# 4. Autistic Adults’ Barriers to Healthcare Services

The Social Determinants of Health (SDH) research categorize autism as a health outcome. As explored in the introduction this research adopts the analytical framework of the Social Model of Disabilities (SMD) and asserts that autism is a socially constructed disability. According to this perception by adopting the right social mitigations autistic individuals could have equal participation in society. To support the research standpoint this chapter seeks to describe and analyze the barriers to healthcare services of autistic adults in Israel and claim that eliminating them will allow autistic adults equal access to healthcare services. Much like inequalities that are caused by cultural differences the Ministry of Health (MoH) in Israel have decided to combat with cultural and linguistic adaptations (Cultural and Linguistic Adaptation and Accessibility in the Health System, 2011), this chapter claim that with neurological adaptation inequalities between autistics and neurotypicals[[1]](#footnote-1) in the healthcare services could be reduced. Illustrating barriers of autistics can be lifted will allow recategorizing autism in light of the SMD as part of the ‘social position’ of the individual in the SDH framework and not as a health outcome. Furthermore, it will set the ground for next chapters analysis that utilizes autism as ‘social position’ to investigate the Social Determinants of Health Inequalities (SDHI) of autistic adults 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 of the healthcare system. From this position the chapter argues that like gender oppression which is a social marginalization structured around biological innate quality – sex (Manandhar et al., 2018), marginalization of autistics is based on their intrinsic neurological difference that encounter unsuited oppressive social structure. Illustrating that the social constructs are marginalizing and not the biological difference itself will exemplify 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 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 for strategies to eliminate it as a barrier using structural changes are presented. Quantitative findings that are relevant for the specific theme are also explored. To understand the importance of addressing these barriers and to complete the analysis from a SDH point of view, although not being the focus of this research, the implications of these barriers on autistic individual’s health is illustrated. Furthermore, the mechanisms in which these implications are affecting health are analyzed.

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

## 4.1. Communication differences as a barrier to healthcare

Communications differences were raised by diverse interviewers as a major barrier for healthcare services. These differences include: distinct rational 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 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 rational for communication

Communication as a concept is usually simplified to the ability to exchange messages. However, the analysis of the qualitative interviews demonstrates that to fully comprehend the communication difficulties autistic adult face when encountering the healthcare system, the concept of communication need to be pulled in to pieces and explained piece by piece. Ronen Gil, an autistic individual, and an advocate for autistics depicted very accurately several basics concepts on the communication process when explaining about his 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 started his explanation with deconstructing the communication process and asserting 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 and the setting in which communication is taking place. Although in this statement Ronen was not referring directly to the 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 the physician office or a hospital as a place to discuss illness should be challenged. While the neurotypical society understands that the clinic is the setting in which you explain to a stranger with a professional title what disturb you and ask for his help, to an autistic individual this setting might be considered as a playground or worst as a place in which painful intrusions to the body called examinations are being held with no real rational. Why, for instance, a residential place who have a potential to be more welcoming and trust building setting then social imposed one cannot be the place an autistic individual shares his difficulties with the stranger which society refer to as a doctor? Ronen explanation mandates to start examining the differences in communication between the autistic individual and the neurotypical society by rethinking the basics of the socially accepted.

Yet, the setting is not the only dimension of communication that need to be explored, the goals of communication, Ronen asserted should be questioned as well. Is it possible that when seeking assistance autistic individual goal is different than the one that is provided at by healthcare services providers? Numerus instances were raised during the interviews of discrepancy between the autistic individuals need for help and the actual assistance that was offer to them. Whether it was behavioral interventions that were offered to an autistic adult that all he needed was a key to make sure he cannot be locked by mistake in the laundry room (Bar and Tomer, parents of an autistic adult), or sleeping peels that were prescribed to suppress anxiety during the travel to the employment center (Dr. Efron, psychiatrist) when different means of transportation could be much more helpful. The most obvious example, however, of discrepancy between the goal of communication that is assigned by the autistic individual and the provider, was raised by Jude, an autistic individual a 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 can not 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 a 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 one socially accepted. Her goal was to understand how she feels different, what is unusual with her body; on the other hand, the doctor as socially accepted was asking about the unusual - about symptoms, in order to find the cause of these symptoms and treat it. This discrepancy in the goal of communication can result in misunderstanding, frustration and disbelieve to the two parties involved. Echoing Ronen’s assertation that an analysis of communication should include understanding the motive of the communication, Jude’s situation exemplifies that even when there is awareness of the goals differences the autistic individual who is the service recipient is expected align with society and not vis versa.

Mitigating these differences is possible yet it requires flexibility and will to make adaptations. First, although thought to be intuitive and social accepted the incentives and motives for reaching out for assistance should be clarified. Following the clarification amendments to the services could be introduced or referral a relevant service provider that can meet the specific goal could be done. In Jude’s case an attentive physician could try and explore with her what is different with her body or refer her to an alternative therapist for exploration. The settings of the encounter could also be reconsidered. Options like home visits of the family physicians or home hospitalization, should be offered and discussed with autistic adults as an alternative for care. Dr. Golda, a psychiatrist working with autistic adults argued exactly that when discussed 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)

Questioning the community clinic as the best solution for examination and treatment of autistic adults Dr. Golda de facto problematized the setting of communication. According to her observation obligating to arrive an unfamiliar setting is on its own a stressor which can also affect the examination. Thus, a neurodiverse accessible healthcare system would have to reconsidered and negotiate the exact goal of the encounter and one that allows changes in the setting of the encounter. Given these barriers to communication could be mitigated by structural accommodations strengthen the argument autism is socially constructed disability that should be regarded as part of the social position of an individual.

Yet, neurodiverse accessible healthcare system would have to also consider the manner of communication. The following sections deconstruct different aspect of the manner of communication that cause barriers to autistic individuals.

