# 7. Preserving privileges: autistic organizations role in constructing inequalities between autistic adults

Departing from previous chapter conclusion that current discourses regarding the reasons for inequlities between autistic adults are limited at best, this chapter analyze Alut’s*,* the largest and oldest advocacy organization for autistics in Israel, role in shaping the autism policy field and argues the main policy regarding autistic adults it promoted contributed to the creation of inequlities between autistic adults. This contribution to inequlities, I argue, was done as a resulted from the predominant representation of parent from privileged groups at Alut’s board and management that advocated for policies that benefited first and foremost their children, disregarding autistic adults from marginalized groups they claimed being represented by the organization. It was the intersected identity of Alut’s founders who are Jewish parents of autistic individuals from high socioeconomic status, residing in Israel center, Ashkenazy, educated, with abundant of social capital privileged groups that allowed them to get recognition as the representing organization and at the same dictated the public tone of the organization and advocated for policies that contribute to inequlities.

To establish this argument the chapter breaks it into three parts. The first section adopting the analytical framework of intersectionality, analyzes the intersected identities of Alut’s founders. Although this analysis requests to examine the founder multidimensional social position on the diverse axes relevant to the Israeli context, to set the bases for the discussion like most scholarly on autistic organizations the analysis begins with exploring the axes related to different dimensions of the autism field such as the position on the “low or high functioning” axis and organization *for* or *of* autistics. Then it focuses on the axes that were identified to be marginalizing autistic social positions in the last chapter and specifically: socioeconomic status, residential area, and ethicity. Following this analysis, I argue Alut’s fuonders social position was marginalized on the ability-disability axis as parents of autistic adults but a very privileged one on other axes relevant to Israeli society. As the analysis utilize the analytical framework of intersectionality it further allows to conclude also on social mechanisms that contribute to the preservation of discriminative social power by privileged social positions.

However, to illustrate the discriminated social structure preservation process that contributed to inequalities between autistic adults, it is not sufficient to simply illustrate the intersected identity of social actors, but the influence of their agency must also be explored. To do so the second section examines Alut’s role in forming policy regarding autistic adults in Israel. It argues that similar to other autism advocacy organization in the world Alut have had a considerable influence on policies and regulations since the 80’s onward. Despite it dominancy in the field has changed along the year and its position was change from integral actor to an external organization its approval is needed he kept being influential in this field.

Then the third section request to answer whether these policies were set to serve the entire autistic population, or mainly those from privileged groups. To answer this question, I examine the direct and indirect effect of Alut’s main advocacy effort for autistic adults - the promotion of residential institutions also known as hostels or ‘houses for life’ as a sole solution for autistic adults. I show how setting private capital as a mean to create high-quality standards of living for small fraction of autistic adults left the majority with no residential opportunities, or suboptimal standard of leaving. To examine the indirect effect of this policy I illustrate how the neglect of community services, that Rimon-Zarfaty, Raz, Bar-Nadav & Vaintropov (2020) also identified, disproportionately negatively affected autistic adults from disadvantage communities. This neglect left community services to the “invisible hand” of private entrepreneurship which created services that relies on self-advocacy and personal capital qualities that unfortunately favor those from privilege groups. Coupling the direct and indirect implications of Alut’s main intervention in policies regarding autistic adults, I argue that despite claiming to advocate for the entire population the policies promoted by the organization contributed to the creation of inequlities between autistic adults in favor of those privileged social groups who were represented in Alut. The emphasize these actors gave to certain policies aspects that were influenced by their identity, I further assert preserved the power and the resources in the hands of privileged instead of redistributing it to all the autistic population they claimed to represent.

The last section cools the judgmental tone of the chapter toward Alut’s founder parents by contextualizing their actions. The section illustrates these actors, mostly women, have operated in a system that supported mother blaming and completely neglected services from all kinds to all autistics. I argue that in this discriminative socio-political context their trail to achieve better conditions for their children should not be critic, rather the government that failed to identify first the autistic adults needs and later the discriminative consequences of the polices promoted by Alut should be the one accountable. To complement this argument, I illustrate that despite Alut’s operation in recent years was still focused on this discriminative policy, Alut acted to narrow disparities between autistics and to promoted public services that benefit the whole community. I claim that environmental changes in the field of autism which some of them are a result of Alut’s policy actions and inner organizational changes in the form of establishing a legal department created the circumstances that allow the founder culture, as Rimon-Zarfaty et al. (2020) defined it, to coexist alongside efforts to reduce inequalities.

Before turning into analytical sections, it is important to clarify that despite this analysis should be applied to all the organizations involved in the autism policy field, the following will be focused on Alut. It is not that other organizations should not be subjected to profound examination, on the contrary as I argue in the discussion intersectional analysis should be an integral part of our understanding of social health movements (SHM); but because historically Alut had prominence and lasting position in autism policy field which resulted in profound data that can be analyzed it is the focus of this analysis. The three other organizations dealing with autistic adults: Effie, ACI, and Mishtalvim Barezef, as presented at the literature review were established after the turn of the millennium; hence, their past documentations are scarce in comparison to that accumulated over the years regarding Alut. Moreover, as the first section is examining identity and some identifiers could be linked directly to a specific interviewee and expose her or his identity not all the quotes below will be accompanied by interview identifier.

## 7.1. Who is in who is out: representation in the autism organizations

To set the stage for the chapter’s main argument that it was the privileged multidimensional social position of Alut’s founder and representatives that influence their decision to advocate for discriminative policies and practices, this section examine Alut’s leading parents’ social position. Although the analysis aims to focus on social axes that are unrelated specifically to the fields of autism or disability organizations those axes cannot be disregarded as they considerably shaped the advocacy efforts of Alut. Thus, following the footsteps of Raz and colleagues (2018) and Rimon-Zarfaty and her partners (2020), I illustrate using my data Alut’s organizational position. Next after strengthening these authors claims, I turn to analyze the leading parents’ social position on other social axes. The analysis demonstrates that on the social dimensions that were demonstrated to be marginalized in the last chapter including socioeconomic status, place of residency, and ethnic relation, Alut’s leading parents were on the privileged side, some could be even considered them to be part of Israel elite. Following this analysis, I argue that although Alut was and is titled The Israeli (national) Society for Autistic Children and Adults[[1]](#footnote-1) claiming to represent all autistics, in practice it represented not only the “low functioning” supporters of medical model of disability (MMD) as the literature demonstrate but also those from privileged social groups.

### 7.1.1. Alut – who they represent and what do they want?

As the literature review illustrate most scholarly concerning autism organizations classify these organization according to one of four dimensions: the “low or high functioning” axis which is specific to autism (Raz et al., 2018), the *for* autistics in oppose to *of* autistic axis and the MMD in oppose to the social model of disability (SMD) axis which relate to disability organizations more broadly (Hutchison et al., 2007), and the role of the organization as an advocacy organization or as services provider which relate more broadly to the non-profit organization literature (Onyx, Dalton, Melville, Casey, & Banks, 2008). These classifications are important to understand who the autism organizations represent and what are their agenda. Similarly to Raz and colleagues (2018) and Rimon-Zarfaty and colleagues (2020), who analyzed Alut position on these axes, as the literature review briefly present, my qualitative analysis demonstrated that despite proclaiming representation of the entire autistic population in Israel in practice Alut as an organization *for* autistics that provide services relevant mostly to “low-functioning” autistics from a MMD approach advocate only for limited section of the community.

To highlight the profound discrepancy between Alut’s representation claims and their actual representation, and as the following sections concerning Alut’s operation in the autism policy field, it is crucial to explore not only Alut’s claims of representation but also how they were perceived in the political arena. My archival research illustrates officials up until recently conceived Alut as the sole representative of all autistics. For example, in a letter written by Gabi Barbash, the MoH director general in 1996 on allowing Alut to operate an hostel in a new facility he states: “The second NGO [the first mentioned was a local NGO] is a national NGO – Alut […] there is only one NGO that operates residential facilities for autistic children and adults, Alut, is it not so? (Barbash, 1996). While in the mid 1990’s Alut was virtually the only organization operating in the autism policy field, the organization status had maintained for decades later. In 2015 parliament discussion that dealt with the Rehabilitation, Advancement, and Inclusion of people with autism in the community Bill which was drafted by Alut without the other organizations, the parliament representative which promoted the law Orly Levi-Abekasis stated: “the original law proposal was in fact written with the autistics and got the consent of most autistics or parent of autistics” (Early Hearing 3 Bill proposal rehabilitation, advancement, and inclusion of people with autism in the community, 2015). Assuming the Knesset member was speaking in good faith, her opinion reflects the widespread assumption among policy makers and the public that Alut is *the* representative of all the autistics in Israel.

However, this assumption could not be further from the truth. Ronen Gil, an autistic advocate, who was also involved in the autism policy field in recent years described in his interview the importance to distinguish between organization *of* and *for* autistics when he discussed the pitfalls, he recognizes in Alut:

Alut tries to present as if the interest of the organization is the interest of the autistics themselves, there is not even one member in Alut that identifies himself or herself as autistics, ok? They are all parents […] they intentionally create this confusion all the time […] presenting their interests as parents of autistics as the interests of the autistic themselves (Ronen Gil, autistic advocate)

Ronen highlights the importance distinguishing between the interest of the autistic person from the interest of the parent. Alut cannot represent the interest of autistics, he argued, as no autistics serve in its board. Recent changes in the organization statute cemented that no autistics could serve at its board or even be a member of the organization. The revised clause states “A member can be a parent that is a guardian of a person that suffers from autism, or other that serve as a guardian” (Alut, 2020). Or in different words not a parent equals not a member. Ronen’s argument that Alut is an organization *for* and not *of* autistics corresponds with Raz and colleagues (2018) observations who asserted the same. Therefore, while Alut is conceived as representative of *all* autistics in practice it represents only *parent of autistics* and not the individuals themselves.

Yet the recent amendment in Alut’s statute, as Rimon-Zarfaty and colleagues (2020) point in their article, do not only exclude autistics themselves from participation in Alut but also families who decided not to appoint a guardian for their adult autistic child. Given that guardians are usually not appointed in cases where autistics are able to be more self-reliant, or what is usually conceived in the autism field as “high functioning” this clause also limit the organization to “low functioning” adults. Gefen, a mother of an autistic adult and activist in the autism field reflected in her interview on this issue:

On the one hand Alut is saying one in a hundred is autistic and waves the growing numbers, on the other hand those Alut really want to serve [who are low functioning] is becoming a minority that shrinks more and more, although today it constitutes half of the administrative board. 400, representative of 400 autistics are constitute 50% of Alut’s board. And it still wants to call itself a national organization. (Gefen, a mother of an autistic adult and an activist)

Gefen claimed that while the rise of prevalence of autistics from across the spectrum serves Alut and it is utilized by the organization to claim for more resources, Alut’s board of representatives does not reflect the entire spectrum but only a small fraction of it. 50% of Alut’s board represent approximately 400 autistics, according to Gefen. These 400 autistics constitute approximately 6% of the 7000 autistic adults that are recognized at MOLSA. Even if Gefen estimations are not accurate and it is not 6% but 20%, these numbers indicate that the representation within Alut board who claim to be the national organization that represent the entire spectrum is not reflective of the autistic population but favor those who are considered “low functioning”, leaving “high-functioning autistics with no representation. It should be stressed that while these two axes, the axis of organizations *of* and *for* and the axis of “low or high functioning” are interconnected and overlap they are not identical. Both because the axis of organizations *of* and *for* is relevant also to non-autism organization such as Alzheimer (Schicktanz, Rimon-Zarfaty, Raz, & Jongsma, 2018), and because “high functioning” autistics can be and occasionally are represented by their parents, as in the case of Effie.

