# 7. Preserving privileges: The role of autistic organizations in creating inequalities among autistic adults

Departing from the previous chapter’s conclusion that current discourses regarding the reasons for inequalities among autistic adults are limited at best, this chapter analyzes the role of Alut*,* the largest and oldest advocacy organization for autistic people in Israel, in shaping the autism policy field and argues that the main policy regarding autistic adults it has promoted has contributed to the creation of inequalities among autistic adults. This contribution to inequalities, I argue, is the result of the predominant representation of parents of autistic children who come from privileged groups on Alut’s board and in the organization’s management, who advocated for policies that benefited their own children above all, disregarding autistic adults from marginalized groups. Alut’s founders are parents of autistic individuals. They are Jewish, Ashkenazi, educated, reside in the geographic center of Israel, enjoy abundant social capital, and have a high socioeconomic status. These factors enabled them to gain recognition as the representative organization for autism while also giving them the power to dictate the public tone of the organization and advocate for policies that contributed to inequalities.

This chapter breaks down this argument into three parts. The first section, adopting the analytical framework of intersectionality, analyzes the intersected identities of Alut’s founders. Although this analysis requires the examination of the founders’ multidimensional social positions on the various axes specifically relevant to the Israeli context, like most scholarly discussions of autistic organizations, the starting point is an exploration of the axes related to commonly discussed dimensions in the autism field, such as the position on the “low or high functioning” axis, and organizations *for* or *of* autistic people. I then focus on the axes that were identified as marginalized autistic social positions in the previous chapter, specifically, socioeconomic status, geographic location, and ethnicity. Following this analysis, I argue that the social position of Alut’s founders’ was a marginalized one on the ability-disability axis, as parents of autistic adults, but was otherwise a very privileged one on other axes relevant to Israeli society. As the analysis utilizes the analytical framework of intersectionality, it further allows me to draw conclusions about the social mechanisms that contribute to the preservation of discriminative social power of those with privileged social positions.

However, to illustrate the processes by which the discriminated social structures that contribute to inequalities among autistic adults are preserved, it is not sufficient to simply illustrate the intersected identity of social actors. The influence of their agency must also be explored. To do so, the second section examines Alut’s role in formulating policy affecting autistic adults in Israel. It argues that, like other autism advocacy organizations around the world, Alut has had considerable influence on policies and regulations since the 1980s. Despite its dominance in the field having been challenged over the years, and its position having changed from one of integral actor to external organization, it remains highly influential to this day.

The third section responds to the question of whether Alut’s policies were established 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 efforts for autistic adults – the promotion of residential institutions also known as hostels or “houses for life” as the sole solution for autistic adults. I show how relying on private capital to create high-quality living standards for a small fraction of autistic adults left the majority with no residential opportunities or suboptimal living standards. To examine the indirect effect of this policy, I illustrate how the neglect of community services, that Rimon-Zarfaty et al. (2020) also identified, disproportionately harmed autistic adults from disadvantaged communities. This neglect left community services to the “invisible hand” of private initiatives that created services that rely on self-advocacy and private wealth and that, unfortunately, favor those from privileged groups. Linking this phenomenon with 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, Alut promoted policies that contributed to the creation of inequalities among autistic adults in favor of those privileged social groups that were represented in Alut. Undoubtedly, the identity of these internal elements in the organization influenced the emphasis they gave to certain policy measures. I further assert that their actions served to preserve the power and the resources in the hands of the privileged, instead of redistributing them to the broader autistic population they claim to represent.

The last section of the chapter aims to mitigate what may appear to be an overly harsh judgment of Alut’s founder parents by contextualizing their actions. The section illustrates that these actors, mostly women, were operating in a system characterized by mother-blaming and the complete neglect of services for autistic people and their families. I argue that in this discriminative sociopolitical context, their efforts to achieve better conditions for their children should not be criticized. Rather, the guilty party is the government that altogether failed to identify the needs of autistic adults. The later discriminatory consequences of the polices promoted by Alut are ultimately the result of this governmental oversight rather than ill intent on the part of the parents. In conjunction with this line of argument, I illustrate that, despite the fact that Alut still promotes its discriminatory policy, the organization has indeed taken actions to narrow disparities among autistic people and to promote public services that benefit the entire community. I claim that contextual changes in the field of autism, some of which were the result of Alut’s policy actions, and internal organizational changes in the form of the establishment of 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 to the analysis, it is important to clarify that, ideally, all the organizations involved in the autism policy field, not just Alut, should be subject to such scrutiny. My focus on Alut should not be taken to imply that other organizations working in the field are without flaws or should not be examined. On the contrary, I would argue that intersectional analysis should be an integral part of our understanding of all social health movements (SHM). However, because of Alut’s historical prominence and enduring position in the field of autism policy, their archival history provides a source of rich data that can be analyzed to develop a picture of the historical development of autism policy in Israel. 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. As a consequence, their documentation is minimal compared to that accumulated over the years by and concerning Alut. To be noted also is that because the first section examines identity, and some identifiers could be linked directly to a specific interviewee and expose their identity, not all the quotes below are accompanied by interview identification.

## 7.1. Who is in who is out? Representation in the autism organizations

This section examines Alut’s leading parents’ social position to set the basis for the chapter’s main argument that it was the privileged multidimensional social position of Alut’s founders and representatives that influenced their decision to advocate for policies and practices that resulted in discrimination against marginalized sections of the autistic community. Although the analysis aims to focus on social axes that are unrelated to the fields of autism or disability organizations specifically, these axes cannot be disregarded, as they considerably shaped Alut’s advocacy efforts. Thus, in line with the work of Raz et al. (2018) and Rimon-Zarfaty et al. (2020), I clarify Alut’s organizational position using data I have gathered. Next, after strengthening these authors’ claims, I analyze the leading parents’ social position on other social axes. The analysis demonstrates that, in terms of the social dimensions that were demonstrated to be marginalized in the last chapter (including socioeconomic status, place of residency, and ethnicity), Alut’s leading parents were decidedly on the privileged side. Some could even be considered part of Israel’s elite. In light of this analysis, I argue that, although Alut is called The Israeli (national) Society for Autistic Children and Adults,[[1]](#footnote-1) thus implicitly claiming to represent all autistic people, in practice, as the literature demonstrates, it represented only the supporters of the medical model of disability (MMD) with a focus on “low functioning” autistic people and those from privileged social groups.

### 7.1.1. Alut – who do they represent and what are their aims?

As the literature review illustrates, most scholarship 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* vs. *of* autistic people axis; the medical model of disability vs. the social model of disability (SMD) axis, which relates to disability organizations more broadly (Hutchison et al., 2007); and the role of the organization as an advocacy organization or as a service provider,which relates more broadly to the non-profit organization literature (Onyx et al., 2008). These classifications are important for clarifying whom the autism organizations represent and what their agendas are. As was briefly presented in the literature review, consistent with Raz et al. (2018) and Rimon-Zarfaty et al. (2020), who analyzed Alut’s position on these axes, my qualitative analysis demonstrated that, despite claiming to represent the entire autistic population in Israel, in practice, Alut, is an organization *for* autistic people that provides services relevant mostly to “low-functioning” autistic people from an MMD approach and advocates only for limited section of the community.

To highlight the profound discrepancy between Alut’s representation claims and their actual 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 that, until recently, officials conceived of Alut as the sole representative of all autistic people. For example, in a letter written by Gabi Barbash, the MoH Director General in 1996 on allowing Alut to operate a hostel in a new facility he writes: “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-1990s, Alut was virtually the only organization operating in the autism policy field, the organization’s leading status was maintained for decades, even after other organizations became active in the field. In a 2015 legislative discussion dealing with the Rehabilitation, Advancement, and Inclusion of People with Autism in the Community Bill, which was drafted by Alut without input from other organizations, the Knesset representative who promoted the law, Orly Levi-Abekasis, stated: “the original law proposal was in fact written with the autistic people and got the consent of most autistic people or parents of autistic people” (Early Hearing 3, bill proposal, Rehabilitation, Advancement, and Inclusion of People with Autism in the Community, 2015). Assuming the accuracy of her remarks, Levi-Abekasis’s opinion reflects the widespread assumption among policy makers and the public that Alut is *the* representative of all autistic people in Israel.

However, this assumption could not be further from the truth. In his interview, Ronen Gil, an autistic individual and autism advocate, who has also been involved in the autism policy field in recent years, describes the importance of distinguishing between an organization *of* and an organization *for* autistic people, a dilemma he recognizes in Alut:

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

Ronen highlights the importance of distinguishing between the interests of the autistic person and the interests of the parent. Alut cannot represent the interest of autistic people, he argues, as no autistic people serve on its board. Recent changes in the organization’s charter confirmed that no autistic people could serve on 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 another person that serves as a guardian” (Alut, 2020). Ronen’s argument that Alut is an organization *for* and not *of* autistic people corresponds with observations of Raz et al. (2018). Therefore, while Alut is conceived as a body representing *all* autistic people, in practice, it represents only the *parents of autistic people* and not the individuals themselves.

