# 2. Methods

This study used a participatory mixed method research methodology that included a qualitative phase and a quantitative phase. The participatory approach, which was adopted at the very early stages of the research, included establishing an advisory committee that shaped the way the research was conducted throughout the various phases. The qualitative phase included in-depth interviews with autistic adults, parents of autistic adults, and relevant professionals. This was complemented by extensive archival research. The quantitative phase included a survey aimed at validating the qualitative findings. Finally, an integrated analysis of all research findings was performed to produce a comprehensive appraisal of the investigated field.

I chose to adopt a critical realism paradigm in this study. This paradigm is based on Roy Bhaskar’s (DATE) philosophy of “transcendental realism” positing that social structures are “true” constructs that can only partially be uncovered by subjective theories and interpretations (Harvey, 2002; McEvoy & Richards, 2006). Research performed in the context of this paradigm seeks to investigate social phenomena from the perspective of the agents operating within the context in question or, more precisely, the relations between sets of structures and operating agents within society. While an agent’s perspective may be limited by the context, the agent is nonetheless in a position to make changes within the context. Given that this study concerns the complex relationships that exist between autism, inequalities, advocacy organizations, policies, and other social positions in their temporal context, this paradigm was the most appropriate. Furthermore, the critical realism paradigm corresponded well with both research methods selected: the participatory approach, which is directed at changing social structures, not merely describing them (Potvin, Bisset & Walz, 2010; Baldwin, 2012), and the mixed methods approach, which is considered the most effective approach for answering critical realist questions (McEvoy & Richards, 2006).

## 2.1 Participatory research

Participatory research is a broad description of a heterogeneous research methodology that includes the participants in the research process itself. This type of research has three features that distinguish it from traditional research: it aims to shape reality; it shifts the role of the researcher from interpreter of reality to mediator of the research process, and it alters the power relations between researcher and participants which, in turn, affect the control over the knowledge produced by the research. However, because participatory research also needs to be highly contextualized, it can vary enormously in terms of the methodology used to conduct it. Categories of research falling under the methodology range from community-based participatory research (CBPR), to participatory action research (PAR), to inclusion research and many others (Maguire, 1987, p.14; Cargo & Mercer, 2008). Therefore, to ensure reliable results, scholars agree that a detailed description of the participatory procedure and the means it employs is required (Maguire, 1987; Walmsley, 2004; Cargo & Mercer, 2008; Balfour, 2013; Bigby Frawley & Ramcharan, 2014).

In the autism research field, although participatory research is still at the margins of academic research (Jivraj, Sacrey, Newton, Nicholas, Zwaigenbaum, 2014; Wright, Wright, Diener, Eaton, 2014), it started to be considered valuable starting in the last decade (Nicolaidis et al., 2011; Crane, Adams, Harper, Welch, Pellicano, 2018; Fletcher-Watson et al., 2018; Nicolaidis, 2019; AASPIRE, 2020). Research in the field of autism has tended to be based on CBPR (Cargo & Mercer, 2008) and, responding to the call of “nothing about us without us,” has drawn on the research tradition established in disability studies that places the insights of disabled people at front and center (Walmsley, 2001; Krumer-Nevo & Barak 2006). Scholars who have applied this practice argue that it can help align research priorities with community priorities (on this discrepancy see Pelicano, Dinsmone & Charman, 2014), change the use of offensive language in autism research, and promote research that is consistent with community values (Nicolaidis et al., 2011). In Israel, unfortunately, only Schneid (2018) and Schneid & Raz (2019), who investigated the conflict between autistic people and society, have conducted participatory research in the autistic community. It should be noted that, despite not being situated in one geographical location, as is the case for most communities participating in CBPR, the autistic community can be regarded as a single community based on other definitions of community, including the notion of the epistemic community (Akrich, 2010) and the virtual community (Rheingold, 1993; Nicolaidis et al., 2011) that articulates its traditions in the real world (Gil, Shoham, Shelly, 2016).

Employing a participatory approach to the research was not my initial intent, nor had I even considered it. The research took the crucial turn towards a participatory methodology shortly after it began. The idea of adopting a participatory approach was raised at a meeting held with one of the founding members of the Autistic Community of Israel (ACI), the only Israeli self-advocacy group for autistic people (Raz et al., 2018). Unlike in most participatory research, the research questions were determined in advance (Baum, MacDougall & Smith, 2006; Nicolaidis et al., 2011) and members of the autistic community were consulted. Having read the research proposal, they agreed that it was worthwhile and should be pursued. After gaining the consent of the autistic community to collaborate with other organizations, including the Ministry of Health (MoH) and Alut (the largest organization for parents of autistic children in Israel), and ensuring that the agendas of these bodies did not conflict with the community values, the participatory research could begin.