Another organizational axis, that is relevant for other disability organizations and was raised also by Raz and colleagues (2018) and Rimon-Zarfaty (et al., 2020) in relation to Alut, is the organization endorsement of certain model of disability. Noa a mother of an autistic adult and an activist in the autism filed situated in her interview Alut as an MMD supporter and claimed:

It [Alut] was very oriented to hostels [segregated residential facilities…] so there are very limited services in the community, I think that this is one of the reasons that parents are taking their children straight to hostels [when the education system finish at age of 18 or 21], because there are no services in the community (Noa, a mother and an activist).

Noa, which was involved with Alut in her past, opened this quote by asserting Alut is invested in segregated residential facilities. Although, they often referred to as “houses for life” and are claimed to be integrated in the community due to their location, these facilities are surrounded by fences and the autistics who resides there need to keep the institution’s schedule and cannot leave. Without getting to the discussion whether other residential alternatives are relevant to “low-functioning” autistics or not, as these institutions are an integral part of the MMD basket of solutions for people with disabilities they clearly situate Alut on this part of the model of disability spectrum, as also Raz and colleagues (2018) identified. The rest of Noa’s quote continues previous interviewees assertation that while claiming to represent the entire autism community Alut disregarded those within the autism community that prefer inclusive solutions that correspond with the SMD. Thus, it can be concluded that Alut is not a representative of all autistics but of *parents of autistics*; and it is not a representative of all parents of autistics either but of *parents of “low functioning” autistics*; and it is not representative of all parents of “low functioning” autistics but of those *who support the MMD*.

But Noa’s argument allows to continue one step forward and ask why Alut claim for being representative of all autistics while in practice favoring small fraction of the community? Did Alut really done it intentionally as Ronen argued, or as implied from Gefen’s quote? To answer these questions, it is first essential to locate Alut on the organizational axis of a *supplier of services or an advocacy organization*. This distinction is historically known in the autism field in regard to the differences between the NAS, National Autism Society based in the United Kingdom who provided service and NSAC, National Society for Autistic Children based in the US who focused entirely on advocacy (Eyal, 2010). Alut, from its initial phases decided to adopt the NAS model and provided service while advocating for autistics. This approach as many interviewees pointed, and as Rimon-Zarfaty (et al., 2020) argued can be conflictual in many aspects, yet Noa’s argument assist in linking this conflict to the representation discrepancies. According to Noa, Alut’s endorsement of one solution was done on the expense of others. By claiming to represent the entire population and advocate for their solution they created a situation that the only services available for autistics is the one they provide. Even if parent could have been interested in alternatives the neglect of these alternatives because they have not been advocated, as Noa asserted, diverted parents of autistics to Alut’s services. In other words, Alut claim for representation despite representing small fraction of autistics was done so its advocacy efforts for the expansion of their services will be well perceived. In a demand-driven system, as the last chapter illustrate, where the “clients” set the needs, advocating for the services you are providing in the name of the entire population result in more investments in your services. Unfortunately, by taking this position Alut also minimized the needs of all those they do not represent.

To conclude, as Raz and colleagues (2018) and Rimon-Zarfaty and colleagues (2020) have also demonstrated, while claiming to be the representative of the entire population Alut represent only a small fraction of parents of autistic adults who are interested in seclusive solutions for “low-functional” autistics. This representation discrepancy was done according to the materialist explanation I propose to priorities services provided by Alut and create a situation where they are demanded. A complement explanation was made by Rimon-Zarfaty and colleagues (2020) that is the founder’s culture that dictated Alut’s preferences on the expenses of new perspectives that join the autism community. Later I will return to these two arguments as I illustrate those mechanisms also contributed to the creation of inequlities between autistic adults from different social groups.

### 7.1.2. Representing the privileged: an intersectional analysis of Alut’s founders

In this sub-section I turn to analyze Alut’s representational claims from an intersectional perspective. While the previous section and most of the scientific literature challenged Alut’s claim from an internal autistic perspective the following analysis request to challenge this claim on other social dimensions. I illustrate that Alut founders and representatives are related to privileged groups and argue that while claiming to be representative of the entire autistic population in practice they represent the interest of a small, very powerful social group.

It should be stressed that the analytical framework of intersectionality is usually concerned with those intersected identities that are marginalized in our societies. As covered in the previous chapter I argue that these multifaceted marginalized social positions should be an integral part of our understanding of inequlities and discrimination also in the case of autism and more broadly in SDH. Nevertheless, we ought to remember, as scholars such as Walby, Armstrong and Strid (2012) remind us, that marginalized social positions also intersect with privileged ones. While the experiences of women of color, for example, are crucial to our understanding of multifaceted discrimination in society, the experiences and more importantly the actions of white privileged women should also be subject for investigation. This investigation, however, should aim to understand the power structures that assist privilege groups to preserve their power in society, not merely to shed light on experience of privileged social groups. In the context of this section the following, in oppose to previous chapter, explores the intersected identity of the founders and representatives of Alut. Their identity combines the marginalized social position of parents of autistics with, as I intend to demonstrate privileged social positions.

From its very first steps Alut was founded by parents of autistic children from privileged social groups. The distinguished lineage of those who established Alut reach much further even than the hegemony of Israel in the 1970’s. As Batia, a professionals working with autistic adults, told me in personal communication after her interview: “the people who establish Kfar Ofarim [the first residential place established for autistic adults in Israel] were and are among the most powerful people in the Israeli economy” (Batia, 11/02/2020). A quick search of the names of Alut’s founders and Kfar Ofarim founders mentioned in a video Alut released for its 40 anniversary (Rosenman, 2014) reveals that indeed some of those parents were related to the Israeli highest elite:

* Ami Hirschstein the **CEO of Dan Hotels**; founder Alut (Hirschstein, 2013)
* Shoshana Bayer, **the head of the high-school teacher organization 1982-1991**; founder Alut (Ichnoled, 2009)
* Leah and Meir Hovav, Phd in Hebrew Literature (1982) and a writer, respectively; founder Alut (Leah Hovav, n.d.)
* Liora Avigdory, **the granddaughter of the funder of Sonol Energy**, founder Alut (Haviv-Grin, n.d. a)
* Yossi Langotsky, a **geologist who discovered the gas in shores of Israel**, founder Kfar Ofarim (Yossi Langotsky, n.d.)
* Irit and Orni Isakson, **the former chairperson of the The First International Bank of Israel (Ha’Bein-Leumi Bank) and Isracard group, and an honorable consul for Norway**, respectively; founder Kfar Ofarim (Irit Isakson, n.d.)

In addition to the personal privileged biographies of Alut’s and Kfar Ofarim founders, from a close observation on the written testimonies available on Alut’s founding group from Feinstein’s (2010) and Mishori’s (2014) books it is clear these parents had an abundance of social capital. Feinstein (2010, p. 248) who wrote about the history of autism and dedicates few pages to Israel writes: “Personal connections really helped. Haim Tzadok, the Israeli Justice Minister, had a niece who was autistic. Leah Rabin [the spouse of Itzhak Rabin who was the prime minister from 1974 to 1977] who happened to be a relative of Mishori’s [Alut’s first CEO] agreed to serve as chairwoman of ALUT’s boards of directors”. Identifying the importance of social capital in establishing Alut, Feinstein demonstrate the close connection of the founders to the political and social elite of Israel.

The last chapter of Mishori’s (2014) book regarding the social struggle of parents to secure service for their autistic children reveals the same picture. Rivka, for instance, who was interviewed for the book describes the parents who funded Alut “There was a group of very nice and *educated people*“ (Rivka, an interviewee, p.184; not an original emphasis DWD). Crossing this saying with a report sent from the psychiatric nursery at Sheba Medical Center, the location where Alut’s founders first met, to the ministry of health in 1977 describes 74% of children were from Ashkenazi descent and 32% of parents had some form of higher education (from a university, seminar, or professionals) (Malory, 1977). These percentages who were much higher than the general population (approximately 9% according to calculations from: the central bureau of statistics: Sicron, 1977) illustrate these parents were from Israel’s higher social classes.

Given this respectful list, and the ties with the prime minster wife, Leah Rabin, it is not surprising the first public commission of Alut, established in 1975 included the highest financial elite of Israel (Figure 7.1) among them the managing directors of the three largest banks in Israel. These connections have continued throughout the years up until these days. For example, the CEO of Alut at the early 90’s Hodorof Péhéra was the wife of Ofer Hodorof the head BTC for business tourism and partial owner of the Dizenhouse tourist group (Haviv-Grin, n.d. b; Hazani, 2018); and Haya Granot a public council representative in 2020 at the residential and employment division of Alut, is David Granot’s Wife (Granot, 2008) who was in 2020 the temporary chairperson of Bezeq (the largest communication company in Israel) and at the board of other several other large companies (Magen, 2019 ;Perez, 2020). Alut was and is clearly entangled with the highest social, political, and financial elite of Israel. [[2]](#footnote-2)

Figure 7.1

(Asir, 1976)

Continue the previous sub-section rational if a social group is not represented in the board of the organization that claim to represent the entire population it means that their interest will not being heard and promoted. For instance, in Alut, there are no autistic representatives, therefore, the autistic voice is not being heard or promoted. Equivalently, having representatives just from Israeli privileged well connected elite means the interest of those from marginalized groups are not being voiced or promoted. But is it really the case? Could someone at a privilege social position who shared an intersected discriminated social position (autism) with those who are from marginalized groups promote policies that would benefit of everyone? And more importantly are those the only parents that are being represented in Alut and setting the organizations agenda?

Unfortunately, the official documentation of those from marginalized groups who did not took an active part in the organization is scares; therefore, their position on the subject cannot be clearly heard. Nevertheless, a newspaper article from February 1995 tilted “Alut against everyone” (Bar-Moha, 1995), sheds light on representation of autistics from the social margins within the organization. In that article a representative of the parents at Rimon school for autistic children which is located near Beit She’an[[3]](#footnote-3) tells the reporter how Leah Rabin, Alut public committee chairperson, have refused twice an invitation from her to visit the school to learn about their children needs even after the parents have fundraised for Alut. Furthermore, Shoshana Baier who was one of the Aluts’ founders and struggle against Alut to open additional residential facility in Jerusalem is quoted saying: “they were taking care of their own children and crony [*mekoravim*] … so it looks good they accepted two or three autistics from lower classes without demanding entrance fees, others with financial difficulties were not accepted to Alut’s facilities.” Both examples from that critical article illustrate that Alut’s image as a representative of all autistic individuals’ interests was inaccurate, to state the least. The first example demonstrates that the management did not make any effort to reach out the geographical periphery and to take in account their needs; the second example, though should be taken in its context, imply that Alut made an active effort to prevent parents from lower socioeconomic status join as active participants in the organization and even use their facilities.

