# 2. Methods

This research was a participatory mixed method research that included two main phases: a qualitative phase and a quantitative phase. The participatory approach who was adopted in a very early stages of the research included the establishment of an advisory committee that had shaped the research conduction throughout the different phases. The qualitative phase included in-depth interviews with autistic adults, parents of autistic adults and relevant professionals, in addition to extensive archival research. The quantitative phase included a survey aimed to validate the qualitative findings. Finally, an integrated analysis of all research findings had been performed to allow comprehensive understanding of the investigated field.

I chose to adopt a critical realism paradigm to the research. This paradigm is built on Roy’s Baskar “transcendental realism” philosophy that asserts social structures are “true” constructs that can be only partially uncovered by subjective theories and interpretations (Harvey, 2002; McEvoy & Richards, 2006). The research goal from this paradigm perspective is to investigate a social phenomenon, or more accurately the relations between sets of structures and operating agents within society, by the agents operating within this specific context that limits their perspective yet allows them to affect it. As I was set to study the complex relation between autism, inequalities, advocacy organizations, policies, and other social positions in their temporal context this paradigm was most suited. Furthermore, the critical realism paradigm corresponded with the research methods, both with the participatory approach to research that is directed to change the social structures, not merely expose it (Potvin, Bisset & Walz, 2010; Baldwin, 2012), and the mixed methods inquiry who is considered most effective approach to answer critical realist questions (McEvoy & Richards, 2006).

## 2.1 Participatory research

Participatory research is a broad description to heterogeneous types of research that inspire to include the researched participants in the research process itself. This type(s) of research has three principals that distinct it from traditional research: it aims to shape reality; it shifts the researcher position from interpreter of reality to mediator of research process; and it alters the power relations between researcher and participants which in turn affect the control over the knowledge. Yet, because participatory research also requests to be radically contextualized even in its methodology its conduction can be varied, and it can be referred to in diverse manner from community-based participatory research (CBPR) to participatory action research (PAR), to inclusion research and many others (Cargo & Mercer, 2008; Maguire, 1987 p.14). Therefore, to avoid mis-conduction of participatory research it is agreed that a detailed description of the participatory procedure and the means it demanded, is required (Walmsley, 2004; Bigby Frawley & Ramcharan, 2014; Cargo & Mercer, 2008; Maguire, 1987; Balfour, 2013).

In the autism research field although still being in the margins of academic work (Jivraj, Sacrey, Newton, Nicholas, Zwaigenbaum, 2014; Wright, Wright, Diener, Eaton, 2014), participatory research has started in the last decade to be considered as valuable (Nicolaidis et al., 2011; Nicolaidis, 2019; Crane, Adams, Harper, Welch, Pellicano, 2018; Fletcher-Watson et al., 2018; AASPIRE, 2020). In the field of autism the research is based on CBPRs conducted in health research (Cargo & Mercer, 2008) and research traditions from the disability community that argued that conduction of research by people with disability can bring novel perspective on disability (Krumer-Nevo & Barak 2006; Walmsley, 2001) and will correspond with the call of ‘nothing about us without us’. Scholars who applied this practice argued it can help to align research priorities with community priorities (on this discrepancy see: Pelicano, Dinsmone & Charman, 2014), change the usage of offensive language in autism research and promote research that is not opposing the community values (Nicolaidis et al., 2011). In Israel, unfortunately, only Schneid (2018; Schneid & Raz, 2019) who investigated the conflict between autistics and society conducted participatory research with the autistic community. It should be noted that despite not being situated in one geographical location as most communities participating in CBPR, the autistic community can be regarded as one based on other definitions of community including epistemic community (Akrich, 2010) and virtual based community (Rheingold, 1993; Nicolaidis et al., 2011) that articulate its traditions to the actual world (Gil, Shoham, Shelly, 2016).

Employing a participatory approach to the research was not my initial intent nor it even cross my mind. The research took the crucial turn to become participatory short time after its initiation. In a meeting held with one of the founding members of the Autistic Community of Israel (ACI), the only Israeli autistics self-advocate group (Raz et al., 2018), the idea to adopt a participatory approach was raised. Unlike most participatory research the research questions were set in advance (Baum, MacDougall & Smith, 2006; Nicolaidis et al., 2011) and the autistic community who read the research proposal agreed they are worthy and should be pursued. After agreeing collaboration with other organizations including the ministry of health (MoH) and Alut (the largest parents of autistics’ organization in Israel) will not encounter an opposition by the autistic community given their agenda might conflict the community values, the participatory research was set to go.

