Collective representation and the founders' culture in non-profit organisations: the case of Israel's national association for autism

Nitzan Rimon-Zarfaty, rimonn@post.bgu.ac.il
University Medical Center, Göttingen, Germany and Sapir Academic College, Israel

Aviad E. Raz, aviadraz@bgu.ac.il
Bosmat Bar-Nadav, bosmatbn@gmail.com
Ella Vaintropov, ellavain@post.bgu.ac.il
Ben-Gurion University of the Negev, Beer-Sheva, Israel

Non-profit organisations (NPOs) have increased in numbers and importance, providing support, services and advocacy. However, who non-profits actually represent is still an open question. To provide an empirical basis for scrutinising how the representational roles of autism advocacy NPOs change (or not) as they develop, in this article we focus on the case of Alut – the Israeli national association for autism. Drawing on documentary analysis and semi-structured interviews conducted in 2015–17 with members, service recipients and office holders, our findings demonstrate the important role of the founders' culture in setting the NPO’s agenda – in Alut’s case, service provision prioritising ‘low-functioning’ autistic people. The role of the founders’ culture is further highlighted in the context of organisational gaps between the association’s actual agenda and its espoused messages regarding collective representation and advocacy. We conclude by discussing the contributions of the findings to debates on NPOs’ development and the maintenance of stability through representational styles.

Key words advocacy and non-profit organisations • autism • collective representation • founders' culture • Israel


Introduction

Since the 1960s, non-profit organisations (NPOs) have increasingly provided support and services as well as advocacy and rights promotion, thus playing a key role in
political systems within Western societies (Schlozman and Tierney, 1986; Berry, 1977, 1999; Walker, 1991; Baumgartner and Leech, 1998; Berry and Wilcox, 2009; Johansson and Lee, 2014; Yoshioka, 2014). During the past 25 years, autism advocacy organisations have also expanded massively (Cusack, 2017). NPOs can potentially convey the interests of groups that are marginalised in general democratic elections (Berry, 1977; Berry and Wilcox, 2009; Johansson and Lee, 2014; Yoshioka, 2014) – a feat that takes on special importance in the context of disability advocacy (Akrich et al, 2008; Luce et al, 2011; Rabeharisoa et al, 2013; Blakey et al, 2016).

Such NPOs are based on the idea that individual interests can be aggregated into collective interests by organisational mechanisms of participation, deliberation and ultimately representation (Jongsma et al, 2018). Collective representation therefore suggests that decisions and advocacy on behalf of a certain group are assigned to representatives, who arguably act on behalf of the collective entity (Pitkin, 1967; Rowley and Schneider, 2004).

However, who is actually represented by non-profits remains an open question, deserving empirical investigation. The extent to which such organisations claim to provide collective representation varies – in terms of size and outreach. They may claim to represent the public, a particular group and/or service recipients. Furthermore, and especially when it comes to advocacy NPOs, organisational leadership is faced with varied and often competing stakeholders (that is, board members, donors, volunteers and funders) with whom it must negotiate and contend (Mason, 2016). When it comes to autism advocacy organisations, this diversity of representation is also manifested and augmented by their diverse constituencies, which may include family members, professionals and autistic people (Fletcher-Watson et al, 2017, 2019).

Within the international autism community, the question of representation has become a matter of dispute between parents and autistic people, with contesting views of framing autism within a biomedical model of disability versus framing it within a social model of disability (Bagatell, 2010; Eyal et al, 2010; Jaarsma and Welin, 2012). The neurodiversity movement that has emerged from the social model refers to autism as a valued difference rather than a disorder (Orsini and Smith, 2010; Jaarsma and Welin, 2012; Runswick-Cole, 2014). The ambivalent relationship between advocates ‘for’ (mostly parents of autistic people) and self-advocates has even been described as ‘autism wars’ (Chamak, 2008; Orsini, 2009).

To provide an empirical basis for scrutinising how the representational roles of autism advocacy NPOs change (or not) as they develop, we focus in this article on a case study of such an organisation, which was founded by parents of autistic children and became a national association whose claims for collective representation are nevertheless contested.

Development paths, path dependency and representational roles of non-profit organisations