My qualitative analysis demonstrates the unequal representation of those from marginalized groups has been continue to this day. Anat, the mother of an autistic child, a professional working with autistic adults and an activist in the autism field, who was involved in Alut described how she perceive her role within Alut:

I represent the higher functions, and I will tell you another thing, I think that I represent, sorry for the expression, but less elitist […] because only those who can afford do so, what about all the parents of autistic children that cannot afford behavioral analysis therapists in five thousand Shekel [about 1450$ USD] a month (Anat, a mother of an autistic child, a professional working with autistic adults and an activist).

Starting with mentioning the underrepresentation on the axis of “functionality” that is discussed above, Anat continued to describe her role as a representative of the less privileged within Alut. The fact she needed to apologize before declaring she represents families from lower classes, emphasizes she realized the class axis is not well accepted in this context. Anat’s quote ends with a concrete example on the marginalization of those from lower socioeconomic status that it can be inferred are not part of the decision-making process in Alut according to the expression she used “what about all the parents …”.

Another example of the underrepresentation and inattention to the needs of those from the geographical periphery was raised by Kira, the mother of an autistic adult and an activist in the autism field, who was involved in Alut in her past. When discussing the issue of inequalities, she said:

And all the time I said Alut is a national organization, a national organization represents all the autistics. But then in one struggle and then in another struggle that I was sure that Alut will support and will do this or that, and every time I discover again that no. That Alut has a group of parents of autistics […] **very very powerful** that the profile of this parents is very low functioning hostels [secluded residential facilities] supporters […] but not all the low functioning and not all those who believe in segregation but **powerful parents, socioeconomic, parents with connections, that means not periphery** (Kira, the mother of an autistic adult and an activist; emphasis of the writer DWD)

During the time Kira was involved in Alut she discovered that only a specific agenda was promoted by the organization. According to her not all struggles were supported by the organization due to two separate yet linked reasons. She first mentioned the leading group of parents were concerned with “low-functioning” autistics and supportive of segregation in line with the MMD, and in accordance to the position of Alut on the axes described above. Yet, she added this group of parents were very powerful in term of their social and financial capital. They were from high socioeconomic status and were well connected to the social elite. Kira’s description of the leading parents that set the organization agenda mirrors Alut founders’ elitist social position. Kira’s explanation ends with the consequences of this exclusive representation, claiming that it is not representing the periphery where she resided. I will return turn to these consequences in the following sections, yet it is clear from her description she argued the parents who led Alut who are related to the highest Israeli elite, promoted struggles that support their children’s interest.

Kira in a later segment of her interview pointed out the leading parents were center oriented to such an extent that they were so content they: “brought the [organization’s] ballot boxes to Be’er Sheva, Haifa and Jerusalem” pointing that they consider “Jerusalem the capital of Israel is periphery, and if Haifa is periphery what about Qiryat Shemona[[4]](#footnote-4)” (Kira, a mother of an autistic adult and an activist). Linking Alut leading representatives’ relation to the center of Israel with the organizational voting procedure illustrate that Alut’s representatives did not regarded equal participation in the organization leadership as essential. Despite being considered a national organization that supposed to represent all autistic individuals in Israel in practice those who reside the periphery could not have been elected equally to lead the organization. Thus, the identity of Alut’s leadership could also be regarded as intersected with residency in Israel’s geographical and socioeconomic center.

Another group that is clearly less represented within Alut leadership is the Arab minority. A quick look on current and past representatives within the management and the public committee reveals that no representatives from the Arab community had never been involved in Alut. Shai, a professional working with the autistic Arab community described in his interview the limited participation of parents from the Arab community:

There are more activist parents in the Jewish sector that can help and assist in developing services for their children […] I think that there are more parents at the Jewish sector that has strong personality, socioeconomic condition, and that they can make themselves available for that, they are more connected to political figures, to the Knesset to governmental ministries, to public figures. […] working with the Arab sector I recognize that there is high percentage of impoverished [*Dalim*] parents. I am sure that also in the Jewish society. (Shai, proffesional who works with the Arab community)

Shai attributed the minimal involvement of parents from the Arab community in autism advocacy organizations to their personal availability. Because organizational participation is mediated by personal availability, for instance by the need to participate in meetings that take place in the center of Israel, it could be argued that unless the barrier of availability is actively addressed participation in the organizations is unequal. Yet, the most relevant point Shai raised, however, in this quote is related to activist parents from the Jewish sector. He portrayed the parents much like described above as well connected with political and public figures and from high socioeconomic class. The parent-activist scholars have described (Eyal, 2010; Waltz, 2013, see literature review) in the Israeli context are not just any parent, according to Shai, but a Jewish privileged one. Shai acknowledged at the end of the quote that there are parents from the Jewish sector that are also “impoverished” and could not participate in the leadership, yet it is clear to him advocates are Jewish.

To sum up, while the previous sub-section demonstrated that despite Alut claim to be a representative of all autistics in Israel and despite it was and is perceived as one, in practice it represented a small subsection of parents of autistic adults that support MMD solutions for “low-functioning” autistics. This sub-section observed these representative parents through the lens of intersectionality and argues those are not just parents or “parent-activists” as referred to in the literature those are Jewish parents from high socioeconomic status that resides in the center of Israel and are well socially connected that founded Alut, and are still very influential within it. The claim that Alut represents the entire autistic population where those from the periphery, low socioeconomic classes, or Arab ethnicity are not equally participating in the organization leadership is misleading. Recognizing these leading parents multifaceted social identity is crucial, I argue, to comprehensively understand their actions and more importantly the consequences of these actions the following sections explore.

## 7.2. Involvement of autism advocacy organizations in the policy arena

Despite Alut representatives are parents from very privileged group, social actors’ multifaceted identity not necessary dictate acting according to the interest of this identity. As critics of identity politics argue this is one of the oldest pitfalls of identity politics that assert identity necessary dictates political actions (Alcoff & Mohanty, 2006). Thus, the following sections further explore the claims of both Keren quoted above and Shoshana Baier cited in the newspaper article (Bar-Moha, 1995) that this unequal representation indeed resulted in disregarding or actively discriminating autistics from marginalized groups. From an intersectional perspective, the next sections examine whether these representatives that their identity combines marginalization with privilege social positions have preserved using their power they claimed within Alut resources in the hands of the privileged or acted to redistribute power and resources. To start answer this question this section examines Alut role in shaping policies regarding autistic adults and argues it was central in constructing and reshaping these policies.

Health social organizations and specifically autism advocacy organizations had been shown to greatly influence the production of knowledge and the construction of policies (Eyal, 2010; Waltz, 2013; Orsini & Smith, 2010). As presented at the literature review Alut have greatly influenced educational policies for autistic children (Shulman, 2000). Although in the scientific literature there is no recollection of Alut’s involvement and later of other organizations in shaping policies regarding autistic adults their influence was immense.

There are numerous examples both in the historical documents and the interviews that illustrate Alut influence. As early as 1986 Edna Mishori, then the director of Yahdaiv school and a member of the management of Alut, participated in an expert committee appointed by the health minister, Mota Gur to draft “the principles and policy for treatment of autistic children, adolescents and adults”. At the beginning of this report the committee highlight that “there is no satisfying solutions for the age group of the autistic adolescents and adults” (Hateb, Skaly, Yoeli, Meir & Mishori, 1986). Alut’s influence is noted throughout this report especially regarding autistic adults. At the first recommendations concerning autistic adults it reads: “Alut is taking upon itself to build the boarding school” (Hateb et al., 1986, p. 142) positioning Alut as a main provider of services. The report ends with a call for establishing a joint committee of “Alut organization, the Ministry of Education, the MoH, the Ministry of Labor and Social Services, and the NII that will accompany the project” highlighting the influence of Alut as a leading body for developing policy for autistics. Following this report there are documentations of meetings between the head of the psychiatric services Dr. De-Shalit and Alut’s management committee, and direct correspondence between the Health Ministers (Mota Gur and Shoshana Arbeli Almozlino) and Leah Rabin (Rabin, 1986; Gur, 1986).

It should be noted that the inexistence of proper services for adults was known to the ministry of health since the beginning of the 1980, yet nothing had been done. A report by Rahav and others submitted after the murder of Ofer Avigdori, an autistic child the son of Liora Avigdori one of Alut’s founder who was murdered by his grandfather in 1980 also stated: “until today there are no boarding school facilities suitable for autistics” (Rahav, Poper, Cohen & Porat, 1981 in: Mishori, 2014 p.197). The repeated conclusions that there are no services for adults emphasize the stagnation in policy regarding autistic adults at the beginning of the 1980’s when Alut was still focusing exclusively on younger ages. More importantly it further emphasizes the essential role Alut involvement had in developing this policy.

The extensive involvement of Alut continued throughout the 80’s and the 90’s. Among the numerous examples that are documented most of the Alut’s involvement in policies regarding autistic adults was as a supplier of housing services and less as advocacy organization. As a supplier of services Alut was actively approached by the MoH to develop additional residential facilities for autistic adults. For instance, in 1989 the head of psychology division Dr. Gilboa promoted the “triangular project” to establish additional residential placement for autistic individuals in Jerusalem. She actively approached Alut as a supplier and Elwin organization who operated a hostel for people with cognitive disability on the same area and ask their willingness to promote such project which was never accomplished (Gilboa,1989; see also later correspondence on that matter with the Health Minister deputy, Mr. Nawaf Massalha, 1993). Yet, The most notable example that signify Alut position as a formal and integral part the state institutions that provide for autistic individuals is found in a report titled “Planning services for autistics for the year 2000” (Cohen & Levinson, 1993). In this report who was written by an inter-ministerial committee and one of his goals was to map the services for autistic, under a tables tilted “Distribution of reported autistics according to responsible ministry and district” Alut appears as ministry, along the MoH, MOLSA and the Ministry of Education (Figure 7.2).



\*Figure 7.2 (Cohen & Levinson, 1993, p.15)

Along the years Alut was also involved to a smaller extent in advocating for autistic adults who were not enrolled in their residential facilities. For instance, in 1989 due to shortage in budget the MoH decided to charge a day fee from every family that their child was hospitalized in mental health institution. Among the families who were asked to pay were parents of autistics. Following an emotional hearing in the Knesset assembly (Mandatory payments for hospitalizing children with autism, 1989) in a meeting held between Alut’s management and the Health Minister, Mr. Ehud Olmert, the Director General, Dr. Moshe Mashiah, The head Mental Health service and others it was decided that autistic parents will not pay hospitalization fees as their expanses of treatments and additional services are already high (Ashkenazy, 1989). Given the decision to charge for hospitalization was applied to all psychiatric patients, this example illustrates the great influence Alut had on both the parliament and the government.