We agreed that forming an independent advisory committee of autistic adults would be optimal for the research and decided that anyone who identifies as autistic could join the committee. Although at the initial stages committee members were asked to commit to the entire research process, after one of the first three autistic people who joined decided he could not participate any longer, we decided that, if an autistic individual wished to join the committee during the research process, they would be welcome provided they remained committed until the end of that research phase. This decision was made given the substantial investment of time and energy entailed in preparing for the participation process, and given the fact that participants were not compensated. Furthermore, we agreed that in the event of disagreement among members of the committee or between them and me, as the researcher, the final decision would be mine. This privilege was exercised a handful of times regarding minor issues, such as the wording of the questionnaire.

The initial recruitment for the committee was done by ACI, that sent an invitation to their members. Later, new members were recruited by actively approaching potential candidates who were recommended by interviewees during the qualitative phase. As a result, the committee became heterogeneous and included not only members affiliated with ACI. Given that committee members had the option to leave the committee throughout the research process, the number of members varied at different phases, ranging from two to five members (see Appendix 2.1 for participation of members in each stage).

Other than not being involved in drafting the research question and goals, the committee played a role at every step of research process. The advisory committee provided input on the qualitative interview guide, on the qualitative themes, on both versions of the survey questionnaires and how it should be delivered, on which relations should be examined in the quantitative analysis, and on the research outcomes and publications.[[1]](#footnote-1) Committee members also helped prepare a grant proposal that was submitted to an international agency and they have been an integral part of an effort to promote accessible services for autistic people at the MoH. Nevertheless, unlike participatory action research, committee members did not take an active part in the data analysis process of the qualitative and quantitative phases. The reason for conducting the analysis myself was a practical one. Considering the training and the resources needed to train the members and the amount of time it would require from them and me, it was agreed that I alone would execute the analysis.

The contribution of the committee exceeded my expectations. Among their numerus contributions, their assistance in the contextualization of the research design, tools, and outcomes was the most prominent. In addition, without their observations, critical themes would not have appeared in the research or could have been completely misinterpreted. The notion of modifying the survey questionnaire would not even have been considered without the input of the committee. Furthermore, the implementation of the research findings at the MoH would have been much less effective without the participation of the committee. Finally, working intimately with the committee has changed my perspective about the field as a future physician. These contributions are aligned with those identified in the literature (Cargo & Mercer, 2004; Walmsley, Strnadová, & Johnson, 2017).

Despite the invaluable assistance of the autistic advisory committee, their participation did entail some challenges. First and foremost, it demanded time and investment of resources. One committee member, for example, requested only verbal communication, as the effort of reading and writing for him was prohibitive. Therefore, his comments on all the documents, including the technical one with its qualitative codes list, were provided via phone call or in face-to-face meetings, which required extra time. Apart from objections to the additional outlay of time and energy, the methodology was not acceptable to some professionals and parents, who argued that the committee’s contribution would be biased. From an institutional perspective, although the idea of participation was accepted and supported, the additional time it demanded was not formally accepted by all research authorities. These difficulties, which are an integral part of participatory research, should be institutionally addressed so more researchers will be able to use this methodology, as the added value of having the community under investigation invested in the research is immeasurable.

## 2.2. Mixed methods study

This research adopted a sequential exploratory design of mixed methods (Creswell & Clark, 2007, pp. 180–182). In this design, the first phase is qualitative and the second phase is quantitative. The rationale for using this mixed methods design was to establish a comprehensive understanding of the field using qualitative methods and only then to explore the findings, their generalizability, and their validity by employing quantitative methods.

This design was chosen for three main reasons. First, it best corresponded with the research paradigm mentioned above, since it allows one to investigate the field under examination from a subjective position while accepting its objective realization (McEvoy & Richards, 2006). Second, as the main research question of this study was focused on the *mechanisms* of inequalities, a qualitative design at its core was essential. In terms of the qualitative-quantitative continuum, this design is qualitative-dominant, mixed method research (Johnson, Onwuegbuzie & Turner, 2007). That is, it subordinated the quantitative methods to the qualitative methods, which were better suited to the nature of the research questions (Hesse-Biber, 2010). Given that the field of autistic adults in Israel has never been investigated, and the reasons for inequalities have been only partly theorized, it could be claimed that the mixed methods design was a good “methodological fit” (Edmondson & McManus, 2007, pp.1165–1167). Lastly, choosing a mixed method design suited the participatory research approach adopted for the research. This is because it both allowed for the application of the insights of the advisory committee from the outset, and enhanced the potential of the research to actually influence the reality of autistic adults. From a pragmatic point of view (Nastasi, Hitchcock, & Brown, 2010), while the qualitative inquiry could explain the complexity of the questions and problematize the research field, the quantitative phase was needed to influence the researched field, given the lower status of qualitative research within the healthcare and health policy fields (Greenhalgh et al., 2016). Adopting mixed methods sequential exploratory design, it can be concluded, was the most suitable for this research.