Moreover the recent amendment to Alut’s charter, as Rimon-Zarfaty et al. (2020) point out, not only excludes autistic people themselves, but also those families that have opted not to appoint a guardian for their adult autistic children. Given that guardians are usually not appointed in cases where autistic people can be more self-reliant, or what is usually conceived in the autism field as “high functioning,” this clause also limits the organization to representing the needs of “low functioning” adults. Gefen, a mother of an autistic adult and an autism activist reflected on this issue in her interview:

On the one hand, Alut is saying one in a hundred people are autistic and points to the growing numbers, on the other hand, those Alut really wants to serve [low functioning individuals] are becoming a minority that is shrinking more and more. But half the administrative board is made up of people representing only 400 individuals, and it still wants to call itself a national organization (Gefen, a mother of an autistic adult and an activist).

Gefen claimed that the increasing numbers of autistic people from across the spectrum is useful for Alut, and that the organization can point to this cohort when trying to raise more resources. However, Alut’s board of representatives does not reflect the entire spectrum, but only a small fraction of it. Fifty percent of Alut’s board represent approximately 400 autistic people, according to Gefen. These 400 autistic people constitute approximately 6% of the 7000 autistic adults that are recognized by MOLSA. Even if Gefen’s estimates are not accurate and the percentage is higher, the representation on the Alut board, which claims to be the national organization representing the entire spectrum, still does not reflect the makeup of the community. The bias is very much in the favor of “low-functioning” individuals, leaving “high-functioning autistic people with no representation. It should be stressed that, while the axis of organizations *of* and *for* and the axis of “low- or high-functioning” are interconnected and overlap, they are not identical. This is both because the axis of organizations *of* and *for* is also relevant to non-autism organizations, such as those for Alzheimer’s Disease (Schicktanz, Rimon-Zarfaty, Raz, & Jongsma, 2018), and because “high-functioning” autistic people 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 in relation to Alut by Raz et al. (2018) and Rimon-Zarfaty et al. (2020), is the organization’s endorsement of the medical model of disability. Noa, a mother of an autistic adult and an autism activist, explained this in her interview:

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 take their children straight to hostels [when the education system finishes at age of 18 or 21], because there are no services in the community (Noa, a mother and an activist).

Noa, who was involved with Alut in the past, began by asserting that Alut is invested in segregated residential facilities. Although they are often referred to as “houses for life” and they are arguably integrated with the community due to their locations, these facilities are surrounded by fences and the autistic people who reside there are required to respect the institution’s schedules and cannot leave. It is beyond the scope of this study to enter into a discussion of whether this residential model is the best way of accommodating “low-functioning” autistic people or not. Suffice it to say that these institutions are an integral part of the MMD portfolio of solutions for people with disabilities and that Alut’s adoption of this residential solution clearly positions it as subscribing to the medical model of disability, as was also noted by Raz et al. (2018). The rest of Noa’s quote reaffirms previous interviewees’ suggestions that, while claiming to represent the entire autism community, Alut disregards those within the autism community who prefer inclusive solutions corresponding to the SMD. Thus, it can be concluded that Alut represents parents of autistic people, rather than autistic people; that it represents mostly parents of “low-functioning” autistic people; that it and parents who subscribe to the MMD.

Noa’s argument raises the question of why Alut claims to be representative of all autistic people when, in practice, it favors a small fraction of the community? Was this really intentional on the part of Alut, as Ronen argued, or Gefen implies? To answer these questions, it is first essential to locate Alut on the organizational axis of *supplier of services* vs. *advocacy organization*. The classic example of the distinction between these two types of organization in the autism field is the difference between the *National Autism Society* (NAS), based in the United Kingdom, which provides services, and the *National Society for Autistic Children* (NSAC), based in the United States, which is focused entirely on advocacy (Eyal, 2010). From its earliest stages, Alut opted for the NAS model and provided services while still advocating for autistic people. This approach, as many interviewees pointed out, and as Rimon-Zarfaty et al. (2020) argue, can serve as a source of conflict in many cases and, as Noa’s argument seems to imply, may be at the root of the discrepancies in representation within Alut. According to Noa, Alut’s endorsement of one solution occurred at the expense of others. By claiming to represent the entire population, and advocating for their proposed solutions, Alut created a situation in which the only services available for autistic people are the ones they provide. Even if parents were interested in alternatives, the neglect of advocacy for these alternatives, as Noa asserts, drove parents of autistic people to Alut’s services. According to this position, Alut’s claim to be representative, despite only representing a small fraction of autistic people, was a calculated element of their advocacy efforts, made in the interests of expanding their services. In a demand-driven system, as the previous chapter illustrated, advocating for the services you are providing in the name of the entire population results in more investments in your services. Unfortunately, by taking this position, Alut also minimized recognition of the needs of all those they do not represent.

To conclude, as Raz et al. (2018) and Rimon-Zarfaty et al. (2020) have also demonstrated, while claiming to be the representative of the entire population, Alut actually represents only a small fraction of parents of autistic adults who are interested in seclusion-based solutions for “low-functional” autistic people. This discrepancy in representation has its roots in the materialist explanation I propose, where the services provided by Alut in turn stimulate demand for their services. A complementary explanation was provided by Rimon-Zarfaty et al. (2020) who claim that it was the founder culture that dictated Alut’s preferences at the expense of newer perspectives on autism. I return to these two arguments later as I illustrate how these mechanisms also contributed to the creation of inequalities among autistic adults from different social groups.

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

In this subsection I analyze Alut’s representational claims from an intersectional perspective. While the previous section, and most of the scientific literature, challenges Alut’s claim from the perspective of the autistic community, the following analysis challenges this claim based on other social dimensions. I illustrate that Alut’s founders and representatives are connected to privileged groups and argue that, while claiming to be representative of the entire autistic population, in practice, they represent only the interests 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 discussed in the previous chapter, I argue that these multifaceted marginalized social positions should be an integral part of our understanding of inequalities and discrimination also in the case of autism and, more broadly, in SDH. Nevertheless, we should recall, 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 the subject of investigation. This investigation, however, should be aimed at trying to understand the power structures that enable privileged groups to preserve their power in society, not merely to shed light on the experiences of privileged social groups. The following section, unlike the previous chapter that focused on different groups of autistic people, explores the intersected identities of the founders and representatives of Alut. Their identity combines the marginalized social position of parents of autistic people with, as I intend to demonstrate, privileged social positions.

As already noted, Alut was founded by parents of autistic children from privileged social groups, and this has shaped the character of the organization from the outset. The distinguished lineage of those who established Alut reaches much further even than Israel’s elite of the 1970s. As Batia, a professional working with autistic adults, explained to me in a personal communication after her interview: “the people who established Kfar Ofarim [Ofarim Village, the first residential establishment 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 (Ofarim Village)’ founders mentioned in a video Alut released for its 40th anniversary (Rosenman, 2014) reveals that, indeed, some of those parents belong to the top echelons of Israeli society. These include figures such as the following:

* Ami Hirschstein, **CEO of Dan Hotels**; Alut founder (Hirschstein, 2013);
* Shoshana Bayer, **the head of Israel’s Association of Secondary School Teachers (1982–1991)** (Ichnoled, 2009);
* Leah and Meir Hovav, PhD in Hebrew Literature (1982) and a writer, respectively; Alut founder (Leah Hovav, n.d.);
* Liora Avigdory, **the granddaughter of the founder of Sonol Energy**, Alut founder (Haviv-Grin, n.d. a);
* Yossi Langotsky, a **geologist who discovered gas off the shores of Israel**, Kfar Ofarim founder (Yossi Langotsky, n.d.);
* Irit and Orni Isakson, **the former chairperson of the First International Bank of Israel (Ha’Bein-Leumi Bank) and Isracard group, and Honorable Consul for Norway**, respectively; Kfar Ofarim founder (Irit Isakson, n.d.).

In addition to the privileged personal biographies of Alut and Kfar Ofarim’s founders, from a close observation of the written testimonies available on Alut’s founding group from Feinstein’s (2010) and Mishori’s (2014) books, it is clear that these parents enjoyed an abundance of social capital. Feinstein (2010, p. 248), who, in his history of autism, dedicates a 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 board of directors.” Identifying the importance of social capital in establishing Alut, Feinstein demonstrates 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 services for their autistic children reveals the same picture. Rivka, for example, who was interviewed for the book, describes the parents who founded Alut, “There was a group of very nice and *educated people*” (Rivka, an interviewee, p.184; emphasis mine). This can be compared to 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. This report indicates that 74% of children were of Ashkenazi descent and 32% of parents had some form of higher education (Malory, 1977). The percentage of educated people among Alut’s founders was much higher than in the general population (approximately 9% according to calculations from the Central Bureau of Statistics [Sicron, 1977]), illustrating that these parents were from Israel’s higher social classes.