A later example can be found in 1996. After a meeting of Alut parents’ representatives together with Ms. Leah Rabin and the Health Minister, Mr. Tzachi Hanegbi, and the Finance Minister, Mr. Dan Meridor on “the autistic problem”, it was decided that Alut representative Mr. Emanuel Dotan will convene with the head of health unit in the budget department at the Ministry of Finance and decide the small details of the program (Mohaliver, 1997). This profound involvement in decision making is yet another example of Ault’s influence on policy.

The qualitative analysis consolidated the imagery of parents’ organizations as an influential force in policy regarding autistic adults. Bat-El, for example, an advocacy lawyer who works with the autism community, reflected on the intimate involvement of Alut with the Knesset and the relevant ministries:

In the macro level Alut has issues, verity of issues […] that they act to promote policy change in them […] they work with the Knesset a lot, all the time in hearings at the Knesset, going to hearings, responding, initiate hearing. They work with the state ministries, mainly the social services, health, and education, with the National Insurance Institute. Their goal is to promote the rights of… of people with autism and promote the services they receive in Israel.

Later in the interview she elaborates:

For instance, an issue that Alut recently promoted, the ministry of health responded and prepared it and today it is just stuck at the ministry of finance […] This is a new subject of broadening the mental health services what’s called The Hospitalization Alternative Law [‘Hok Halufot Ishpuz’]. How was it adopted? It was adopted because it became a sexy issue, because everyone is talking about hospitalization alternatives, on balancing houses [Batim Meaznim] you can’t ignore it. It got adopted because it was important to parents at the management [of Alut], to many parents at the management. It is important for them that both the Ministry of Health will address it and that Alut will develop services (Bat-El, an advocacy lawyer who works with the autism community)

Describing Alut’s operation in the policy arena Bat-El depicted in her interview what is also reflected from the archival documents: Alut is greatly involved in the construction process of policy regarding autistics. She portrayed Alut’s involvement in both the parliament and the ministries and depicted along her interview numerous examples where parents were actively involved in creating and advocating for certain policy. Bat-El’s example summaries the process of policy construction that is used in recent years in a brief. It depicts how priorities that are set by parents at the organization are promoted by lawyers and the advocacy department in the organization to such an extent that they are the ones who draft the laws. When the time is “right” and the topic is “sexy” the ministries adopt it and take it forward. Parallel to policy promotion Alut as a service provider have the ability to develop operative models for the services that will be needed according to the law. The circularity of this process that start with policy and ends with providing the service can work also the other way around when policy is promoted to secure the provision of services. In addition to reenforce the problem in having a dual role as a provider of services and an advocacy organization, Bat-El’s example demonstrate that Alut’s involvement in policy had changed along the years. If in the 80’s and 90’s Alut was an integral part of policy decision making, in recent years Alut is considered as an external actor that can suggest policies but is not sitting at decision making table.

The focus on Alut’s dominant representatives’ agenda in the autism policy field had also transformed in recent years. Given the main organization in the field did not represent the agenda of all autistics and their parents and in certain cases, as I will show later, was promoting policies that conflicted new actors’ agenda, these actors had to act on their own and be involve in the policy field. As Rimon-Zarfaty and colleagues (2020) have pointed some of the parents that promoted policies independently or as part of organization were parents who left Alut. Gefen, the mother of an autistic adult and an activist, described how deeply she and other parents were involved in the autism policy filed:

We [a group of parents] actually set and wrote the bill, and then some lawyer gave us a format of how a bill looks like. He explained that there are definitions, goals and this and that. And we worked [on it] and wrote it and send it to a lot of people to get their feedback […] We set down with the legal advisors of the Committee for Social Affairs at the Knesset [… and] The law got the P [פ] which is the approval of the legal department […] We [then] met with Knesset members […] explained, persuaded and got their signature (Gefen, the mother of an autistic adult and an activist).

Gefen portrays in detail the creation of a new bill that regard autistics. A policy construction process in which parents who are not part of Alut not only act as advocates but lead the process throughout its different phases. Although in a later part of the interview she expresses her astonishment by the central part she had in writing the bill, saying “like who are we? From where the Huzpa is?”, her actions were not new to the field of autism policy. The continues involvement of Alut which began in the 70’s created the conditions in which parents can be the ones who create policies. Therefore, her and other parents who are unrelated to Alut involvement in the autism policy field further highlight the influential position Alut had and has in this field.

The involvement of parents like Gefen, who are not members of Alut, in policy construction clearly introduce to the autism policy arena novel voices; nevertheless, Alut influential position within the field was and is maintained. Major policy changes have not been passed without Alut’s green light. Gefen’s bill, for instance, was sent for review and comments to Alut and all other organizations including Mishtalvim BaRezef, Effie and ACI. Gefen mentions: “They [Alut] did not understand where it came from, but soon later, and they should be credited for it, they regained their senses, and said ‘this bill is better than the one we wrote’, and let us sit together” (Gefen, a mother and an activist). Their support made it possible for the bill to be considered seriously and not counter a great opposition especially from the Knesset members who supported Alut’s original bill.

The dominant position Alut gained over the years in the policy arena can also be illustrate by analysis of Alut’s financial reports. A detailed observation on Alut’s annual financial report reveals enormous financial enterprise. This enterprise includes in addition to gigantic annual payments from MoH and MOLSA for operating their facilities, respectable sums of donations, a huge investment portfolio, which is unusual for non-profit organization, and several types of assets that sum to 180,088,626 NIS (48,023,633$) (See below Table 7.1 Alut’s Budget; UHY Shtainmetz Aminoach & Co., 2019). Yet, the most striking information is not Alut’s financial data in absolute numbers which are equivalent to those of a large company, but the organization capital in comparison to other services providers. Among the organizations that provides services for individuals with disability, Alut was ranked first in the financial benefits it got from the state. In addition, while the median annual economic cycle of the 122 organizations who submitted their financial reports was 1,120,312 NIS (298,749$), Alut’s annual economic cycle was 252,088,316 NIS (67,223,550$) (The Budget fundamentals, n.d.). This data illustrates Alut’s immense influence in the political arena, even relative to other organizations providing for individuals with disability.

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| --- | --- | --- |
| Table 7.1 Alut’s Budget\* |  |  |
| Budgetary Item | Sum in NIS | Sum in US Dollars\*\* |
| Annual payments from MoH  | 73,267,953 NIS  | 19,538,120$ |
| Annual payments from MOLSA | 116,819,329 NIS | 31,151,821$ |
| Donations | 29,197,119 NIS | 7,785,898$ |
| Investment portfolio* Governmental bonds
* Stocks market
 | 40,824,670 NIS2,076,113 NIS | 10,886,578$553,630$ |
| Assets Total* Permanent assets
* Temporal assets
* Other assets
 | 180,088,626 NIS121,198,399 NIS27,474,624 NIS31,415,647 NIS | 48,023,633$32,319,573$7,326,566$8,377,506$ |

\* Source UHY Shtainmetz Aminoach & Co., 2019. The table is a partial summary of the organization budget.

\*\* Exchange rate 1 USD = 3.75 NIS

Before turning to the question of whether Alut’s involvement in policy resulted in inequalities, it should be noted again that the main narrative that allowed Alut to get such influence is that they are representing the whole community. Although, as I show above this representation was biased towards certain populations, Alut used this argument in the public policy arena and was perceived in that manner. For instance, in the article mentioned above titled “Alut Againt Everyone”, the head of donation at the ministry of education, Avner Kligman, in response to a question why Alut got more donations money than other organizations is answering: “Alut is not like other non-governmental organizations ‘for’ children, but an organization for self-help that all the members are parents of autistic children […] everything they ‘pay’ is for themselves or their sons” (Bar-Moha, 1995, p.15). Adopting the self-representation narrative, Kligman, illustrate in his answer the importance of the representation narrative in gaining legitimacy and capital from official bodies. A remarkable example of how Alut representatives utilize this narrative is found in the 2012’s Israel comptroller report. In response to question sent by the comptroller regarding anomalies in the salaries paid by the organization, including wages for therapists who were below the minimum required, the organization replied that “the organization is run by parents of autistic individuals, and all the decisions are made by the parents including those that regard to additional fees and paying salaries for their workers. *MOLSA or any other formal body does not have a mandate to tell the parents to take risk in treating their children*” (Comptroller annual report, 2012, p.932; emphasis by the writer DWD). Alut’s answer to the comptroller exemplify the significance of this narrative. To Alut’s representatives this argument is powerful to such an extent that it allows supremacy in decisions making over the public formal bodies that fund the services and create the policies. Given the issue of representation is crucial for the legitimacy of the organization and its influential position within the policy arena it should evoke the question is this eligible representation does not benefit the represented parents and their autistic children over others?

To conclude, Alut has had an extensive involvement in the autism policy field. Its influence began at the 80’s and continued until these days. Although along the years Alut’s role had changed from being an integral part of the decision-making process and being considered another branch of the executive authorities, to an advocacy organization that propose, construct and push policies that interests it representatives, it maintain its dominancy in this field. This could be understood both from Alut’s integral role in promoting policies even if proposed by external bodies and from the financial supremacy it acquired along the years in absolute and in relative terms in comparison to other services providers that are supported by the government. Moreover, Alut consolidated the ability of those involved in the autism field to take an influential role in shaping the policies concerning this population. It was Alut’s representational claims that gave them the ability to be that influential in the policy field, despite as discussed above this clam does not reflect Alut’s leading members. The next section examines whether Alut’s influence in the policy field benefited the entire autistic population or favored those who are represented within it, those that their social position intersects with privileged groups.

## 7.3. Unequal representation as a fertilizer for inequalities

After establishing Alut has represented only a small, privileged section of the autistic community and its influential role in promoting policies regarding autistic adults, this section examines the consequences of these policies on different social groups. As the main policies and regulations issue regarding autistic adults Alut had promoted along the years was ‘houses for life’ (segregated residential facilities) that the organization operated, the analysis examines the direct and indirect consequences of this advocacy efforts. I argue, following a detailed analysis of this policy that it directly discriminated those form lower economic status. Requesting entrance fees before institutionalization and additional monthly allowance, excluded those from low socioeconomic status from these services, or more accurately favor those from affluent backgrounds. The indirect influence of this advocacy efforts, I argue, also further marginalized those from discriminated social groups in three manners. First by assuming that autistics from all social groups want or need the same services Arab autistics and their parent who prefer community service were discriminated. The reluctant to actively address the issue of community services also caused the emergence individualistic enterprises who are not economically, geographically or lingually equally accessible; thus, contributing for discrimination of certain sectors. Lastly, the neglect of community services deteriorated the quality of services in the community that are available and diverted those who have the resource to private alternatives. This section, in other words, open the pandora box of reasons for inequlities between autistic adults and argues Alut the ‘national’ autism organization have contributed to its creation, while using the power of its privileged representative group to secure resources for *their* autistic children on the expense of those from marginalized communities.

