

## ORIGINAL PAPER



# "Nothing About Us Without Us" in Volunteerism Too: Volunteering Among People with Disabilities

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**Abstract** Viewing disability as a form of social capital, this paper examines the unique contribution of volunteers with disabilities and the meaning that volunteering holds for them. Of the 35 volunteers with disabilities interviewed, all were volunteering in self-help organizations for people with disabilities, half of them in administrative and leadership roles. The interviews revealed rich and active stories. Their areas of activity were diverse and encompassed various organizations. The volunteers crossed over from the role of merely extending services to their beneficiaries to becoming activists for political and social change. Their practices suggest that the volunteers' selfidentity as individuals with disabilities has shaped their supportive approach. Therefore, understanding their unique resources as people with disabilities is key to developing an organizational culture that promotes integrative recruitment of volunteers.

**Keywords** Volunteering  $\cdot$  People with disabilities  $\cdot$  From beneficiary to volunteer  $\cdot$  Peer support  $\cdot$  Qualitative study

# Introduction

Volunteering is an alternative employment option for people with disabilities due to their low employment rates in the job market and therefore constitutes an important means for improving their quality of life (Barlev et al. 2015; Barron et al. 2009; Shier et al. 2009). Volunteering is an arena for

independent and creative activity which improves one's selfimage (Yanay-Ventura and Yanay 2008; Yanay-Ventura 2016; Carone et al. 2007; Itzhaky and Schwartz 1998; Kulik 2018; Miller et al. 2002). It offers a chance to develop ties with the community and provides a framework of social belonging (Balandin et al. 2006a, b; Oman et al. 1999). Studies on volunteering among people with disabilities show that volunteering increases volunteers' sense of personal responsibility and reduces feelings of alienation and loneliness (Choma and Ochocka 2005; Ochocka and Lord 1998). Furthermore, it allows the individual with disability to transform from being a typical recipient of welfare services into an empowered provider of services to others (Miller et al. 2005).

Yet, even voluntary frameworks are not free of obstacles. Very few organizations offer volunteering positions to people with disabilities (Graff and Vedell 2003; Krause et al. 1996; Miller et al. 2003), and those that are accepted encounter various difficulties including lack of accessibility (Andrews 2010; Reilly 2005), low awareness of their physical limitations, prejudice (Bruce 2006; Roker et al. 1998), rejection by a portion of their colleagues and a lack of capable staff to support them (Balandin et al. 2006a, b; Miller et al. 2005). Therefore, the meaning of quality volunteering for volunteers with disabilities needs to be more deeply understood.

The literature on volunteerism among people with disabilities mainly discusses the volunteers' difficulties and challenges, suggesting specific adaptations required by organizations (Andrews 2010; Balandin et al. 2006a, b; Bates 2002; Bruce 2006; Carone et al. 2007; Reilly 2005; Roker et al. 1998; Trembath et al. 2010). Although these aspects are important and even essential, their theoretical implication is that volunteers with disabilities are "other" volunteers who have special needs. Very few studies



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directly discuss disability as a resource and outline the unique contribution of these volunteers precisely because of their disability (Campolieti et al. 2009; Miller and Schleien 2010; Morton et al. 2010; Roker et al. 1998; Trembath et al. 2009a). Furthermore, the common discourse on volunteer's management is rooted in support programs rather than models dealing with rewards for volunteers and with management strategies for working with them.

In the current paper, based on the Bourdieu's forms of capital (1986) we view disability as a social capital that derives from the unique experience of living with disability. This means that disability serves as a structuring force: it limits and narrows the ability to engage in certain practices. In short, Bourdieu views social capital as a personal asset that embedded in social relations but its access and use reside with the individual. Thus, this capital cannot be transferred or exchanged with other groups (e.g., people without disabilities) but can be converted into financial, symbolic and cultural capital used by people with disabilities. Putnam (1995; 2000) refers to social capital as an asset consists with a collective community (not to individuals) acquired by means of community attributes, such as social networks, norms and shared reciprocal trust. This capital constitutes a unique resource which promotes its well-being of the community, and whose use increases the group's capital. By combining Bourdieu's and Putnam's conceptualizations, we assume that volunteers with disabilities use their social capital as people living with disabilities while at the same time, volunteering helps them further develop social capital which, in turn, can facilitate upward mobility, purposive actions and economic returns.

Therefore, the current study examines volunteering among adults with disabilities who volunteer at self-help organizations for people with disabilities. The study raises three questions: (1) what does volunteering mean for people with disabilities and how does it contribute to their lives? (2) What is the unique contribution of volunteers as people with disabilities helping similar beneficiaries? (3) What would be an effective model for working with volunteers with disabilities from the perspective of the volunteers? To answer these research questions, the study uses qualitative research, employing a narrative case study approach, in which conduct in-depth interviews. 35 volunteers participated, mainly with physical disabilities, all of them volunteered in self-help organizations for people with disabilities.

Therefore, the contribution of this paper is threefold: (1) Understanding the meaning of volunteering among adults with disabilities and the impact this has on their lives and self-perception; (2) Discussing disability as social capital and understanding the unique contribution it makes in assisting beneficiaries with disabilities; and (3) Discussing

effective management of volunteers with disabilities. In delving into these important issues, the present paper joins a series of studies that investigate the "New Volunteering" phenomenon (Hustinx 2001; Hustinx and Lammertyn 2003; Hustinx et al. 2010), especially the enrollment of new volunteer populations. According to this approach, volunteering is a result of unique biographies that are created, due, among other things, to social and economic changes. These bring new volunteers into the fold, with brand new commitments, benefits and volunteering patterns derived from their life experience.

# Volunteering Among People with Disabilities

Volunteering is an act of giving one's time to freely chosen and deliberate helping activities that extend over time, often through formal organizations without expectation of material compensation (Snyder and Omoto 2008). The broad and common theory for understanding the motivation to volunteer is the Volunteer Functions approach (Clary et al. 1998) which underline the individuals' dedicating time, energy, and talents to an activity that will meet his/her needs; this approach includes with the reasons, the purposes, the plans and the goals that generate volunteerism.

The literature on volunteerism among people with disabilities offers a broad view of the motivation behind volunteering, and its benefits. For example, studies among adults with intellectual disability emphasized the employment motive behind their volunteering. (Grant 2008; Roker et al. 1998; Trembath et al. 2010). These adults come into the paid employment market with multiple obstacles, e.g., lack of confidence, low mathematical and verbal literacy, fear of unpleasant attitudes toward them, difficulties in understanding the unwritten rules of work (Jahoda et al. 2008; Winn and Hay 2009). Therefore, volunteering is seen as an opportunity for them to gain professional skills and experience which may help them obtain suitable job later on (Butcher and Wilton 2008; Held and Granholm 2007). In other cases, opting for volunteering stems from its flexible nature and from seeing it as an adapted employment framework. Bates (2002), for example, reported that adults with mild intellectual deficits preferred volunteering over conventional work, since it fits better with family commitments. Volunteering reinforces the volunteers' sense of self-worth, empowers them, improves verbal communication (Miller et al. 2002), and enables them to engage with social networks (Balandin et al. 2006b; Barlow and Hainsworth 2001; Cummins and Lau 2003).