### 4.1.2. Difficulties in expression

Diverse interviewees, including autistic adults, parents of autistic adults and professionals have raised the issue of the difficulty of autistic adults to express themselves. Given communion difficulties are integral to autism diagnosis this is not a surprising finding; yet, if these difficulties are disregarded and not addressed properly, 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 in non-verbal autistic adults:

“One of the subjects we discuss is early detection. We if we have something that hurt us, we will say. They [the autistic adults] will not say. Especially those who are non-verbal. 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 of non-verbal autistics to express pain or symptoms can affect the ability of the physician to find a problem and treat it. She together with other advocating for autistic adults suggested that given these circumstances a proactive approach that search for treatable diseases will take place as long as it is not too invasive. This proactive approach which can be framed as an investigative approach to examination similar to the one enacted in pediatrics, as Dr. Mor, a family physician working with autistic adults claimed in her interview she is using, are a form of mitigation that should be available for all autistic adults.

In the case of non-verbal autistic adults, it is intuitively understood how the difficulty to express oneself can be a barrier to services. Unfortunately, many other disabled persons such as patients with progressive Alzheimer disease suffer from the same barrier. Nevertheless, it became evident throughout the research that this is also a problem of verbal autistics who are conversant and take active part in the community. Bruce, for instance, an autistic adult and an activist in the autism field who shared his experience in the physician office recalled:

“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, taking care of his mother and was employed in the past, described a distressing experience in the physician office. He clarified that due to his difficulty to explain himself and his slower processing time physicians silenced him and were reluctant to hear what he had to say. Considering anamnesis is essential component of the clinical process an inability of the patient to express himself especially in a stressful and impatience setting could be a great barrier to care. Bruce suggests that a mitigator will join the intimate meeting with the physician to try and explain in a manner physician understand the issues raised by the autistic individual. Bruce’s statement engulfs much more than the difficulty to express oneself clearly, and later I return to his quote; however, his statement clarifies that the difficulties to express themselves are not just of nonverbal autistic but of most autistic.

Difficulties in expression clearly qualifies as a barrier to healthcare services. Those who endorse the Medical Model to Disabilities (MMD) will easily roll the responsibility to the side that has difficulty to express his opinion, the autistic individuals. However, it should be acknowledged that difficulties to express viewed from the opposite direction are in fact a difficulty of the provider to understand. From this perspective, a SMD perspective, this barrier is socially constructed and can be lifted by mitigating between the two sides of the communication end. It should be noted in this point that this barrier is very relevant to the bureaucratic process. Difficulties in expression can manifest, for instance, when scheduling an appointment and may result in unwanted outcome. The options for mitigation portrayed by Bat-el, Dr. Mor, and Bruce, are examples among others that can be enacted to lift or at least reduce this barrier for autistic individuals. Understanding one of the core traits of autism is mostly result from social construction of the system further strengthen the claim autism is, like 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 accompany 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 in 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 office, described not only a difficulty to express thoughts but a slower pace of engagement. Considering that she as his sister finds it difficult to communicate with him given the slower engagement pace, 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 the providers the importance of patience as a mitigating tool is all that required. Tiferet, a secretary in a psychiatric clinic caring for autistic adults, shared from her experience:

“They [the 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 loosing my temper” (Tiferet, a secretary in a psychiatric clinic caring for autistic adults)

Tiferet in her description not just repeated the claim autistic adults have difficulties in understanding and a longer processing time, but also portrayed what this kind of communication requires from her, the provider. Mitigating the bureaucratic process in Tiferet’s case, demands when an autistic individual is ‘stuck’ a will to repeat explanations to guide 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 own thoughts that tamper autistic adult’s communication with the service provider; the time frame to process the situation and response also serve as barrier for communication. Given the healthcare system operates in a tight schedule whether it is in the doctor office where she has 10 minutes for patient, the pharmacy with a long que at the back, or the phone when trying to schedule an appointment, it is not surprising autistic adults find it inaccessible. Rushing care in a tight schedule is a barrier for healthcare services of autistic adults. This barrier can be lifted by structural arrangement that allows autistics extra time with the provider together with explanation to providers patience is not just an empathic expression but a service requirement without it care could be harm. Eliminating longer processing time as barrier will allow autistic adults more equal access to healthcare services; as such this example once again demonstrates social structures are discriminating autistic, and autism should be qualified as a social position.

### 4.1.4. Alternative communication manners

By this point it is clear communications mishaps are an integral part of autistic adults’ encounter with the healthcare system. Yet, mishaps not only occur due to difficulties in expression or long processing time, but also partially occur due to failure to recognize and acknowledge alternative communication manners autistic adults utilizes. Alternative manners could be different means of communications or completely alternative roots of communication. While different means of communications such as Augmentative and Alternative Communication (AAC) or written communication are visible, different roots of communications could be easily overlooked if not actively searched for. Ronen Gil, an autistic adult, and an activist, in his interview when discussing the meaning of different communication referred to an accurate example 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)

Ronen in this example illustrated how easily alternative means of communication can be missed. This example also shows that being unaware to a manner of communication does not mean it is not there; and that interpreting it with the limited tools one has might result not just in wrong meaning but in degrading explanation. Whether it is sign language, higher or lower tone of speech in 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 communications autistic adults utilize, difference in communication manners should be actively searched for.

Although most physicians and service providers are educated adopt the MMD and therefore would claim no common manners of communication equals no communication at all, some professionals interviewed to the 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 kind of communication that need to be searched for when looking for expression 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 looking for any sign of communication. It is clear from her words that she is not sure exactly what are those signs of communication, but she does agree that those are there even in non-verbal autistics. From her description higher alertness and attention is needed to every sign of change that might mean communication either a behavioral changes, mood changes, or physical changes. In addition, Dr. Mor recognized the search for communication is a quest for each and every autistic that will demand close collaboration with the immediate care givers and a lot of mistakes in the process as communication be relevant to other spheres in the autistic adult life; nevertheless, she asserts those are mandatory.