Given this illustrious list of elite individuals, and the ties with the then Prime Minister’s wife, Leah Rabin, it is not surprising the first public commission of Alut, established in 1975 included members of the highest financial elite in Israel (Figure 7.1), among them the managing directors of the three largest banks in Israel. These connections have persisted through the years and remain significant today. For example, the CEO of Alut in the early 90s, 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). Haya Granot, a public council representative in 2020 at the residential and employment division of Alut, is the wife of David Granot (Granot, 2008), who was, in 2020, the interim chairperson of Bezeq (the largest communications company in Israel) and on the board of 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)

Text

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Figure 7.1

(Asir, 1976)

Continuing with the reasoning of the previous subsection, if a social group is not represented on the board of an organization that claims to represent the *entire* population, it means that their interests are unlikely to be heard and promoted. For example, there are no autistic people represented on the board of Alut; consequently, the autistic voice is not being heard or promoted. Equivalently, having representatives from just the privileged and well-connected elite of Israeli society arguably means the interests of those from marginalized groups are not being voiced or promoted. But is this really the case? Could someone in a privileged social position, who shares an intersected discriminated social position (parent of autistic person) with those who are from marginalized groups, promote policies that would be to the benefit of everyone? Even more importantly, are these the only parents that are being represented in Alut and setting the organizations agenda?

Unfortunately, official documentation concerning individuals from marginalized groups who have taken an active part in the organization is scarce; therefore, their position on the subject cannot be clearly ascertained. Nevertheless, a newspaper article from February 1995 entitled “Alut against Everyone” (Bar-Moha, 1995), sheds light on the representation of autistic people from the social margins within the organization. In this article, a representative of the parents at the Rimon school for autistic children, located near Beit She’an,[[3]](#footnote-3) tells the reporter how Leah Rabin, the chairperson of Alut board of directors chairperson, twice refused an invitation to visit the school to learn about their children’s needs, even after the parents at the school raised funds for Alut. Furthermore, Shoshana Baier, who was one of the Alut’s founders, engaged in a struggle with Alut to open an additional residential facility in Jerusalem, is quoted saying: “they were taking care of their own children and cronies [*mekoravim*] … for appearance’s sake, they accepted two or three autistic people from lower classes without demanding fees but 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 say the least. The first example demonstrates that the management did not make any effort to reach out to the geographical periphery and to take their needs into account, while the second example, although it should be taken in context, implies that Alut made an active effort to prevent parents from lower socioeconomic status from joining as active participants in the organization and even from using their facilities.

My qualitative analysis demonstrates that the unequal representation of those from marginalized groups continues to this day. Anat, the mother of an autistic child, a professional working with autistic adults, and an autism activist, who was involved with Alut, describes how she perceived her role within Alut in the following extract from her interview:

I represent the higher functioning individuals, and, I will tell you another thing, I think that I represent, sorry for the expression, the less elite people […], what about all the parents of autistic children that cannot afford behavioral analysis therapists at five thousand shekels [about $1450 USD] a month (Anat, a mother of an autistic child, a professional working with autistic adults and an activist).

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

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 autism activist, who was involved with Alut in the past. When discussing the issue of inequalities, she says:

And all the time I said: “Alut is a national organization, a national organization represents all the autistic people.” But then in one struggle and then in another struggle, which I was sure that Alut would support and would do this or that, and every time I discovered again, that no. Alut has a group of parents of autistic people […] **very, very powerful,** the profile of which is parents of very low functioning residents of 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).

During the time Kira was involved with Alut, she discovered that only a specific agenda was being promoted by the organization. According to her, not all struggles were supported by the organization as the result of two, separate, but linked, factors. She first mentions that the leading group of parents was concerned with “low-functioning” autistic people and supportive of segregation in line with the MMD, and in accordance with the position of Alut on the axes described above. She added that this group of parents was very powerful in terms of their social and financial capital. They had high socioeconomic status and were well connected to the social elite. Kira’s description of the leading parents who set the organization’s agenda mirrors Alut founders’ elite social position. Kira’s explanation ends with the consequences of this exclusive representation, claiming that it does not represent the periphery where she resides. I return to the consequences of these realities later, but it is clear from her description that the parents who led Alut, with their links to the Israeli elite, promoted struggles that supported their children’s interest.

Later in the interview, Kira points out that the leading parents were geographically center-oriented to such an extent that they were self-congratulatory for having “brought the [organization’s] ballot boxes to Be’er Sheva, Haifa, and Jerusalem.” If the implication is that “Jerusalem, the capital of Israel, is periphery, and if Haifa is periphery…,” she asks, “…what about Qiryat Shemona?”[[4]](#footnote-4) (Kira, a mother of an autistic adult and an activist). Linking Alut’s leading representatives’ relation to the center of Israel with the organizational voting procedure illustrates that Alut’s representatives did not regard equal participation in the organizational leadership as essential. Despite being considered a national organization that claimed to represent all autistic individuals in Israel, in practice, those who resided in Israel’s real periphery could not have been elected 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 not represented within Alut leadership is the Arab minority. A cursory look at current and past representatives within the management and the public committee reveals that no representatives from the Arab community have ever been involved with Alut. Shai, a professional working with the Arab autistic community describes the limited participation of parents from the Arab community in his interview:

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 in the Jewish sector that have strong personalities, socioeconomic conditions, and that 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, professional 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 – for example, participation in meetings that take place in the center of Israel – is mediated by personal availability, it could be argued that unless the barrier of availability is actively addressed, participation in the organizations will remain unequal. Yet, the most relevant point Shai raised in this quote is related to activist parents from the Jewish sector. He portrayed the parents, much like the above descriptions of other interviewees, as enjoying a high socioeconomic status and being well connected to political and public figures. The parent-activist described by scholars (Eyal, 2010; Waltz, 2013,) in the Israeli context is 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 who are also “impoverished” and could not participate in the leadership; yet it is clear to him that the advocates are Jewish only.

In summation, while the previous subsection demonstrated that, despite Alut’s claim to represent all autistic people in Israel, and despite its widespread public perception as doing so, in practice, it represents only a small subsection of parents of autistic adults who support MMD solutions for “low-functioning” autistic people. This subsection described these parent representatives through the lens of intersectionality and argued that they are not just parents or “parent-activists,” as referred to in the literature, but they are Jewish parents of high socioeconomic status who reside in the center of Israel and are well connected socially, founded Alut, and are still very influential within it. The claim that Alut represents the entire autistic population is misleading, given the low representation among their leadership of those from the periphery, low socioeconomic classes, or the Arab community. Recognizing the multifaceted social identity of these leading parents is crucial, I argue, in order to comprehensively understand their actions and, more importantly, the consequences of these actions which following sections explore.

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

Despite that fact that most Alut representatives are parents from very privileged groups, a social actor’s multifaceted identity does not necessarily dictate that they will act in the interests of their identity. As critics argue, the argument that identity necessarily dictates political action is one of the most significant shortcomings of identity politics (Alcoff & Mohanty, 2006). The following sections, therefore, 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 a disregard of or active discrimination against autistic people from marginalized groups. From an intersectional perspective, the next sections examine whether these representatives, whose identities combine marginalization with privileged social positions, have preserved a concentration of Alut’s resources in the hands of the privileged or have acted to redistribute power and resources in their favor using their power and influence. To start answering this question, this section examines Alut’s role in shaping policies regarding autistic adults and argues that it was central in creating and shaping these policies.

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

There are numerous examples, both in the historical documents and the interviews, that illustrate Alut’s influence on policy. As early as 1986, Edna Mishori, the then director of Yahdaiv school and a member of the management of Alut, participated in an expert committee appointed by then-Health Minister Motta Gur to draft “the principles and policies for the treatment of autistic children, adolescents and adults.” At the beginning of this report, the committee highlighted that “there are no satisfactory solutions for the age group of autistic adolescents and adults” (Hateb et al., 1986). Alut’s influence is noted throughout this report, especially regarding autistic adults. Concerning recommendations for autistic adults, the report reads: “Alut is taking it 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 “the Alut organization, the Ministry of Education, the MoH, the Ministry of Labor and Social Services, and the NII that will accompany the project,” thus highlighting the influence of Alut as a leading body for developing policy for autistic people. Following this report, there is documentation of meetings between the head of the psychiatric services Dr. De Shalit and Alut’s management committee, and direct correspondence between the Health Ministers (Motta Gur and Shoshana Arbeli Almozlino) and Leah Rabin (Gur, 1986; Rabin, 1986).

It should be noted that the Ministry of Health had been aware of the absence of proper services for adults since the beginning of 1980, yet did nothing. A report by Rahav and others submitted after the 1980 murder by his grandfather of Ofer Avigdori, an autistic child, son of Liora Avigdori, one of Alut’s founders, also stated: “still today there are no boarding school facilities suitable for autistic people” (Rahav et al., 1981 in Mishori, 2014, p.197). The repeated conclusions that there were no services for adults emphasize the inertia in policy regarding autistic adults at the beginning of the 1980s, when Alut was still focusing exclusively on younger ages. More importantly, it further emphasizes the essential role played by Alut in developing this policy.