It is very important to differentiate clearly between volunteering and paid work. Various studies report that individuals with intellectual disability viewed their volunteering as a job, even if unpaid, stressing their status in the



organization and the importance of their volunteer work to their daily routine (Trembath et al. 2009b). Such findings were also reported by Roker et al. (1998) and Nieto et al. (2015), who raised a serious concern that young volunteers with intellectual disability may agree to volunteering without being made aware of the real employment options available to them; or, alternatively, agreeing to a certain role in the organization without knowing what other volunteering options are available to them. The responsibility in this case lies with the organization's staff, who need to explain the essence of volunteering, understand the volunteers' motivation (volunteering vs. paid work) and enlist family members for support and advocacy (Nieto et al. 2015; Roker et al. 1998).

Five common motivations for volunteering have been identified among adults with multiple disabilities. They wish to (1) remain active and busy; (2) help people; (3) gain work experience; (4) meet people; and (5) "pay back" for the support received from their community. Additionally, finding a volunteering venue is an achievement in itself, bringing a higher sense of satisfaction and independence during the volunteering (Choma and Ochocka 2005). Morton et al. (2010) interviewed 60 homeless persons with developmental disabilities from a purposive, snowball sampling on the streets of targeted urban areas in USA. They found that nearly half of the study sample were volunteers (48%) and suggested that homeless persons with disabilities volunteer at a significantly higher rate than the non-homeless general population. They saw this high rate of volunteering as an indicator that these volunteers desire to help others, despite the common belief that they spend most of their time just surviving. Bowgett (2005) supported the same findings of a high rate of volunteering among homeless people with disabilities explaining their motivation by the desire to feel better about themselves (66%), to increase employability (23%) and to give something back (11%). He reported that 79% of them had never volunteered prior to becoming homeless and that many of them continue doing so regularly. Thus maintaining a high level of stability in their roles, which indicates that volunteering expands their positive encounters with the community and considerably reduces time spent on aimlessly wandering the streets.

From an organizational perspective, a complex picture of contributions and obstacles emerges. On the one hand, working alongside volunteers with disability strengthens social ties and cohesiveness in an organization and generates a deeper meaning of work in the minds of employees. The presence of volunteers with disability educates staff about the reality of living with disabilities and helps create an empathic awareness which aids in dealing with social issues (Golan and Bar 2013; Choma and Ochocka 2005). The beneficiaries witness how volunteers who live with

disabilities are able to rehabilitate themselves; this carries great weight and value in their own rehabilitation process (Balandin et al. 2006b). Thus, volunteers with disabilities can help organizations to improve the quality of their service and accessibility, creating a bridge for employees and clients alike. On the other hand, the main challenge in dealing with volunteers with disabilities is to find the right job for their needs and cope with their disabilities (Bruce 2006; Miller et al. 2010; Trembath et al. 2009b). Balandin (2006a) reported that sometimes the attention of the staff shifts from clients to the volunteer; for example, an epileptic volunteer who requires immediate treatment, or a volunteer with mild intellectual disability who gets into disagreements and finds it hard to work with others. Coordinators stressed that although they were in need of specialized training as well as specific knowledge and equipment, their organization lacked the necessary resources. As a result, staff members may sometimes give volunteers the impression of being distant and unapproachable, which the volunteers might misinterpret as exclusion and/or objection to their presence in the organization. Therefore, a number of organizational support mechanisms have been suggested, such as obtaining prior background information on volunteers, appointing mentors to train volunteer coordinators, providing resources for purchasing equipment and improving their physical access.

From the volunteers' perspective, organizations tend to underestimate their abilities, offering them marginal roles that don't suit them and even offend them. Volunteers report feelings of alienation, claim they are not encouraged to participate fully and regard the organizations as being inaccessible to them (Roker et al. 1998). This is liable to create a vicious cycle: The individual with disability feels excluded from society and as a result doesn't form social and professional contacts which, in turn, might enable him/ her to rejoin society and obtain easier access to resources, and so on. This vicious-cycle only exacerbates their distress and passivity (Arten-Bergman and Rimmerman 2009). Therefore, social organizations ought to be more proactive in locating and recruiting volunteers with disabilities—while, at the same time, bridging environmental and social gaps and removing obstacles that deter them from participation.

#### Social Capital and Volunteers with Disabilities

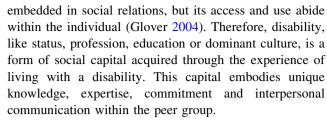
Social capital is a sociological construct that is increasingly gaining currency within volunteerism. The literature suggests that the decision to volunteer is shaped in part by a person's social capital (Putnam 2000). Coleman (1988) drew the initial distinction between *human capital*—i.e., personal circumstances that can promote volunteering (such as employment, place of residence, education etc.),



and social capital—i.e., social circumstances that can promote volunteering (such as an individual's social networks and relationships). According to this view, social capital increases the likelihood of volunteering. For example, people who participate in the labor market are more rooted in the community through social networks and formal organizations that encourage them to volunteer (Apinunmahakul and Delvin 2008; Freeman 1997; Lee and Brudney 2009). Education increases the interest in exploring career paths, and the desire to build skills which encourage volunteerism (Gomez and Gunderson 2003; Dee 2004; Freeman 1997). Family support and parents who have been engaged in voluntary activities may serve as a role model and provide an incentive for their children to volunteer (Bassani 2007). People with high income can afford the consumer value of volunteering in terms of time and financial resources; therefore, they volunteer more compared to those who lack financial means (Freeman 1997). This suggests that volunteering is a social privilege, reserved for people with economic capital which, in essence, discriminates against vulnerable populations.

Using Putnam's theoretical framework (1995, 2000), the literature suggests that volunteering can increase both the volunteer's bridging social capital (which aid in forming connections and social networks with external groups) and bonding social capital (which reinforcing the volunteer's identity and connections with the internal group, i.e., the members of his/her peer group) (Kay and Bradbury 2009; Day and Devlin 1998; Morgan 2013; Wilson and Musick 2000; Gesthuizen et al. 2008). Through volunteering, an individual can acquire symbolic capital, which is manifested in various aspects of volunteering, such as in developing skills, crystallizing values and identification with the beneficiary population, developing an identity of social awareness, and even attaining economic capital while volunteering, as a route to paid employment. Evidence in this area is diverse and has been used in relation to vulnerable populations and in particular in relation to volunteers with disabilities (Butcher and Wilton 2008; Cummins and Lau 2003; Held and Granholm 2007; Lee and Brudney 2012; Miller et al. 2010).