Dr. Mor was not alone in recognizing the importance of understanding the alternative manners of communication of autistic individuals. Rachel, a deputy head nurse in a tertiary medical center who is also involve in promoting the hospital accessibility, explained in her interview about a new form the hospital is trying to apply. Together with residential places and organizations taking care of autistics and cognitive disabled individuals in the hospital surroundings they created a form called the traffic light form. This form should introduce the autistic adult to the hospital crew upon arrival. Holding the form, Rachel said:

“I will explain the rational [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 construction of the traffic light from. First, people with neurodevelopmental disabilities can communicate in their own way. Second, each patient has distinct way of communication and distinct preferences. As such the medical team cannot a priori know or be familiar with every one of them. Finally, it recognizes there is a need to be attentive for these preferences and communication manners and allow the disabled individuals 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; yet, in this point it demonstrates the quest for alternative manners of communication should not always be done by the healthcare service providers, but without their recognition and active request for these manners during the care process these important alternatives would be left out and autistics’ barriers to 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 was during the advisory committee work. While most members could use either spoken or written communication two committee members asked me not to communicate with them only with one of these means. One committee member did not manage with written communication and asked that all communication will be conducted using audial means. To allow his participation I had to read for him entire sets of written text including the research questionnaires and a summary of the research. He then told me his comments, and I transferred them to a written language and read him the new version again so he could comment again. While this process demanded an incredible investment of time on the phone it was necessary to allow his participation. Choosing not to respect his request would have excluded his participation from the research. The other member on the contrary asked me to communicate with her only in written communications. Picking up a phone call, for instance, and asking her to rush her comments on the final report was not an option. The accepted unwritten social convention that a phone call means 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 asked to be used (see for instance: Iacono, Trembath, & Erickson 2016; Levi, 2019). Although this example is not given directly from the healthcare services realm its implication to the healthcare system are obvious. For instance, sending an autistic individual that does not manage with written communication with a form to follow up, means in practice sending him with empty hands. Not respecting an autistic adult AAC when trying to schedule a follow appointment at the secretary office would mean no appointment will be schedule. Thus, it could be claimed that not recognizing alternative communication means and allowing their use is a barrier to healthcare services.

To sum up, an important aspect of the communication barrier autistic adults face at the encounter with the healthcare system is the reluctance of providers to acknowledge alternative manners of communication autistic adults use. The qualitative inquiry demonstrated that some healthcare providers recognize the need to look for alternative manner of communication and invest some efforts discovering them. Means of communications despite being continuously developed and widely used by autistic individual are not always welcome in the healthcare settings. Refusing to acknowledge these distinct communication manners, especially different means of communications marginalize autistic adults and deprive them from equal access to healthcare services. This example further strengthens the claim 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 massage

The difficulties to communicate with the 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 it could easily be understood incorrectly and be manifest as a barrier to healthcare. This barrier often referred to at the scientific literature as language barrier, cause misunderstanding of the healthcare provider 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 of autistic individuals are articulated differently. Many autistic adults that communicate in neurotypical manners do understand the words that are being said to them, but they might understand them literally instead with their social-attached interpretation. Barak an autistic individual interviewed together with his autistic partner Shlomi 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, autistic adult couple)

Although it is not health-related, this example uses a very common scenario that is probably familiar to most readers and demonstrate the literate translation and the social-accepted translation could have opposite meanings. The phrase ‘what have I done?’ can be said literally with an intention to discover the answer or as an act of trying to play as innocent. Confusing between these two meanings as Barak shared can be harmful in a school setting. What is striking in this example 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 hear the question understand it literally. Barak ends by generalizing his experience to other instances and to other autistics individuals. The qualitative inquiry established that in relation to the healthcare system he is totally correct.

Among the examples that were raised in the research the example Naomi a social worker working in an autistic young adults’ program have shared when she discussed the setbacks of available psychiatric care, showing 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 place 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 the psychiatrist interviewed her could completely change his risk assessment. Asking ‘how do you feel’ was understood by that woman in present tense without regarding to her recent history, two hours earlier, of profound emotional distress and the expression of suicidal thoughts. This example illustrates that without special attention to the wording during a conversation with autistic adults, language can become a serious barrier to healthcare services. Moreover, Nomi’s final remark that she needs to mitigate the autistic woman who is under her responsibility everywhere, clarifies this language barrier is possible to overcome if providers are being taught to recognize them.

Finally, it should be stressed that being concrete and literate works both ways. Autistic individuals, when they speak, might say directly what they think disregarding the consequences of being honest might have on the surroundings. Example of such direct speech was mentioned by Cohav, an autistic woman, in her interview. Talking about her employment experience she explained her difficulties 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 laud, burned me [an 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 autistic adult)

Although Cohav example is taken from her work experience it illustrates how a small talk conversation can create a negative atmosphere and even have consequences on the autistic individual reality. In a healthcare setting a practitioner that is not familiar with the literal understanding of autistics can find them rood and offensive. In a calm environment it can just result in lack of empathy and motivation to give care; however, in a stressing environment like the one is often found in healthcare setting such as emergency department, this could result in reluctant to hand assistance or can deteriorate to violence. Although an instance like that did not came up in the interviews, Bruce the autistic adult cited above regarding his difficulty to express himself mentions “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 although he was just trying to express his opinion that his decisiveness and direct approach made him sound rude.

Whether being the right interpretation of this instance or not, concretization of language is a barrier to healthcare services of autistic adults that is affecting all level of care and should be considered when promoting access to autistic individuals. This language difference can be mitigated by an external translator, like the one that should be provider for people who are using sign language, or by teaching providers to manage empathically this difference. Furthermore, as written language is also open for interpretation, language concretization can be a barrier to healthcare services even in indirect manner (example for possible misinterpretation due concretization of written language can be found in appendix 4.1). Therefore, medical documents should be modified to be neurodiverse suitable. Above all this section clarifies there is a need to recognize autistics as a distinct group that have specific language sensitivities which pose a barrier to healthcare services. Recognizing autistics as a distinct group further strengthen the claim autism is part of the social position of the individual.