NPOs are often founded by and based on a grassroots community that provides them with initial values and a core mission (Valeau, 2015). This ‘founders’ culture’, which imprints (Stinchcombe, 1965) and pushes the organisation to develop (or not) in certain paths (Schein, 1983; Feldman and Feldman, 2006) may sometimes be critically viewed as regressive or past-oriented (Sanfuentes and Acuna, 2014). In time, as NPOs
develop professionally, the original values and vision are often balanced against new requirements (often presented by the government or philanthropic funders) particularly for technical efficiency, accountability and economic considerations (Hwang and Powell, 2009). Previous studies have discerned two types of tensions or conflicts that accompany such balancing. First, the inherent tension between the close-knit sociality of the grassroots community and the need to be more efficiently organised (for example, Kelley et al, 2005; Kreutzer and Jager, 2011). Second, the tension between adapting to changes and the tendency to continue to do things as they have been done traditionally (Schein, 1983; Garcia-Alvarez et al, 2002). The latter tension has also been discussed within the institutional approach in the context of ‘path dependency’, which implies institutional persistence and inflexibility (Schreyögg and Sydow, 2011; Acheson, 2014). It emphasises the organisation’s inability to rapidly change in response to environmental ‘disturbances’ due to its embeddedness in founding conditions, values, knowledge and structures (Krasner, 1984; Romanelli, 1991; Ramanath, 2009). This situation has been analysed as irrational and as greatly limiting the organisation’s ability to develop and even to survive (Hall et al, 2001; Brunninge et al, 2007). While the tensions surrounding ‘path dependency’ and the founders’ culture have been examined mainly in business organisations (Garcia-Alvarez and Lopez-Sintas, 2001; Garcia-Alvarez et al, 2002; Rodrigues, 2006), they are no less relevant to NPOs where the importance of formative ideology can be very significant (Leiter, 2008; Ramanath, 2009; Acheson, 2014).

Drawing on insights from political representation literature, another important issue in the development of NPOs, which is also strongly connected to the founder’s effect/ path dependence, is the NPO’s representational roles (Gerhards et al, 2017; Yoshioka, 2014, 2017). The concept of ‘representational roles’ encompasses the connection between the representational foci (that is: Who does the NPO aim to represent?) and the representational style (How does the NPO act on behalf of its members?) (Eulau et al, 1959; Yoshioka, 2014, 2017). The traditional debate in political representation contrasts two types of representational styles: the delegate and the trustee. According to this debate, a representative may be understood either as merely a delegate, carrying the mandate of its focal group, or alternatively as a trustee exercising independent judgement about the right thing to do for and on behalf of its constituency (Pitkin, 1967; Young, 2000; Yoshioka, 2014, 2017; Gerhards et al, 2017). While previous scholars challenged the homogeneity of this distinction (Pitkin, 1967; Young, 2000), others highlighted how different representational styles can become mixed in one NPO, and their relations to trust (Gerhards et al, 2017). Representational roles are influenced by those who provide the non-profits with financial and other resources – founders, leaders and/or donors who may define policy goals based on their interests (Wilson, 1995; Berry, 1999; Pfefeer and Salancik, 2003; Yoshioka, 2014, 2017).

**Autism services and organisations in Israel**

According to the Israeli Ministry of Welfare, 17,000 children and 15,000 adults were diagnosed as being on the autism spectrum in 2017, with a total ratio of 18.3 per 10,000 people (Amikam, 2018). This number has quadrupled since 2007 leading to a serious shortage in resources (Yaron, 2016). Families of autistic children are entitled to a monthly allowance of about 2,500 NIS (approximately 650 USD) until the
child reaches the age of 18. Children are also entitled to other healthcare services, for example: three-weekly paramedical treatments. However, the actual costs of caring for autistic people are at least twice as high as the actual welfare budget (Bitzur, 2017).

Autism emerged as a diagnostic category that was expanded, elaborated and broadened following deinstitutionalisation processes in the US. These processes led to distinctions between different categories (for example, low intellectual capacities, mental illnesses and so on) previously brought together under custodial institutions. When those institutions were closed, and other arrangements had to be established (for example, community care, special education, early intervention programmes and so on), this led to increasingly differentiated terms of reference for autism. Those, in turn, led to an expansion of autistic spectrum diagnoses (Eyal, 2013).

Until the late 1970s, autism was considered a mental illness in Israel and elsewhere, and people diagnosed as autistic lived in psychiatric wards. Alut, the parent-led Israeli National Autism Association, was founded in 1974 to counter this situation. As part of the expansion in autism categories and diagnosis, in 2001 the Israeli Asperger Association (Effie) was founded by parents of Asperger children. ACI, the autistic community of Israel, led by and composed of autistic people, was founded in 2006; and in 2015, parents who resigned from Alut established Yozmot Hashiluv (‘Integration Initiatives’ in Hebrew) to promote the inclusion and integration of autistic people.

Since the establishment of Alut, welfare services in Israel have been increasingly privatised (Katan, 2008). The Israeli Ministry of Welfare currently pays NPOs as well as for-profit companies to operate about 57 residences for about 1,400 autistic people. Alut is the second largest operator, currently operating 18 of those residential facilities (called ‘hostels’ in Israel; Alut, 2020a). These facilities are in urban neighbourhoods, but are segregated and gated (Shulman, 2000). Alut, the national association, therefore became a large service contractor, which also operates an early childhood diagnosis centre, nurseries, day care, leisure activities (for example, youth clubs, summer camps and family vacations), employment centres and a centre for the family.