## 2.3. Qualitative phase

The qualitative phase of this study was performed using the grounded theory method and included data collection and analysis from diverse sources. While the main source of data was in-depth interviews, additional qualitative data was utilized, including documents and records of the policy process. The data was analyzed according to thematic analysis procedures.

Among the methods of qualitative research (Starks & Trinidad, 2007), I adopted the grounded theory method. This method, which draws on Blumer’s interactionism theory (1969, in: Wells, 1995), was originally developed by Glaser and Strauss (1967) and holds that using inductive reasoning while constantly comparing empirical data collected systemically throughout the research can provide the investigator with a contextual understanding of the social structures from the perspective of social actors. This approach, which clearly matched the research paradigm adopted in this study, is widely used in health research and is also equipped to investigate power relations in society (Lichterman, 2002). However, because the “pure” original perspective of the grounded theory method insists that the investigator should arrive at the field without presumptions and only draw conclusions from the field itself, I adopted a more recent iteration of this method. Contemporary scholars argue that investigators *always* approach a field conditioned by their own subjectivity and naturally will pose research questions arising from their own perspective (Corbin & Strauss, 2015 pp.17–27). As I set out to investigate not just the social structures, but also associated discriminatory practices, I clearly arrived with a hypothesis. Therefore, I adopted a more current approach to the grounded theory method that was better suited to this research.

Since qualitative (and some might argue also quantitative) analysis, in spite of being executed with precise methods, is affected by researcher observations (Clarke, 2007), it is crucial to position the researcher, myself in this case, in the field of investigation to enhance the credibility of the results (Tracy, 2010) and their reflectivity (Mays & Pope, 2000). Apart from being a Jewish man from mixed Ashkenazi-Mizrahi origin, who grew up in a middle-high income family in the geographical center of Israel, and whose parents immigrated from Argentina, two additional aspects of my personal biography affected my position in terms of the investigated field. The first was my medical education. While conducting this research, I was enrolled in medical school and had absorbed the values and, most importantly, the unfortunately embedded perception in the field of medicine that disability and, specifically, autism is a disease that should be eliminated. The medical model of disability (MMD) endorsed as part of my training as a physician clearly affected my position entering the field. The second aspect of my personal biography that affected my perspective was my past experiences in social activism with oppressed communities in Israeli society, including public housing residents, Palestinians, non-Jewish immigrant workers, unionized Israeli workers, women and more. While my adherence to the medical model of disability had clearly shifted toward the social model, owing to the long discussions I had with advisory committee members, which reshaped my perceptions, the critical perspective on social structures I gained through my activism clearly shaped my observations of the autism field. These aspects, I believe, are the most essential features of my personal *habitus*[[2]](#footnote-2) that the reader should be aware of in order to understand my perspectives on the investigated field.

### 2.3.1. Procedure of data collection

Two complementary sets of qualitative data were collected for the research. The first primary data source was in-depth interviews with autistic people, guardians of autistic people, and professionals working in the field. The second data source was treated as secondary qualitative data and was aimed at describing the policy process and the historical context of the field in Israel. The following sections describe the procedures of data collection for the qualitative phase.

#### 2.3.1.1. In-depth interviews

Since the goal of the research interviews was dual – to explore the needs and barriers to health and social services of autistic adults, and to understand the evolution of policy regarding autistic adults – stakeholders with diverse experiences in the field needed to be identified and interviewed. To achieve the first goal, the participation of autistic adults, family members of autistic adults, and professionals who work with this population was needed. For the second goal, key figures from organizations, government officials, and involved experts who were expected to provide relevant information needed to be included. Therefore, I employed several strategies to identify interviewees who would represent the diversity of stakeholders relevant for the research and that could be considered as good informants (Palinkas et al., 2015; Malterud, Siersma & Guassora, 2016, p.3).

The following identification strategies were exercised between October 2016 and July 2019: direct communication with potential interviewees recommended by the advisors was initiated; a call for participation was disseminated by the four organizations for autistic adults in Israel – Alut, ACI, Mishtalvim Barezef and Effie (see Appendices 2.2, 2.3, and 2.4 for formal collaboration letters; see Appendix 2.5 for call to participate); key figures who were relevant to the study were approached at conventions or events; experts identified on the internet were contacted via email or phone; the snowball sampling technique was employed (Noy, 2008); and interviewees from the Keshet Clinic in the Sheba Tel Hashomer Medical Center were directly recruited based on specific identifiers (see Appendix 2.6 formal collaboration letter ; see Appendix 2.7 for additional details on identification strategies).