The extensive involvement of Alut continued throughout the 1980s and the 1990s, with their activities regarding autistic adults primarily revolving around providing housing services, with much less emphasis on advocacy, according to the numerous documented examples. As a supplier of services, Alut was actively approached by the MoH to develop additional residential facilities for autistic adults. For example, in 1989, the head of the psychology division, Dr. Gilboa, promoted the “triangular project” to establish additional residential placements for autistic individuals in Jerusalem. She actively approached Alut as a supplier and the Elwin organization, which operated a hostel for people with cognitive disabilities in the same area, and asked if they would be willing to promote this project, but it was never carried out (Gilboa,1989; see also later correspondence on that matter with Deputy Minister of Health Minister Nawaf Massalha, 1993). The most notable example indicating Alut’s position as a de facto formal and integral part of state institutions that provide for autistic individuals is found in a report entitled “Planning Services for Autistic People for the Year 2000” (Cohen & Levinson, 1993). In this report, written by an inter-ministerial committee, one of the goals of which was to map the services for autistic people, there is a table captioned “Distribution of reported autistic people according to responsible ministry and district”, Alut appears as though it were a ministry along with the MoH, MOLSA and the Ministry of Education (Figure 7.2).

Table

Description automatically generated

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

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

A later example can be found in 1996. After a meeting of Alut parent representatives with Leah Rabin, the health minister, Tzachi Hanegbi, and the finance minister, Dan Meridor on “the autistic problem,” it was decided that Alut representative Emanuel Dotan would convene with the head of the health unit in the budget department at the Ministry of Finance and decide on the finer details of the program (Mohaliver, 1997). This deep and integral involvement in decision-making is yet another example of Alut’s influence on policy.

The qualitative analysis consolidated the reputation 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:

At the macro-level Alut has issues, a variety of issues […] that they act to promote policy change […] they work with the Knesset a lot, all the time in hearings at the Knesset, going to hearings, responding, initiating hearings. 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 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 operations in the policy arena, Bat-El depicted in her interview what is also reflected in the archival documents: Alut is greatly involved in the process of policy creation regarding autistic people. She portrayed Alut’s involvement in both the Knesset and the ministries and depicted numerous examples where parents were actively involved in creating and advocating for certain policies. Bat-El’s example summarizes the process of policy creation that has been applied in recent years. It depicts how priorities that are set by parents in the organization are promoted by lawyers and the advocacy department of the organization to such an extent that they are the ones who draft the bills. When the time is “right” and the topic is “sexy” the ministries adopt it and push it forward. Parallel to policy promotion, Alut, as a service provider, has the ability to develop operative models for the services that will be needed according to the new bill. The circularity of this process, that starts with policy and ends with providing the service, can also work the other way around when policy is promoted to secure the provision of services. This reinforces the problem of having a dual role as a provider of services and an advocacy organization. Bat-El’s example demonstrates that Alut’s involvement in policy has changed along the years. While in the 1980s and 1990s, Alut was an integral part of policy decision-making, in recent years, Alut has been considered an external actor that can suggest policies but does not sit at the decision-making table.

The dominance of Alut’s agenda in the autism policy field has also shifted in recent years. Given that the main organization in the field did not represent the agenda of all autistic people and their parents and, in certain cases, as I will show later, was promoting policies that conflicted with new actors’ agendas, these actors had to act on their own and become involved in the policy field. As Rimon-Zarfaty et al. (2020) have pointed out, some of the parents who promoted policies independently, or as part of the 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 field:

We [a group of parents] actually sat and drafted the bill, and then some lawyer gave us a format of what a bill should look like. He explained that there are definitions, goals and this and that. And we worked [on it] and wrote it and sent it to a lot of people to get their feedback […] We sat 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 drafting of a new bill regarding autistic people – a policy creation process in which even parents who were not part of the Alut organization, not only acted as advocates, but led the process throughout its different phases. Although later in the interview she expresses her astonishment at the important role she played in writing the bill, saying “like who are we? Where did we find the chutzpah?,” her actions were not new to the field of autism policy. The continued involvement of Alut, which began in the 1970s, created the conditions in which parents could be the ones who created policies. Therefore, she, and other parents who were not connected with Alut’s involvement in the autism policy field, further highlight the influential position Alut had, and continues to have, in this field.

The involvement of parents like Gefen, who were not members of Alut, in policy creation clearly introduced new voices to the autism policy arena; nevertheless, Alut’s influential position within the field was 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, 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 to encounter strong 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 illustrated by an analysis of Alut’s financial reports. A detailed observation of Alut’s annual financial report reveals an immense financial enterprise. This enterprise includes, in addition to substantial annual payments from the MoH and MOLSA for operating their facilities, respectable sums in donations, a large investment portfolio, which is unusual for a non-profit organization, and several types of assets that total NIS 180,088,626 ($48,023,633 USD) (See Table 7.1 Alut’s Budget; UHY Shtainmetz Aminoach & Co., 2019). Yet, the most striking information is not Alut’s financial data in absolute terms, which is equivalent to that of a major company, but the organization’s capital in comparison to other service providers. Among the organizations that provide services for individuals with disabilities, Alut was ranked first in the financial benefits it received from the state. In addition, while the median annual economic cycle of the 122 organizations that submitted their financial reports was NIS 1,120,312 ($298,749 USD), Alut’s annual economic cycle was NIS 252,088,316 ($67,223,550 USD) (The Budget Fundamentals, n.d.). This data illustrates Alut’s enormous 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 | 19,538,120 |
| Annual payments from MOLSA | 116,819,329 | 31,151,821 |
| Donations | 29,197,119 | 7,785,898 |
| Investment portfolio   * Governmental bonds * Stocks market | 40,824,670; 2,076,113 | 10,886,578  553,630 |
| Assets Total   * Permanent assets * Temporal assets * Other assets | 180,088,626  121,198,399  27,474,624; 31,415,647 | 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 = NIS 3.75

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 enabled Alut to attain such influence is that they claim to represent the entire community. Although, as I showed above, this representation is biased toward certain populations, Alut used this argument in the public policy arena and was perceived in this manner. For example, in the article mentioned above entitled “Alut Against Everyone,” the head of funding at the Ministry of Education, Avner Kligman, in response to a question concerning the reasons for Alut receiving more funding than other organizations, answers: “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 children” (Bar-Moha, 1995, p.15). Adopting the self-representation narrative, Kligman, illustrates in his answer the importance of the representation narrative in gaining legitimacy and funding from official bodies. A remarkable example of how Alut representatives utilize this narrative is found in the 2012 Israel State Comptroller report. In response to a question sent by the comptroller regarding anomalies in the salaries paid by the organization, including wages for therapists that 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 regarding additional fees and salaries for their workers. *MOLSA or any other formal body does not have a mandate to tell the parents to take risks in treating their children*” (State Comptroller Annual Report, 2012, p.932; author’s emphasis ). Alut’s answer to the State Comptroller exemplifies the significance of this narrative. To Alut’s representatives, this argument is so powerful that it allows them to exercise dominance over the decision-making of the public formal bodies that fund the services and create the policies. Given that the issue of representation is crucial for the legitimacy of the organization and its influential position within the policy arena, the question inevitably arises as to whether this level of representation benefits the represented parents and their autistic children more than it does others.

To conclude, Alut has had extensive involvement in the autism policy field. Its influence began in the 1980s and has continued to the present day. Although, over the years, Alut’s role has changed from being an integral part of the decision-making process and virtually being considered another branch of the executive authorities, to an advocacy organization that proposes, drafts, and promotes policies in the interests of those it represents, it maintains its dominance in this field. This can be understood both in terms of Alut’s integral role in promoting policies (even if proposed by external bodies), and from the financial supremacy it has acquired over the years in absolute and relative terms compared to other service providers that are supported by the government. Moreover, Alut consolidated the ability of those involved in the autism field to assume an influential role in shaping the policies concerning this population. It was Alut’s representational claims that gave them the ability to be so influential in the policy field, despite the fact that these claims do not reflect the reality of 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 whose social position intersects with privileged groups.

## 7.3. Unequal representation as a cause of inequalities

Having established that Alut represented only a small, privileged section of the autistic community, and having shown its influential role in promoting policies concerning autistic adults, this section examines the consequences of these policies on different social groups. As the main policy concerning autistic adults Alut promoted over the years was the establishment and management by the organization of segregated residential facilities known as “houses for life,” I now examine the direct and indirect consequences of this advocacy effort. Following a detailed analysis of this policy, I argue that it directly discriminated against those of lower economic status. Requiring entry fees before institutionalization and additional monthly fees made these services beyond the reach of those of low socioeconomic status, thereby excluding them, or, more accurately, favoring those from affluent backgrounds. The indirect result of this advocacy effort, I argue, also further marginalized those from discriminated social groups in three ways. First by assuming that autistic people from all social groups want or need the same services, Arab autistic people and their parents, who prefer community service, were discriminated against. Second, the reluctance to actively address the issue of community services also caused the emergence of private, independent initiatives that were not equally accessible, economically, geographically or linguistically, thus, contributing to the exclusion of certain segments of society. Lastly, the neglect of community services in favor of the residential solution resulted in a deterioration of the quality of available services in the community, driving those who had adequate resources to avail themselves of private alternatives. This section, then, discusses the reasons for the emergence of inequalities among autistic adults, and argues that Alut, the “national” autism organization, contributed to these inequalities while using the power of its privileged representative group to secure resources for *their* autistic children at the expense of those from marginalized communities.