### 7.3.1. Houses for life- Demanding quality, discriminating the marginalized

From the very beginning of Alut’s advocacy for ‘houses for life’ at Kfar Ofarim it was clear that an entry fee for being accepted to the residential facility will be demanded, as well as monthly allowance that parents will have to pay for operating the facility. This entry and monthly fares were paid in addition to the sums invested by the states to establish these residential facilities and the monthly budget the state transfer for each resident. A demand from the autistic family to pay from their private capital to get services that are funded by the government. Around the time of Kfar Ofarim (Ofarim Village) establishment in 1989, the MoH had continues correspondence with Alut’s treasurer then Ami Hirschstein, one of Alut founders and Dan’s Hotels CEO, on the entry criteria and monthly stipend. A letter sent from the minister office titled “Autistics in Israel” illustrate how consistent Alut were about the fees; the letter reads:

The entry fees for the village are 20,000 dollars. It was agreed that family that can not afford this amount could sign their autistic child to the institute. […] The ministry demanded that the acceptance criteria will be based on the registration order. […] The ministry recommended that families would participate according to their income, Alut insistently refused, and demanded that participation will be equal to all. (The Health Minister chambers, 1989, p.38).

In this short report several aspects of Alut’s decisions that resulted in discriminatory practices toward autistics from lower socioeconomic status are revealed. First is the high entry fees and monthly payment, which although today might seem relatively low, for the monetary situation in 1989 were high, especially when considering this was a public institution. This can be learnt, for instance, from parents testimonies such as the one wrote by Gila Bai at Alut’s website: ”In preparation for Amir’s [her son] entry to Kfar Ofarim [in 1989] I started working to overcome the high expenses of Amir maintenance at the village (that demanded much more than one salary)” (Bai, n.d.). In her testimony Gila reveals the hardship in financially maintaining an autistic adult at Ofarim Village. Another example is found in a letter sent to the Minster of Immigrant Absorption (Klita), Mr Yair Tzaban, from a social worker of an autistic adult who immigrated to Israel. In her letter she specify that he is “an autistic individual that was accepted to “Kfar Ofarim” […] but although he got accepted he can not enter the place until he pays deposit fees in the sum of 64,000 NIS to Alut organization”. The social worker continues and draft the difficult circumstances of the family and their inability to pay. In this case donations that were collected with the help of the Aliyah (Immigration) and Integration Ministry and the Zionist Forum, this autistic adult was able to enter the institute (Liran, 1993).

What is more striking at the health minister letter is Alut’s consistent refusal to allow differential participation for parents with lower financial abilities. Coupling this statement with Shoshana Baier’s assertion mentioned above about Alut’s preference autistic from higher socioeconomic status (Bar-Moha, 1995); and hearings at the Knesset that show that 90% of autistics had to pay those fees (Suspicion for abuse at "Kfar Shimon" an institution for autistics, 1999), it seems it would be hard to claim that despite the high stipend there was no discrimination of autistics from lower socioeconomic status.

The correspondence between the MoH, Alut and0 Elwin on the “triangular project” reveals additional acceptance criterions Alut had for joining their ‘houses for life’. In their proposition for screening practices for the new village they add additional acceptance terms which include:

1. Alut membership – 3 years.
2. Additional scoring for seniority.
3. Entry rights for the village – 15,000$ (US Dollars)
4. Monthly stipend of 300 NIS

(Guidance for sorting of candidates to the village that will be estublished by Alut (proposition),1987, p.30)

These criterions reveal not only a financial requirement but a necessity to be a member of Alut. In response to this suggestion Dr. Avi Ramot, Elwin’s CEO, reply that “These requirements are not professional requirements but political” (Ramot, 1987). Despite being a legitimate request as Dr. Ramot also mentioned in his letter these requirements left parents with no other option but to join Alut. Thus, the suggested requirements favored those from affluent background in two manners. Similar to the previous case, by demanding entry fees those from low socioeconomic status were discriminated. By demanding membership in Alut and favoring seniority, the organization further enhance its political influence in the autism field while not proposing equal participation for discriminated groups,[[5]](#footnote-5) and it gained additional resources from the annual membership fees. While these fees might seem minimal they could be another burden on families from low socioeconomic status.

Along the years the potential disparities between autistics from different socioeconomic background were challenged by some Knesset members and the relevant ministries, although this practice was originally approved by the executive authorities. One such example can be found in a hearing of the Labor and Social Affairs Committee of the Knesset. During this discussion several Knesset members were challenging the MoH on the entry fees requirement that could sum up to 35,000 USD. Knesset member Ilan Gilon, quoted in previous chapter in regard to the marginalization of autistics from low socioeconomic status responded to MoH representative who described the enrollment demands: “According to this demand [to pay entry and monthly fees] you need to be very rich”, and Knesset member Yair Peretz later asked: “I still did not got an answer to a very urgent questions on the issue of tariffs…Why do parents need to participate and pay these high amounts of money when these are public solutions?”. To this Dr. Daniel Meir the head of the autistic ward at Eitanim Hospital later added: “For now we are left with the most difficult cases that cannot move [to another residential arrangement] either because of their situation or because of financial problems. In our department the care is free” (Suspicion for abuse at "Kfar Shimon" an institution for autistics, 1999). This discussion brought to the parliament table not only the injustice of this practice who was originally introduced by Alut, but also the dire consequences it had on autistics from lower socioeconomic status who found themselves hospitalized for life. While Alut intensively advocated and fundraised for hostels for those with financial resources claiming they are representing the whole autistic community, those who could not afford joining those hostels found themselves in the public system who had no proper solutions and considerably less resources.

In an earlier hearing of the parliament when the issue of entry fees was mentioned Leah Rabin, then the head of the Alut’s public committee divulged the reason for deciding to request entry fees:

Regarding the issue of the initial sum that parents invest, I think that there is a natural part in any parent to assist his child. […]. We are an organization of very involved parents, parents that care and that it is important for them how their child will live. Look for example at Kfar Ofarim, and see how every child live in a sceprate room, nice room, decorated, organized. Those things are important for us. This is not an institution as Mr. Levi [Maxim, the head of the Labor and Social Affaris comittee] described, that it was scary to get in to. We value very much the qulity, this is why at the beginning of our path where nothing was available the initial sum [parents needed to pay] was cardinal. I wish days will come and we could adapt the institutions acoording to our standarts and believes, using only with govermental assistance. (The Autistics in Israel, 1997)

In her appeal to the committee Mrs. Rabin, confirmed what was later will be claimed by others and appears at Mishori’s book (Mishori, 2014), that no resources for autistic adults were available; therefore, parents had to pay in order to establish residential places. According to this narrative if parents would not pay autistic adults will still be hospitalized in mental health institutions for their entire life. However, from this statement it is clearly understood that the reason for requesting entry fees was not just to establish the residential places, who got support from the government, but to make sure their quality is high. While demanding high quality services for people with disabilities is praiseworthy, doing so on the expense of individual with lower financial abilities might be less acceptable. It should be stressed that unfortunately the high standards in Alut’s ‘houses for life’ has not been accepted as a benchmark for hostels that were later established by other organizations creating two separate standard within the public system. Inbal, a professional consulting to autistic adults, and previously the manager of a residential facility for autistic adults, raised this issue in her interview:

So the first thing, at the top of the list [to change], is the model of two at a room, this model has to be terminated. 40 years old [autistic] individual, should not be [living] with another person in the room unless he whishes […] I think that the Ministry of Social Affairs should change the policy, the guidelines […] one bathroom for four five people, even for three… [is too much]. (Inbal, a professional consulting to autistic adults, and previously the manager of a residential facility for autistic adults)

While in Alut the standard is one person per room, as it should be, as Inbal testified hostels operated by other organizations are not require meeting this standard; thus, the desired quality remains for those who have affluent parents while those who cannot afford the entry fees but are also represented by Alut live in places where it is “scary to get in to”, as Mrs. Rabin described.

Lastly, in Leah Rabin’s appeal to the committee there is a hidden criticism for parents who cannot afford the entry fees or are not proactive in their autistic adult’s child life. Framing the entry payment as a “natural” act of parents who want to assist their kids and stressing in her words that the parents in the organization are parents who “care how their child live”, concealed a belief that parents who do not act in this manner are thoughtless or uncaring. Unfortunately, her words echo a hegemony belief regarding resourceless marginalized groups that are neglecting their kids and invest their capital in meaningless things instead of valuables.[[6]](#footnote-6) Her hidden claim also remind the common practice mentioned last chapter in the analysis of the reasons of inequalities – transferring the responsibility away from the privileged to those who are discriminated and indirectly accusing their “culture”.

Despite the critique the policy of entry and monthly fees received in the parliament only in 2007 after an internal committee of MOLSA was convened to examine this issue the director general of MOLSA had adopted a recommendation that parents should not be demanded to pay monthly fees for their child who resides in a public residential facility. In 2011, the comptroller discovered that the largest body running hostels for autistic adults, Alut, was still charging parents mandatory monthly fees of 1200NIS (approximately 350$; Comptroller annual report, 2012, p.932-933). This sum, it should be noted, was paid in addition to the entire disability stipend of the autistic individual and the monthly budget provided for each tenant by MOSLA. Alut who repeatedly claimed along the years to be the representative of the autistic community knowingly continued to employ this discriminative policy, even when it was done against formal regulations. While the situation today is different and monthly fees are not mandatory, entry fees although not demanded can “buy” a place in a “quality” residential facility, as some interviewees had testified.

An additional issue that causes discrimination of autistics from families with less resources is the vague acceptance procedures. Although not formalized, from the interviews it appears that the scarcity in “high-quality” residential facilities which is a biproduct of the entry fees policy, result in search and acceptance practices that discriminate individuals with less resources. Hila, for instance, a sister of two autistic adults, described in her interview:

I needed to put tones of efforts so my brother [with lower cognitive abilities] will be accepted to the place he [currently] resides. And… A family that don’t have enough energy, time, resources, to take someone [a social worker] privately, as far as I know need to wait for many years, I mean this is a miracle he got accepted […] if not this [institution] he would be hospitalized […] You need to be healthy in this state or healthy or have a lot of money (Hila, a sister of two autistic adults)

Describing the searching process for a residential place to her younger brother Hila mentioned she hired a private social worker to help her identify and be accepted to a suitable place. She added that her ability to invest her personal social and financial capital was the reason he found a place. Hila’s assertion that those who do not have capital find themselves waiting for years is supported also by additional interviewees. Bar and Tomer, for example, parents of an autistic adult, mentioned in their interview: “Whoever we talk to and we say that we are with him at home [… says to us] but you have to consider that if tomorrow you will want [a hostel] it will take about three, four, five years to find a place, so maybe you should go and reserve a place […] I have friends that did it and made sure their child have a place, so half the week he is there and half at home” (Bar and Tomer, parents of an autistic adult). Reaffirming Hila’s claim that long waiting lists for residential places exist Bar and Tomer also reveal another practice that could negatively affect autistics from less affluent backgrounds. The practice of reserving a place in a hostel which means paying the monthly disability stipend to the hostel despite the child is not fully enrolled in the institution, just to have a chance to have a good place for the future. Despite not being intentional, creating two housing systems with different living standards within the public system created practices that discriminate those who are less well-off.