Using these methods, I identified participants from the following categories of people: autistic adults with verbal abilities; guardians (parents, siblings, grandparents) of autistic adults unable to communicate intelligibly with me or who did not want to participate in the research directly; a variety of professionals treating autistic adults, including psychiatrists, psychologists, family physicians, nurses, speech therapists, behavioral therapists, occupational therapists, relationship and sexual therapists, social workers, and managers of hostels and programs dedicated to autistic adults; actors involved in policy creation, including key figures from advocacy organizations, officials from the relevant ministries; and activists. As has been previously recognized in the literature, actors in the field of autism often belong concurrently to more than one of the groups described above (Eyal, 2010; Eyal, 2013; Waltz, 2013). An autistic individual could also be an advocate, or a parent, or could work as a therapist and have a key position in an advocacy organization or a relevant ministry. The overlap of eligible interviewees’ backgrounds added more interviewees from each category, but, more importantly, it allowed exposure to complex perspectives on the various issues. Finally, during the interviews stage, I ensured there was a fair representation of autistic individuals with different communicative and cognitive ability levels, genders and sub-populations in Israeli society. For a full list of interviewees’ personal characteristics, without personal identifiers, see the participants’ information in Section 2.6 below.

The number of interviews was not predetermined. I continued to conduct interviews until saturation was achieved (Baker & Edwards, 2012). While saturation on certain subjects, such as the needs and barriers of autistic adults, was quickly achieved, in other areas, such as information on the policy processes, it took longer to reach saturation. Interviews were held in the place and time preferred by the interviewee. Among the places used were private homes, university offices, personal offices, and outdoors. In line with interviewees’ informed consent (see Appendix 2.8, informed consent forms) the interviews were recorded and transcribed verbatim. It should be noted that one interviewee, Ronen Gil, an autistic autism advocate, insisted before signing the consent form that he would be quoted by his full name in every document or report. Following an approval from the ethics committee, his request was respected. Interviewees were asked if they wanted the transcript sent to them for validation ([Mays & Pope, 2000](#_ENREF_83)). Only five interviewees did ask to receive the transcribed interview back. Among these, two approved the entire interview, two asked for the deletion of several sentences or introduced amendments, and the last requested that the entire interview be retracted. Following each interview, a researcher diary was recorded. The recorded diary included initial thoughts about the interview in terms of how it was conducted, the flow of the interview, and potential avenues for analysis.

The interviews were semi-structured to allow the interviewee to raise novel themes (Berg, 1988), yet they directly addressed matters concerned with this research. The initial interview guide was drafted by the researcher (see Appendix 2.9, Initial Interview Guide). It contained topics relevant to the research, covering health and social determinant related needs, barriers to healthcare, involvement in the policy process, inequalities between autistic adults’ needs, policy processes, international knowledge transfer, and inequalities. The guide was then sent to the advisor for approval and two pilot interviews were executed. Then the guide was sent to and reviewed by the participatory advisory committee. Following the committee’s recommendations and conclusions from the pilot, changes were introduced and dedicated guides were developed for different stakeholders – autistic adults, family members, and professionals. Developing stakeholder-unique interview guides was necessary to capture the backgrounds of the variety of stakeholders who participated in the interviews, and for the discussion of focused topics relevant only to some stakeholders, such as diagnosis experience (see Appendix 2.10 finalized interview guides).

#### 2.3.1.2. Policy process and historical context

To be able to fully grasp the evolution of the autism field since its emergence in Israel, and the process of creating autism-related policy, archival research was conducted. Systematic searches of two main resources were performed. First, to gain an internal perspective on the policy creation process, the Knesset (Israeli Parliament) archive and the Israeli State National Archives, which includes the archives of the internal ministries, were searched. Second, to understand the interpretation of the law and to gain a broader perspective in terms of the context in which the policies were created, a search of major Israeli newspapers was performed. The period surveyed was from 1965, the year the National Society for Autistic children was established in the United States, to 2015, the year I started the research. All data collected was stored electronically and then transferred to the qualitative analysis software, Atlas.ti, for further analysis (for full search strategy, see Appendix 2.11).

Moreover, to acquire firsthand understanding of the development of the autism field in Israel, I also utilized primary data collected as part of the Autism Oral History project in Israel. During the summers of 2013 and 2014, twelve interviews with key historical actors in the field of autism were conducted. During the interviews, the researchers inquired about the development of the field of autism in Israel, and, specifically, about the personal role the actors had played in its development according to predetermined interview guides (see Appendix 2.12). Each interview was recorded and transcribed, and the transcriptions were used as part of the secondary qualitative data for my final analysis. In the following Chapter, I specify every time I used data drawn from the Autism Oral History project (additional information on the Autism Oral History project in Israel can be found in Appendix 2.13).