### 7.3.1. Houses for life – demanding quality, discriminating against the marginalized

From the very beginning, with Alut’s advocacy for “houses for life,” first at Kfar Ofarim, it was clear that parents would have to pay an entry fee for the residential facility, as well as monthly operating fees. These entry and monthly fees were paid in addition to the sums invested by the state to establish these residential facilities and the monthly allowance from the state for each resident. This essentially amounted to the family of the autistic person having to pay from their private capital to receive services that were funded by the government. Around the time of the establishment of Kfar Ofarim in 1989, the MoH was in constant communication with then Alut’s treasurer, Ami Hirschstein, one of Alut founders and the CEO of Dan’s Hotels, concerning the entry criteria and monthly stipend. A letter sent from the office of the Minister entitled “Autistic people in Israel” illustrates Alut’s intransigent policy concerning fees. The letter reads:

The enrollment fee for the village is 20,000 dollars. It was agreed that families that cannot afford this amount could enroll their autistic child in the institute. […] The Ministry demanded that the acceptance criteria would be based on the registration order. […] The Ministry recommended that families would participate according to their income, Alut insistently refused, and demanded that participation would 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 autistic people from lower socioeconomic status are revealed. First is the high entry fees and monthly payments, which by the standards of 1989 were very expensive, especially when considering that these were supposed to be public institutions. This can be ascertained, for instance, from parents’ testimonies, such as the one posted by Gila Bai on Alut’s website: “In preparation for Amir’s [her son] entry into Kfar Ofarim [in 1989] I started working to overcome the high expenses of Amir’s maintenance at the village (which required much more than one salary)” (Bai, n.d.). In her testimony, Gila reveals the financial hardships imposed by maintaining an autistic adult at Ofarim Village. Another example is found in a letter sent to the Minster of Immigrant Absorption, Yair Tzaban, from a social worker concerning an autistic adult who immigrated to Israel. In her letter she specifies that he is “an autistic individual who was accepted at Kfar Ofarim […] but, although he got accepted, he cannot not take his place until he pays a deposit fee in the sum of NIS 64,000 to Alut.” The social worker continues the letter by explaining the difficult circumstances of the family and their inability to pay. In this case, with the help of donations that were collected with the help of the Aliyah (Immigration) and Integration Ministry and the Zionist Forum, this autistic adult was able to enroll in the institute (Liran, 1993).

What is more striking in the health minister letter is Alut’s consistent refusal to allow differential participation for less financially able parents. Coupling this statement with Shoshana Baier’s assertion, mentioned above, about Alut’s favoring of autistic people of higher socioeconomic status (Bar-Moha, 1995), and hearings at the Knesset that show that 90% of autistic people had to pay fees (Suspicion about Abuse at Kfar Shimon, an Institution for Autistic People, 1999), it is impossible to claim that the high stipend was not a form of discrimination against autistic people of lower socioeconomic status.

The correspondence between the MoH, Alut and Elwin on the “triangular project” reveals additional acceptance criteria applied by Alut for enrollment in their houses for life. In their proposition for screening practices for the new village, they add additional acceptance criteria which include:

1. Alut membership – 3 years;
2. Additional scoring for seniority;
3. Entry fee for the village – $15,000 USD;
4. Monthly stipend of NIS 300

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

These proposed criteria reveal not only the financial requirement, but the requirement of Alut membership. In response to this suggestion, Dr. Avi Ramot, Elwin’s CEO, replied that “These requirements are not professional requirements but political ones” (Ramot, 1987). Despite being a legitimate requirement, as Dr. Ramot also mentioned in his letter, these requirements left parents with no option other than to join Alut. Thus, the suggested requirements favored those from affluent backgrounds at two levels. Not unlike the previous case, by demanding participation fees, those from low socioeconomic backgrounds were discriminated against. By demanding Alut membership and favoring seniority, the organization further enhanced its political influence in the autism field while not providing equal participation for discriminated groups,[[5]](#footnote-5) as well as gaining additional resources from annual membership fees. While these fees might seem minimal, they could be another burden on poorer families.

Over the years, the potential disparities between autistic people from different socioeconomic backgrounds were challenged by some Knesset members and the relevant ministries, although this practice was originally approved by the executive authorities. One example can be found in a hearing of the Labor and Social Affairs Committee of the Knesset. During this discussion, several Knesset members challenged the MoH concerning the enrollment fee requirement given that it could amount to up to $35,000. Knesset member Ilan Gilon, quoted in the previous chapter with regard to the marginalization of autistic people of low socioeconomic status, responded to the MoH representative who described the enrollment demands in the following terms:

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 get an answer to very urgent questions on the issue of fees…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 the Eitanim Psychiatric 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 of abuse at Kfar Shimon, an institution for autistic people, 1999). This discussion brought to the attention of the Knesset not only the injustice of this practice, which was originally introduced by Alut, but also the dire consequences it had on autistic people of lower socioeconomic status who found themselves hospitalized for life. While Alut intensively advocated and fundraised for hostels for those with financial resources claiming they were representing the whole autistic community, those who could not afford these hostels found themselves in the public system, which had no proper solutions and considerably fewer 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 enrollment fees:

Regarding the issue of the initial sum that parents invest, I think that is is a natural for any parent to help their child. […]. We are an organization of very involved parents, parents that care and for whom it is important how our children will live. Look for example at Kfar Ofarim, and see how every child lives in a separate room, a 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 was “scary to get in to.” We value quality highly; this is why, at the beginning of our journey, when nothing was available, the initial sum [parents needed to pay] was crucial. I hope a day will come when we can adapt the institutions according to our standards and beliefs, using only govermental assistance (The Autistic People in Israel, 1997).

In her appeal to the committee, Leah Rabin confirmed what was later claimed by others and which is discussed in Mishori’s book (Mishori, 2014), that no resources for autistic adults were available, forcing parents to pay in order to establish residences. According to this narrative, if parents did not pay, autistic adults would still be institutionalized in mental health facilities for their entire lives. However, from this statement, it is clear that the reason for enrollment fees was not just to establish residences, which received support from the government, but to make sure they were of high quality. While demanding high quality services for people with disabilities is praiseworthy, doing so at the expense of less well-off individuals could be subject to criticism. 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 thus creating two separate standards within the public system. Inbal, a professional consultant to autistic adults, and previous 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 per room, this model has to be terminated. 40 year old [autistic] individuals, should not be [living] with another person in the room unless they wish to […] I think that the Ministry of Social Affairs should change the policy, the guidelines […] one bathroom for five, four or even for three people… [is not enough]. (Inbal, a professional consulting to autistic adults, and previously the manager of a residential facility for autistic adults)

While in Alut facilities, the standard is one person per room, as it should be, as Inbal testified, residences operated by other organizations do not meet this standard. Thus, the minimum quality standard remains reserved for those who have affluent parents, while those who cannot afford the entry fees, but are also supposed to be represented by Alut (given that it claims to be a national organization), live in places where it is “scary to get in to,” as Leah Rabin described.

Lastly, in Leah Rabin’s appeal to the committee, there is an implication that parents who cannot afford the entry fees 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 children and stressing, in her words, that the parents in the organization are parents who “care how their children live,” reveals a belief that parents who do not act in this manner are thoughtless or uncaring. Unfortunately, her words echo a hegemonic belief regarding under-resourced marginalized groups as neglecting their children and wasting their limited capital instead of investing in things that really matter.[[6]](#footnote-6) Her implication is also reminiscent of the common practice, mentioned in the last chapter in the analysis of the reasons of inequalities, of transferring the responsibility away from the privileged to those who are discriminated against and indirectly indicting their “culture.”

The criticisms of the entry policy and the monthly fees being received in Knesset only in 2007, after an internal committee of MOLSA was convened to examine this issue, the director general of MOLSA adopted a recommendation that parents should not be required to pay monthly fees for their children who reside in public residential facilities. In 2011, the State Comptroller discovered that the largest body running hostels for autistic adults, Alut, was still charging parents mandatory monthly fees of NIS1200 (approximately $350; State Comptroller Annual Report, 2012, pp. 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 resident by MOSLA. Alut, which has ceaselessly claimed over the years to be the representative of the entire autistic community, knowingly continued to employ this discriminative policy, even when it was forbidden by formal regulations. While the situation today is different, and monthly fees are not mandatory, entry fees, although not demanded, can secure a place in a quality residential facility, as some interviewees testified.

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

I needed to put in tons of effort so my brother [with lower cognitive abilities] could be accepted to the place where he [currently] resides. And a family that doesn’t have enough energy, time, or resources, to take on someone [a social worker] privately, as far as I know, needs to wait for many years. I mean, it is a miracle he got accepted […] if it were not for this [institution], he would be hospitalized […] You need to be healthy in this country: either healthy or have a lot of money (Hila, a sister of two autistic adults).

Describing the process of searching for a residential place for her younger brother, Hila mentioned that she hired a private social worker to help her identify a a suitable place for her brother where he would be accepted. 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 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 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 would 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 autistic people from less affluent backgrounds. Reserving a place in a hostel requires the payment of the monthly disability stipend to the hostel, despite the child not being fully enrolled in the institution, just to remain on the waiting list. While perhaps not intentional, creating two housing systems with different living standards within the public system has created practices that discriminate against those who are less well-off.