Bourdieu (1986) lays the theoretical foundation for viewing disability as social capital. In his theory, social capital is the resource available to actors as a function of their location in the structure of their social relations. In its embodied state, it includes behaviors that help the individual to interact with people, particularly with members of his own group. Its effects flow from the information, influence, and solidarity that is available to the actors. It also encompasses the social capital that is available to an actor by virtue of already established ties and from the social capital that actor can mobilize by forming new ties (Adler and Kwon 2002). Social capital is, therefore,



The first to suggest this within the theoretical framework of volunteering and disability were Campolieti et al. (2009, p. 196). They argued that "Social capital could be in the form of a disability that is present since birth, increasing the likelihood that an individual with a disability would have formed attachments based on trust and understanding with individuals like him or her." Trembath et al. (2009a, p. 87) also noted that "people with lifelong disability and those who use augmentative and alternative communication naturally develop a range of skills by virtue of their disability that are useful in a variety of volunteering roles. These skills include problem-solving abilities, a strong awareness of the need to communicate clearly, negotiation and time management skills, budgeting skills, and the ability to organize staff based on their own experiences organizing personal assistants."

This conception is still rare in the volunteering literature but is commonly represented in the critical view of disability (Oliver 1996) which emphasizes that people with disabilities not only have equal rights but can be defined as specialists possessing the ability to bring about change. The current study aims to deepen this viewpoint and focus on the unique contribution of volunteers with disabilities by virtue of their disability. It goes one step beyond Campolieti et al. (2009) by focusing on volunteers with disabilities who work in self-help organization for people with disabilities. Based on the theoretical literature we assume that volunteers with disabilities make use of their social capital as people with disabilities, while at the same time increasing their social capital through volunteering. This assumption underlies the aim of the current study in learning about the unique contribution made by volunteers due to their disability and suggests the following questions.

# **Research Questions**

There are three main research questions:

- 1. What does volunteering mean to adult individuals with disabilities volunteering in self-help organizations for people with disabilities? Two secondary questions derive from this:
  - (A) What is the motivation behind volunteering, transitioning from the status of "beneficiary"



- (service recipient) to that of a "volunteer" (service provider)?
- (B) What do volunteering and its benefits, challenges and experiences mean?
- 2. What are the unique insights of volunteers who assist other individuals like them with disabilities?
- 3. What do volunteers with disabilities suggest as an effective model for working with them?

## Design

The study used a qualitative design, utilizing a narrative case study approach, in which conduct in-depth interviews in order to obtain an in-depth understanding of volunteering among adult volunteers with disabilities. Since the structure of the narrative interview invites the narrator to relate to the past (that is, events that occurred prior to the interview) as well as to the future (near or distant), it creates an opportunity to investigate the narrator's personal perception of the changes that he and/or his surroundings have undergone, and to learn about the meaning they attach to these changes (Chase 2005). The narrative also constitutes a means for the narrator to make his voice heard (Spector-Mersel 2010), and is therefore essential to a study focusing on silenced and disadvantaged groups, whose narratives, either as individuals or as a collective, have not been given sufficient social expression in the past.

#### The Setting

The study targeted self-help organizations for people with disabilities. It included diverse and numerous major, longstanding Israeli organizations that engage in an array of issues, providing supportive services to people with physical disabilities (Access Israel, Ilan-Israel, Yad-Sarah, Milbat NGO), hearing disabilities (Bekol-Organization for the Hard of Hearing in Israel), mental disabilities (ENOSH—The Israeli Mental Health Association), intellectual disabilities (AKIM Israel) and visual disabilities (Almanarah). These organizations' activities include training people with disabilities, loaning equipment and devices, training and enrichment activities as well as advocacy vis-à-vis the authorities. One particularly interesting organization is Almanarah—an Arab organization from Nazareth, which provides a variety of services to blind Arab citizens. Their activities include a pioneering social enterprise maintaining a one-of-a-kind Arabic audio library for the blind in Israel, featuring original Arabic and translated literature from around the world. Another interesting organization is "Inbar," which aims to promote romantic relationships among people with disabilities by providing courses and training, organizing social meetings, and even matchmaking. Few organizations were governmental; nearly all of them belonged to municipal councils' departments caring for special populations. These organizations' volunteers were representatives of the municipal council, and their activities focused on connecting disabled citizens with the council's services. In a small number of municipalities, the activities of the department for special populations included forming local acting and choral groups for people with disabilities. Another few organizations offered hostels for people with mental disabilities.

## Sampling

The sampling method was purposive (Shkedi 2003), aimed at locating adult volunteers with disabilities volunteering for beneficiaries with disabilities. The rationale behind identifying and enlisting people from such organizations was based on studying their unique insights and attitudes toward the beneficiary client population. Another aim of the sampling was to locate adult volunteers who have been active in the organization for over a year. Our rationale for more than 1 year's volunteering was to study continuous, long-term volunteering and the specific insights gleaned from it. We began by interviewing volunteer coordinators and were later referred to volunteers who agreed to be interviewed. In some cases, we used the snowball sampling method, through which interviewees referred us to others whom they thought were relevant to the research.

The sample consisted of 35 volunteers, females (58%) and males (42%) with various disabilities including: impaired vision (28%), disabled limbs (26%), chronic illnesses (15%), impaired hearing (11%), mental disability (11%) and intellectual disability (9%). Most of them were Jews (78%) and the rest were Arabs (22%). The majority of participants were married (60%), and the rest single (35%) and widowed (5%). Most were educated (80%)—half (52%) being college graduates and the remainder with a high school education (20%), post-high school vocational education (20%) and postgraduates (8%). Most were not working (78%), with the rest working either part time (14%) or full time (8%). Many of them volunteered four five days a week (37%), and the others 2-3 days (28%), 1 day (20%) or less than 1 day a week (15%), typically for several hours on a weekly or biweekly basis. All have been volunteering for over a year. Many have been volunteering for over 10 years (35%), and the rest for 7–10 years (22%), 4-6 years (20%) or 1-3 years (23%). Their roles were diverse: regional special populations coordinator, seminar presenters, lecturers, teachers of Braille, reading, writing, playing music and acting. Some currently hold management positions: special population coordinators, committee



chairs and other management roles within their organizations.

#### The Interviews

The narrative interviews were designed to obtain a comprehensive picture of the interviewees' volunteering experiences, the impact of volunteering on their lives, and their contribution, as people with disabilities, to beneficiaries with similar disabilities. To this end, the interview was divided into three main parts.