### 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 the need to ask for assistance, to self-advocate, when consuming services. While the scientific literature mainly discuss self-advocacy in the patients encounter with their provider (Wiltshire, Cronin, Sarto, & Brown, 2006), the qualitative analysis made it clear that the bureaucratic process in itself, 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 many times means not getting the service that is needed. Dr. Yair a psychiatrist working with autistic adults in the community when asked about the non-psychiatric health related care of autistic adults 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 working with autistic adults in the community)

Dr. Yair, speaking from his experience with autistic adults, declared very bluntly what he thinks prevents autistic adults from getting 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 services utilization. Yair observation was echoed by other interviewees as well. Sigal, for instance, a mother of young autistic adult woman 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 autistic adult and an activist)

Although pointing to a different situation in which help is needed, this scenario demonstrates that even in a known environment asking for assistance can be a barrier. Sigal’s description encapsulate additional hurdle to this barrier. According to her view although her daughter comprehends she need to ask for assistance, she would not. Thus, attempts to train autistic self-advocacy as a sole strategy to improve this skill without reciprocate efforts to mitigate the system, might deem ineffective.

Omer an autistic individual interviewed for the study also describes a scenario in which he did not ask for help despite needing it. In one of his former jobs his co-workers were used to scare him often as a joke. It got to a point he accidently spilled a hot coffee on himself and was a minimally injures. In an attempt to understand the situation, I asked:

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

*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 autistic adult)

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

The ability to self-advocate is essential to be able to utilize needed service at the realm of the Israeli healthcare system. Having difficulties with this ability cause a genuine barrier for autistic adults. The qualitative analysis illustrates addressing this barrier should include in addition to effort to develop this ability, a counterpart solution which include a point person that is sensitive for the inability to express needs and that is ready to advocate for the autistic person. The fact that the need to self-advocate at bureaucratic process to get to the medical services, was not previously reported to my knowledge as a barrier to healthcare services, support the claim that autism is a distinct social group that suffers from unique barriers to healthcare service.

This section tries to illustrate one of the core traits of autism - communication differences can be a considerable barrier to healthcare for autistic adults. To overcome this barrier, communication need to 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 need to be clarified to both parties; preparation or mitigation by external helper should be considered to overcome difficulties to express oneself; additional time and patience should be devoted for any interaction with healthcare providers; alternative communication means and manners should be recognized, investigated for, and be accepted; the concept of concretization of language should be familiar to all service provider and take in consideration both when communicating a message and when receiving one; finally it should be recognized that in the current Israeli healthcare system structure many of the small bureaucratic procedures demand self-advocacy, which is a challenge for autistic individuals thus being another barrier to services. The section demonstrated that with the right approach, structural changes and providing the suppliers with the right tools these communication barriers can be overcome. Illustrating these barriers are a result of an inaccessible healthcare system that marginalize autistic adults, support the chapter claim that autism is a distinct social category that should be analyzed as one in the context of SDH.

## 4.2. The need for certainty and familiarity

This section claims the need for certainty and familiarity which is one of the manifestations of repetitive behaviors serve as a barrier to healthcare services for autistic adults. Furthermore, it asserts this barrier if addressed properly can be minimized in a lot of the cases and services could become much more accessible. Together both claims further support the chapter claim that autism is 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 as causing difficulties in the setting of a healthcare system, why repetitive behaviors, which are considered one of the fundamental characteristics of autism according to formal diagnosis guidelines, can be barrier to healthcare services should be explained. Understanding in its simplistic manner that observe the manifestation of this act: doing the same thing again and again, misses the reason for such behaviors. A dominant theme emerged in the qualitative analysis have 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, the encounter of most individuals with the healthcare system is often unfamiliar and saturated with uncertainties, whether it takes place during an unusual examination or at hospitalization. The conflict that emerges when the need for certainty and the uncertain conditions meets can cause a barrier and have long term ramifications.

The need for certainty and the usage of repetitive behaviors to maintain such certainty had appeared in the interviews mostly as coping technic of parents with their adult child difficulty when encountering the system. One example that has repeatedly emerge in the interviews was the practice of visiting the 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 adults individual 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 are still taking their son to the pediatrician but reveal the reason they kept attending his office: the familiarity with the place. This familiarity according to their description is working both ways. The physician and the office are familiar with their son, thus avoiding any inconvenience, and 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 son who was a 34-years-old (Carmit and Tuvia, parents of autistic adult).

Following the qualitative analysis, to understand the scope of this phenomenon a question was added to the survey on the frequency of replacing family physician. Among the responders (n=102) 20.6% have responded they are still going to their pediatrician. The age range of this group was 19 to 30, and the average age was 23. From those who are still attending their pediatrician 71.4%, were verbal and answered the survey themselves. These quantitative findings indicate that fifth of the population utilize the practice of going to their pediatrician in adulthood, most likely because they prefer to preserve familiarity of their healthcare provider than search for adult suitable alternative. This population age range indicates this practice continues to the thirties; and the fact the majority who still utilize this practice answered the questionnaire themselves imply it is not related to a relative convenience practice to avoid stigma, but to a genuine need to maintain familiarity.

Yet, utilizing the technic of going to familiar places was not limited to the continues care by pediatrician throughout adulthood. For instance, later in the conversation Bar further elaborate on their coping strategy with 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 description of her practice to take her son to annual blood examination even if are not medically indicated strengths 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), its was not recognized as a barrier healthcare services (Mason et al., 2019; Walsh, Lydon, O’Dowd & O’Connor, 2020), despite its anecdotal use in intervention programs at healthcare services settings (Walsh, O’Connor, Walsh & Lydon, 2021). Although her practice raises questions about risk and benefit to their son, her partner’s description of going back and forth several times for blood examinations and each time going through lengthy explanation process illustrates the importance of such practices. It exemplifies that unfamiliarity could really be a barrier as not everyone would agree to a lengthy and repeated visits to the infirmary just for blood tests. Moreover, the quote emphases that with proper arrangement that allows 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 at the autism field, this practice is not always done because the sick funds look for their own financial interest before the autistic individual’s needs.