In summary, this section analyzed the details of the houses for life policy promoted by Alut over the years. I claim that the intention of Alut’s leading parents to provide quality of life for their children using private money within the public system created inequalities between autistic adults from different socioeconomic backgrounds. While claiming to represent all autistic individuals and fundraising on their behalf, Alut, in effect, promoted the interests of certain sections of the autistic community – those from affluent families. Alut’s involvement in policy, therefore, not only directly resulted in discrimination against autistic individuals from lower socioeconomic status, but also diverted resources that could have been used for this population into the hands of individuals from better resourced families. Finally, the creation of a high-quality option within the public system, over the years, resulted in discriminative mechanisms that, again, benefit those with more capital.

### 7.3.2. Neglecting community services – indirect marginalization caused by Alut’s policy

In this section I describe the indirect consequences of Alut’s policy efforts to promote houses for life and argue they resulted in inequalities between autistic adults. I begin this section by illustrating that the advocacy efforts for this solution were at the expense of promoting alternatives in the community. I then show how this neglect caused inequalities on three levels. 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 rendered public services inaccessible to them, thus diverting public funds away from them and creating inequalities. Second, the focus on houses for life left a void of services in the community. In this void, private initiatives developed but, as those who developed these initiatives were from high-resource backgrounds, their distribution across Israel, and their reliance on private capital discriminated against 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, thus directing better resourced families to private “quality” solutions and widening the gaps among members of the autistic community.

First and foremost, it should be stressed that the priority given to promoting residential facilities over the years came at the expense of community services. 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, which is mentioned above, to Alut’s suggested entry criteria. He wrote: “The decision that the village will be a ‘permanent house’ is not right to my mind. It should be considered, despite the possibility seeming very far-fetched, that the residents could be integrated in less protective settlements” (Ramot, 1987). Responding to Alut’s suggestion that the village would be a permanent place for life, Dr. Ramot highlights Alut’s perspective on houses for life as the sole option for autistic individuals. It is implied that devoting the advocacy efforts to one defined solution that includes most of the services in-house makes investment in other, less segregated, solutions redundant.

While in 1987 it could be claimed that no other solutions were even conceived of in Israel, despite the deinstitutionalization movement which called for less segregated services having 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 indicate that, on Alut’s lists of priorities, houses for life were valued far above community services. Kira, the mother of an adult 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 autistic rights, their disability stipend […] we sat down and analyzed the bill and came to the conclusion that it is a horrible bill. It calls itself the autistic law, but it is going to work against autistic people. It is the hostels bill, it is a law the fruits of which only a small fraction will enjoy and all the others will suffer, and it will cause damage (Kira, the mother of an autistic adult and an activist).

After closely analyzing the law together with other parents, Kira came to the conclusion that this bill, which was proposed by Yair Lapid and supported by Alut, was directed at enriching the hostel system. Describing the bill and its possible effects in harsh terms, Kira explained that it would direct resources away from the community into houses for life, which serve only a small fraction of the community. As mentioned above, Alut gave up on this bill in favor of the one drafted by Gefen and other parents, but their initial intent was to promote the houses for life, which they manage. From a historical perspective, Alut’s policy effort totally succeeded. The permanent, secluded, all-services-included residential places are the most common services for the autistic adult today, while community-based services are scarce.

It should be noted that the neglect of community services could be framed as promoting MMD solutions for “low-functioning” autistic adults at the expense of the SMD and “high-functioning” autistic people, 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 consolidate and expand their main operation, and were therefore invested in advocating for it (see section 1.1). Nevertheless, the question that should be asked in relation to this section, which focuses on inequalities, is not whether those who want community services are less content, or whether autistic people with higher cognitive abilities are discriminated against, or whether these efforts financially benefit the organization, but, rather, whether this practice created disparities among autistic individuals from different communities by further marginalizing those from oppressed groups.

The most notable example of a marginalized social group that was further discriminated against by the neglect of community services is the Arab autistic minority. Shai, a professional who works with the autistic Arab community, described the preference among Arab parents for community solutions as opposed to permanent residential arrangements:

They [the parents] tell me, regarding [their] adult children: “I prefer for him to 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 a stipend, on the other hand the expenses can be hundreds or thousands of shekels a month […] It is not common in the Arab community 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 large portion of 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 for parents’ reluctance to send their autistic children to live in permanent residential facilities: one instrumental and the other cultural. The instrumental-economic reason is that because the child can be maintained with the assistance of the extended family at home while receiving the state stipend, there is no reason to find another residential placement far from home. This argument was reiterated by other interviewees. For example, Dr. Efron, a psychiatrist, said that: “Economically [speaking], an autistic person gets a high stipend, [but] when they are institutionalized or at a hostel, the family don’t get [the money] so they leave them at home […] The sum is not enough in the Jewish community but definitely enough in the Arab community, so they keep them at home and deal with their aggression in their house” (Dr. Efron, a psychiatrist who works with autistic adults in the Jerusalem district). Reiterating Shai’s argument, Dr. Efron claimed that in the Jewish community, the economic incentive is less consequential, as the expenses are higher. In the Arab community, however, especially 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” at home, without formal assistance, but with the resources available in the Arab community, such as the extended family. The second argument Shai raised is that families from the Arab community are reluctant to send their adult children to permanent residential facilities outside their community for 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, that the reluctance to find permanent residential placements is rooted in a community preference for at-home care.

Coupling these two arguments, it is clear that, in the current socioeconomic and cultural context, most Arab autistic adults do not benefit from the main solution promoted by Alut. In this reality, while it could be argued that the families of autistic individuals may “benefit” from the stipend while having to “manage” the needs of autistic family members by themselves, for Arab autistic adults, the lack of community services could mean inadequate care and seclusion, which could definitely harm them. It should be stressed that the difficulties in caring for an autistic adult at home are enormous, as confirmed in the interviews, and this was the driving force for establishing “houses for life in the first place” (Mishori, 2014). Thus, even if a family is eligible for financial benefits, having no community services available also probably negatively affects both the family and the community. To conclude, the focus of Alut on houses for life, which led to the neglect of community services, was not in the interest of Arab autistic adults, and further deprived them of resources provided by the state. The underrepresentation of Arab autistic people, or their families, within Alut’s management and board of directors clearly contributed to inequalities between Jewish and Arab autistic people and widened the gap between these social positions. These gaps, it should be noted, were already wide to begin with.

Overlooking community services promoted inequalities by means of another mechanism, as well. Because there was always a gap between the demand for residential placements and the actual placements available, and because some parents preferred their children to be in a less protective environment and more integrated into the community, the void in state-provided community services created fertile conditions for the establishment of private services. These private initiatives, which include diverse services, from employment opportunities to social groups and leisure activities, were established by parents or entrepreneurs. Unfortunately, solutions and services based on private resources and social capital are not equally distributed. As in the case of public education in Israel, the moment there is scarcity in public services, parents from well-off 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 of low socioeconomic status, who reside in the periphery of the country and who are from the Arab community are less available.

Even a cursory internet search will reveal numerous private initiatives that are essential for autistic adult who reside in the community (see for example: One House, n.d.; Argaman Institute, n.d.). However, because these services are not publicly funded, their costs are unregulated and can reach very high sums that the autistic adult or the 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 cost up to NIS7500 ($2140) for 19 sessions per person. In addition to their cost, which clearly makes them less accessible to autistic people of low socioeconomic status, these private services are less accessible to autistic people who reside 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 afternoon services, the inaccessibility of services for those who reside in the periphery:

What I can say about leisure, there are some non-governmental organizations… if you leave the Gush Dan area [the center of Israel], there is nothing. There is a 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 autistic adults, Gila remarked, are provided by non-governmental organizations (that were established by parents or entrepreneurs) that are located mostly in Israel’s center or, to a lesser extent, in Jerusalem. Coupling Gila’s claim with the clear discrimination against autistic adults who reside in the periphery described in the last chapter, especially the difficulties in establishing social groups due to geographical and transportation restraints that Gefen mentioned, it is clear that these private initiatives are not distributed equally in Israel. Regarding Arab autistic people, Shai, a professional who works with the Arab autistic community, gives an example of the scarcity of services for Arab autistic adults: “There are a lot of parent initiatives, and a lot of organizations, businesses […] all in the Jewish sector.” This observation indicates that some of the gaps between the Jewish and Arab communities arise as a result of the private initiatives being those of parents in the Jewish community. His claim highlights that, in this case too, the problem of leaving the establishment of services to the “invisible hand” of the market will dispropotionatly favor those from privileged communities.

Calanit, a mother of an adult and an activist in the autism field, who has opted out of the residential solution, sums this issue up very accurately in a personal communication we had after the interview:

The bottom line is that what allows us to give our son what he needs are our financial resources […] living in the center, cultural capital […], our ability to acquire knowledge and specialized care […] and the organization (Calanit, personal communication, August 19, 2019).