### 2.3.2. Method of data analysis

The systematic analysis of the content gathered during the data collection was a continuous process that included four main phases. First, the pilot interviews were analyzed in order to form main categories and subcategories. Then the list of categories was sent for review to the advisor and the advisory committee. Third, using the revised categories list, I analyzed the additional interviews as they were conducted. Finally, the themes that emerged during the interview analysis were used to explore the policy documents.

After the interviews were transcribed, I read the entire interview thoroughly to ascertain novel angles of inquiry. Then I listened to my recorded researcher diary to explore whether the ideas that emerged immediately after the interview and that were influenced by the personal interaction and not only the content could, in any way, have a bearing on, or contribute to the analysis. The next categorization process was executed by constant comparison practice using Atlas.ti software, versions 7 and 8. For the first two interviews, I used both categories that emerged from the text itself and categories related to the predetermined theory I set out to explore in the research. Then, a detailed index was created in what Shkedi (2003, pp. 97, 111–113) classifies as the “initial analysis stage.” As mentioned above, the initial list of categories was reviewed by the advisor and the advisory committee. While not exposed to the data, the committee advised on several amendments to the codes list, including clarifications and explanations, recategorization of several codes, and the introduction of new codes. The finalized codes list (see Appendix 2.14) served as a departure point for the analysis of all the interviews conducted afterwards. Yet, if additional codes were required for an accurate analysis, they were added. This procedure was agreed upon with the advisory committee in advance. The interview analysis was sequential because the hypotheses were redefined during the process of data gathering and categorization ([Pope, Ziebland, & Mays, 2000, p. 114](#_ENREF_102" \o "Pope, 2000 #96); [Shkedi, 2003, p. 96](#_ENREF_115)). Finally, links between the categories were outlined to identify the type of relationships existing between categories (see Appendix 2.15 for an example of a codes linkage map concerning policy construction). This process was done twice: once during the classification process and once when the analysis was completed. The data was then reorganized for each category using Atlas.ti – “mapping stage” ([Pope et al., 2000](#_ENREF_102); [Shkedi, 2003, pp. 97,111–113,121–122, 138](#_ENREF_115" \o "Shkedi, 2003 #107)).

Using the categories derived from the interviews, policy documents were analyzed ([Shkedi, 2003, pp. 194–197](#_ENREF_115" \o "Shkedi, 2003 #107)) and the relevant data was added to each category. The reason for first analyzing the interviews and later enriching the inquiry with findings from documents and not vice versa or in parallel was that most health researchers see archival documents as secondary to human sources ([Shkedi, 2003, pp. 194–196](#_ENREF_115" \o "Shkedi, 2003 #107); Prior, 2010). From this perspective, the content of the documents is analyzed as a constant, not as an active agent in determining social reality; therefore, their ability to determine the trajectory of a research project is secondary to data generated by interviewees. Despite initially adopting this approach to the analysis, I utilized in the research documents not solely as a source of information, written and forgotten, but as beacons that signify a path for policy and social realm. From this perspective, documents represent both the summation of an entire historical process and the foundation for directing the path towards future social structures. In line with Prior’s (2010) categorization, I use documents both by focusing on their content as a source of information and by understanding their use and function as structures in the research field that are produced by actors who are reproducing their vision. Using multiple data sources, diverse stakeholders, and different perspectives on the data helped triangulate the research and contributed to producing a more layered and thus more reliable study (Mays & Pope, 2000; Melia, 2010; Tracy, 2010).

Based on the list of codes and categories, a summary of the main categories was produced. These were selected based on the initial research objectives and according to the richness of the data available in each category. Data from the main categories was then summarized by Atlas.ti software, and the description and analysis of main themes was conducted. This corresponded to the “centered analysis stage” ([Shkedi, 2003, pp. 143–153](#_ENREF_115" \o "Shkedi, 2003 #107)). It should be noted that the entire process, apart from the analysis itself, was made transparent to the advisory committee, which further enhanced the validity of the research (Tracy, 2010).

## 2.4. Quantitative inquiry

As mentioned above in the section discussing mixed methods, I conducted sequential exploratory mixed methods research. Thus, I utilized the quantitative inquiry for validating and generalizing the qualitative findings. The quantitative part was composed of a survey that focused on the needs for and barriers to access to healthcare and social services faced by autistic adults in Israel.