We agreed together an independent advisory committee of autistic adults would be optimal for the research and decided that all who wish to participate and identify as autistics could join the committee. Although at the initial stages committee members were asked to commit to the entire research, after one of the first three autistics that joined decided he could not participate, we decided together that if an autistic individual wish to join the committee during the research process he or she are welcome as long as they stay until the end of that research phase. This decision was made given the amount of time and energy needed to invest in the research, and the fact the participants are not given any compensation. Furthermore, we agreed that in case of disagreement among members of the committee or between them and me, the researcher, the final decision will be mine. This privilege was executed handful of times, and regarding minor issues as wording in the questionnaire.

The initial recruitment for the committee was done by ACI who sent an invitation to their members. Later, new members were recruited by actively approaching potential candidates who were recommended by interviewees at the qualitative phase. As a result, the committee became heterogeneous and did not include only members affiliated with ACI. Given members could left the committee throughout the research the number of members had changed in different phases where two members was the lowest and five the highest (see appendix 2.1 for participation of members in each stage).

Other than not being involve in drafting the research question and goals the committee had a role in every step of the way. The advisory committee provided input on the qualitative interview guide, on the qualitative themes, on both versions of the survey questioners 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 have also directed a grant proposal that was submitted to an international agency and been an integral part of an effort to promote accessible services for autistics at the MoH. Nevertheless, unlike participatory action research, committee members did not take active part in the data analysis process of the qualitative and quantitative phases. The reason for conducting the analysis my self 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 together that the analysis will be execute by me.

The contribution of the committee was beyond any anticipations. Among their numerus contributions their assistance in contextualization of the research design, tools, and outcomes was the most prominent. In addition, without their reflection cardinal themes would have been missed from the research or could have completely misinterpreted. The notion of mitigating the survey questionnaire would not even be considered without committee. Furthermore, the implementation of the research finding at the MoH would be much less effective if the committee was not participating. Finally, the intimate work with the committee have changed my perspective on the field and as a future physician. These contributions are aligned with the one identified in the literature (Cargo & Mercer, 2004; Walmsley, Strnadová, & Johnson, 2017).

Despite the enormous contribution, having an autistic advisory committee inflicted some difficulties. First and foremost, it demanded extended amount of time and investment of resources. One committee member, for example, requested to communicate only verbally as the efforts he needed to invest in reading and writing were gigantic. Therefore, his comments to all documents including the technical one as the qualitative codes list, were provided via phone call or in a face-to-face meeting which required extra time. Apart from efforts, this methodology was not well accepted by some professionals and parents, who argued the committee contribution must be biased toward their perceptions. From an institutional perspective, although the idea of participation was accepted well and supported, the additional time it demanded have not been formally accepted by all research authorities. These, difficulties which are an integral part of participatory research should be institutionally address so more researchers will use this methodology, as the added value of having the community under investigation invested in the research is beyond measurable.

## 2.2. Mixed methods study

This research adopted a sequential exploratory design to mixed methods (Creswell & Clark, 2007, P.180-182). In this design the first phase is qualitative, and the second phase is quantitative. The rational for using this mixed methods design was to first enable comprehensive understanding of the field using the qualitative methods and only then exploring the findings generalizability and validity employing quantitative methods.