First, interviewees were asked to give a brief, introductory description of themselves. The instructions in this section were intentionally vague so as to allow interviewees to introduce themselves as they see fit, with or without the disability, along with their past and present areas of interest. In cases where they asked the interviewer for guidance, they were repeatedly told to reply as they wish: "Start with whatever you like," "We're not looking for anything in particular," "Whatever you choose will be fine."

This was followed by an open part, in which interviewees were asked to tell the story of their volunteering from the moment they decided to volunteer up to the present. They were encouraged to give as many details as possible about experiences, events, people, roles, dilemmas and anything else that they deemed important in the context of their volunteering. In this part, adopting the approach suggested by Rosental (1993), we made every effort not to interrupt the narration, including avoiding asking interim questions or clarification questions, to allow interviewees to construct their story fluently from start to finish. During this part, we made note of any questions we wished to clarify later on. At the end of the narrative, we asked them for clarifications, examples and topics they had risen. In line with the aim of the research, the questions paid special attention to their attitudes as people with disabilities and to understanding the connections, insights and practices they described as such. For example, "Why did you use this particular practice?", "What, as a person with a disability, contributed to the result you described?", "In your opinion, has the fact that you are an individual with a disability influenced the initiative you've proposed to the organization and, if so, how?" and so on. This part enabled us to delve into the initial narrative ascertain the various contexts, experiences, related people, attitudes and personal outlooks, including the contribution of their disability to their volunteering.

In the third and final part, we used a uniform semistructured protocol for all interviewees, which we designed based on the extensive existing literature on volunteering. It contained 12 topics, as detailed herein: (1) motivation why they decided to volunteer, how they chose their field of volunteering, and why; (2) entering volunteer work training received upon taking on the role, their intake by the organization; (3) volunteering experiences, both positive and negative; (4) the essence of the role(s) they performed; (5) typical dilemmas and how they dealt with them; (6) relations with other volunteers and office holders in the organization; (7) burnout—did it occur, and if so, how they coped with it; (8) dropout—did it occur, and if so, what dilemmas were involved; (9) their view on how their disability contributed to their volunteering; (10) essential management methods for working with volunteers with disabilities; (11) the contribution of volunteering to their lives as people with disabilities; and (12) future personal goals. In this part we allowed the interview to evolve naturally without a predefined structure. Where certain topics had already been addressed in the second part, we skipped them. The aim of the instructor was to ensure that all the topics with all the interviewees would be covered.

The interviews were conducted face to face, in a quiet location chosen by the interviewees. Half of them took place at the organization in which they volunteer, and the other half in a quiet café or in their homes. The average interview lasted approximately 55 min, with a range of 35–90 min. Interviews were conducted in the interviewee's mother tongue (Hebrew or Arabic) and were recorded and transcribed verbatim. Interviews in Arabic were translated to Hebrew by a bilingual interviewer. The names of interviewees were omitted from the transcript replaced by aliases, for purposes of data analysis and writing of the findings.

Interviews were conducted by five interviewers—four of whom carried out 27 interviews in Hebrew, and one interviewer who handled eight interviews in Arabic. To prevent any bias derived from the difference in interviewers, the author and the interviewers worked together to formulate a uniform protocol, analyzing the transcripts of the first ten interviews as a pilot (the first two interviews performed by each interviewer). During these meetings, we discussed the interview methods, how to deal with clarification questions, and issues that should be elaborated on in the interviews. In this way, we tried to increase, as much as possible, the interviews' uniformity and their adherence to the research aims, and to minimize the effect of the different personal styles as much as possible.

#### **Data Analysis**

Thematic analysis was used to interpret the data, a flexible and active qualitative method for underdeveloped topics (Braun and Clarke 2006). Coding was primarily inductive (bottom-up), and an audit trail was maintained, including development of a coding manual, where each code was defined, negative cases identified, and participant quotes



extracted. However, reading the data was also deductive (top-down), searching whether or not volunteers' experiences supported existing assumptions about volunteering as a space through which social capital is generated or in which it is utilized (Ravitch and Carl 2016).

In the first stage, the author read the interviews repeatedly, one after the other, with reference to the main research questions, i.e., the meaning of volunteering, the contribution of volunteers as people with disabilities, and managing volunteers with disabilities. After gaining familiarity with the interviews, the process of open coding began, in which topics related to each question were coded according to the smallest units. Coding was not mutually exclusive, that is, one meaning unit (i.e., the volunteers' background) could be represented in more than one code. Initial open codes were clustered into preliminary themes, and then refined for coherence, with a central organizing concept defining each. Seven main categories emerged: a space without a disability; pooling resources; from volunteering to activism; volunteers' help strategies; managing volunteers; and quality volunteering. At this stage, we started reviewing themes by examining the compatibility of each unit to its corresponding category based on predefined criteria, and by examining the category map and the possibility of unifying and/or splitting the categories. Finally, an additional analysis conducted when producing the report yielded four base categories: (1) a space without a disability—including the meaning of volunteering for volunteers with disabilities, referring mainly to changes in personal insights that arose among the volunteers following their volunteering; (2) pooling of resources—illustrating another meaning of volunteering, which is reflected in the increase in volunteers' resources; (3) the social capital of volunteers with disabilities—referring to the unique contribution of these volunteers as people with disabilities; (4) quality volunteering—including the volunteers' perception of effective management strategies. All the names presented below are aliases. Quotes are presented verbatim in the interviewees' own words. The interpretations are by the author only.

# **Findings**

This chapter presents the findings concerning the meaning of volunteering among people with disabilities who volunteer within their peer group—beneficiaries with disabilities. The chapter is divided into four sub-sections: the first "A Space Without a Disability" will discuss the meaning of volunteering for adults with a disability, as manifested in the unique space that emerges for volunteers with disabilities within self-help organizations for people with disabilities; the second section "Pooling Resources" will continue to discuss the meaning of the role of volunteering

in the context of how it can increase the volunteers' social capital. The third section "The Social Capital of Volunteers with Disabilities" will examine the contribution of the disability to volunteering and, finally, the fourth section "Quality Volunteering" will discuss the conditions, resources and management strategies that foster meaningful volunteering for volunteers with disabilities.