**Alut: organisational overview**

Alut is the first and largest Israeli association of parents of autistic people. It is estimated to have about 4,000 members while providing services to approximately 14,000 families (Raz et al, 2018). In its official mission statement, presented in the association’s website, Alut defines three main organisational tasks inter–connecting advocacy and service provision: ‘(1) promoting the rights of children and adults on the autistic spectrum and their families; (2) the establishment, operation and development of services for the child, the adult and the family; and (3) the promotion of knowledge and research in the field of autism’ (Alut, 2020b). Alut also defines itself as The National Association, claiming to provide collective representation for ‘children and adults from every origin, age and gender, who are diagnosed on the autistic spectrum according to the guidelines of the Ministry of Health’ (Alut, 2020c).

At the same time, Alut defines itself as a parents’ organisation where only parents (or legal guardians) of autistic people can be members (Alut, 2020c). Autistic people are not eligible to be members of Alut. As we argue later, this situation can be traced back to Alut’s foundation by parents of ‘low– to medium-functioning’ autistic people, at a time when these were the majority in the autism community. To this day, only parents have the right to vote and to be elected as office–holders in Alut. Since 2017,
Alut has three divisions, each related to service provision, entitled ‘Housing and Employment’, ‘Toddlers’ and ‘Education, Leisure and Development’. The divisions are represented by two divisional managements (each consisting of 12 Alut members and three public representatives), elected every four years by Alut’s general assembly. Alut’s board of directors consists of six members from each divisional management (along with a hired chairperson and three public representatives). The association also employs paid professionals, for example in its three independent professional sections entitled Rights Promotion, the Center for the Family and the Center for Autism. The organisational structure also includes five operational sections – logistics, human resources, finances, public relations and resource development. As already noted, Alut was founded by parents of ‘low- to medium-functioning’ autistic people when these were the majority in the autistic community. Over time, due to changes in diagnosis patterns, ‘high-functioning’ autistic people became a large part of this community. The impetus for this study was to understand the disputes among members regarding Alut’s original claims for collective representation. By empirically focusing on these disputes, we highlight several social mechanisms shaping organisational development and the lingering effect of the founding culture. By focusing on Alut’s case, we aim to provide in–depth understanding of NPOs’ ageing processes, the related tensions between continuity and change and the way different representational styles are used to negotiate such tensions.

Methods

This article is based on a qualitative case-study methodology. In the first stage, beginning in 2015, we collected and analysed reports, newsletters and website information related to Alut. Following IRB (institutional review board) approval (#1253), we conducted 29 semi-structured interviews with Alut’s office holders, members and service recipients. All interviewees were given a description of the study and consented to participate. Interviews were conducted between 2015 and 2017. We conducted six interviews with various office holders, including three paid professionals and three members elected to Alut’s management and board. To protect the respondents’ anonymity, further details of their position have been deleted. We also interviewed 13 Alut members and ex-members; three parents who are recipients of Alut’s services but are not members; and seven autistic people who have been service recipients of Alut. Interviews were conducted in Hebrew, at the office, the home of the respondent or over the telephone (when preferred by the interviewee) and lasted 30–90 minutes. They were tape recorded following participants’ agreement and fully transcribed. Association members were recruited via office holders, the association’s website and newsletter, and snowball sampling.

In the interviews, office holders were asked about the history of the organisation, its activities and goals, successes and failures, relationships to other associations, and the ways in which they define and maintain democratic and participatory decision making, including the association’s policies regarding the adequate representation of the range of voices present within its member community. Association members and autistic people (over the age of 18) were asked about the organisational activities with which they were involved, their patterns of participation in organisational decision-making processes, and how satisfied they were with it. Interview transcripts were analysed to uncover discursive themes and categories of themes recurring
within and across organisational groups (Denzin and Lincoln, 1994). The coding and thematisation process was generally based on the grounded theory approach to data analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1990; Charmaz, 2002). The ensuing analysis compares how Alut presents itself and how its members see it. Extending the functionalistic perspective of management-oriented analysis, we therefore pursue a broader normative-critical perspective focusing also on alternative voices and gaps (Martin, 2002). We first describe Alut’s founders’ culture and then focus on how Alut is seen by its members and service recipients.

**Findings**

*Alut’s founders’ culture and organisational path*

The official narrative of Alut’s genesis is described on the organisation’s website (Alut, 2020d): ‘Alut was founded … out of the deep distress of families of children diagnosed with autism, who found that … the therapeutic frameworks in Israel do not meet the needs of their children …’. The website tells the tragic story of Liora Avigdori, founder and member of Alut’s public council, whose father, ‘after seeing the difficult struggle, helplessness and hopelessness, took my child, his beloved first grandson Ofer Avigdori, to the Carmel forest in January 1980, killed him and committed suicide’. This tragic story became part of Alut’s genesis. Alut was founded by parents who were seeking service provision in terms of housing, education and later also employment for their ‘low- to medium-functioning’ autistic children. This is typically explained in the following quote from an interview with a member:

‘Look, there are the low-functioning children, Alut has been mainly built for them…. Alut was created to provide solutions for children who could not be kept at home or in regular frameworks. They built Alut according to what was the right thing for autistic people back then … and the association still works according to this paradigm.’