Accommodating the uncertain and unfamiliar environment of the healthcare system can be achieved using another technic - early preparation and prior introduction. The qualitative inquiry has demonstrated this technic is utilized by diverse stakeholders. Tali, the grandmother and the guardian of a non-verbal autistic adult who was residing at home, demonstrated the significant effect 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 needed extra personnel and attention accomplished the CT examination effortlessly after a mitigated explanation and surprised all the parties involved. Tali’s example demonstrates the value of preparation for the medical providers as well. In this case it allowed them to plan for the arrival of her grandson and to lower possible stigmas they might had on autistics. Although it is not guaranteed that such intervention will be successful each time with every autistic individual the simplicity of this measure and the fact it is was repeatedly mentioned demands that it will be endeavored. Moreover, it illustrates the barrier of unfamiliarity can be mitigated.

The importance of the practice of preparation to enhance certainty and familiarity of autistic adults with medical procedures is 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 had before having a gastroscopy examination. In an attempt to ease the examination, she explained her son almost all stages at the expected procedure following the explanations she got from the attended physician. This explanation included the whole process from the injection of the sedative to the insertion of the camera through the oral cavity. When her son arrived the examination chair and was about to go through the procedure, he was asked to insert a protective plastic to his mouth. Although he agreed to do the examination, and he understood what is about to happen next, he refused to insert the protective plastic which was not part of the original sequence of events. Due to incomplete explanation that missed only one stage of the procedure the whole examination was almost cancelled. Fortunately, despite it involved a short distress that included awful attitude from the physician after additional reassurance from his mother he agreed proceed (Einat, personal communication, July 18th 2021).

Einat’s example illustrates that unfamiliarity could be a real barrier to healthcare services. The fact that because such a ‘small’ fraction of the examination was not communicated well in advance the whole examination was jeopardize emphasis the significance of an exact and detailed explanation on autistic adults’ 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 of autistic individuals.

Shlomi, an autistic individual, interviewed together with his partner, when asked what can be done to improve healthcare services emphasis the importance of accurate preparation also of 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)

Having access to healthcare services, Shlomi argued, means for autistic individuals knowing what problem they have, what they are expected to go through next, and comprehend what these next steps will include and will look like. In addition to this assertation that sums up previous interviewees quoted above, he argued that an accessible system will 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 unfamiliarity and the need for certainty are a barrier to healthcare service of autistic adults. His practical suggestions to alleviate this barrier, demonstrate this is socially constructed barrier that with a suitable practices and mitigation could be lifted.

To conclude, the need for certainty and familiarity of the autistic adult with the medical system, procedures and bureaucratic process is a barrier to healthcare services. In an unfamiliar 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 by preparation and detailed explanation of the about to happen. Accessible system would have an embedded procedures to alleviate this barrier, such as suitable forms that explains in detail what one should expect when going into medical procedure (for example of an unsuitable explanation form see appendix 4.2). Considering this is a structural barrier for autistic adults that can be relatively easily eliminated, further support the claim that autism socially constructed disability and is part of the social position of an individual. It also illustrate that in the current context this social position is being marginalized.

## 4.3. Sensory Differences

Sensory differences although not account for one of the main characteristics of autism is recognized as part of the formal diagnosis minor-criterion and it is known to be prevalent among autistics (Robertson & Baron-Cohen, 2017). This section argues these differences which can be manifested as hypersensitivity or reduced stimulation in the current Israeli healthcare system structure creates barriers to autistic adults in two manners. First, sensory overload within healthcare setting is causing autistic adults anxiety and overwhelming experience to an extent that prevent them from getting services. Second, hyperstimulation or low sensation of pain and symptoms result in wrong diagnosis. The following explores the manifestation of these sensory differences in the healthcare system and illustrates they do not have to be a barrier if proper accommodations to the system are introduced. Together these arguments adds another nail to the overall argument of the chapter that autism is a distinct social category that is being discriminated in the current Israeli healthcare.

### 4.3.1. Sensory overload

Sensory overload was identified as a barrier to healthcare services. Diverse interviewees recognized waiting areas as sensory overwhelming places. The combination of florescent lights that flicker, noisy and often smelly environment makes the waiting area unbearable for autistic adults. Jude, an autistic adult, a mother of an autistic adult, and an activist at the autism field, mentioned waiting areas as a guanine difficulty during her interaction with 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 laud, speaking in their phones and yelling, hearing music out laud. And the florescent lights, which you probably heard already from everyone [interviewed for the research], it is a nightmare, these florescent 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 florescent lights and the noises surrounding her that are unbearable for her. Jude not only framed this issue as an access issue marking sensory overwhelming as a barrier to healthcare system from the initial sentence of the quote; but also explained, waiting areas are preventing her access to such an extent, that despite having public insurance she seeks for alternatives in the private sector to avoid this obstacle. Her choice demonstrates overwhelming experience in waiting areas are an avoidable barrier that can be mitigate by changing the settings to a more sensory suitable one. 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 who is also involved in promoting the hospital accessibility, not only was aware to the stress waiting area can cause but suggested similar solution to the one Jude use:

“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 which also involve in promoting the hospital accessibility)

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

Another alternative to cope with the barrier waiting area 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 during her wait to the 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 florescent [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 near by 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 florescent lights and crowded waiting area, also describes an unbearable situation. Unlike Jude and taking in 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 have arrived. Mitigating services using this technique could be easily implement, yet in the current neurodiverse inaccessible healthcare system structure this mitigation is not widely available.

The qualitative inquiry demonstrated sensory overwhelming conditions, which often exist in waiting areas, are a barrier to healthcare services for autistic adults. Interviewees have suggested several strategies to overcome this unbearable barrier, some can be easily applied within the system. All this example affirms autistics are a distinct social group that with the right structural changes could have equal access to services.