This design was chosen for three main reasons. First, it best corresponds with the research paradigm, as mentioned above, since it allows to investigate the researched field from a subjective position while accepting its objective realization (McEvoy & Richards, 2006). Second, as the main research question this research was set to answer was regarding the *mechanism* of inequlities a design that its core is qualitative was needed. As on the qualitative-quantitative continuum this design is considered qualitative dominant mix-method research (Johnson, Onwuegbuzie & Turner, 2007), and it subordinates the quantitative methods to the qualitative methods (Hesse-Biber, 2010) it was best suited to answer the research questions. Given the autistics adult field in Israel was never investigated and the reasons for inequalities were only intermediately theorized it could be claimed that mixed methods design was a “methodological fit” (Edmondson & McManus, 2007, p.1165-1167). Lastly, choosing a mixed method design suited the participatory research approach adopted for the research. It did so both because it allowed to introduce the insights the advisory committee presented from the very first steps of the research, and because it enhanced the ability to answer the research goal to shape 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 problematizes the researched field the quantitative phase was needed to influence the researched field, given the lower status qualitative research have within 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 done according to 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 utilize 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 who draws from Blumer interactionism theory (1969, in: Wells, 1995) and was originally developed by Glaser and Strauss (1967), asserts using inductive reasoning while conducting constant comparison of empirical data collected systemically throughout the research can provide the investigator a contextual understanding of the social structures from the perspective of social actors. This approach which clearly match the research paradigm 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 grounded theory method asserts the investigator should arrive to the field without presumptions and only draw conclusions from the field itself, I adopted a more recent perception of this method. Contemporary scholarly argued the investigator always arrives with her or his own perceptions on the field and ask his research questions from his perspective (Corbin & Strauss, 2015 p.17-27). As I was set to investigate not just social structures but their discriminative practices, I clearly came with hypothesis to the field; therefore, I adopted more current approach to grounded theory method that was better suited for this research.

Since qualitative (and some might argue also quantitative) analysis in spite executed with precise methods is affected by the researcher observation (Clarke, 2007), it is crucial to position the researcher, myself in this case, on the field of investigation to enhance the sincerity, the credibility (Tracy, 2010) and the reflectivity (Mays & Pope, 2000) of the research. Apart from being a Jewish man from mixed Ashkenazy-Mizrahi origin, that grew in a middle-high income family in the geographical center of Israel, and that his parents immigrated from Argentina, additional two aspects of in my personal biography affected my position on the investigated field. The first aspect is my medical education. In parallel to conduction of this research I was enrolled in medical school and absorbed the values and most importantly the unfortunate imbedded perceptions 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 in my personal biography that affected my perspective is my past experiences in social activism with oppressed communities in the Israeli society, including with public housing residents, Palestinians, non-Jewish immigrant workers, unionized Israeli workers, women and more. While the adoption of the MMD had clearly shifted to the social model owing to the long discussions I had with advisory committee members and reshaped my perceptions; the critical perspective on social structures I gained throughout my activism have clearly shaped my observation of the autism field. These aspects I believe are the most essentials aspects of my personal habitus[[2]](#footnote-2) that the reader requires in order to understand my perspectives on the investigated field.

### 2.3.1. Procedure of data collection

To sets of qualitative data were collected for the research, that complement each other. The first primary data was in depth interviews with autistics, guardians of autistics, and professional working in the field. The second data collection was treated as secondary qualitative data and was aimed at depicting the policy process and the historical context of the field in Israel. The followings 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 formation process of policy regarding autistic adults, stakeholders who have diverse experiences in the field needed to be identify and interviewed. To achieve the first goal identification autistic adults, family member of autistic adults and professionals who work with this population was needed. For the later goal key figures from organizations, government officials and involved experts were expected to yield more relevant information. Therefore, I employed several strategies to identify interviewees that will 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 to July 2019: direct communication with potential interviewees the advisors recommended; a call for participation was sent by the four organizations of or 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); approaching key figures who were relevant for the study in conventions or events; contacting experts identified in the Internet via email or phone; snowball technic (Noy, 2008); and direct recruitment of interviewees from the Keshet clinic in Tel Hashomer Medical Center according to specific identifiers (see appendix 2.6 formal collaboration letter ; see appendix 2.7 for additional details on identification strategies).

Using these methods I identified autistic adults with verbal abilities; parents, siblings and grandparents who are guarantors of autistic adults that either do not have communication skills that I was able to understand or that did not want to participate in the research; variety of professionals treating autistic adults including: psychiatrists, psychologists, family physician, nurses, speech therapists, behavioral therapists, occupational therapists, relationship and sexual therapists, social workers, and managers of hostels and programs dedicated for autistic adults; and actors that were involved in policy construction process including: key figures from advocacy organizations, officials from the relevant ministries, and activists. As been previously recognized in the literature, actors in the field of autism often pertain to more than one of the groups described above (Eyal, 2010; Eyal, 2013; Waltz, 2013). An autistic individual could be also an advocate, or a parent could work as a therapist and have a key position in an advocacy organization or relevant ministry. The overlap of interviewees backgrounds eligibly added more interviewees from each category, but more importantly it allowed exposure to complex perspectives on the researched subjects. Finally, during the interviews conduction I assured there is a representation of autistic individuals from different communication and cognitive ability levels, gender and sub-populations in Israeli society. For a full list of interviewees’ personal characteristics, without personal identifier see section 2.6 below participants information.

