calculation. This form should be completely amended; however, this sentence in particular specifically could confuse adults who have autism and give them the impression the entire form is irrelevant.

## Appendix 4.2



This form is not accessible for many reasons, including the abundance of legal information, the fact it is not divided into sections, and more. However, in relation to the issue of early preparation, what this form misses above all is an explanation of the expected procedure. Should the patient bring their own sleeping clothes? Will food be provided? How long will the test take? Will any equipment be attached to the patient’s body? There are many unanswered questions, which makes the procedure unclear and intimidating. Creating a mitigated form that includes a detailed explanation of what to anticipate would make the procedure much more accessible, both to individuals with autism and to the entire population.

1. Neurotypical is an alternative term for an individual with common neurological function, the ‘normal’ (Rosqvist, Stenning & Chown, 2020). [↑](#footnote-ref-1)