A Space Without a Disability

One of the major findings was the volunteers' scope of activity. The volunteers described projects they had initiated, often alongside other projects and within several organizations, in diverse areas of interest. In some cases, their work encompassed a great deal of activity and resulted in very busy schedules. The scope and demands of their daily routines caused one to wonder exactly which disability they faced as individuals and whether it was present during their volunteering. The paradox was that personal narratives revealed oftentimes complex and multifaceted disabilities while, at the same time, the volunteering-related discourse was free of limitations and disabilities. This apparent contradiction was characteristic of all interviewees, most pointedly in Dina's story. Dina is a woman under long-term care who claims she needs 24/7 assistance. There is almost no daily activity, she says that she can perform alone, including moving about and getting out of bed, without her husband's help. Dina was injured in a car accident during her military service and became 100% disabled. As a volunteer, she has developed a very rich career that includes parallel activity in various spheres and organizations; e.g., delivering lectures at universities and social organizations, focusing on handicap devices (that help move the paralyzed body), guiding groups of Jewish and Arab women with disabilities; developing and leading a training course for sexuality counsellors for people with disabilities using technology; holding workshops on sexuality among people with disabilities; editing and publishing the NGO's quarterly newspaper; planning and organizing its annual general assembly meetings.

This is how she sums up her narrative of volunteering:

From the start, I preferred volunteer work over paid work, since as a volunteer I have much more flexibility, can make choices, and not be under some manager who restricts me. Giving to the community has massive power. Yes, I do need plenty of help constantly; I can do almost nothing on my own. I'm talking about showers, going to the bathroom, getting dressed, even turning in bed and getting in and out of bed. I can't do these things on my own. But when I give to the community I am simply a human being



and even more: I expand my boundaries as a person because I contribute something to the community and change it. I have no idea what would have happened otherwise, were it not for the accident. I don't know for certain, but I find it hard to believe my life could have been so exciting!

Dina's story is fascinating. The contradiction between her severe disability and the scope of her volunteering is awe-inspiring. Dina describes volunteering as a vast open field filled with freedom and the ability to move around. In this space, she initiated projects, which usually related to her disability, developing, implementing and leading them to fruition. At the same time, Dina emphasizes the severity of her disability three times, particularly the fact that there is almost nothing she can do on her own even getting out of bed or taking a shower. The synergy between her daily need for nursing assistance and her social leadership and ability to make an impact through volunteering makes one wonder about the unique space that has been created in the course of her volunteering to facilitate this for Dina, and what characterizes this space, which removes the boundaries and limitations of her work. In the meantime, says Dina, this synergy between her disability and the extensive freedom of action she enjoys when volunteering empowers her greatly and expands her boundaries as a human being. As she puts it, it makes her a proud person attuned to her disability and to life.

Another woman, named Leah discovered volunteering following severe deterioration in her hearing. She began volunteering at the information desk for the hearing impaired which had given her assistance. In her volunteering work, she accompanies the hearing impaired, delivers training on accessibility, counsels people on hearing aids, runs an MOH information counter and has established relevant support groups which she leads.

Eli, totally blind following an eye disease, said he uses all of the technology available to the blind, e.g., a talking PC, telephone, watch and other talking gadgets. He began his path with a minor position in the municipal welfare department, going on to acquire knowledge about people with disabilities, all the while expanding his collaborative relationships. As part of his volunteering as a special population coordinator in the city where he lives, he produces all sorts of activities accessible to individuals with disabilities including classes, trips and lectures.

Limited space does not allow us to describe all of the interviewees, but we can see how similar their stories are. Their particular disability determines the content and essence of their contribution. Their volunteering belongs to a wide spectrum of activities and achievements. In contrast to the prevalent perception of people with disabilities as being people whose lives revolve around coping with their

difficulties and limitations, the interviewees in this study describe rich, multi-disciplinary volunteering careers that involve team management, social projects and promoting processes for bettering their future. They regard themselves as people who are making a contribution; consequently, their sense of self-worth is high. Their practices illustrate volunteering as a professional career, including training and promotion of knowledge-based processes.

In analyzing all the case studies, it was concluded that when individuals with disabilities volunteer for other individuals with disabilities, their disability has no more restrictive role. Since volunteers are present within their peer group, their disability ceases to be a key component of their identity, and they manage to escape it while highlighting other traits and attributes of their identity. As Eli said, "When volunteering, I'm not a blind man; but just a man." That means that when people with disabilities volunteers within their peer group it not only take advantage of their profound ability to identify with the beneficiaries, but also allows them to break loose from the paradigm of being limited.

It is apparent that in self-help organizations for people with disabilities space is created that is quite detached from daily reality, and gives volunteers an opportunity to enter into a new dialogue between themselves as well as between them and the professionals. Once the disability constitutes social capital an opportunity arises for them to gain recognition for their expertise and change their perceptions of disability. In Dina's story, her initiatives were not fulfilled in a vacuum; for her to actualize them, she needed the professionals around her to recognize her expertise and provide her with tangible resources with which to implement her projects. This indicates that Dina's relationship with them is based on their need for her contribution, on their faith in her and her initiatives and on system-wide cooperation to implement them. Therefore, for Dina as well as other volunteers, volunteering in this unique space opens up new opportunities for self-determination as well as new, optimistic outlooks on of their future.

## Let's hear Dina once again:

I got in touch with a program for female mentors whose task is to inform clients of their rights and entitlements. That was my first time in female company, including Arab women, which was something I had always wanted. I also wanted to be with women because of the feminist angle. I suddenly identified myself with people with disabilities after previously feeling closer to people without them, simply by virtue of being just a regular, normal woman. Don't forget, my injury happened when I was just 19.5, and most of my life until then, I was a woman, a person



without disability. So, I joined [the organization]. And this was a life-changing event for me. I realized I had the ability to make an impact. So here I am, sitting there with several groups, a woman with severe disability; I am not mildly disabled, we can admit. But on the other hand, it makes a more open discourse possible, because it allows the women to know themselves better. What I also discovered was that once I charge my volunteering with political awareness—meaning, that I see how my volunteering can change people's consciousness and help them or increase their independence—then I can affect social change through my disability.

Dina points out here some important additional meanings of volunteering in relation to disability. She describes a circular journey, from being a person without a disability, getting injured at a young age, recognizing her deficiencies without feeling part of the community of people with disabilities; then getting acquainted with this community and being exposed to its needs, and finally, dedicating her efforts for the sake of people with disabilities and thereby reshaping her social identity as human being and citizen. She says she was surprised by the degree of influence her disability afforded her. Her severe disability "allows women to open up" and drives them to take action. As soon as she realized that all her preconceived notions regarding disability changed, as did the scope of her volunteering. The additional insight that emerges here is that volunteering among their peer group does not only increase volunteers' ability to influence and take action; it also turns disability into a source of pride.