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 other such on the policy process took longer accomplish. Interviews were held in the place and time preferred by the interviewee. Among the places were private homes, university offices, personal offices and outdoors. Subordinate to interviewee 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 advocate, insisted before signing the consent form that he will be quoted by his personal name in every document or report. Following an approval from the ethics committee his requested was respected. Interviewees were asked if they interested the transcription would be sent back to them for validation ([Mays & Pope, 2000](#_ENREF_83)). Only five interviewees did ask to receive the transcribed interview back. Among those two had approved the whole interview, two asked to delete several sentences or introduced amendments, and the last asked to retract the entire interview. Following each interview, a researcher diary was recorded. The recorded diary included initial thoughts about the interview both on the conduction and 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 it directly addressed matters this research was concerned with. The initial interview guide was constructed by the researcher (see appendix 2.9 initial interview guide). It contained relevant topics the research covered including health and social determinants related needs, barriers to healthcare, involvement in the policy process, and inequlities between autistic adults needs, policy process, 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 and reviewed by the participatory advisory committee. Following the committee’s recommendations and conclusions from the pilot changes were introduced, and dedicated guides for different stakeholders: autistic adults, family members, and professionals were constructed. Developing stakeholder-unique interview guides was necessary to capture the background of the variety of stakeholder participated in the interviews and specific topic 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 particularly the construction process of autism-related policy archival research was conducted. Systematic search of two main resources was performed. First, to gain an internal perspective on the policy construction process the Knesset (Israeli parliament) archive and the Israeli-State National Archives that includes internal ministries archives were searched. Second, to understand the law interpretation and to gain broader perspective on the context in which the policies had been constructed a search in Israeli major newspapers was performed. The period searched was from 1965, the year the National Society for Autistic children was established in the United States, to 2015, the year I have started the research. All data collected was stored in a computer and then transferred to Atlas.ti software for further analysis (to full search strategy see appendix 2.11).

Nevertheless, 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 asked about the development of the field of autism in Israel and specifically about the personal role the actor had in its development according to predetermined interview guide (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 the data it was part of 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 reach content gathered during the data collection was a continues process that included four main phases. First, the pilot interviews were analyzed, to form main and sub-categories. Then the list of categories was sent for the review of 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.

In detail, after the interviews were transcribed, I read the entire interview thoroughly to raise novel angles of inquiry. Then I listened to the researcher diary to explore whether the ideas appeared right after the interview and that were influenced from the personal interaction and not only the content could also attribute to the analysis. Next categorization process was executed by constant comparison practice using Atlas.ti software version 7 and version 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 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. Despite not being expose to the data, the committee have advised on several amendments to the codes list including clarifications and explanations, recategorization of several codes, and introduction of new codes. The finalized codes list (see appendix 2.14) served as departure point for the analysis of all the interviews conducted afterwards. Yet, if additional codes were required for an accurate analysis, they had been added. This procedure was agreed with the advisory committee beforehand. The interviews analysis was sequential as during the process of data gathering and categorization hypothesis were redefined ([Pope, Ziebland, & Mays, 2000, p. 114](#_ENREF_102); [Shkedi, 2003, p. 96](#_ENREF_115)). Finally, Linkage between the categories was then outlined to identify the type of relationships between categories (see appendix 2.15 for an example for codes linkage map concerning policy construction). This process was done twice: once during the classification process and once when the analysis was finished. The data then was 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)) .

Using the categories from the interviews policy documents were analyzed ([Shkedi, 2003, pp. 194-197](#_ENREF_115)) 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 vis versa or in parallel is that as most health researchers see documents as secondary to human sources ([Shkedi, 2003, pp. 194-196](#_ENREF_115); Prior, 2010). From this perspective the content of the documents is analyzed as constants not as an active agent in determining social reality; therefore, they ability to determine the trajectory of a research 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. In this perspective documents mark on the one hand the summation of an entire historical process, and from the other make the foundation for directing the path forward to the future, a new social structure. To use Prior’s (2010) categorization I use documents both by focusing on their content and seeing them as a source of information; and by understanding their use and function as structures in the researched field that are produced by actors and are reproducing their vision. Using multiple data sources, diverse stakeholders, and different perspectives of the data had enriched the triangulations and crystallization processes and thus the credibility of the research (Tracy, 2010; Melia, 2010; Mays & Pope, 2000).

