



## Representing autism: Challenges of collective representation in German and Israeli associations for and of autistic people



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### ABSTRACT

The important work done by various associations of and for people with disabilities is legitimated by their claim for collective representation. However, there is little empirical research that examines the organizational basis for such claims. We focus on patient/disability advocacy associations that illustrate a split of representation between organizations *of* and *for* autism. Drawing on documentary analysis and semi-structured interviews conducted in 2015–2017 with members and office-holders of autism associations in Germany and Israel, we highlight several common gaps and their relations to the organizational characteristics of the associations: Representing only part of the autism spectrum, and lack of efficient procedures for including the variety of members. We conclude by discussing the language and epistemology of „high-functioning”/”Aspies” vs. „low-functioning”/”Kanners” as politically and culturally embedded, highlighting the significance and difficulties of dialogue amidst autism-related epistemic communities.

Patient organizations and disability advocacy associations have gained increasing recognition in most Western countries in the last few decades, based on their claim for collective representation. Collective representation can vary in size and outreach, from a smaller group of people with disabilities to a larger constituency including relatives (Shakespeare, 1993). Styles of collective representation can further vary, from being bounded to the interests of the group to setting an agenda for the group (Gerhards et al., 2017; Yoshioka, 2014). Some have criticized patient organizations for having sectional interests (Fredriksson and Tritter, 2017). Since the involvement of such organizations in deliberative health governance is relatively new, their internal practices of decision-making as well as impact on policy-makers must yet be critically evaluated (Epstein, 2011). Nevertheless, these claims for representation in the context of civic mobilization are seen as an important democratization of health politics (Dryzek, 2000) and justified as countering expert domination in the context of health governance (Wehling et al., 2015; Raz et al., 2014).

Little is known about how these representational claims are realized and perceived by organizational members, especially considering the complex constituency of such associations. To provide an empirical point-of-departure for scrutinizing these issues, we focus on patient/disability advocacy organizations that illustrate a split of representation between organizations *of* people with disabilities, and organizations *for*

them. Such a split in collective representation and advocacy has been studied mainly in the contexts of autism, deafness, and mental illness (Orsini, 2009; Padden and Humphries, 1988; Crossley, 2006). We aim to provide a novel look at ‘the backstage’ of these associations to scrutinize how the mechanisms of representation are perceived by members. By comparing Germany and Israel, we aim to critically reflect upon the theoretical distinction between organizations *for* and *of* autists as well as how cultural and political backgrounds diversify such categorizations. We examine how this distinction is blurred by organizations that comprise both family members and autists. Furthermore, we explore additional categorizations such as the „high-functioning” vs. „low-functioning” (or „Aspies” vs. „Kanners”) that, although being questioned, appear to strongly influence debates of representation and rivalries among advocacy groups.

### 1. Patient/disability advocacy organizations: questions of representation

Following claims for providing patients with more representation in decision-making on a collective level, various countries have legislated patient involvement in joint governmental committees dealing with health policies. Previous studies focused on the involvement of such organizations and health professionals in the governance of medical

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technologies (Akrich et al., 2008; Rabeharisoa et al., 2013). Some of these organizations collaborate with the medical establishment to provide care and services, while others challenge biomedicine and advocate alternative views on disability (Brown et al., 2004). In the recent context of ‘autism wars’ (Orsini, 2009; Chamak, 2008), associations for and of autists debate whether to frame autism within a biomedical model and advocate for a cure, or to focus on a social model of autism as neurodiversity rather than a disease (Eyal et al., 2010; Bagatell, 2010, 2010; Jaarsma and Stellin, 2011; McGuire, 2016; Thibault, 2014; Ripamonti, 2016; Waltz et al., 2015).

Both Germany and Israel have issued declarations about the importance of the participation of disability associations in Parliament Committee hearings and Governmental Committee deliberations, yet the actual involvement of such associations in the political sphere is not well-regulated (Graumann and Grüber, 2004). Both countries are at the cutting edge of Western medical progress, with a well-developed socialized health system. In both countries, there is an overall rather similar Disability Act with differences in practice because in Germany the disability movement appears to have formed a mature coalition (Heyer, 2002), while in Israel there is no such coalition and the disability community is divided between sectors (e.g. disabled veterans/workplace disability/general disability, see Mor, 2006).

## 2. Services and organizations for autism in Israel and Germany

The inherent diversity of autism requires that each autistic person is seen for their own individual needs. In many service-providing organizations, however, the diverse “autism spectrum disorder” is often broken down into the sub-categories of “low functioning” (Kanner’s autism) and “high functioning” (Asperger’s). Generally speaking, the formers are offered (often gated) housing, special (often segregated) education and behavioral therapy, while the latter are offered help with integrative education, job finding and support groups. The newer associations often demonstrate a change from more separatist to possibly more integrative approaches, where parents and autistic people cooperate. This also involves opening the “high-” vs. “low-functioning” distinction that has been a central axis of split in prioritizing certain organizational agendas, a point we elaborate on later.