Another member who is also an elected office holder similarly explained: “Alut specialises … in the low and medium functioning … the hardest ones. … Out of those who provide services, no one wants to deal with the hardest ones, everybody prefers to deal with those who can speak and cooperate.” This explains the agenda of the parents who founded Alut and the path along which Alut has developed ever since. It reflects Alut’s path dependency in terms of the services provided and how Alut still chooses to invest its resources.

While Alut is one of the few service providers willing and able to provide such necessary and important services, many of our interviewees were critical about the fact that large parts of Alut’s activities and financial resources are generally invested in residential facilities (‘hostels’) and employment centres for ‘low- and medium-functioning autistic people’. Some of the office holders also emphasised the services Alut offers to ‘high-functioning’ autistic adults and children and their family members, especially in younger ages (for example within Alut’s day care and leisure activities), and what they saw as genuine attempts to reach a wide scope of recipients. Office holders also indicated the association’s attempts to adjust itself to the steadily growing
numbers of autistic people in general and particularly ‘higher-functioning’ autistic people diagnosed in more recent years. Furthermore, they also claimed that within its advocacy and rights promotion, Alut aims at representing the entire autistic spectrum. This position was exemplified by a senior hired office holder:

‘In terms of promotion and advocacy I think it takes care, wants to take care of the entire population. … in the ongoing operation, I think it provides answers, … the younger ones … for them it’s for the entire spectrum…. For adults, the framework that Alut operates is more for the low-medium functioning.’

Some of our interviewees, mainly current and former members and service recipients, criticised this priority-setting as neglecting activities and solutions aimed at higher-functioning autistic people, such as more integrative housing and more investment in integrative educational solutions. This criticism also illustrated a gap between Alut’s mission statement of providing national collective representation and its actual practice, as demonstrated by the following member and volunteer in Alut:

‘The whole issue of integration is very, very undeveloped … even if they use it as a slogan they do not really push it, advocate it and promote it. In fact, most of their activities … include the low functioning, which is fine, only they declare otherwise, they declare that they are the association for everyone.

Similar criticism demonstrating this gap was voiced by service recipients, as illustrated by the words of an autist person who was a service recipient of Alut:

‘If it calls itself “a national organisation for autism”, I expect that they will represent everybody … it succeeds in representing people with low-functioning autism. Regarding the high-functioning the answer is no. … In my opinion, if you ask them, those with high functioning are not really autistic.’

Alut’s image of autism

Alut’s 2012 fundraising campaign, entitled ‘1 in 100’, was designed to raise public awareness concerning the rapid growth in the diagnosed autistic population and the growing deficit in resources required to care for this population (Weiler-Polk, 2012). In a related media report, the head of Alut’s board (the father of an autist person) described the moment he learned about his child’s diagnosis in a typical style stressing the dreaded attributions of autism: “I felt a strong blow to my stomach when they told me that my son Niv was autistic. I knew three things at the time – autism is the hardest disability, there is no cure, and as a family we will deal with it all our life, alone.” While the campaign was aimed at promoting the rights of autistic people, it also reflected a negative image of autism, thus reaffirming and strengthening its social stigma. According to parents of ‘high-functioning’ autistic people and members of ACI (the Israeli community of autistic people), cited by Weiler-Polk (2013), Alut’s continuing use of campaign slogans such as: ‘1 in 100’, ‘Autism – the plague of the
21st century’ and ‘Autism – you do not wish that for your child’, identify autism with suffering in ways that offend and stigmatise autistic people.

One of Alut’s paid office holders explained how Alut presented the image of autism for fundraising purposes:

‘The division of fundraising told us: “We want to make the kind of publicity that will bring money…. We need to show the difficulties. When you tell about the successes … it does not bring money….” The guys with [that is, the parents of] the high-functioning kids said: … “We want to show the hope, the strengths…. This human diversity is very wide.” How can you reconcile this? … they are all right.’

In recent years there seems to be a change in Alut’s campaigns towards a more balanced representation of autism and autistic people. For example, in a video-clip aired by Alut in 2018, ‘low-functioning’ adults are presented alongside young autistic children in Alut’s day care and their improvement in communication skills. In addition, in the video a mother whose two daughters are in Alut’s day care explains her belief in the future integration of her daughters in society (Alut, 2018). Similarly, in a newspaper report of Alut’s annual fundraising day (Margulin, 2018), the mother of a ‘low-functioning’ 21-year-old autistic person described not only the many challenges faced by her family but also spoke about his achievements. She quoted her son who said that ‘autistic people are smart’ and that he deserves a ‘good and interesting life’.