Based on the list of codes and categories summary main categories were identified. Recognition was done according to initial research objectives and according to richness of the data in each category. Data from main categories was then summarized by Atlas.ti software, to be properly handle, and the description and analysis of main themes was conducted - *Centered Analysis stage* ([Shkedi, 2003, pp. 143-153](#_ENREF_115)). It should be noted that the entire process, apart from the analysis itself was transparent to the advisory committee which further enhance the research validity (Tracy, 2010).

## 2.4. Quantitative inquiry

As mentioned above at the section of mixed methods I have conducted a 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 and barriers of autistic adults to healthcare and social service 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 questioner was a needs assessment questionnaire used in Pennsylvania, US 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. Additional short questionnaire that focuses on barriers to healthcare services was also adopted for the research (Raymaker et al., 2017). Two potential biases that were identified and address during the translation process to Hebrew. The first was dual reply on one autistic individual, by the individual and by a family member; and second was participation of self or peered diagnosed autistics that do not have formal medical diagnosis. To address those issues two questions were added one to the guardian questionnaire asking to confirm the adult did not already answer himself and the second regarding the type of diagnosis to the autistic questionnaire. Next, following the qualitative inquiry the questionnaire was contextualized and additional themes that emerged at the qualitative phase were inserted. Then, the amended questionnaire was sent for comments and validation by the advisor and another academic member, the autistic advisory committee, and several other stakeholders from advocacy organizations and relevant governmental ministries. Finally, the two final versions of the questionnaire (see fin al questionnaires in appendix 2.16 –autistic adults, and appendix 2.17 - guardians) were translated to Arabic and were also made available in female form[[3]](#footnote-3) and auditory from that included audio file with the questions and answers read out laud. All questionnaires were transformed to electronic form using Qualtrics software (Provo, UT) that allows reply both on computer and on mobile phone (see appendix 2.18 for detailed description and explanations of the questionnaire development process).

### 2.4.2. Validation measures

Several validation measures were taken to ensure the relevancy and accuracy of the questionnaire. The advisory committee had reviewed the questionnaire to enhance both the structure and content validity. Experts validation was done twice. First, during the questionnaire formation process by Prof. Davidovitch and Dr. Shwed, and then following the completion of its formation 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 had been made to refine some of the questions and additional answers that were not included as options were added. Validation of the translation to Arabic to trace cultural nuances was performed by an experienced Palestinian nurse Dr. Ahmad Abu al Halaweh and the head of the Arab community coordinator at Alut.

Parallel to the expert validation a pilot was executed. 20 participants answered the pilot among them 7 autistics and 13 guardians. I asked those who agreed to participate in the pilot to add a written evaluation of the questionnaire. Several issues were rose during the pilot including unexpected ones. For example, a father of autistic adult individual who comment that the questionnaire is emotionally challenging and that he would benefit if the introduction had a notice that the issues dealt in the questionnaire might be overwhelming; his comment was accepted.

### 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 individuals that live in Israel, estimations of the population size were based on MOLSA’s data from 2016. According to the official publication there were 6099 autistic individuals above the age of 15 registered to receive service from MOLSA in 2016 (Shafran & Goren, 2017). By the end of 2019 when the dissemination of the survey began all have reached to age18. Nevertheless, as not all autistic individuals and especially autistic adults are registered at MOLSA we estimate that the actual number is higher, especially if considering individuals who are not formally diagnosed and most of the individuals that were 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 that are identified as autistics living in Israel. This estimation corresponds with calculations of data from the NII which appears at Raz, Weisskopf, Davidovitch, Pinto & Levine (2014) which is considered more reliable.[[5]](#footnote-5)