Reflecting on her interview, Calanit summed up that her social, cultural and economic capital is what enables her to provide her son the services he needs in the community. Depicting her privileges, she is precisely specifying the resources one is required to have if they wish to manage the void in community services left by Alut’s historical focus on residential placements as the main solution for autistic adults in Israel.

Lastly, focusing mainly on advocacy for residential places has marginalized autistic people from underprivileged social positions 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 turn, diverts those coming from resourced families towards better financed services or employment opportunities, and, once more, contributes to the gaps between autistic adults. Anat, for example, the mother of an autistic child, a professional working with autistic children, and an autism activist in the mentioned in her interview:

The condition which they [autistic adults] are in, the maintenance of the place, the unbearable ease with which they give them jobs… the fact that they are low functioning doesn’t mean they can’t do more productive things […] it is also the issue of those [parents] with resources that can approach a factory owner they know and they will accept him [their autistic adult child] and go easy on him, and he will come in to work for just four hours a day, 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 the difficult circumstances in which autistic people perform meaningless, unproductive jobs 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. Carmit, a mother of an autistic adult, echoed Anat’s criticism, complaining that her son, “wastes his life [in the employment center…], it doesn’t develop him, and it doesn’t treat him. They [the employment center] causes them to regress. They show them [on television] *Yuval Ha’Mebulbal* [a show for kindergarten-aged children], to adult people, all of them above the age of 20” (Carmit, a mother of an autistic adult). Reinforcing Anat’s claim, Carmit described the services given to her son as not only poor in content and meaningless, but as a having deleterious cognitive effect. She also asserts, based on her own experience, that those who can find and afford an alternative for their autistic adult children, those 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 thanks to the right personal connections. Alut’s efforts to promote residential facilities, it can be concluded, also came at the expense of the few community services that have been developed. The quality of these services is, as a direct result, low and diverts those from affluent backgrounds to private solutions, leaving autistic people from marginalized social groups in poorer conditions, further marginalizing them.

In summary, this section described the direct and indirect effects of the main advocacy efforts of Alut to promote residential places on the development of inequalities. The first subsection illustrates that Alut, in an attempt to create quality services for the children of those who were represented in the organization, demanded high entry fees for their institutions and high monthly payments. This decision was taken and upheld despite the criticism it received over the years for favoring those from privileged families. In addition, I demonstrated how Alut’s neglect of community services has widened the gaps between autistic adults in three ways. First, disregarding the Arab community’s preference to keep autistic adult children at home widens the gaps between autistic Jews and Arabs. Second, Alut’s extensive work within the policy field to promote hostels did not represent the only effort of parents from affluent families to develop services for their adult autistic children. Unfortunately, being private initiatives, their affordability, geographical distribution, and linguistic accessibility favored those from privileged social groups. In effect, neglecting 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 toward the development of houses for life caused and continues to cause neglect of the public community services that were established over the years. This neglect, in turn, left autistic individuals from disadvantaged communities with poor services, while autistic people from privileged families could find alternatives using their private capital.

In conclusion, Alut’s intensive advocacy efforts to promote permanent residential facilities for autistic people at the expense of community service contributed directly and indirectly to inequalities among autistic adults from different socioeconomic levels, geographical areas, and ethnicities. Thus, the marginalization of autistic people from discriminated social groups, elucidated in the previous chapter, can partially be attributed to Alut’s actions. However, these actions should also be interpreted as mechanisms of power preservation. The representatives, whose marginalized social position of parents of an autistic child intersects with privileged social positions, by claiming that they are representatives of the entire autistic population, could advocate for resources for their children while partially knowingly, and partially, albeit inadvertently, preventing those resources from reaching autistic people from marginalized groups. If, indeed, the neglect of community services directed autistic people 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 exacerbated by this mechanism. This is because the organization’s advocacy efforts contributed to the diversion of public resources to solutions that benefited first and foremost those from privileged backgrounds. Acting in this manner, not only not redistributed public funds de facto but directed them away from members of the autistic community who needed them in the most.

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

Up to this point, the analysis has focused on the role of the privileged parents, who led Alut from its establishment, in creating inequalities between autistic adults. Although the analysis defiantly critiques their actions, some of which, as the chapter illustrates, were done in spite of the fact that the negative consequences of some of them on the very same autistic people and parents they claimed to represent were known, it is not my intention to judge their actions. On the contrary, as this section illustrates, the context in which these parents had to operate was that of total neglect of their children’s needs coupled with institutionalized blame inflicted on them for their children’s 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 where the current discussion on inequalities among autistic adults has been made possible. I further argue the establishment system, or, more precisely, the health and social services systems, that created this context and choose to overlook the creation of inequalities resulting from the policies supported by Alut should be held accountable, and more importantly, the authorities should be aware of its pitfalls in the future. Furthermore, I claim in the second subsection, in line with Rimon-Zarfaty et al. (2020), that despite the founder culture dominating Alut, contextual and internal changes have pushed the organization to acknowledge inequalities between autistic people 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 in Mishori’s book as a struggle against “the alienating institutions” (2014, p.183; see more at pp 165–170), not only represents the parents’ genuine voices and perceptions, but it also corresponds with the circumstances that those parents faced from the mid-1970s in Israel and worldwide.

In the 1970s, the diagnosis of autism was hardly known worldwide or in Israel (Feinstein, 2010). Those who were familiar with autism mostly attributed it to parents’ emotionless care of their children (Eyal, 2010; Waltz, 2013). Professor Zimmerman the head of the Tel HaShomer’s daycare facility for autistic children since 1975, who recently passed away, was interviewed as part of the autism Israeli history project, and recalled:

The psychoanalytic perspective wasn’t just Kanner’s […] he was followed by a whole school of psychoanalytic thought that blamed 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 (Zimmerman, autism oral history project).

Professor Zimmerman, 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’s differences was well-accepted. In North Atlantic countries, these circumstances drove 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. Zimmerman mentioned:

What happened in Israel was 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, as 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’s difference, Professor Zimmerman notes that professionals were not active in promoting services. In this context, the parents’ quest to promote solutions for their children began with the call to establish a facility in the Tel Aviv area. From 1968, parents of autistic children, who organized under the Nitzan organization for children with learning disabilities, (Nitzan Association, n.d.) applied to Knesset members and the Health Minister Y. Barzilai to find a solution for their autistic children for whom no suitable educational facility was available (Derrin, 1968). The parents, after continuous efforts, which involved securing the placement and the funds (The Parents Committee, 1969; Shiba, 1969), achieved their first victory for their children when the Ministry of Health established the first daycare facility for autistic children at Tel HaShomer hospital – the daycare later directed by Prof. Zimmerman.

Mishori explains how, in the face of the only option for autistic children too old to be educated at the Tel HaShomer daycare being hospitalization in psychiatric wards, parents decided to establish the first school for autistic children, Yahdaiv (Mishori, 2014, p.189). The model adopted by the parents for operating the Yahdaiv school was different from the daycare at the Tel HaShomer hospital. Instead of being a state-run facility with an active parents’ committee, it was a parent-run facility, established in 1974, and partially financed by the Ministry of Education under the umbrella of Alut. Later, following the murder of Ofer Avigdori by his grandfather in 1980 (Tzvi, 1980; Mishori, 2014, pp.193–194), the leadership of Alut invested their efforts in promoting long-term housing solutions for autistic individuals. Mishori recalls 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 live in 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)

In this passage, Mishori expresses a sincere intention to provide better lives for their autistic adult children compared to what they would have had otherwise: creating houses for them within the community with a holistic approach that would help them lead fulfilling lives rather than languishing in psychiatric wards for years. Her words, which were also heard in different Knesset hearings by Leah Rabin (see above, The Autistic People in Israel, 1997) and Dr. Gilboa, the head of Psychology Department at MoH (Suspicion for Abuse at Kfar Shimon, an Institution for Autistic People, 1999), clearly indicate that the incentive of those parents was to improve their children’s lives. From this perspective, the fact that Alut’s leadership had connections to Israel’s social and financial elite was the very advantage that enabled them to secure the funds required and open the doors of the political system.

Coupling this historical context with the government inclination to cut social services and to privatize services since the mid-1980s (Svirsky & Hason, 2008, pp. 5–8; Mendelkarn, 2012), shows that responsibility for the inequalities among autistic people and the resulting struggles lay first and foremost at the door of the state, this despite the previous sections showing the role of Alut in contributing to fostering inequalities as well. The circumstances that motivated the parents throughout their struggles must be acknowledged within this context of the state abdication of responsibility. The health and social systems failed to recognize the need for decent continuous care for autistic adults outside psychiatric wards and to formalize public care for them, and, therefore, when the need emerged, parents had no choice but to act privately. Furthermore, these ministries failed to recognize that the policies promoted by Alut were disproportionately benefiting the children of Alut representatives, leaving autistic people from marginalized groups with no care, or suboptimal care. When the authorities did recognize this phenomenon, they failed to equalize the standards for all autistic people, and allowed the creation of two public services: one for the rich and one for the poor. These ministries, as Inbal, noted above, are still failing even today.