## Pooling Resources

Another issue that emerged clearly from our findings was the pooling of volunteers' resources through their volunteer activity. Although it was evident in previous stories of volunteering (Dina, Leah and Eli), this issue emerged in many of the interviewees' narratives, and it is important to gain an in-depth understanding of how this pooling occurs during volunteering. We shall begin with Hila's story. Hila described a long and fascinating rehabilitation process, which revolved around volunteering. Hila, a social worker by profession, had undergone a psychotic episode following which she sought occupational rehabilitation. As part of supported employment, Hila started to work in sales in the free market, achieving remarkable success and appreciation from her team members. This motivated her to move on from working part-time to a full-time job in sales. As she progressed, the competitive, goal-oriented job caused her stress and triggered a second mental crisis. In response to her distress, a social worker assigned to her case offered her a training course for service providers which would, in effect, enable her to re-enter the same profession she had studied before becoming ill, in the role of rehabilitation mentor for people suffering from mental illness. Hila described this decision as a defining moment in her life, which has "restored her ability to dream again" and mostly, to return to her profession. At the end of the training course, the social worker suggested that she work as a volunteer. Hila declined the offer, because she wanted to regain her status as a regular employee. However, after failing to find a paid position, and following some deliberation, she accepted the social worker's advice and started volunteering as rehabilitation supporter in a hostel near her home. Within a short time, she was offered a part-time paid job at the hostel. This offer, and the transition from volunteering to paid employment in her profession greatly empowered her, and she regards this as the high-point of her rehabilitation process.

Hila's story is instructive of the role of volunteering in the rehabilitation process and of its being a high-quality substitute for paid work. It enabled Hila to return to her profession, in an organization and area of her choice in comfortable conditions that suited her. In retrospect, volunteering later served as a bridge to employment, but not only from Hila's perspective; the job market also took her in with greater ease. Before volunteering, she was not hired to paid positions for reasons which she did not specify in the interview. But by volunteering she could exhibit her skills, and it was her manager who asked to expand her position. Hila's story shows that volunteering is a product of various resources, such as institutional support (her local social worker), and Hila's high motivation to develop and learn. Another interesting motif of her story is the external encouragement to volunteer (the social worker's advice), which indicates that external motivation can be a tool to harness and mobilize volunteers and that it does not undermine the volunteer's internal motivation.

Gil'ad, crippled from birth, graduated high school and went on to complete a master's degree in computer sciences, eventually finding himself at home with nothing to do. The job market would not accept him and placed many obstacles in his path. As a person with training in information systems, he decided to launch a non-profit organization devoted to advocating rights for people with disabilities. After a while, the organization became a social club run by a committee of nine members. With Gil'ad too, like Leah, Dina, and Hila his disability was what determined his type of occupation. His disability and repeated rejections spurred him to launch a project that made him independent and expanded both his resources and his social circles.

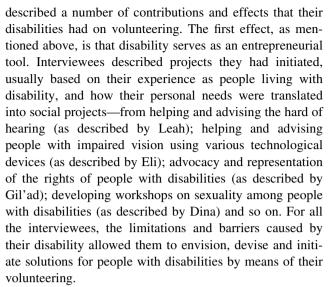
It is apparent from Hila and Gil'ad's stories that volunteering increases volunteers' social capital—including their *bridging* social capital (their contacts with external



groups—professionals, institutions, people without disabilities), as well as their bonding social capital (familiarity, closeness, empathy and forming relations with the peer group). Yet, the interviewees' stories differ somewhat in relation to social capital. For example, the position of Dina and Eli differs from that of Hila and Gil'ad. Dina emphasized her ability to choose between paid employment and volunteering, preferring the latter, which gave her more freedom and flexibility compared to paid work. Eli's biography includes a medical pension from his workplace alongside his volunteering. By contrast, Hila and Gil'ad started off without resources and underwent experiences of rejection from the job market; it can even be argued that it was a lack of choice that led them to volunteer. This reflects the current reality for people with disabilities: some have recognized disabilities (following workplace accidents or injuries during military service) and receive an increased disability allowance (from both their workplace and the state), while people with unrecognized disabilities receive only a state allowance. People with recognized disabilities in Israel (who receive an additional allowance) who participated in the present study acknowledge the fact that their volunteer work is made possible by their financial backing, alongside the additional advantages that volunteering gives them: social status, freedom and mobility. Indeed, the stories of Hila and Gil'ad demonstrate how volunteering can increase social capital: Hila managed to find paid employment in her chosen profession. Gil'ad managed to expand his work within a short period of time and turn it into a non-profit organization that advocates the rights of people with disabilities, which also became a social club managed by nine board members. His social activism leveraged his financial resources and expanded his social networks. Perhaps most importantly, it emerges from the interviews that even interviewees who started out with no resources were able to attain them through volunteering, and the quality of their volunteer work was not inferior to that of volunteers who did possess such resources. Hence, volunteering has a circular effect on an individual's resources: for people with resources, it serves as fertile ground for activism, while at the same time increasing the volunteers' resources. Another important aspect in this context is the initial path to volunteering. The interviews show that external support from different sources—welfare departments, social workers, self-help organizations—is a driving force for volunteering; therefore, encouraging volunteering from the outside is important as a means to increase volunteers' social capital.

The Social Capital of Volunteers with Disabilities

This chapter focuses on the unique contribution of volunteers as people with disabilities. The interviewees



A second effect of disability described by the volunteer interviewees was their ability to motivate beneficiaries. They describe their disability as a means of making the organization's services more accessible to clients, mainly due to a sense of potential partnership and identification that are formed with volunteers with disabilities. We saw this with Dina, who said that her disability makes the discourse within the women's group more open and intimate. In her own words, "If a woman with such a severe disability talks about her own life, then more and more women can open up about their feelings about the limitations in their lives." Therefore, communicating with volunteers with disabilities invites beneficiaries to somewhat lower their personal defenses when receiving help. Avi says:

Well, I don't look like I'm disabled, but if tomorrow I go to people's homes to check on them, the first thing I'll tell them will be: "Look guys, I'm also disabled, don't think that I'm perfectly fine... I'm also disabled, and we just came to help, to find out your problems, how you're getting on, if you have children or not, who brings you your medications, who brings you food. That's all."

Avi describes the reluctance of beneficiaries to be exposed as people with disabilities. Avi is a special populations coordinator in his town. He stressed that getting to know people with disabilities is an essential first step in helping them. This help often entails bringing them food, helping them to obtain a medication or even inviting them to a social gathering. Providing these services is possible only if they can be identified as people with disabilities. In his role as special populations coordinator, Avi visits their homes and asks them to join the town's community of people with disabilities. In the interview, he described the great complexity and delicacy which prevent the municipal



council from disclosing information about these people due to their right to privacy; yet, paradoxically, without obtaining this information, it is impossible to help them, promote their needs and increase their participation in the community. As a solution, Avi decided to initiate visits to the homes of people with disabilities whose demographic details he had received from other community members, and to reveal his own disability upon entering their homes as a first step to reduce the fear of being labelled as a person with disabilities. By doing this, he has been able to expand the community of people with disabilities in his town, and this has been spread by word of mouth.