Given the population size is relatively small, that the rationale behind the survey was to try and verify the qualitative finding, and there is no accessible registries that allow proportionate sample of the diverse sections of this population I decided to use multiple strategies and try reach out for the entire population. A response rate of 8% to 10% was set as goal to allow enough power for the statistical analysis. Because the response rate in the similar survey taken in Pennsylvania was 14.2% (Bureau of Autism Services, 2011c), this goal seemed reasonable. Furthermore, despite the low response rate in the national survey, other strategies yield a higher response rate. For instance, in surveys that disseminated questionnaires by directly approaching adults or guardians who are receiving services in designated place the response rate reach to about 80% (Kamio, Inada, & Koyama, 2013: 79.9%; Kohler, 1999: 83%). Internet surveys were also found to be helpful in reaching out for this population (Pellicano et al., 2014; Rhoades, Scarpa, & Salley, 2007; Hodapp & Urbano, 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 December 22nd, 2019, to October 20th, 2020. Six dissemination strategies were utilized to try and reach a response rate of 8-10%: The first was by the Ministry of Labour and Social Affairs (MOLSA) who after formalization the collaboration (See appendix 2.19) lunched a request to local social workers and providers to disseminate the survey to service recipients (see detailed explanation on the dissemination procedure for social workers - appendix 2.20, and providers – appendix 2.21). Second, MOLSA representatives provided a list of community service and residential place for autistic individuals (see appendix 2.22). With the assistance of Cohen Institute in 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 connection with the managers, they dedicated specific time and resources so their services recipients or guardians will 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 in social networks was done by key figure who endorsed the research after their in-depth interviews. Finally, an add was publish in the reception office of the Keshet clinic for autistic adults in Chaim Shiba Tel Ha’Shomer 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 to Qualtrics. The insertion procedure was controlled by second inspection of selected data. The dataset from Qualtrics was downloaded to Excel spreadsheet. Then irrelevant entries were deleted, and the dataset was cleaned and transferred for further analysis in 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 full list of novel variables in appendix 2.26). A descriptive analysis for standard measurements including frequencies, mean, and medians were calculated. To identify differences between groups T-test for independent samples, One Way ANOVA, and χ2 were be 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 significant was considered in P value <0.05.

## 2.5. Ethical considerations

The research was approved by both the institutional ethical committee of Ben Gurion University of the Negev (see appendices 2.28 and 2.29 after revisions) and the Helsinki committee of Haim Sheba, Tel Ha’Shomer 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 performed 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. First, 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 extended ethical discussion on the subject see: Weksler-Derri et al., 2019). Second, including autistic individuals who have guardians in the survey without the formal approval from their guardian. 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 individual answered the questionnaire without the approval of the guardian, I inserted a question about guardianship and type of guardianship into the autistic questionnaire. If a participant answered he or she has a guardian or they do not know if they have one, they were directed to make sure they do not have one and ask for permission to participate. For additional ethical dilemmas that emerged during the research conduction see Weksler-Derri and colleagues (2019).

## 2.6. Results summary

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

### 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 to her request. Parents that were interviewed together regarding the needs of their adult child were considered for the analysis as one interview. Because many of the interviewees were suited for more than one category strengthening the multiple identities or roles characterizing stakeholders at the autism field (Eyal, 2010; Waltz, 2013) the richness of the data collected reach beyond 42 interviews as the whole in this case is greater than the sum of its parts. 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 grouping

|  |  |
| --- | --- |
| Classification 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 that were suited to 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 they 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.

|  |  |
| --- | --- |
| 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 filled both electronically and by hand, 112 were included in the final analysis. Questionnaires that were retracted from the final analysis either terminated at the initial stages of the questionnaire or lacked cardinal 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 analyses later represented include all 112 questionnaires; some were conducted with 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 Ministry of Health deviation to districts. c We allowed to 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 with high expenses. 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 had not approved this manuscript, but a short summery 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 be phrased or for male participant of for female participant. Usually, documents directed for both genders are written in Male tense 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 MOLSA. [↑](#footnote-ref-4)
5. The article reports cumulative incidence of ASD at the age of 8 since 1992 until 2009 from the NII database. The NII is considered reliable registry source for autism because in order to receive the autism stipend which is entitled until the age of 18 it is mandatory to be registered at the NII. 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 percentage of 1992 cumulative incidence. This figure allows to calculate the 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 autistics in 1992 was calculated using the figure of total live births in 1992 (110062) from 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 estimation 5053-5512 individuals diagnosed with autism between 1992-2001, correspond with the estimations because it does not include individuals who were diagnosed after the age of 8 and before 1992. [↑](#footnote-ref-5)