### 2.4.1. Development of research tools

The development of the research questionnaire was a long process that continued over a period of more than a year. The skeleton of the questionnaire was a needs assessment questionnaire used in Pennsylvania by the Bureau of Autism (Bureau of Autism Services, 2011c). Following the approach of the Bureau of Autism’s survey, I created two versions of the questionnaire: one for autistic adults, and the other for guardians of autistic adults. An additional short questionnaire that focused on barriers to healthcare services was also adopted for the research (Raymaker et al., 2017). Two potential biases were identified and addressed during the translation process into Hebrew. The first was duplicate responses by the autistic individual and the guardian; and the second was the influence of self- or peer-diagnosed autistic people who have not received a formal medical diagnosis. To address these issues, two questions were added: one to the guardians questionnaire asking them to confirm that the adult had not already answered themselves, and the second concerned the type of autism diagnosis which applied. Next, following the qualitative inquiry, the questionnaire was contextualized and additional themes that emerged at the qualitative phase were inserted. Following this, the amended questionnaire was sent for comments and validation from the research advisor and another academic, the autistic advisory committee, and several other stakeholders from advocacy organizations and relevant governmental ministries. Finally, the two final versions of the questionnaire (see final questionnaires in Appendix 2.16 – Autistic Adults, and Appendix 2.17 – Guardians) were translated into Arabic, were made grammatically appropriate for women participants,[[3]](#footnote-3) and were turned into an audio format with the questions and answers read out loud. All the questionnaires were converted into electronic form using Qualtrics software (Provo, UT) which allowed participants to answer on a computer or on a mobile phone (see Appendix 2.18 for a detailed description and explanations of the questionnaire development process).

### 2.4.2. Validation measures

Several validation measures were taken to ensure the relevance and accuracy of the questionnaire. The advisory committee reviewed the questionnaire to enhance both the structure and content validity. Expert validation was done twice. First, during the questionnaire formation process by Prof. Nadav Davidovitch and Dr. Shwed, and then, following its completion, by professionals and key figures from the four major organizations working with or for autistic adults in Israel and relevant ministries.[[4]](#footnote-4) During this process, suggestions were made to refine some of the questions and provide additional answers that had not originally been included as options were implemented. Validation of the translation into Arabic with a focus on accounting for cultural nuances was performed by an experienced Palestinian nurse, Dr. Ahmad Abu al Halaweh, and the head of the Arab community coordinator at Alut.

A pilot was executed concomitant with the expert validation. Twenty participants answered the pilot, among them seven autistic people and thirteen guardians. I asked those who agreed to participate in the pilot to add a written evaluation of the questionnaire. Several issues arose during the pilot, some of which were quite unexpected. For example, a father of an autistic adult individual commented that the questionnaire was emotionally challenging and that he would have benefitted from a warning in the introduction specifying that the issues dealt with in the questionnaire might be overwhelming. His comment was accepted and the warning was included.

### 2.4.3. Population and sample

The research population was defined as autistic individuals above the age of 18. Since no accurate data exist on the absolute numbers or rates of adult autistic individuals who live in Israel, estimations of the population size were based on the Ministry of Welfare and Social Affair’s (MOLSA’s) data from 2016. According to the official publication, there were 6099 autistic individuals above the age of 15 registered to receive services from MOLSA in 2016 (Shafran & Goren, 2017). By the end of 2019, when the dissemination of the survey began, all participants had reached the age of 18. Nevertheless, as not all autistic individuals, and especially autistic adults, are registered with MOLSA, the actual number is probably much higher, especially considering that many individuals are not formally diagnosed and that many people are diagnosed in adulthood. As no other authority has a more accurate estimation of the number of autistic adults in Israel, the working hypothesis was that there are approximately 7000 adults who are identified as autistic living in Israel. This estimation corresponds with calculations of data from the National Insurance Institute (NII) which appears in Raz et al. (2014), which is considered more reliable.[[5]](#footnote-5)

Given that the population size is relatively small, that the rationale behind the survey was to try and verify the qualitative finding, and that there are no accessible registries that allow proportionate sampling of the diverse sections of this population, I decided to use multiple strategies to try reach the entire population. A response rate of 8% to 10% was established as a goal to ensure that the results were statistically relevant. Because the response rate in the similar survey taken in Pennsylvania was 14.2% (Bureau of Autism Services, 2011c), this goal seemed reasonable. Furthermore, in contrast with the low response rate in the national survey, other strategies have yielded a higher response rate. For example, in surveys that disseminated questionnaires by directly approaching adults or guardians receiving services in designated places, the response rate reached about 80% (Kohler, 1999: 83%; Kamio, Inada, & Koyama, 2013: 79.9%). Internet surveys were also found to be helpful in reaching this population (Pellicano et al., 2014; Hodapp & Urbano, 2007; Rhoades, Scarpa, & Salley, 2007). Thus, distributing the survey using multiple strategies was suitable both to allow representation of diverse groups from this population and to reach the response rate goal.