Advocacy and service provision

Alut’s official credo presents a dual mission of service provision and advocacy, including rights promotion (vis-à-vis state institutions, local authorities, the Israeli Knesset and so on), also demonstrated in its by-laws (Alut, 2020c) and mission statement (Alut, 2020b). This duality does not pose any legal challenges as there are no legal restrictions in Israel limiting NPOs’ attempts at combining service provision with advocacy. In contrast, Alut’s US counterpart NPO called Autism Speaks is not involved in service operations such as housing (Autism Speaks, 2019). Similarly, the English national autism NPO, the National Autistic Society, does not operate residential services but does, however, operate educational/school services (National Autistic Society, 2018b). It therefore seems that Alut’s intensive service operation is unique.

Alut’s resources are often heavily invested in service provision aimed at ‘low- and medium-functioning’ autistic people, rather than in ‘high-functioning’ autistic people or advocacy in general – thus representing another possible gap between the official mission statement and actual practice. Alut’s 2014 financial workplan shows that 60% of its budget was allocated to supporting about 500 autistic people (approximately 2.5% of the diagnosed autistic population in Israel) in ‘low-functioning’ residential settings and employment centres. There are only two areas clearly devoted to advocacy in Alut’s workplan (‘awareness, advocacy and rights promotion’ and Alut’s ‘centre for families’). Alut invests about 2% of the annual budget in these areas (Cassuto-Shefi, 2014). It is possible that other advocacy activities are also conducted within the framework of other budget sections, but this is not presented in the report.

Importantly, much of Alut’s budget is derived from the state under service operations for autistic people. In contrast, there is no state money dedicated to autism advocacy.
Decisions on allocating fundraising money are made by the association’s board in a way that arguably prioritises high-profile/high-cost operations, as the following quote from an interview with an Alut member and elected office holder illustrates:

“So there is a rule for the “non-marked” budget. … Usually the highest operating costs are in the adults’ division. … There is, of course, the operation of the headquarters, which is a considerable cost, and from what is left, 30% goes to the adult's division. … If there are extras, then this usually goes to the opening of additional frameworks, the provision of additional services, or to development.”

Nevertheless, some of our interviewees highlighted some advocacy achievements and recent developments, as demonstrated by the following quote from an interview with a member and elected office holder: “The advocacy department became stronger in recent years, to answer the needs of those the association cannot support in terms of [its operated] frameworks … the organisation devotes its energies to operation, [but] its advocacy improved.” Some in Alut still see the dual mission and ongoing challenge to improve the balancing of service provision and advocacy as an organisational advantage:

‘Alut has a group of professionals who advocate, not big enough in my view, for budgetary reasons; and Alut also has a group of professionals [responsible for operation] … I see how they work with each other … the fact that the person in charge of the advocacy and rights promotion, also knows the real problems … and does not only speak for some theoretical premise written in some regulation … it’s a huge advantage.’ (Member and elected office holder)

In contrast, several interviewees highlighted the tension between advocacy and service provision, suggesting an inherent contradiction between these two functions: “I do not want to idealise, many times it is one at the expense of the other … our ability to criticise the Welfare Ministry is very limited because we are its contractor and operator” (hired office holder). Several respondents mentioned in this context Alut’s hesitation in supporting new legal initiatives aiming at adding alternatives to guardianship in the form of supported decision making. The legal change to supported decision making was successfully promoted in 2017–18 by a coalition of 18 disability advocacy organisations led by Bizchut (‘by right’, in Hebrew) – the Israeli Human Rights Center for People with Disabilities. According to some of our interviewees, Alut (which operates a paid-for service for conventional guardianship solutions) took a passive position and joined the initiative when the legal amendment was already about to be approved by the Israeli Knesset. Several of our respondents explained this as characteristic of the dominant agenda of parents of ‘low-functioning’ autistic people who usually become legal guardians of their children and therefore do not prioritise the promotion of alternative models.

As the national association, Alut pertains to serve as an advocate for the entire autistic community. This community, however, holds fundamentally different orientations and agendas. As Alut maintains a strong resource base in services funded by the government, combined with a hard core of parents of ‘low-functioning’ autistic people, its particular mode of advocacy is increasingly challenged by the new autism movement.
Alut's organisational change

During the past two decades, Alut has been faced with dramatic changes – the rising number of 'high-functioning' autistic people/Aspies (that is, Asperger's Syndrome autistic people) and their parents, the branching out of competing autism associations (Effie, ACI, Integration Initiatives), also promoting alternative advocacy agendas, and most recently the legal changes surrounding the shift from guardianship to supported decision making. This was summarised by a member and elected office holder in Alut: “This is an association that was established for hostels … and suddenly, it finds itself in a situation where most of the autistic people are high functioning…. It is possible that Alut needs to decide who it serves and focus on this specific target audience.”