### 4.3.2. Hypersensitivity or reduced stimulation

The second barrier autistic adults have in the current Israeli healthcare system that relates to their sensory difference manifests in their encounter with health practitioners. It became evident during the qualitative inquiry that sensation of pain or the interpretation of sensory stimulus as pain of autistic adults differs from unautistic individuals. Given pain is a marker of disease which deserves to be addressed experiencing it or not experiencing it in uncommon circumstances can lead to inappropriate diagnosis and treatment. While sensory experience can change from one individual to the other, the fact that many clinicians are unaware sensory differences are common in the autistic population, and do not respect autistic individuals self-reporting of pain is resulting in 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 that 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, a mother of an autistic adult and an activist)

Sigal’s daughter physician who could not find any objective cause for her pain concluded it is psychosomatic pain given her daughter diagnosis of autism. Sending her away with no solution, as Sigal testifies, seriously affected the entire family quality of life, especially her daughter who suffered tremendously. Not accepting this physician observation Sigal described later at the interview how she found a specialist who found a source for the pain, an autoimmune disease of the vagina which usually manifest differently and therefore was not even considered. Sigal’s daughter case illustrates how wrong perceptions of autism coupled with ignorance about sensory difference of autistic individuals is a barrier to quality healthcare services. Mitigating this barrier requires above all acknowledgement in the sensory difference, not stigmatizing pain as an emotional manifestation and 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 is quoted above. When discussing her and her son’s experiences with physicians she delayed on the sensory difference as for her it was a major barrier:

“The measurement of pain. ‘Yes… 1 to 10 how much that hearts you?’ What does it mean between 1 to 10? My one and your one is not the same, my 10 and you 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 for the literal meaning (see above article 4.1.5) of the pain scale could not understand how such different experiences of pain can be measured so subjectively. She explained that in hers 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 fracture that caused her minimal inconvenience. Finishing with the question ‘what is pain?’ Jude challenged the idea subjective report of pain could be used when examining autistic individuals. In other words, the reliance on the common neurotypical pain scale to conclude on the health issue in autistic adults could result in wrong impression and diagnosis. The fact that clinicians are unaware of this difference is a barrier to healthcare.

To sum up sensory differences of autistic adults can cause serious barriers to healthcare either by causing sensory overwhelming experience or by misunderstanding and misinterpretation of their symptoms. The sensory overwhelming barrier manifests especially at waiting areas or at crowded noisy environment such as emergency department and can be relatively easily mitigated and accommodated using diverse structural changes. The different experience of symptoms such as pain demands expanding the knowledge and enhancing the acceptance of this difference among clinicians. This section illustrates sensory differences which are prevalent among autistics are a barrier to healthcare services that can be diminished by introducing systemic changes. Thus, this section contributes to the chapter argument by adding another aspect autistic adults as a distinct social group are suffering from barriers and structurally marginalized at the healthcare system in Israel.

## 4.4. Barriers of autistic adults to healthcare services in numbers

To further understand the extent of these barriers in the autistic population and following the sequential exploratory design to mixed methods of this research, several questions that directly explore barriers to healthcare of autistic adults were included in the survey. As have been mentioned in the methodology chapter a lingual adapted contextualized version of the barriers to healthcare short questionnaire developed by Raymaker and colleges (2017) was inserted. In addition, two questions exploring barriers specifically to mental healthcare services, and additional services were included. Additional paramedical services is an inclusive definition that refer to paramedical services including occupational therapies, speech therapies and others.

Among the individuals who replied to Raymaker’s et al. (2017) adopted questionnaire (n=94) 74.4% marked four or more barriers to healthcare services, while 42.5% marked 10 or more (See table 4.4). The barriers that were marked by at least 50% of responders or more were: 1) Difficulties filling 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%) 6) Difficulties in following examination and treatment continuation (53.2%) (see table 4.5 for additional details).

In the two additional barriers related questions three choices among the twelve available choices specifically touched the encounter of the autistic individuals with the healthcare system: 1) Bureaucratic difficulties 2) Scheduling difficulties 3) Communication difficulties. Other choices were related to other dimensions of marginalization (such as cultural barriers) or broader systemic issue (such as lack of providers). Among the responders who answered regarding psychiatric service (n=100), 26.0% marked bureaucratic difficulties, 25.0% marked scheduling difficulties, and 8% marked 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% marked these issues as constitute difficulties (see table 4.6 for additional details).

These results separately and combined indicate that autistic adults suffer from great barriers to healthcare services in Israel. Both bureaucratic barriers and barriers that manifest at the encounter with the provider were found in more than 60% of the population, signifying both the processes are marginalizing autistic adults. These results strengthen communication and sensory barriers that were rose as major themes in the qualitative analysis are indeed significant barriers for this population. Furthermore, Raymaker’s et al. (2017) as part of their research tried to identify a cutoff that differentiating autistic adults from other disabilities by the number of barriers individuals suffer form. In their questionnaire a cutoff of four barriers out of 18 was argued to be differentiating. In this research almost 75% of responders marked four barriers or more, while above 40% marked ten barriers or more. These results indicates that while 4 barriers could be differentiating between autistics and other people with disabilities, a large portion of the autistic population are deprived access to a much greater extent. These quantitative findings support the claim autistic adults are a distinct social group that is being deprived from equal access to healthcare services in Israel.

|  |  |
| --- | --- |
| Table 4.4: Number of barriers to healthcare services |  |
|  | N (94) | Percentage | Cumulative percentage |
| 1-3 Barriers | 24 | 25.5% | 25.5% |
| 4-9 Barriers | 30 | 31.9% | 57.4% |
| 10 and more | 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 to schedule 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 suitable healthcare provider | 20 | 21.2% |
| Providers do not discuss health decisions  | 22 | 23.4% |
| Communication with 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 discomforts  | 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 family physician ǂǂ | 28 | 29.7% |

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

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

\*Unlike 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 providers specializes only in autistic children | 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 implication of the barriers mentioned above on the health of autistic adults. While the four previous sections were aimed to ground the major argument of this chapter that autism should be considered as part of the individual’s social position based on its distinct marginalization, this section completes the analysis from an SDH point of view and demonstrates this marginalization is affecting health. Furthermore, despite the initial goal of the research did not include identifying or quantifying these consequences, they emerged as a significant theme at qualitative investigation and therefore should be explored. Lastly as this research is participatory research that approach the field from a critical stance and wish to influence it, the section is required to explain policy makers that ignoring the barriers mentioned above have ramification on this population and beyond.