#### 2.6.3.1 Dissemination of survey

The web-based survey was active from 22 December 2019, to 20 October 2020. Six dissemination strategies were utilized to try and reach a response rate of 8–10%: The first was through the MOLSA who, after formalizing the collaboration (See Appendix 2.19), launched a request to local social workers and providers to disseminate the survey to service recipients (see a detailed explanation on the dissemination procedure for social workers in Appendix 2.20, and Appendix 2.21 – Providers ). Second, MOLSA representatives provided a list of community services and residential places for autistic individuals (see Appendix 2.22). With the assistance of the Cohen Institute of Tel Aviv University, all the providers were contacted and asked to disseminate the survey for the service recipients. Third, in some institutions, following the establishment of close connections with the managers, specific time and resources were set aside so that their service recipients or guardians could answer the questionnaire. Fourth, a call for participation in the survey was sent via the mailing lists of the four main advocacy organizations operating for or with autistic adults in Israel: Alut, ACI, Mishtalvim Ba’Resef, and Effie. Fifth, dissemination via social networks was done by key figures who endorsed the research after their in-depth interviews. Finally, an advertisement was displayed in the reception office of the Keshet Clinic for autistic adults in the Sheba Tel HaShomer Medical Center (see Appendix 2.23) and a call to participate was sent via the clinic newsletter (see Appendix 2.24). All these methods were utilized to try and reach the anticipated response rate (for detailed description of the dissemination procedure see Appendix 2.25).

### 2.4.4. Methods of data analysis

Printed questionnaires were inserted manually by the researcher into Qualtrics. The insertion procedure was checked by a second inspection of selected data. The dataset from Qualtrics was downloaded onto an Excel spreadsheet. Irrelevant entries were then deleted and the dataset was organized and transferred for further analysis into SPSS software version 26. New variables were created to enable statistical analysis. Among the variables were: number of needs, number of barriers, and deviation of settlement according to Ministry of Health districts (see a full list of novel variables in Appendix 2.26). A descriptive analysis for standard measurements including frequencies, means, and medians were calculated. To identify differences between groups T-test for independent samples, One Way ANOVA, and χ2 were used. Spearman correlations were conducted to examine the relations between income and several numeric variables (see list of statistical tests in Appendix 2.27). Statistical significance was considered at P value <0.05.

## 2.5. Ethical considerations

The research was approved by both the institutional ethics committee of Ben-Gurion University of the Negev (see Appendices 2.28 and 2.29 after revisions) and the Helsinki committee of Sheba Tel HaShomer Medical Center (see Appendix 2.30). The Ben-Gurion institutional committee approved all the research, while the approval of the Helsinki committee was given only for the collection of data from patients receiving treatment in the medical center. Both approvals were obtained twice, once before the qualitative phase and once before the quantitative phase.

Two unique ethical considerations that were approved by the committees are important to note. The first is allowing autistic interviewees to waive their anonymity and disclose their full name when quoting them in publications. This issue might pose an ethical challenge because autism is considered a medical diagnosis and disclosing it means publicly exposing a medical diagnosis of an individual (for an extended ethical discussion on the subject see Weksler-Derri et al., 2019). The second was including autistic individuals who have guardians in the survey without formal approval from their guardians. As the survey is self-administrated and web-based, anyone, including autistic individuals who have legal guardians, could have answered the questionnaire. To try and avoid a situation where such autistic individuals answered the questionnaire without the approval of the guardian, I inserted a question about guardianship and type of guardianship into the questionnaire for autistic people. If a participant answered that he or she has a guardian or that they do not know if they have one, they were directed to make sure they do not have one or to ask for permission to participate. For additional ethical dilemmas that emerged during the research conduction see Weksler-Derri et al. (2019).

## 2.6. Results summary

As portions of the data collected using the methods mentioned above is utilized in every chapter of this study, I decided to present the summary of the collected data before turning to the analytical chapters.

### 2.6.1. Qualitative phase

In the final analysis, 42 interviews were included. Two were amended by the interviewees as part of the quality assurance process and one was retracted altogether by the interviewee at her request. Parents who were interviewed together regarding the needs of their adult child were considered for the analysis as one interview. Because many of the interviewees fitted into more than one category, highlighting the multiple identities or roles characterizing stakeholders in the autism field (Eyal, 2010; Waltz, 2013), the data collected reached over 42 interviews, resulting in a picture provided by the data that is rich and varied. Table 4.1 describes the number of interviewees interviewed from each identity group. Table 4.2 describes interviewees geographical relation.

**Table 4.1 Interviewees Classification according to Identity Group**

|  |  |
| --- | --- |
| Classification according to identity group a | Number of interviewees |
| Autistic Adults |  |
| Parents of an autistic adult |  |
| Other relatives of autistic adults |  |
| Activists or policy maker at the autism field b |  |
| Professionals working with autistic adults |  |
| Psychiatrists |  |
| Psychologists |  |
| Physicians |  |
| Nurses |  |
| Social workers |  |
| Program manager |  |
| Other professional c |  |
| Interviewees who fit into several groups |  |

a To avoid identification of interviewees who can be classified into several identity groups, they are not classified as a different conjoined group, but were counted in each category separately. b Includes representatives from relevant governmental branches, activists from representative organizations, and lawyers specializing in autism.

c Includes speech therapists, occupational therapists, behavioral therapists, service coordinators, and sexual therapists.

|  |  |
| --- | --- |
| Table 4.2 Classification According to Geographic District a |  |
| Tel Aviv and Center |  |
| Haifa and North |  |
| Jerusalem |  |
| South |  |

a The table includes geographical district relation of all the interviewees. The geographical district of a professional was determined according to his or her area of professional activity and not according to district of residency, following the assumption that the area of professional activity represents the place of residency of autistic individuals they meet. Nevertheless, if a professional was both an autistic adult or a parent *and* a professional, their geographical district was assigned according to place of residency.