To what extent were these external changes reflected in internal changes? Most of the parents who established the alternative autism associations were previously members and elected office holders in Alut, who failed to promote the change they wanted from within Alut's organisational structure. This is typically described by one of the founders of Yozmot Hashiluv (Integration Initiatives), a former member and elected office holder in Alut:

‘What happened in Alut when a large group of voting parents didn’t feel represented? … Alut was founded by parents 40 years ago and its worldview remained the way it was 40 years ago. … We tried to change … and handle all the spectrum. … in Alut – the major activity, where most of the money goes to, are the hostels … this is Alut’s power centre…. Instead of making the change from within Alut … we decided to resign, and we will try to promote our agenda in the new organisation.’

Following these external changes and internal conflicts, Alut initiated a process of organisational counselling and strategic change in 2017. The results of this organisational change process boiled down to a structural reform: replacing the previous structure of age-based divisions (toddlers, youth and adults) with three new divisions: Housing and Employment, Toddlers and Education, Leisure and Development (Alut, 2020e). The Housing and Employment division manages the operation of Alut’s residential living facilities and employment centres. The community management (elected from the Toddlers and Education, Leisure and Development divisions) is responsible for leisure activities, support services for family members, child care facilities, advocacy and rights promotion, education services and research. However, despite the many responsibilities of the community management, it comprises 50% of Alut’s board, while the other 50% of the board come from the service-oriented management of the Housing and Employment division (Alut, 2020f). Presented by Alut as a means for realigning its organisational structure with the goal of all-inclusive national collective representation (also reflected in the new fundraising campaigns Alut recently sponsored and its recent investments in advocacy and rights promotion), the perceived asymmetry of representation that is built into the hierarchy of the new structure can be seen as reproducing old power relations within Alut. According to several of our respondents, the change will strengthen the political power of parents of (about 500) ‘low-functioning’ autistic adults living in Alut’s residential living facilities (hostels). While in the previous organisational structure of three age-based divisions those parents belonged to the ‘adults division’ and comprised a third of the
board, they now comprise half of Alut’s board. This interpretation, and the actual future implications of the organisational change, require further empirical research.

Discussion

Our findings highlight the interplay of change and continuity in NPOs as an increasingly heterogenous collective representation challenges Alut’s founders’ culture. On the one hand, Alut is in a position where it needs to play the politics of addressing and engaging the new political climate. However, in the meanwhile, supported by government money, it also has the mission of providing services to ‘low- to medium-functioning’ autistic people. Alut therefore faces the challenge of retaining stability and its position as the national autism organisation in the face of a changing social and political environment. Within this context, organisational stability takes the form of maintaining a constant path – that of the founders’ culture. Alut’s controlled process of careful change (as exemplified in the new campaigns, advocacy activities and structural reforms) demonstrates how the founders’ culture continues to influence its organisational path. The founders’ culture thus has a crucial effect on the gaps we found between the association’s mission statements, its actual practice of prioritising service provision for ‘low- to medium-functioning’ autistic people, and how it is viewed by members and service recipients.

As essentially ideological and value-laden organisations, the establishment and maintenance of NPOs have often been identified as having much to do with an authentically democratic organisational form (Rothschild and Milofsky, 2006). In her seminal work on Alcoholic Anonymous, Borkman (2006) highlighted a particular case of such ideological orientation by focusing on the role of equality and equal relationships (reflecting egalitarian values) in the NPO’s success. Our case study further reinforces such claims by focusing on an opposite case. Alut’s culture is based on maintaining a path of stability within the built-in conflict of inequality. Anyone who tried to increase equality between autistic people and their parents or between different functioning levels was either leaving or forced to leave Alut. The branching out of new non-governmental organisations representing autism in Israel (Effie, ACI and Yozmot Hashiluv) therefore resulted from the need to promote and represent agendas such as integration, self-representation, self-advocacy, neurodiversity and de-medicalisation, which were seen by certain ex-members to be neglected by Alut.

The case of Alut highlights how the ‘pressures of the past’ (Marquis, 2003) continue to shape organisational development. According to Stinchcombe (1965), the environment at founding, as well as the founders, imprint an organisation with lasting characteristics of structure and activity. More recent studies have examined how initial founding conditions affect rates of change in non-profits (Tucker et al, 1990). Although there has been significant interest in the effect of founding conditions on organisational outcomes, little attention has been given to the social mechanisms that maintain historically imprinted patterns. Our findings highlight the interconnectedness of two mechanisms, in line with Stinchcombe’s (1965) original, broad articulation of imprinting: environmental pressures since founding and the founding culture. Like agency and structure, we see these two sources of influence as complementary in practice, with the founding culture shaping how the organisation adopts/adapts to certain environmental pressures (rather than others) while also maintaining stability through a strategic organisational embedding of representational style.
The founding culture and the environment

Over time, faced with resource scarcity, NPOs often become more hierarchal and bureaucratic (Rothschild and Milofsky, 2006). Our case study sheds light on the complex dynamics and interconnected factors involved in such processes, indicating that they cannot be understood only in terms of bureaucratisation versus original missions.