The qualitative investigation had illustrated barriers to healthcare of autistic adults is directly and indirectly influence this population health. Despite barriers to healthcare services could eligibility be intuitively linked to health outcome this link does need elucidation. Most often this link is investigated, as presented in the literature review, quantitatively by demonstrating disparities between autistic individuals and neurotypical health outcomes. The qualitative research conducted cannot answer this research question; however, it did discover three mechanisms in which health barriers are linked to health outcomes in the Israeli context. Frist, these barriers can lead to incompatible treatment provision that can result in adverse health outcomes; second, because these barriers inflict additional burden on autistic adults and families when seeking healthcare services they encourage them to avoid care which directly affect their health; and third, unsuited services that trigger anxiety and resistance of the autistic individual can translate to the use of force to provide needed treatment, a practice that is known to harm health (Castle & Engberg, 2009; Rakhmatullina, Taub & Jacob, 2013). These mechanisms are essential to understand as they can be addressed directly by policy makers and they should be utilized as a proxy measurement to health outcome when introducing programs to alleviate barriers, in the case of this distinct population.

### 4.5.1. Unsuited care

Unsurprisingly one of the major themes emerged in the qualitative investigation regarding the implications of barriers to healthcare was inappropriate care. Autistic adults, family members and professionals, although not physicians, reported encountering cases of unsuited treatment. Hila, for instance, a sister of two autistic adults and the guardian of one of them, have portrayed her brother 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, a sister of two autistic adults)

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

One such example was raised during the interview with Bina, a manager at a residential place for autistic adults, who discussed the need for mitigating 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. May be 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 place for autistic adults)

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

Autistic adults’ barriers to healthcare services unfortunately impact these individuals’ health daily, first and foremost because they do not get the appropriate care, as neurotypicals. To used Bina’s words, it is a ‘duty’ to develop ways to mitigate those services. Not only because other autistic individuals’ serious illness is mistreated but because this population of autistic adults is aging, and sickness will be inevitably more prevalent. To conclude, barriers to healthcare services negatively affect autistic adults’ health by preventing them suited treatment for their illness.

### 4.5.2. Avoidance of care

Additional significant mechanism by which barriers to healthcare services influence health outcomes is avoidance of care. Despite being an indirect effect of the unsuited, and often unpleasant, experience in the healthcare system it has great ramifications on health. Repeatedly mentioned by diverse stakeholders’ avoiding the interaction with the healthcare system altogether is a strategy utilized both by autistics and by guardians who anticipate dire experience when encountering the system. One such example was expressed by Carmit, the mother of an autistic adult, when she described her experience in 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, a mother of an autistic individual)

Carmit testified 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 her and her partner behavior calling themselves criminals, she explained this experience will be harsh given her son lack of cooperation. Her chose of wording when analyzed carefully also conceal the attitude she previously experienced from the system toward her son’s incompliance. Instead of trying to mitigate the services or search where it sets the barriers for her son, the system representatives were looking at her as the one responsible for these difficulties. Carrying this responsibility for the systems’ misconducts 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 the caregivers of autistic adults who reside in the community are getting older together with their children and the encounters of their children with the healthcare system is expected to expand given their age, keeping healthcare services inaccessible 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 they avoid care among them Ronen Gil, an autistic adult and an activist who bluntly said: “I avoid reaching out to this [healthcare] system”, or Bruce, an autistic adult and an 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 important as it sheds lights on the relation 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 these struggles and the systemic dissatisfaction can cause avoidance is essential to understand this link. In the context of this section, the healthcare system who is posing 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 barriers are actively causing avoidance of care. Dr. Yair adds to this struggle another implication of unsuited services discussed below (see next sub-section 4.5.3 ‘using force’) - the coercion of treatment. He asserts compulsion of treatment also reenforce the negative experience, ‘the phobia’, and causes avoidance of care.

These examples put together demonstrate avoidance of care is a serious implication of barriers to healthcare services of autistic adults. Considering that when an autistic individual that is usually avoiding care does approach to receive assistance in serious situations, he or she will encounter barriers again, portray a vitious cycle of inaccessible healthcare services that nurtures itself to the point of being irrelevant for the autistic adult. Although avoidance is neither relevant just for autistic adults, nor it is the first time to be linked with barriers to healthcare services (Kannan & Veazie, 2014; Taber, Leyva, & Persoskie, 2015), its ramifications on health mandate this issue would be targeted as part of any future effort to improve services for autistic adults.

### 4.5.3. Using force

One of the direst implications of unsuitable healthcare services on autistic adults is the need to use force to treat them. In cases where a treatment is required, to mediate the resistance of the autistic patient force is sometimes being applied in the form of physical or pharmacological restrain. While in the qualitative inquiry some unfortunate examples had been depicted, Dr. Efron’s, a psychiatrist working with autistic adults, analysis of the experience one of his autistic patients had during a medical treatment she needed to receive following a self-inflicted hand fracture 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 in an earlier part of the interview have told me that he used his personal connections so this patient will go trough the operation she needed, express his frustration from the fact she was tide to her bed for an entire week. He rises two reasons why this act is wrongful. The first reason he rises is the moral issue. Tying a patient to the bed to make him go through a procedure he needs, while taking his autonomy on his body out of his hands, has long been morally debated (Gastmans & Milisen, 2006; Mohr, 2010). Although Dr. Efron dismisses this argument trying to focus on the practicality, the moral implications of such practices should be taken in consideration and discussed both in relation to autistics marginalized position in society and in the context of the barriers to healthcare services covered above. The second argument of Dr. Efron is that this practice of restrain has implications on the autistic patient. In a separate part of his interview, he explained that the implications of restrains are on the autistic individuals wellbeing and their mental health. Despite arguing against restraining, he concluded in the closure sentence that this practice is inevitable, and he would not expect for different treatment. His finale exemplifies 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 relation between the existence of unsuited healthcare services and the use of force was illustrate by Carmit and Tuvia, parents of an autistic adult. Talking about their son’s experiences with the medical system they illustrated how a pharmacological restrain was avoided when 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, a father of an autistic individual)