#### Nidal said:

There are many types of disabled [people] in the organization; not all of them are blind. When I started volunteering here I heard a lot of talk among the children how I could possibly help them if I was blind, and things like that. I think it was not intended as disparagement but rather showed a lack of understanding. Eventually they realized that I am able to teach them despite my disability, so that feeling went away. By the way, it's quite natural to encounter this kind of talk. I've experienced it a lot in my life, not only in the organization but even when studying for my degree—people were always wondering how I managed. Even as a small boy people doubted if I'd manage to get anywhere in life, and I think it's because of that attitude that I am where I am today. It's one way to prove to me, and to others, that they were mistaken about me.

Nidal, who also speaks about disability as a way to lower defenses, presents in an interesting way the paradox of disability. He volunteers for an organization that helps people with various disabilities (not only visual). He describes the suspicions and doubts he often faces about his ability as a blind man to assist clients with physical and other disabilities; he therefore need to deal with rejection and exclusion, even in volunteering, from people with disabilities. Nidal points out that his life experience protects him from insult and that he has the emotional skills necessary to deal with such situations; in a conciliatory tone, he says that he is used to "such suspicion" and that it motivates him to "prove they were mistaken about him." He accepts the situation without making judgment, believing that "it's natural for them to think that way," while adopting a "long-distance vision" that by being able to teach them as a blind person, he can remove barriers and stabilize his relationship with them in the long run.

Interviewees also mentioned the role of the volunteer with disability as a rehabilitator. Interviewees stressed that encountering independent, autonomous and fulfilled volunteers has strong therapeutic value for beneficiaries. They considered a volunteer who has overcome his disability as an important social statement. The role model such a person offers—as someone who is actively involved in society—shatters the image of people with disabilities as being needy.

#### Here's how Leah described it:

In all modesty, I think I'm a very good example of a hearing-impaired person. The fact is I'm working, contributing to society, managing a family... actually doing everything. I'm not letting my disability hold me back. Oh, and when people come to the information desk, they see me having a conversation for about 3/4 hour, offering in-depth explanations, handing out my calling card for people to contact me by email, and always happy to help. If you summon me to Eilat [a distant southern resort town] tomorrow to deliver training on hearing loss, I'll be happy to go. I'm doing what I do very happily.

So, the rehabilitation is not only for the beneficiaries' sake. The volunteers view their volunteering as a contribution to societal rehabilitation. A person's role as a help provider, supporter, initiator and change agent leads to the altering of common perceptions of people with disabilities and increases this population's perceived social and economic value. The partnership that is formed between people with and without disabilities during voluntary activities breaks down social barriers and prejudices, since the act of volunteering demonstrates that similarity is greater than difference and that "disability" is a rather variable or universal issue.

# Here's Kamal:

I always love to help and train others, especially those who don't have this disability. I simply don't like to say "normal" people, since we all have certain limitations such as fear of elevators, or darkness, or flying—all of these sorts of disabilities—which may not be obvious but interfere with everyday life. So, it's fine to be aware of it and talk about it; not to let your fear affect your daily routine. In many of my lectures I handle questions from embarrassed children; but once I explain and share with them how I deal with my disability and how I still manage to live a regular life, they open up to me and share those things that restrict them in their lives...

Kamal's words illustrate that societal rehabilitation through volunteers with disabilities is achieved by changing the perception of disabilities: both by revealing the social capital inherent in the disability, and by changing the



perception of the disability itself. Instead of a binary view of disabilities—either being with or without a disability—it views disability as a range: an explicit or implicit disability that exists, one way or another, in everyone's life.

## Quality Volunteering

This is the final section of our findings. While reviewing the literature, we witnessed the multiple obstacles placed in the path of such volunteering including difficulties pairing volunteers with roles, a lack of trained staff able to support them, alienation and loneliness. The interviewees in this study suggested another angle—their narratives barely touched on difficulties, disappointments or lack of fulfillment, they saw volunteering as an engine for political and social fulfillment and for increasing their self-worth. Therefore, it is essential to understand what factors contributed to the volunteers' sense of success in the course of volunteering and, especially, what led them to expand their voluntary activities, as occurred throughout the current study.

All interviewees appear to have received freedom of action in their voluntary roles. They raised different ideas for helping beneficiaries with disabilities similar to their own and described their implementation; hence, they were given resources and leeway to implement their ideas. The language they used in the interviews reveals a high degree of autonomy: they described themselves as leaders, decision makers and in some cases managers of teams, projects, discussion groups, etc. Their status, as reflected from their description of their tasks, attests to the trust they gained and the centrality of their roles. The interviewees spoke about being significant to their beneficiaries and perceived themselves as vital contributors to society. Therefore, their work environment was characterized by their acceptance as volunteers and by recognition of their contribution. Another interesting aspect is how often they mentioned training and courses in their narratives. It is evident that many had been exposed to internal training-classes, workshops, discussion groups with colleagues and courses.

As for management strategies in working with them, some interviewees claimed that volunteering is done primarily through self-management; the volunteer is out there on his/her own, acting at his/her own discretion. They highlighted that such management is not a sign of weakness or a result of insufficient resources, but rather represents an effective approach whereby volunteers are not the organization's beneficiaries but its "partners" as well. They are given a free hand to plan, conceive and implement the assistance they provide, sometimes with no formal training but based solely on their life experience. The volunteers accepted the self-management style and considered it empowering. Some said they were activists, not volunteers, since they perform their volunteering with no

one supervising them. In general, the word "activists" reflected for them both their equal status as members of the organization and the political awareness which brought them to volunteering.

#### Here's what Galina said:

We have no budget. We have to start everything from scratch, and I'm currently trying to get a budget for a club for the hearing impaired. We didn't have any training on how to volunteer, either; it came from our soul. I received my training through my work experience. We aren't defined as volunteers; therefore, no one supervises us. We do volunteer work but are called 'activists'.

It seems that Galina accepts the need to "figure it out" on her own and, as a rule, this was one of the study's conspicuous findings. It is also evident that she defines herself as an "activist" rather than a "volunteer." She explained that although she does unpaid volunteer work, she is autonomous in her role and is not subject to highly regulated supervision. Other interviewees shared Galina's definition, and it seems that referring to themselves as "activists" demonstrates their awareness of the significance of volunteering in civic activity, and their political motivation to volunteer to advance the interests of people with disabilities in society. In terms of management, it the meaning of these remarks concerns the organizations' ability to provide volunteers with a solid foundation for activism and social change through appropriate management strategies-including granting them autonomy in carrying out their tasks, encouraging initiative and allowing them freedom to develop designated projects. The interviewees' stories indicate that effective management is the kind that grants them equal representation, access to resources and means to realize the vision that drove them to volunteer. These results highlight the main role of management—developing social initiatives among volunteers.