One main environmental factor is Alut’s dependence on government funding policies – which can be theoretically connected to institutional predictions (Kondra and Hurst, 2009; Ramanath, 2009; Acheson, 2014), while demonstrating the converging effect of national isomorphisms in the form of impositions enforced by the state and by normative professionalisation processes (Leiter, 2008; Kondra and Hurst, 2009; Ramanath, 2009; Hemmings, 2017). Specifically, the case of Alut illustrates the strategic persistence, in line with the ideology of the founders, of emphasising sectorial services (rather than universal advocacy) that are isomorphic with governmental funding allocation schemes. Indeed, Gidron and Katz (2002) demonstrated how the Israeli governmental funding allocation schemes de facto encouraged the development of NPOs providing health and welfare services in the name of the government, while reducing and even ignoring other roles such as advocacy and entrepreneurship. The US NPO Community Catalyst (2017: 5) warned in this context that ‘organizations must keep funding streams separate because of distinct expectations and restrictions that come with that funding…. This can be particularly difficult when certain staff have roles in both service delivery and advocacy.’ Alut’s strategic retaining of its main role as service provider also reflects the fit between the values of Alut’s founders and the Israeli welfare regime of disability that is still dominated by the biomedical model and the discourse of welfare regulations – dictating sectorial treatment and rehabilitation regimes at the expense of implementing a universal rights perspective (Mor, 2005; Soffer et al, 2010).

From an organisational behaviour perspective, our findings reflect a structural inertia leading to the routinisation and institutionalisation of organisational activities (Schreyögg and Sydow, 2011). The prioritising of existing services, structures and frameworks, as exemplified in Alut’s case, can be interpreted as a form of structural reproduction featuring rigidity (Schreyögg and Sydow, 2011); it could also be the result of workers who may be trained for and wish to continue with existing work arrangements.

Maintaining stability through representational styles

Our findings highlight how a combination of representational styles and hence of representational roles is strategically embedded in Alut’s organisational culture. By enabling only parents (and/or legal guardians) of autistic people to become members and essentially prohibiting such status and rights (that is, taking part in elections or decision making) from autistic people, the organisation is first and foremost based on the trustee style. It has been previously shown that the trustee style may be used in situations in which those represented are believed to be misled, misinformed or irrational about their needs or interests (Yoshioka, 2014). The trustee role is also echoed in Alut’s hesitation in supporting more autonomous alternatives to the traditional guardianship model, such as supported decision making. In parallel, the delegation style is manifested in relevant organisational mechanisms of elections and office rotation instituted by Alut to ensure that the NPO democratically represents
its members’ views (Pitkin, 1967; Young, 2000; Yoshioka, 2014). However, since membership status is limited to parents only, Alut’s claim for collectivistic-democratic representation is being questioned. It therefore seems that Alut represents a unique case of representational style in which delegate representation is being confined, in line with the founders’ values, within the context of trustee representation. Our findings further indicate how Alut was seen by many members as a delegate of the founders and their successors. In that sense, some of Alut’s members criticised the organisation for presenting itself as a delegate while being a trustee.

Our analysis shows how the strategic organisational embedding of representational styles is a mechanism that maintains historically imprinted patterns. While Milofsky and Blades (1991) emphasise the important role of constituents in forcing health NPOs to become accountable and receive fuller representation in decision-making processes, we show how such attempts challenge organisational stability and path dependency and may therefore be rejected.

We do not suggest an a-priori normative evaluation of what accountable representation in NPOs should be. Rather, the comparison of different interpretations of recurrent gaps allows for critically questioning the often-hidden normative premises of the complex idea of representation.

Throughout its history, Alut has stood out as an important service provider for Israelis. Our analysis of the tensions and dilemmas involved in the dual mission of services operation and advocacy should not be read as discounting the great value of service provision for autistic people and their families (Cutress and Muncer, 2014). Similarly, our analytical focus on the parents’ dominant role in Alut’s founders’ culture should not be read as discounting the overall legitimacy of parents’ claim for representing their autistic children. One does not necessarily have to be an autistic person to represent a group of autistic people in the sense of identifying, understanding and articulating the group’s interests. In line with Cusack’s (2017: 131) warning, we should avoid ‘an overly simplistic populist narrative’ in portraying the different groups or voices comprising the autistic community. It is, however, crucial to recognise how much political power each ‘voice’ has relative to others (Parkinson, 2004), especially in light of the diversity of voices identified in our study claiming to represent not only parents and autistic people but also ‘high-’ and ‘low-functioning’ autistic people.