Tuvia depicts a grim situation in which dental care could be done only under anesthesia. Although this practice is subsidized by the state for autistic individuals and other individuals with disabilities following 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 the care, has its complications and should be used if there is no other option. Tuvia and Carmit continued to explain their position and gave an example for 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 autistic individual)

Tuvia and Carmit describe their son’s childhood dentist who had retired. His attitude which involved games and music along treatment, made corporation possible. Instead of pharmacological restraining he utilized alternative practices of communication that allowed participation. Both Tuvia and Carmit agree 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 not know how to utilize alternated approaches. This instance illustrates that physical or pharmacological restrains although prevalent and broadly accepted are not a mandatory practice. Lifting barriers could assist reducing their use and minimize their implications on health, as intervention programs have shown (Sturmey, 2018).

To sum up current barriers to healthcare service have great implications on the health of autistic adults. Thus, they can be classified as a determinant of health inequalities. The serious consequences of the barriers presented in the previous sections mandate urgent notice by policy makers and position holders within the healthcare system. Receiving unsuited care, avoiding care due to maltreatment, and using force in cases treatment could not be avoided are three distinct mechanisms by which barriers affect health. These mechanisms especially avoidance and the use of force should be addressed on their own and could be used to monitor intervention programs to reduce barriers of autistic adults.

## 4.6. Conclusions

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

In addition to closing the gap in the SDH literature this argument is essential for practical reasons. The medical establishment, specifically in Israel, have yet recognized autism as a social group of reference; therefore, it overlooked the marginalization of this population within the healthcare system. From a practical perspective the analysis the chapter propose request autistics will be regarded as a social group, and therefore the efforts to reduce their discrimination within the healthcare system should be done under the umbrella of reducing inequalities, similar to the efforts invested to reduce culturally discriminating practices. Furthermore, the analysis high-resolution allows understanding the distinct barriers this population encounter in the Israeli healthcare system. It also proposes practical measurements for overcoming these barriers that had been mentioned by diverse stakeholders.

Three intrinsic characteristics of autism were raised as inflicting barriers: communication difficulties, repetitive behaviors, and sensory differences. Communication difficulties unsurprisingly involve difficulties in expression; nevertheless, as had been demonstrated other factor affect communication difficulties of autistic adults. These include discrepancies in the perceptions on the settings and the goals of the communication, longer processing time during an interaction, the usage of alternative communication means and manners that are not recognized, understanding messages literally, and specific difficulty in self-advocacy and reaching out for assistance. Repetitive behaviors are manifest as the need for certainty and familiarly when utilizing healthcare services. Not recognizing the need for proper and detailed explanation of the medical process, or the need for prior introduction to a facility or a procedure can be a great barrier to healthcare service. Finally, the role of sensory differences as a barrier to healthcare service is analyzed. Manifested as oversensitivity or insensitivity this difference affect both the ability of clinicians and autistic adults themselves to understand their symptoms and get to the right diagnosis, and the ability to wait in overstimulating spaces often found in the healthcare system. While most of these barriers are recognized in the scientific literature (Walsh, Lydon, O’Dowd & O’Connor, 2020), others such as concretization of language and the lack of self-advocacy as a barrier were first mentioned in this work. In addition, this research is the first to explore this barriers in Israel.

The quantitative findings from the survey strengthen the qualitative analysis. By showing more than 70% of responders experienced four barriers or more, a number that was found to be differentiating between autistics to other disabilities, it demonstrates this population could be regarded as a distinct group despite its heterogeneity. The findings further indicate that above 40% of this population have even greater challenges as they encounter 10 barriers or more, consolidating the magnitude of this problem. While the qualitative inquiry demonstrated the barriers could be manifest both in the encounter with the provider and the bureaucratic, the quantitative findings indicated a great portion of the barriers are tampering the process to get the services; therefore, indicating mitigation structural efforts should not neglect the bureaucratic aspect.

To complete the analysis from a SDH perspective the chapter demonstrates these barriers have serious health implications. Yet using the distinct perspective the qualitative inquiry allows not just the health implications were depicted but the main mechanisms they work through were described. These mechanisms include provision of unsuited care, avoidance of contact with the healthcare services, and the need to use force either physical or pharmacological to provide needed treatments. Understanding the mechanisms that marginalize this group are crucial also 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 expected surge in the number of autistic individuals and the fact that autism traits are permanent, 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 to the health of the autistic population. These structural changes should include variety of mitigation strategies, some as the chapter illustrates are already utilized by different stakeholders. In addition, direct confrontation with the mechanisms that affect health outcomes is needed. Above all this change should be perceptional that regard autistic adults as a distinct social group that deserve equal health care services in light of the National Health Insurance Law (1994) principals.

## Appendix 4.1



This form who was handed by a genetic counseling center include many unclear points. Some issues might confuse also neurotypicals. For instance, including all the mutations name within the form, could confuse also someone who is not from a medical background. The second to last sentence of the forms that reads “These results are a statistical calculation based on the information you provide us and known medical research” can easily confuse any autistic individual. If read literally, the meaning could be that all the above is irrelevant as it is just a calculation. This form should be amended from top to bottom, however, this sentence specifically could confuse autistic adults and make the impression the whole 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. Yet, in relation to the issue of early preparation what this form miss above all is an explanation f the expected procedure. Should the patient bring his own sleeping closing? Would dinner be provided? For how long the test is taking? Would any equipment be attached to the patient body? Many unanswered questions that make the procedure unclear and intimidating. Creating a mitigated form that include a detailed explanation of what to anticipate would make the procedure much more accessible to autistic individuals and to the entire population.

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