To sum up, this section analyzed the small details of the ‘houses for life’ policies promoted by Alut along the years. I claim that the will of Alut’s leading parents to provide quality of leaving for their children using private money within the public funded services created inequalities between autistic adults from different socioeconomic backgrounds. While claiming to represent all autistic individuals and fundraise for all of them, Alut in effect promoted certain sections from the autistic community - those from affluent families. Alut involvement in policy, therefore, not only directly resulted in discrimination of autistic individuals from lower socioeconomic status, but also diverted resources that could have been used for this populations away to individuals from more resourceful families. Finally, the creation of high-quality option within the public system along the years resulted in discriminative mechanisms that again benefit those with more capital. To conclude, this section described how representation of privileged social groups within Alut directly caused discrimination of autistic individuals from disadvantages communities.

### 7.3.2. Neglecting community services - the indirect marginalization of Alut’s policy

In this section I depict the indirect consequences of Alut’s policy efforts to promote “houses for life” and argue it resulted in inequalities between autistic adults. I begin this section by illustrating the advocacy effort for this solution was done on the expense of promoting alternatives in the community. Then I show how the implication of this neglect affected inequlities in three manners. First, among those who prefer communal living arrangements and services are those from minority groups, specifically those from the Arab community. Neglecting their voice in setting the national organization policy agenda made public services irrelevant for them; thus, diverting public funds away and creating inequalities. Second, the focus on ‘houses for life’ left a void of services in the community. In this void personal initiative were developed; yet, as those who developed these initiatives were from resourcefulness background their distribution across Israel, and their reliance on private capital discriminate marginalized populations. Finally, as most advocacy efforts were directed to ‘houses for life’ the public services that have been developed in the community are sometimes of low quality directing more resourceful families to private ‘quality’ solutions and widening the gaps between communities.

First and foremost, it should be stressed the wight that was given to promoting residential facilities throughout the years was done on the expense of community services. Back in 1987 when discussing the establishment of a new ‘house for life’ in Jerusalem as part of the “triangular project”, Dr. Avi Ramot Elwin’s CEO, responded in a letter, that is mentioned above, to Alut’s suggested entry criteria. He wrote: “The decision that the village will be a “permanent house”, is not right in my mind. It should be considered despite this possibility seems very far, that the residents could be integrated in a less protective settlement [in the future]” (Ramot, 1987). Responding to Alut’s suggestion that the village will be permanent place for life, Dr. Ramot highlights Alut’s perspective on ‘houses for life’ as the sole alternative for autistic individuals. It is implied from his sentence that devoting the advocacy efforts for one definite solution that includes most of the services in-house make it redundant to invest in other solutions, less seclusive ones in the community.

While in 1987 it could be claimed that no other solutions were even thought of in Israel, despite the deinstitutionalization movement who called for less segregated services have started much earlier (Eyal, 2010), the “Autistic Bill” (Rehabilitation, development, and integration of people with autism in the community, 2013. פ/798/19) promoted by Alut more than twenty five years later clearly exemplify that in Alut’s lists of priorities ‘houses for life’ were much above community services. Kira, the mother of an adults individual and an activist described how she and other parents viewed the bill promoted by Alut:

The bill proposed by Yair Lapid[[7]](#footnote-7) is really bad […] this bill proposal is going to hurt in autistic rights, their disability stipend […] we set down and analyzed the bill and understood it is a horrible bill. It called the autistic law, but it is going to be against autistics. It is the hostels bill, it is a law that only a small fraction will enjoy its fruit and all the others will suffer, and it will cause damage. (Kira, the mother of an autistic adult and an activist)

After a close analysis of the law together with other parents, Kira came to a conclusion this bill who was proposed by Yair Lapid and supported by Alut is directed to enrich the hostels system. Using harsh words to describe the bill and its possible effects Kira explained it will direct resources away from the community into ‘houses for life’ which serve only a small fraction of the community. As mentioned above, Alut neglected this bill for the one written by Gefen and other parents, but their initial intent was to promote the ‘houses for life’ they supply. From a historical perspective Alut’s policy effort totally succeeded. The permanent secluded all-services-included residential places are today the most common services for autistic adult while community-based services are scarce.

It should be noted that the neglect of community services could be frame as promoting MMD solutions or solutions for the “low-functioning” on the expanse of the SMD and “high-functioning” autistics as mentioned above. In addition, as I propose above from a materialist perspective, it could be claimed that Alut as a supplier of services wanted to stabilize and expand their main operation, therefore invested in advocating for it (see section 1.1). Nevertheless, the question that should be asked in relation to this section which focus on inequalities, is not whether those who want community services are less content, or is autistic with higher cognitive abilities were discriminated, or is these efforts financially assisted the organization; but is this practice created disparities between autistic individuals from different communities by further marginalizing those from oppressed groups?

The most notable example for a marginalized social group that was further discriminated by the neglect of community services is the Arab autistic minority. Shai, a professional who works with the autistic Arab community, described the inclination of parents from the Arab community for community solution and not permanent residential arrangement:

They [the parents] tell me regarding [their] adult children: “I prefer he will stay with me than to send him to a residential facility or even for employment.” Because he might [find] work with his father or his uncle, or another relative few hours a day, not something formalized with paycheck and everything. Maybe it is also economically worth it [to keep him at home] because he will still be given stipend, on the other hand the expenses can be hundreds or thousands of Shekels a month […] It is not common in the Arab society that you turn [to residential placement], you can also see lower referral rates to retirement homes [for the elderly], although it is gradually changing. […] A remarkable part of the autistic adults can stay at home with their mother, and we would really know nothing about them. (Shai, a professional who works with the autistic Arab community)

 Shai raised two reasons why parents would be reluctant to send their autistic child into a permanent residential facility, an instrumental reason and a cultural reason. The instrumental-economic rational is that because the child can be upheld with the assistance of the extended family in his house while getting his stipend, there is no reason to find another residential placement far from home. This argument was supported by other interviewees. For example, Dr. Efron, a psychiatrist, said that: “Economically [speaking] autistic person gets high stipend, when he is in hospitalization or at a hostel the family don’t get [the money] so you leave them at home […] The sum is not enough in the Jewish community but definitely enough in the Arab community, so they hold them at home and deal with their aggressions in their house” (Dr. Efron, a psychiatrist who works with autistic adults in the Jerusalem district). Repeating Shai’s argument Dr. Efron claimed that in the Jewish community the economic incentive is irrelevant as the expenses are higher. In the Arab community, however, especially the one residing in east Jerusalem, where unemployment is high especially among women (Naftali, Caspi & Omer, 2020) it is easier to use the stipend and manage “the aggressions” in home, without formal assistance, but with the resource available in the Arab community such as the extended family. The second argument Shai raised is that families from the Arab community will be reluctant to send their adult child to a permanent residential facility outside their community due to cultural reasons. Supported by data regarding retirement homes for the elderly (Azaiza, Lowenstein & Brodsky, 1999; Portugaly, 2006; Dwolatzky et al., 2017), Shai asserted, like other interviewees, the reluctant to find a permanent residential placement is rooted in communal believe of in-home caring.

Coupling these two arguments together it is clear that in current socioeconomic and cultural context most of Arab autistics adults do not benefit from the main solution promoted for adults by Alut. In this reality while it could be argued the family of the autistic individual may “benefit” from the stipend while have to “manage” the autistic needs by themselves, for Arab autistic adults the void in community services could mean inadequate care and seclusion, that most definitely could harm them. It should be stressed that the difficulties in raising an autistic adult at home are great as appear from the interviews and were the driving force for establishing ‘houses for life’ (Mishori, 2014) so despite the eligible financial benefit, having no community services also probably negatively affect the surrounding family and the community. To conclude, the focus of Alut on ‘houses for life’ which lead to the neglect of community services, was not in the interest of Arab autistic adults and further deprived them from resources provided by the state. The underrepresentation of Arab autistics or their families within Alut’s management and board of directives clearly contributed to inequlities between Jewish and Arab autistics and widen gap between these social positions. These gaps, it should be noted, were already wide to begin with.

Overlooking community services promoted inequalities also in another mechanism. Because there was always a gap between the need for residential placements and the actual placements available, and because some parent preferred their children will be in a less protective environment in the community, the void in state provided community services created a fertile ground for private services to be established. These private enterprises which include diverse kinds of services from employment opportunities to social groups and leisure activities were established by parents or entrepreneurs. Unfortunately, entrepreneurship that is based on private resources and social capital is not equally disseminated. In great resemblance to the case of public education in Israel, the moment there is scarcity in public services parents from resourceful families who are disproportionally of Jewish ethnicity and live in the center of Israel establish alternatives for their children (See Dagan-Buzaglo, 2010 p.11 on the privatization of the education system in Israel). As a direct result community services for those who are from low socioeconomic status, who resides in the periphery and that are from the Arab community are less available.

A quick search on the Internet will reveal numerous of private initiatives that are essential for autistic adult who reside in the community (see for instance: One House, n.d.; Argaman Institute, n.d.). Yet, because these services are not publicly funded their costs are unregulated or refunded and can rise to great sums, that the autistic adult or his family need to pay. For example, the social group for autistic adults suggested by One House (One house, n.d.) which is located in the center of Israel can sums up to 7500NIS (2140$) for 19 sessions per individual. In addition to their cost, that clearly make them less accessible for autistics from low socioeconomic status, these private services are less accessible for autistics who resides in the periphery. Gila, for example, the mother of an autistic child and a therapist of autistic adults, mentioned in her interview when asked about services for adults at their afternoon spare time the inaccessibility of services for those who resides in the periphery:

What I can say about leisure, there are some non-governmental organizations… you go out from Gush Dan area [the center of Israel] and there is nothing. Little in Jerusalem but it is very very difficult [to find] (Gila, the mother of an autistic child and a professional working with autistic adults).

 The few community services that do exist for adults, Gila remarked, are provided by non-governmental organizations (that were established by parents or entrepreneurs) that are located mostly in Israel center or to a lesser extent in Jerusalem. Coupling Gila’s claim with the clear discrimination of autistic adults who reside in the periphery described last chapter, especially the difficulties in establishing social groups due to geographical and transportation restrains that Gefen mentioned, it is clear these private initiatives are not distributed equally in Israel. In regarding to Arab autistics, at the last chapter in Shai’s, a professional who works with the Arab autistic community, quote that exemplify the scarcity of services for Arab autistic adults he said: “There are a lot of parents initiatives, and a lot of organizations, businesses […] all in the Jewish secotr”, This quote points that some of the gap between the Jewish and Arab communities is a result of the private initiatives of parents from the Jewish sector. His claim, highlight that also in this case the problem of leaving the creation of service to the “invisible hand” of the market will dispropotionatly favor those from privilidged communities.

Calanit, a mother of an adult and an activist in the autism field sums this issue very accurately in a personal communication we had after the interview:

The bottom line, what assists us [my husband and I] to give our son what he needs [in the community]: our financial resource […] leaving in the center [of Israel…] Cultural capital […] our ability to acquire knowledge and specialty […] and by the organization [she involved in] (Calanit, personal communication, August 19, 2019).

Reflecting on her interview, Calanit summed that her socio-cultural-economic capital is what enabled her to provide her son the services he needed in the community. Depicting her privileges, she is precisely specifying the resources one should aspire to have if he wishes to manage the void in community services left by Alut historical consistency to focus on residential placements as the main solution for autistic adults in Israel.