The complementary theoretical frameworks that were mentioned illustrate the richness of Alut’s case study, with its inherent tensions of making a transition from the founding stage to accommodate varied constituency groups, tensions that are relevant to many NPOs. While we cannot generalise from the case of Alut, it nevertheless provides us with relevant insights concerning the challenges and dilemmas involved in NPOs’ claim for collective representation and the gaps that emerge between the association’s statements, its actual practices, and how it is viewed by members and service recipients. Examining autism and other disability NPOs in other countries would be useful in understanding how our critical observations inform the broader landscape in disability representation and advocacy. Joining the recent change in ‘cause regimes’ that accompanies the opening up of disability advocacy (O’Donovan et al, 2013; Raz et al, 2018), this study will hopefully pave the way for more needed research into transparency and accountability within collective representation in autism non-governmental organisations.
Notes
1 We use the terminology ‘autistic children/people’ instead of ‘children/people with autism’. This terminology is preferable among autism activists who view themselves not as ‘people with autism’ (where autism is seen as an add-on defect rather than an inherent part of one’s identity) but as autistic people (National Autistic Society, 2018a).
2 The common functioning-based classification that roughly divides autistic people into ‘low-functioning’ or ‘high-functioning’ has been widely criticised as labelling and as too general, since every autist person may have both low- and high-functioning skills (Cowen, 2009; Dawson, 2010). Our use of this classification does not mean to dismiss such criticism, but rather follows its usage in Alut.
3 The estimated income from fundraising in 2014 was 10 million NIS (Cassuto-Shefi, 2014), more than 7% of the yearly budget.
4 On March 2016, the Israeli Knesset voted in favour of an Amendment to the Legal Capacity and Guardianship Law (Amendment No. 18, 5776-2016). This amendment constitutes a substantial reform recognising the rights of individuals to have supported decision making (rather than court-appointed guardianship) and reduces the cases in which a guardian must be appointed. The amendment emphasises that a decision-making supporter will not make decisions instead of the supported person, and compels the court to consider appointing a decision-making supporter before opting for guardianship. The amendment also limits the ability of a guardian to force a decision relating to fundamental issues.

Funding
This work was supported by the State of Lower Saxony, Hannover, Germany under grant number: 11762519917/14 (ZN3010).

Acknowledgements
This work was generously supported by the Lower-Saxony – Israeli community project ZN3010, ‘Organized Patient Participation in Health Care: Collective Advocacy, Representation and Autonomy in Socio-Ethical Perspective (OPARA)’. We would like to thank Alut, the Israeli association for children and adults with autism, for enabling us to conduct the research and for their cooperation and to all the participants for sharing their opinions.

Conflict of interest statement
The authors declare that there is no conflict of interest.

References
Alut: the Israeli Society for Children and Adults with Autism (2020a) Residential living facilities, https://www.alut.org.il/%d7%93%d7%99%d7%95%d7%a8/%d7%91%d7%99%d7%aa-%d7%9c%d7%97%d7%99%d7%99%d7%9d/ [in Hebrew].
Collective representation and the founders’ culture in non-profit organisations


Alut: the Israeli Society for Children and Adults with Autism (2020c) By-laws, [https://www.alut.org.il/%D7%9E%D7%98%D7%A8%D7%95%D7%AA/%D7%AA%D7%A7%D7%9A/%D7%95%D7%9F/](https://www.alut.org.il/%D7%9E%D7%98%D7%A8%D7%95%D7%AA/%D7%AA%D7%A7%D7%9A/%D7%95%D7%9F/) [in Hebrew].


Alut: the Israeli Society for Children and Adults with Autism (2020e) Organizational structure, [https://alut.org.il/%d7%9e%d7%98%d7%a8%d7%95%d7%aa/%d7%9c%d7%91%d7%a0%d7%94-%d7%90%d7%a8%d7%92%d7%95%d7%aa0%d7%99%/%d7%9e%d7%99-%d7%90%d7%a0%d7%97%d7%aa0%d7%95/](https://alut.org.il/%d7%9e%d7%98%d7%a8%d7%95%d7%aa/%d7%9c%d7%91%d7%a0%d7%94-%d7%90%d7%a8%d7%92%d7%95%d7%aa0%d7%99%/%d7%9e%d7%99-%d7%90%d7%a0%d7%97%d7%aa0%d7%95/) [in Hebrew].

Alut: the Israeli Society for Children and Adults with Autism (2020f) Board of directors, [https://www.alut.org.il/%d7%9e%d7%98%d7%a8%d7%95%d7%aa/%d7%9e%d7%91%d7%a0%d7%94-%d7%90%d7%a8%d7%92%d7%95%d7%aa0%d7%99%/%d7%94%d7%95%d7%a2%d7%93-%d7%94%d7%9e%d7%a0%d7%94%d7%9c/](https://www.alut.org.il/%d7%9e%d7%98%d7%a8%d7%95%d7%aa/%d7%9e%d7%91%d7%a0%d7%94-%d7%90%d7%a8%d7%92%d7%95%d7%aa0%d7%99%/%d7%94%d7%95%d7%a2%d7%93-%d7%94%d7%9e%d7%a0%d7%94%d7%9c/) [in Hebrew].

Amikam, I. (2018) The data on people with autism spectrum disorder, Ynet News, 11 November, [https://www.ynet.co.il/articles/0,7340,L-5415713,00.html](https://www.ynet.co.il/articles/0,7340,L-5415713,00.html) [in Hebrew].