In Israel, 12,000 autism cases were registered at the Ministry of Welfare in 2015. There is currently no official figure on the number of autistic people living in Israel, but it has been estimated to be around 20,000 (Yaron, 2016). The increase has led to a serious shortage in resources for autists (Yaron, 2016). Families of autistic children are entitled to a monthly allowance of about 2500 NIS (~650 USD) until the child reaches the age of 18. However, the cost of caring for an autistic person is at least twice as high as the welfare budget (Bitzur, 2017). Until the late 1970s, autism was considered a mental illness in Israel, and people diagnosed as autists lived in psychiatric hospitals. *Alut*, the parent-led Israeli National Autism Association, was founded in 1974 to counter this situation. Housing, special education and care for autists have been largely privatized, with *Alut* being one of the major service-providers. In 2001, the Israeli Asperger Association (*Effie*) was founded by parents who claimed that *Alut* neglected “high-functioning” autistic children (we bracket the term as a reminder that it is used by parents with good intentions but also in a political rather than objective manner). *ACI*, the autistic community of Israel, led by and composed of autists, was founded in 2006. In 2015, parents who resigned from *Alut* established *Yozmot Hashiluv* (“Integration Initiatives”) to promote inclusion and integration of autistic people.

In Germany, it is estimated that about 820,000 people have autism, which is approximately 1% prevalence rate, but there are no official figures available ([http://www.awmf.org/uploads/tx\\_szleitlinien/028-018l\\_S3\\_Autismus-Spektrum-Stoerungen\\_ASS-Diagnostik\\_2016-05.pdf](http://www.awmf.org/uploads/tx_szleitlinien/028-018l_S3_Autismus-Spektrum-Stoerungen_ASS-Diagnostik_2016-05.pdf); accessed April 28, 2017). The umbrella organization established in 1970 by parents, *Autismus-Deutschland e.V.* (e.V. stands for *eingetragener Verein*, registered association) has 60 relatively independent regional

organizations and a hierarchical structure of internal representation. *Autismus-Deutschland* is supported by the health insurance. Like its Israeli counterpart (*Alut*), it provides public information and support for autistic people and their families, and operates residential communities. Similarly, it also supports autism-related research initiatives. Autistic adults who did not feel well-represented by the parents’ associations formed associations for self-representation and self-advocacy. There are several German associations of autistic people, one of the largest being *Aspies e.V.*, established in 2004.

German families of autistic children are entitled to a monthly allowance per diagnosed grade of care and depending on the parents’ income. Some critically argue that in Germany, “there exists a huge market of quacks and phony services for the [autism] families” (Keenan et al., 2010: 135). To be eligible for funding for treatment at an autism therapy center, a diagnosis has to be made by a psychiatrist. Yet only some university hospitals in Germany offer a specialist clinic for diagnostics and/or treatment for adult autists, and self-help organizations report a considerable lack of diagnostic services (Michel et al., 2010).

## 3. Methodology

Motivated by our long-time interest in the sociology of patient/disability organizations and aiming to empirically and theoretically explore the issue of self and collective representation in such organizations, the study began in 2015 with a background analysis of guidelines and policies regarding patient/disability advocacy associations in Germany and Israel. After obtaining research ethics approval from the Research Ethics Committees of Ben-Gurion University (Israel) and University Medical Center Göttingen (Germany), the second stage consisted of interviews (5 in each country) with relevant governmental disability commissioners and office holders in umbrella organizations for disability advocacy. We also collected and analyzed reports, newsletters and website information of autism associations in Germany and Israel. In Israel, we focused on two associations: *Alut* – the National Association for Autistic Children and Adults, and *ACI* – the Autistic Community of Israel. In Germany, we focused on *Autismus Deutschland e.V.* – the federal organization established by parents and two of its regional organizations (*Autismus Bremen e.V.*, *Autismus Karlsruhe e.V.*), as organizations for autistic people. In the context of associations of autistic people, we focused on *Aspies e.V.*, as well as on *Autland Nürnberg* (a web-based initiative by a group of autistic people) and *Autismus-Forschungs-Kooperation* (a cooperation initiative of autists and scientists). The organizations studied are the main organizations of and for autism in the two countries. We then conducted 54 interviews (18 in Germany and 36 in Israel) in 2016–17 with office holders, members and ex-members (see Table 1). Interview collection was finalized when the research teams agreed that thematic saturation was reached, meaning that no new topics were raised in the subsequent interviews. In Israel, this took more interviews.

Interviews were conducted in the office or home of the respondents and lasted 30–90 min. About 20% of the interviews were done over the phone, and we did not notice a bias due to this difference. Association members were recruited via the office holders and the associations’ website or newsletter; we used the snowball method to reach additional members. Participants received an informed consent form explaining that the research purpose was to explore collective representation in their association by learning about organizational practices of representation and their interpretation by members. Interviews were conducted by the research teams, using the local language and the same semi-structured interview guide. Office holders were asked about the history of the organization, its activities and goals, 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 (ies). Association members were asked with which organizational activities they are involved,

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