Lastly, the third mechanism by which focusing mainly on advocacy for residential places marginalized autistics form underprivileged social positions is by leaving the public community services that were established such as employment centers (some run by Alut – Meital [מית"ל]) without enough resources. The suboptimal conditions of these services in tern divert those coming from resourceful families to better financed services or employment opportunities, and once more contributed to the gaps between autistic adults. Anat, for example, the mother of an autistic child a professional working with autistic children and an activist in the autism field mentioned in her interview:

The condition in which they [autistic adults] are in, the maintenance of the place, the unbearable ease they give them jobs… the fact that they are low functioning it doesn’t mean they can’t do more productive things […] it is also the issue of those [parents] with resources that will approach a factory owner they know and they will accept him [their autistic adult child] and forgive his mistakes, and he will come for four hours, just to find normal employment. (Anat, , the mother of an autistic child a professional working with autistic children and an activist)

Opening her quote on the current situation in the employment centers, Anat, described difficult circumstances in which autistics are doing unmeaningful unproductive works in miserable conditions. Although, of course, not reflecting the situation in every employment center her claim is supported by parents’ testimonies from other areas of Israel. Such statement, for instance, was made by Carmit, a mother of an autistic adult that said her son: “waste his life [in the employment center…] it doesn’t develop, and it doesn’t treat him. They [the employment center] regress them. They show them [on Television] Yuval Ha’Mebulbal [a kindergarten children show], to adult people, all of them above the age of 20” (Carmit, a mother of an autistic adult). Enforcing Anat’s claim, Carmit described the services given to her son as not only poor in content and insignificant, but as a deteriorating environment. Yet, Anat quote does not end there, she also asserted based on her own experience that those who can find and afford an alternative for their autistic adult children, those who are from privileged social groups, do so. She demonstrates her point, which was supported by other interviewees, by describing private employment opportunities in the free market that are found with the right personal connections. Alut’s effort to promote residential facilities, it can be concluded, were also on the expense on the few community services that had been developed. The quality of these services as a direct result is low and divert those from affluent backgrounds to private available solutions, leaving autistics from marginalized social groups in lower conditions and further marginalize them.

This section described the direct and indirect effects the main advocacy effort of Alut to promote residential places had on inequalities. The first subsection illustrates Alut in an attempt to create quality services for the children of those who were represented in the organization demanded high entry fees to their institutions and high monthly payment. This decision was made and upheld despite the criticism it got along the years for favoring those from privileged families. In addition, I demonstrated how Alut’s neglect of community services have widen the gaps between autistic adults in three manners. First, disregarding the Arab community preference to maintain the autistic adult child at home, widen the gaps between autistic Jews and Arabs. Moreover, Alut’s extensive work within the policy field to promote hostels did not stop parents from affluent families to develop services for their adult autistic children. Unfortunately, being private initiatives, their affordability, geographical distribution, and lingual accessibility favored those from privileged social groups; thus, in effect avoiding the promotion of community services that were needed and leaving it to the “free market” contributed to the creation of inequalities. Lastly, directing most efforts for the development of ‘houses for life’ caused a continues deprivation of the public community services that were established throughout the years. This deprivation in turn left autistic individuals from disadvantage communities with poor services while autistics from privileged families could find alternatives using their private capital.

In conclusion, Alut’s intensive advocacy efforts to promote permanent residential facilities for autistics on the expense of community service contributed directly and indirectly to inequlities between autistic adults from different socioeconomic status, geographical area, and ethnicity. Thus, the marginalization of autistics from discriminated social groups demonstrated last chapter can be partially attributed to Alut representatives’ actions. But these actions should also be interpreted as mechanism of power preservation. The representatives who their social identity intersect the marginalized social position of parent of an autistic child with privileged not to say elitist social positions, by claiming they are representatives of the entire autistic population could advocate for resources for their children while partially knowingly and partially indirectly preventing those resources from autistics from marginalized groups. If indeed the neglect of community services directed autistics and their families to Alut’s institutions and enhanced the demand for these services, as I argue above regarding Alut’s dual role as a supplier and advocacy organization, the unjust situation was further enhanced also by this mechanism. This is because the organization’s advocacy efforts contributed to the diversion of public resources to solutions who benefited first and foremost those from privileged background. Acting in this manner, de facto not only not redistributed public wealth but directed it to those from the autistic community who needed them the least.

## 7.4. Contextualizing the representatives’ actions - should they be blamed?

Up until now the analysis focused on the role of the privileged representative parents led Alut from its establishment onward in creating inequlities between autistic adults. Although the analysis defiantly critic their actions which some of them as the chapter illustrate were done despite knowing its negative consequences on some of the very same autistics and parents they claimed to represent, it is not my intention to point an accusing finger toward them. On the contrary, as this section illustrate the context in which these parents had to operate in, was that of total neglect of their children needs coupled with institutionalized blame inflicted on them for their children condition. Thus, I argue they should definitely be acknowledged for their contribution to the autism community and the sacrifices they made to get to a point when the current discussion on inequalities between autistic adults had been made possible. I further argue the establishment, or more accurately the health and social services systems, who created this context and choose to overlook the creation of inequalities supported by Alut should be hold accountable, and more importantly be aware of its pitfalls in the future. Furthermore, I claim in the second sub-section following the footsteps of Rimon-Zarfaty and colleagues (2020), that despite that the founder culture have dominated Alut, environmental and internal changes have pushed the organization to acknowledge inequlities between autistics and actively address them.

The accepted narrative in the Israeli autism field that was nurtured by Alut, is that its founders acted to establish Alut and promote policies in the absence of any other alternative. This narrative which is comprehensively presented at Mishori’s book as a struggle against “the alienating institutions” (2014, p.183; see more at pages: 165-170), not only represents the genuine parents’ voices and perceptions, but it corresponds with the circumstances that those parents faced from the mid 70’s in Israel and worldwide.

In the 70’s the diagnosis of autism was hardly known worldwide and in Israel (Feinstein, 2010). Those who were familiar with autism mostly attributed it to parents’ emotionless care of their children (Waltz, 2013; Eyal, 2010). Professor Zimerman the head of the Tel Ha’shomer daycare facility for autistic kids since 1975, who recently passed away, was interviewed to the autism Israeli history project, and recalled:

The psychoanalytic it wasn’t just Kanner […] he was followed by a whole school of thought a psychoanalytic thought that blame the mother, and generations of psychoanalytically trained psychologists mainly […] just continued with it and they continued with it here [in Israel] and it is still going on it hasn’t stopped […] but then it was the leading paradigm (Zimerman, autism oral history project).

Professor Zimerman, confirmed that in Israel, like in many countries around the globe mainly north Atlantic countries, the theory that parents were to blame for their autistic children difference was well-accepted. In north Atlantic countries these circumstances evoked parents to create alternatives for their children and establish self-help or advocacy organizations (Eyal, 2010; Waltz, 2013). In Israel it appears the situation was no different. Zimerman mentioned:

What happened in Israel that the leadership for… or the motivation to do something for autistic kids came from the parents not from the professionals […] but that was very important because the parents knew intuitively that they weren’t to blame. (Professor Zimerman, autism history project).

In addition, to confirming that in Israel like in north Atlantic countries the incentive to promote services for autistic children came from parents who knew they should not be blamed for their children difference, Professor Zimerman note that professionals were not active in promoting services. In this void, the parents’ quest to promote solutions for their children have begun in the call for establishing a facility in Tel Aviv Area. From 1968 parents of autistic children who organized under Nitzan organization for children with learning disabilities (Nitzan Association, n.d.) have applied to Knessent members and the Health Minister Mr. Y. Barzilai for finding a solution for their autistic children who did not have any suitable educational facility (Derrin, 1968). The parents after continues efforts which involved securing the placement and the funds (The parents committee, 1969; Shiba, 1969) achieved a first triumph for their children as the ministry of health established the first daycare facility for autistic children at Tel Hashomer hospital, the daycare later Prof. Zimerman have directed.

Mishori complement this history and explain how given the only option for autistic children who got too old to be educated in Tel Ha’shomer daycare was to be hospitalized in psychiatric wards, parents decided to establish the first school for autistic children Yahdaiv (Mishori, 2014, p.189). The model, however, the parents adopted for operating Yahdaiv school was different than the daycare in Tel Hashomer hospital. Instead of state-run facility with an active parents committee, a parents-run facility partially financed by the education ministry under the umbrella of Alut who was established in 1974. Later following the murder of Ofer Avigdori by his grandfather in 1980 (Mishori, 2014 p.193-194; Tzvi, 1980), the leadership of Alut invested their efforts in promoting long term housing solution for autistic individuals. Mishori recalled in her book:

The special education law that gave us sponsorship [to operate the school] was over [at the age of 21] and we found ourselves once again in the hands of the psychiatric-medical system [… we] the parents who believed in the right of our children to life at the community and not in psychiatric hospital […]. Our goal was to give them a “house for life” with a different perception than the one the institution had. (Mishori, 2014, p.196)

Mishori expresses in those words a sincere intention to provide better lives for the autistic children who became adults in comparison to the one they would have otherwise. Creating for them houses within the community area with a holistic perception that will help them to fulfill their life, instead of hospitalization in psychiatric wards for years. Her words, which were also heard in different parliament hearings by Mrs. Leah Rabin (see above, The Autistics in Israel, 1997) and Dr. Gilboa , the head of psychology department at MoH (Suspicion for abuse at "Kfar Shimon" an institution for autistics, 1999), clearly indicate the incentive of those parents was to improve their children life. From this perspective the fact that Alut’s leading group had connections to Israel social and financial elite was not a problem, but an advantage that allowed them securing the needed funds and open the doors to the political system.

Coupling this historical context together with the government inclination to cut social services and to privatize services since the mid 80’s onward (Mendelkarn, 2012; Svirsky & Hason, 2008, pp. 5-8), although the previous sections place the responsibility on Alut in contributing to the creation of inequalities between autistic adults, it should be noted that this responsibility lay first and foremost on the establishment. The circumstances that led the parents throughout their struggles cannot be debated and indicating otherwise will be false. Therefore, the health and social systems which failed to recognize the need for respectable continues care for autistic adults outside psychiatric wards, and then when the need emerged by parents instead of formalizing public care decided to leave a void within it parents had to act, are the one that should be accounted. Furthermore, these ministries failed to recognize the policies promoted by Alut were benefiting first and foremost Alut representatives’ children leaving autistics from marginalized groups with no care, or suboptimal care. When they did recognize it, they fail to equal the standards for all autistics, and allowed the creation of two public provided services one for the rich one for the poor. These ministries, as Inbal quoted above noted, are still failing to do so even today.

### 7.4.1. Opposite trends: narrowing the gaps

It is essential to highlight before concluding the chapter that despite the harsh criticism this part of the dissertation inflicts on Alut some of Alut’s actions in recent years were directed to reduce inequalities between autistics. Following Rimon-Zarfaty and colleagues (2020) who identified Alut still preserve the founder culture to this day, but have introduced changes given environmental shifts, I argue the efforts invested to reduce inequlities are a result of contextual changes Alut’s past actions have caused. These changes, I further claim, were brought to Alut’s table following internal organizational alternations in the form of establishing a legal department.