### 2.6.2. Quantitative phase

Among the 256 questionnaires that were completed both electronically and by hand, 112 were included in the final analysis. Questionnaires that were retracted from the final analysis were either terminated at the initial stages of the questionnaire or lacked responses to key demographic questions. Among the 112 questionnaires that were included in the final analysis, 58 were of autistic individuals, and 54 were of relatives of autistic individuals. See Table 4.3 for additional characteristics of responders. It is important to note that not all the analyses discussed below include all 112 questionnaires; some were conducted with a lower ‘n’ (number of responders), as responders were allowed to skip questions they did not wish to answer.

**Table 4.3 Demographic Characteristics**

|  |  |  |  |
| --- | --- | --- | --- |
|  | Relatives of autistic adults | Autistic adults | Total |
| Number of responders  Included in final analysis |  |  |  |
| Sex  Male  Female |  |  |  |
| Age a |  |  |  |
| Area of residency b  Tel Aviv  Center  Ashkelon Haifa  North  Jerusalem  South |  |  |  |
| Religion  Jewish  Other |  |  |  |
| Place of Birth  Israel  Other |  |  |  |
| Education  Pre-high school  High School  Attempt of Higher Education  Higher Education |  |  |  |
| Employment  With assistance  At the free market  Unemployed |  |  |  |
| Residential arrangement  Independent  At the community  With the family  Holistic residential place |  |  |  |
| Age of diagnosis  0-12  12-18  18+  Don't know or not formally diagnosed c  Average (SD) |  |  |  |
| Average Abilities a,d |  |  |  |

a Average (Standard deviation). b According to MoH deviation to districts. c We allowed autistic adults who are diagnosed informally or at an unrecognized institute to participate in the survey because formal diagnosis in adulthood is available only privately at a high cost. d Calculation of several daily and complex abilities. The value 1 represents complete inability to execute the ability, the value 5 represents complete independence.

1. The research committee has not approved this manuscript, but has approved a short summary in Hebrew written as part of the grant by The Israel National Institute For Health Policy research. [↑](#footnote-ref-1)
2. Bourdieu described the *habitus* as innate cognitive structures, the “transposable dispositions, structured structure,” embodied in an agency, in the actor, which in turn direct its operation in the world as it is “function as structuring structures” (Bourdieu, 1980, p. 53). [↑](#footnote-ref-2)
3. In Hebrew every direct sentence, or question in this case, can take a masculine or feminine form. Usually, documents directed to both genders are written in masculine form with a note that the document is directed for both genders. [↑](#footnote-ref-3)
4. Alut (the head of the legal and advocacy department), Effie (the leader of the intimate relationship program), Mishtalvim BaRezef (one of the founders) and ACI (one of the founder that is not part of the advisory committee); and the manager of the autism department of at the MoH and the autism knowledge coordinator at the Ministry of Welfare and Social Affairs (MOLSA). [↑](#footnote-ref-4)
5. The article reports cumulative incidence of ASD at the age of eight since 1992 until 2009 from the NII database. The NII is considered reliable registry source for autism because it is mandatory to be registered at the NII in order to receive the autism stipend to which under 18s are eligible. A calculation was performed to estimate the number of individuals diagnosed with ASD according to the reported data from 1992 to 2001 (above age 18 in 2019). Figure 1 reports cumulative incidence as a percentage of the 1992 cumulative incidence. This figure allows the calculation of a total increase in percentage of the individuals diagnosed with autism from 1992 to 2001, as it represents the increase in percentage as a proportion of the incidence in 1992. The absolute number of autistic people in 1992 was calculated using the figure of total live births in 1992 (110062) from a Central Bureau of Statistics Israel (2016) publication and the incidence from figure 3 at Raz et al. (2014) which is between 0.11% to 0.12%. Thus, the number of autistic individuals from 1992–2001 is 0.11%\*110062\*(41.74) = 5053 to 0.12%\*110062\*(41.74) = 5512. This estimate of 5053–5512 individuals diagnosed with autism between 1992–2001, corresponds with the estimates (which estimates?) because it does not include individuals who were diagnosed after the age of 8 and before 1992. [↑](#footnote-ref-5)