### 7.4.1. Contrary trends – narrowing the gaps

Before concluding the chapter, it is essential to highlight that, despite the harsh criticism this part of the dissertation levels on Alut, some of Alut’s actions in recent years have been directed at reducing inequalities among autistic people. In line with Rimon-Zarfaty et al. (2020), who identified that Alut still preserves the founder culture to this day but has introduced changes given historical shifts, I argue that the efforts invested to reduce inequalities are a result of contextual changes which Alut’s past actions have caused. These changes, I further claim, were brought to Alut’s attention following internal organizational changes in the form of establishing a legal department.

An example of Alut’s efforts in the policy arena to reduce inequalities among autistic adults is cited by Bat-El, an advocacy lawyer who works with the autism community:

Alut raised it [the issue of inequalities], they [discuss] disparities in the geographical periphery and the cultural periphery all the time. 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 the active involvement of Alut in reducing inequalities between autistic people from diverse communities and backgrounds. She depicted the organization’s involvement in narrowing disparities on different social axes, including cultural, geographical, and specific disadvantaged communities. Bat-El’s claim is supported by numerous examples. Among them is the hearing of the Labor, Social Affairs and Health Committee of the Knesset regarding a program to deal with autism in the Arab community (Data and Overview of the Autism Phenomenon in the Arab Sector, 2018), which was initiated by Alut and was directed entirely at discussing and promoting solutions for Arab autistic people. Considering Alut’s political power and status, it is not surprising that 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 the as part of The Negev Convention for Child Safety in 2019.

This shift in perspective regarding inequalities within Alut, I argue, was a result of internal organizational structure changes introduced at the turn of the 21st century. Noa, a mother of an autistic adult and an autism activist 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 formed, they answered “no,” [then] they answered “yes,” so I came with it well-formed 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 1990s. She had to present them with a “well-formed” policy, and “drive them crazy” for them to endorse it and promote it in the policy arena. The process she portrayed is somewhat different from the linear process earlier described by Bat-El (see section 2) that moves 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 department at Alut. Forming this department in the first decade of the 21st century created an opportunity to promote policies that come from “the ground.” This change facilitated the airing of voices of parents who were not part of the management, thus democratizing the organization, and, more importantly in relation to this chapter, enabling Alut to assemble cases of parents from marginalized groups who were not accessing the rights they were entitled to 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 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 benefitting from Alut’s past efforts, the laws Alut had promoted regarding autistic children, and put inequalities on the organization agenda.

At the same time that Alut invested in reducing inequalities, the “autistic (hostels) law” promoted by the organization ran counter to these efforts, as I demonstrated above. Here I embrace Rimon-Zarfaty et al.’s (2020) argument that it was the founder culture, the elite representatives influence in the context of this chapter, and that is still prominent within Alut, that counters these efforts to reduce inequalities. This dual position of the organization is an articulation, in the case of inequalities, of the interplay between past structures and present context, that Rimon-Zarfaty et al. (2020) have identified and discussed cogently. But the link between past structures and present context does not just articulate itself in the present conflicts; it is also evidenced in the interplay between social actors’ actions and the structures they create from a historical perspective. In the case of Alut, it was the actors from “past organizational structures” who promoted policies for autistic children. These polices then changed the social structure, the context, in which the very same actors now had to operate. While the actors remained the same, or, more accurately, the organization did not change and kept adopting the founder culture that disregarded inequalities, the new context they themselves created or, more accurately, the consequences of this new social structure forced them to react to these inequalities. This circularity that led to the current efforts of Alut to reduce inequalities further emphasizes that the organizational entity aspired and continues to aspire to promote the well-being of all autistic people, despite past advocacy efforts which contributed to inequalities. At the very least, it could be argued that, if Alut had situated itself in this position and claimed this as its goal from its beginnings, the historical trajectory would have brought it there.

Alut’s representative role in contributing to inequalities cannot be understood without reference to the context in which parents were operating. Considering this sociopolitical context, it was not the parents who are to blame, but the health and social systems that failed to recognize the needs of autistic adults and failed to promote equal distribution of quality. The recent efforts of Alut to narrow inequalities should also be taken into consideration to mitigate the criticism of Alut. These efforts, I argue, were made despite the dominance of Alut’s founder culture 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 founders, who wrote a book regarding the experiences of parents of autistic people in Israel, asks in the introduction to her chapter about the social struggle for services for autistic people: “was it the parents’ personal characteristics that grouped together to form a unified alliance with an ability to influence?” (2014, p.183). I argued in this chapter that it was not the personal characteristics of the parents, but the organization representatives’ intersected social position and claims for representation that allowed them to influence policies concerning autistic adults, yet, at the same time, it was this social position and their inaccurate claims that also contributed to inequalities between autistic people adults.

The first section analyzed the position of Alut’s leading representatives. It began by situating these representatives on internal autistic, disability related and organizational axes that are usually explored in the autism literature. I found, like Raz et al. (2018) and Rimon-Zarfaty et al. (2020) before me, that these representatives, despite claiming to represent the entire spectrum, actually represent parents of “low-functioning” autistic people who support solutions reflecting the MMD approach, and have chosen to both advocate for autism issues and provide services. I then applied the analytical framework of intersectionality, demonstrating they were not “just” parents of autistic adults, but that their identity intersected with privileged social positions. These are Jewish parents from the center of Israel, that are from a very high socioeconomic status, and that possess an abundance of social capital. Therefore, despite their claim to represent the entire spectrum, they represented a small, elite social group.

However, because being privileged is not a synonym for being oppressive, nor does it necessarily lead to a disregard of the needs of those from disadvantaged groups, I next examined the consequences of this representation on inequalities among autistic adults. In the second section of the chapter, I describe Alut’s dominance in the autism policy field. Based on the archival research and my qualitative analysis, I argued that although its position has changed from an integral body in the policy construction process to an external entity whose authorization is essential for promoting policies, Alut retained an influential role in this field due to its representational claims.

After establishing that Alut played a fundamental role in constructing policies, I explored how these policies influenced marginalized social groups which were not represented in the organization’s leading bodies and were found to be marginalized in the previous chapter. I demonstrated that the main policy regarding autistic adults Alut had promoted, “houses for life” as an inclusive permanent solution, discriminated directly and indirectly against autistic people of low socioeconomic status, autistic people who reside on the periphery, and Arab autistic people. I argued that it was the representatives’ 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 autistic people from oppressed communities. From an intersectional perspective, I argued that this reality in the case of autistic people represents a mechanism of power preservation by the privileged social groups who position themselves as representatives of the marginalized group and claim resources first and foremost for their own benefit.

Lastly, I provided more nuance to my argument by contextualizing these actions of Alut’s representatives. I show that, like in North Atlantic countries, the parents, who established and led Alut for years needed to deal with healthcare and social systems that not only saw them as the cause of their children’s disability, but also totally neglected their needs. I argued that, in this context, the blame should not be placed on parents, but on the establishment. The authorities not only neglected the needs of autistic people, but also allowed the creation of two parallel publicly funded systems, one for the rich and the other for the poor, while disregarding the implications of not providing alternative solutions in the community. I concluded by demonstrating that, in recent years, Alut has been actively working to address inequalities among autistic people. I claim it is the establishment of the organization’s legal department that allowed voices “from the ground” to be heard in the context of systemic shifts that occurred within Alut’s structure. Continuing the argument of Rimon-Zarfaty et al. (2020), I claimed it was the coexistence of the founder culture with the reaction to contextual changes that enabled this contradictory position on inequalities to persist.

Understanding the causes for health inequalities, as the abundant literature on SDH demonstrates, is complex. In this chapter, using the case study of autistic adults in Israel, I analyzed one of the mechanisms that contributed to inequalities in the distribution of SDH among autistic adults. This unequal distribution, in turn, resulted in health inequalities. In the words of Sir Marmort (2010), I tried to explain the “cause of causes.” While the reasons for inequalities between different health related social positions cannot be accounted for by only one factor, this chapter made the case that those who are perceived as actors working in the interests of reducing inequalities, health social movements (HSM; Brown & Zavestoski, 2004), can actually themselves contribute to the creation of inequalities. By shedding light on the intersected social position of the representatives who claim to represent the entire population, the chapter illustrated that their actions intentionally and unintentionally served, first and foremost, their own interests, even at the expense of the marginalized community they were supposed to represent. As the blame for this cause for inequality, as I claim, should not be put on the organizations themselves that struggle to promote services in conditions of total neglect, but on the government, this chapter has important implications not only for our understanding of HSM, but on the health policy construction process. These implications will be further discussed in the following chapter.

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. This is just a limited sample. Multiple additional examples of Alut’s links to the top Israeli elite can be found 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 on the board of several leading financial institutions including Leumi Bank (Voilder Livnat, 2017), and Amos Shapira who served as the CEO of El Al airlines, and 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 is reminiscent of the Histadrut working union recruitment policy that was characterized by providing health services to paying members only (Shvartz, 2003). The Histadrut, in the same way as Alut, wanted to increase the political influence 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 and party leader who replied to a mother from the periphery who complained about high fees for school “Ma’am, with the money you paid for 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 the Yesh Atid party, the former minister of finance, currently the Minister of Foreign Affairs and the Alternate Prime Minister, and the father of an autistic woman. [↑](#footnote-ref-7)