An example for Alut’s efforts in the policy arena to reduce inequalities between autistic adults can be found in Bat-El’s, an advocacy lawyer who works with the autism community, interview:

Alut raised it [the issue of inequlities], they [discuss] all the time disparities in the geographical periphery and the cultural periphery. The Arab population, the Ultra-orthodox population, this is a subject that they are dealing with a lot (Bat-el, an advocacy lawyer who works with the autism community)

Bat-El described an active involvement of Alut in reducing inequalities between autistics from diverse communities and backgrounds. She depicted the organization involvement in narrowing disparities on different social axes including cultural, geographical and specific disadvantage communities. Bat-El’s claim is supported by many examples. Among them the hearing of the Labor, Social Affairs and Health committee of Kneset regarding a program to deal with autism in the Arab sector (Data and overview of the autism phenomenon in the Arab sector, 2018), which was initiated by Alut and was directed entirely to discuss and begin promoting solutions for Arab autistics. Considering Alut’s political efforts, it is not surprising the special project to screen and diagnose autistic children from the Bedouin community in the Negev was promoted by Alut (The need to establish infrastructure to treat autistic children from the Bedouin sector, 2008), and that it was Alut’s initiative to discuss disparities in treatment services and diagnosis in The Negev Convention for Child Safety in 2019 (Negev Convention for Child Safety, 2019).

This shift in perspective regarding inequlities within Alut, I argue, was a result of internal organizational structure changes introduced in the turn to the 21st century. Noa a mother of an autistic adult and an activist in the autism field who was involved in promoting policies for autistic children reflected on her past experience with Alut and recalled:

So I came with it [the policy] to Alut when it was already cooked, they answered ‘no’, [then] they answered ‘yes’, so I came with it well cooked and then Alut decided to invest themselves in it, and I drove them crazy […] Today not, then it was like that. Then they didn’t have a legal department so… and they didn’t regard [outsiders’ notions] […] they were more focused on residential placements. (Noa, a mother and an activist).

Noa described the efforts she needed to invest in persuading Alut to promote the policy she saw as crucial at the late 90’s. She had to serve them the policy “cooked”, and “drive them crazy” so they endorse it and promote it at the policy arena. The process she portrayed is somewhat different then the linear process earlier described by Bat-El (see section 2) that goes from the parents to the legal department of Alut. Noa explained this difference in Alut’s orientation and organizational structure, which included the establishment of the rights promotion flank at Alut. Forming this flank at the first decade of the 21st century created an opportunity to promote policies that come from “the ground”. This change enabled to hear voices of parents who were not part of the management, thus, democratizing the organization; and more importantly in relation to this chapter it enabled Alut to assemble cases of parents form marginalized groups who did not get the rights they are entitled by the law. In Bat-El’s words: “If you don’t know from the ground that the law does not work as it should, or that the policy of the Ministry of Social Affairs, Ministry of Health, and the Ministry of Education is not applied as it should, you will have no idea that you need to work there on something” (Bat-El, an advocacy lawyer who works with the autism community). Thus, the internal organizational change in the form of opening a legal department brought to the corridors of Alut the voices of those who were not benefiting from Alut’s past efforts, the laws Alut had promoted regarding autistic children, and put inequlities on the organization agenda.

At the same time Alut invested in reducing inequlities the “autistic (hostels) law”, as I demonstrate above, promoted by the organization counter these efforts. I embrace here Rimon-Zarfaty and colleagues (2020) argument that it was the founder culture, the elite representatives influence in the context of this chapter, that is still prominent within Alut, that counter these efforts to reduce inequlities. This dual position of the organization is an articulation, in the case of inequlities, of the interplay between past structure and present context, that Rimon-Zarfaty and colleagues (2020) have identified and discussed accurately. But the link between past structure and present context is not just articulating in the present conflicts, but in the interplay between social actors’ actions and the structures they create in an historical perspective. In the case of Alut, it was the actors from “past organizational structure” that promoted policies for autistic children. These polices then had changed the social structure, the context, the very same actors now had to operate in. While the actors remain the same, or more accurately the organization did not change and kept adopting the founders’ culture which disregarded inequalities, the new context they themselves created or more accurately the consequences of this new social structure mandated them to react to these inequlities. This circularity that led to the current efforts of Alut to reduce inequalities, further emphasis the organizational entity was and is aspires to promote the well-being of all autistics, despite past advocacy efforts who contributed to inequlities. At the very least it could be argued that if Alut had situates itself in this position and claim this is its goal, the historical trajectory will bring it there.

Alut’s representative role in contributing to inequlities cannot be understood regardless to the context parents had operated in. Considering this sociopolitical context, it was not them who are to blame but the health and social systems who failed to recognize the needs of autistic adults and failed to promote equal distribution of quality services despite Alut representatives’ position. The recent efforts of Alut to narrow inequalities should also be taken in consideration when discussing the criticism of this chapter to its representatives. These efforts, I argue, have been made despite the dominancy of Alut founder culture in the organization, and are a result of internal organizational changes that allowed the voices of those who did not benefit from Alut’s past legal actions to be heard.

## 7.5. Conclusions

Edna Mishori one of Alut’s founder who wrote a book regarding the experiences of parents to autistic in Isreal, asks in the introduction to the chapter about the social struggle for services for autistics “was it the parents’ personal characteristics that grouped together to form a unified alliance with an ability to influence?” (2014, p.183) I argue in this chapter that it was not the personal characteristic of this parents but the organization representative’s intersected social position and claims for representation that allowed them to influence on policies regarding autistics adults; yet, at the same time it was this social position and the inaccurate claims that also contributed to inequalities between autistics adults.

The first section analyses the position of Alut’s leading representatives. It begins with situating these representatives on internal autistic, disability related and organizational axes that are usually explored in the autism literature. I demonstrate like Raz and colleagues (2018) and Rimon-Zarfaty and colleagues (2020) before me that these representatives despite claiming to represent the entire spectrum are representing parents of “low-functioning” autistics, that support solutions in line with the MMD and have chosen to both advocate and provide services. Then applying the analytical framework of intersectionality, I demonstrate those are not “just” parents of autistic adults, but that their identity crisscross with privileged social positions. These are Jewish parents from the center of Israel, that are from (a very) high socioeconomic status, and that they possess abundance of social capital. Therefore, despite their claim for representation of the entire spectrum they represented a small, elite social group.

However, as being privileged is not a synonym for being oppressive or necessary means disregarding the needs of those from disadvantage groups, I next examine the consequences of this representation on inequlities between autistic adults. At the second section of the chapter, I demonstrate Alut dominancy in the autism policy field. Building on the archives findings and my qualitative analysis I argue that although its position has changed from an integral body in the policy construction process to an external entity that is authorization is essential for promoting policies, it kept an influential role in this field due to its representational claims.

After establishing that Alut had a fundamental role in constructing policies, I explore these policies influence on the marginalized social groups that were not represented in the organization leading bodies and were found to be marginalized in the previous chapter. I demonstrate the main policy regarding autistic adults Alut had promoted, “houses for life” as an inclusive permanent solution, discriminated directly and indirectly Autistics from low socioeconomic status, Autistics who reside in the periphery, and Arab autistics. I argue it was the representative multifaceted social position, that on one hand allowed them to claim representation of the entire autistic population and on the other hand promoted solutions that served the social elite and further marginalized autistics from oppressed communities. From an intersectional perspective I argue that this case demonstrates a mechanism of power preservation by the privileged social groups, who position themselves as representatives of the marginalized group that they are part of and claim resources first and foremost for their own benefit.

Lastly, I asked to complicate my argument by contextualizing these actors, Alut’s representatives, actions. I demonstrate that like in north Atlantic countries the parents who established and that led Alut for years needed to deal with healthcare and social systems that not only saw them as the cause for their children disability but that totally neglected their needs. I argue that in this context the accusing finger should not be directed to parents but to the establishment. The authorities not only neglected the needs of autistics but also allowed the creation of two public funded system one for the rich and the other for the poor, while disregarding the implications of not suggesting alternative solutions in the community. I finish by demonstrating that in recent years Alut have actively requested to address inequlities between autistics. I claim it is the establishment of the organization legal department that allowed hearing the voices “from the ground” in conjoined with environmental shifts that occurred by Alut’s past actions that enabled the internal organization agenda shift. Continuing Rimon-Zarfaty and colleagues (2020) argument I claim it is the coexistence of the founder culture together with the reaction to environmental changes that enable this dual position on inequlities at the same time.

Understanding the causes for health inequalities as the abundant literature on SDH demonstrate is complex. In this chapter using the case study of autistics adults in Israel, I tried to understand one of a mechanism that contributed to inequlities in the distribution of the SDH between autistic adults. This unequal distribution in turn result in health inequlities. Put in the words of Sir Marmort (2010), I tried to explain the cause of “cause of causes”. While the reasons for inequlities between different health related social positions cannot be summarized to one factor, this chapter demonstrated that those who are perceived as an actor that reduce inequlities, health social movements (HSM; Brown & Zavestoski, 2004) can contribute to the creation of inequlities. By demonstrating the intersected social position of the representatives that claim to represent the entire population, the chapter illustrated their actions intentionally and unintentionally serve first and foremost their interest, even on the expense of discriminating marginalized community they supposed to represent. As the blame for this cause for inequality, as I claim, should not be put on the organizations themselves who struggle to promote services in conditions of total neglect, but on the government, this chapter has important implication not only on our understanding of HSM, but on health policy construction process. These implications will be further discussed.

1. The English title of the organization does not include the word national, yet in the Hebrew title this word does appear. [↑](#footnote-ref-1)
2. These examples are just the tip of the iceberg. Multiple additional examples on Alut’s relation with the highest Israeli elite can be found whether by searching the genealogy of management and the members board of directors or by following the personal connections of those individuals. Most notable are the former chairpersons Sharir Izhak who is at boards of several leading financial institution including Leumi Bank (Voilder Livnat, 2017), and Amos Shapira who served as the CEO of El-Al airlines, and the president of Haifa University (Amos Shapira, n.d.). [↑](#footnote-ref-2)
3. Beit She’an is a city in the northern geographical periphery of Israel. [↑](#footnote-ref-3)
4. Qiryat Shemona is a city located in the far north of Israel. [↑](#footnote-ref-4)
5. This practice reminds the Histadrut working union recruitment policy that was enhanced by providing health services only to paying members of the organization (Shvartz, 2003). The Histadrut same as Alut wanted to enhance the political power of the organization using this method. [↑](#footnote-ref-5)
6. An example among many for this belief can be found in a quote by Tommy Lapid, a television presenter and a Knesset member who replied to mother from the periphery who complained about high fees for school “Mam, in the money you invested in your haircut you could educate your kid for a year” (Yosef Lapid, n.d.) [↑](#footnote-ref-6)
7. Yair Lapid is a Knesset member, the head of Yesh Atid party, the former minister of finance, currently the minister of foreign affairs and the alternate prime minister, and a father of an autistic woman. [↑](#footnote-ref-7)