Finally, let us introduce Dr. Revital Schwartz-Savirsky, who asked to be identified by her full name. Many of the interviewees mentioned her as a symbol of the activities of people with disability in Israel. Revital suffered from polio, which affected her arms and legs. While her arms have improved over the years, her lower limbs are still semiparalyzed. All her life she studied in mainstream schools thanks to her parents, who encouraged her and taught her there's nothing she cannot achieve with will power and effort. After high school she moved straight on to academia and completed her post-doctorate degree at the Technion—Israel Institute of Technology. Afterward, she had several paid positions and was never unemployed despite her disabilities. Following a request from the local mayor, Revital resigned her paid job and joined him, as a volunteer, to



undertake the position of city councilor. In that capacity she chaired four committees: Welfare, Transportation, Environmental Affairs and Women. Later on, she was asked to launch and manage *Access Israel—North.*<sup>1</sup> She sits on the board of *Etgarim*<sup>2</sup> and of *Mifras Ba'Galil [Sail in the Galilee]*, all of which are non-profit organizations. She also volunteers in *ILAN*, which for Revital represents closure of a sort—as it was that Foundation that had attended to her rehabilitation and sports training.

Revital's story is yet another major success story. Her volunteering career is expansive and eclectic. She has grown and advanced from the municipal to the regional and national arenas; she has crossed over the line from being a service provider to becoming a social and political activist in several organizations simultaneously. Revital's story joins the stories of the many interviewees in the current study, proving that there are people with disabilities who have positioned themselves at the center of society and not in its margins. The current study shows that volunteers are the ones that hold the organizational reins, in light of their key role in leading designated projects. These insights emphasize their central importance in planning and implementing social policy. Understanding the uniqueness of one's disability, which is manifest in the volunteers' social capital, is key to developing a culture that promotes integrative recruitment of volunteers.

#### Discussion

The present study points to "disability" as social capital and calls attention to the unique contribution of volunteers with disabilities to the community and to self-help organizations. Volunteers with disabilities bring with them unique knowledge related to their life experience as people coping with disabilities. This experience empowers them to generate dedicated projects, normally drawn from their own disability, as well as to provide assistance, based on partnership and equality, to beneficiaries with disabilities. Disability as social capital embedded in social relations and grants members social "credits" that can be used as capital to facilitate purposive action (Bourdieu 1986, pp. 248–249) has been strongly supported in this study: volunteers with disabilities can often empathize with beneficiaries and

profoundly understand the experience of living with disability. Their disability is a source of intimacy, and it therefore helps lower defenses among those receiving help, fosters openness and drives change. Volunteers with disability provide beneficiaries with a role model for rehabilitation, which they can then build upon as an attainable vision of their own. Even reactions of exclusion and suspicion on the part of beneficiaries had the effect of motivating volunteers to act in such a way as to prove "otherwise," a response attributed by volunteers to the skills they had gained through their own personal encounter with social exclusion. In his theory, Bourdieu is primarily concerned with how this capital interacts with wider structures to reproduce social inequalities (1986, pp. 253–256). It appears, however, that the same quality he mentions—the fact that social capital cannot be exchanged with other groups and is maintained by the group that possesses the capital—is also a means of curtailing inequalities in volunteering and of encouraging greater inclusion of volunteers with disabilities. According to this perspective, although volunteers with disabilities are neither more, nor less, competent than professionals or volunteers without disabilities, they are irreplaceable, and their uniqueness as people with disabilities is a key factor in the organization's success. As the current study indicates, volunteers with disabilities help organizations to improve the quality of their service and accessibility, thus creating a bridge for employees and clients alike.

Another important aspect that emerges from the current study is that volunteering increases the volunteers' social capital in numerous ways, according to the concepts put forth by Putnam (1995, 2000), Coleman (1988) and Bourdieu (1986). That is, volunteering helps volunteers build personal skills directly derived from their voluntary activity and deepens their partnership with colleagues, as well as their sense of belonging to the community of people with disabilities. It enables them to forge new social relationships, use their contacts to implement projects they initiate and, in some cases, even obtain financial resources by finding paid employment indirectly through their volunteering. It is therefore evident from our study that volunteering increases the volunteers' human, bridging and bonding capital. Volunteering, as described by our interviewees, was particularly influential in the shaping of their identities as people with disabilities; it allowed them to renegotiate their disability, their relations with others and their own identity as individuals in society. It turns out that in self-help organizations for people with disability, the disability no longer has a restrictive role. Since volunteers are present and act within their peer group, their disability stops being the sole key component of their identity (usually based on its deficits), and they manage to escape it while highlighting other traits and attributes of their



<sup>&</sup>lt;sup>1</sup> A non-profit organization aimed at promoting accessibility for people with disabilities and their families.

<sup>&</sup>lt;sup>2</sup> "Etgarim", meaning "challenges" in Hebrew, is a non-profit organization dedicated to integration of people with disabilities through outdoor sports, mainly cycling.

<sup>&</sup>lt;sup>3</sup> A non-profit organization aimed at providing for the needs of residents of the Western and Upper Galilee regions of Israel who do not benefit from the existing welfare and social services.

<sup>&</sup>lt;sup>4</sup> The Israeli Foundation for Handicapped Children.

identity. That means that volunteering in their peer group not only takes advantage of their profound abilities in interactions with the beneficiaries, but also allows them to break out of the paradigm of "being limited." Through this renegotiation, volunteering opens up new opportunities for self-determination as well as new outlooks on their future.

But is this negotiation, which occurs when volunteering within a unique space detached from the external reality, valid in other organizations that do not focus on providing support for people with disabilities? Based on our findings, we believe that it is. The study participants reported recognizing their own value and demonstrated self-efficacy in carrying out projects they had envisioned. They moved beyond the boundaries of their specific voluntary roles within help organizations and became activists for social change, which attests to their ability to use their social capital outside the narrow confines of volunteering. Social capital for Bourdieu (1986 p. 254–255) consists of two key elements: firstly, social networks and connections: contacts and group memberships which, through the accumulation of exchanges, obligations and shared identities, provide actual or potential support and access to valued resources; and secondly, sociability—the ability and disposition to sustain and use one's networks. In other words, according to Bourdieu, actors need to recognize their networks as a resource in order for these networks to constitute "social capital." Indeed, volunteers spoke extensively about this recognition. They were surprised to discover the effect of their disability on their volunteering and said that it was a defining "eureka!" moment of insight. According to their descriptions, from the moment they realized it, their attitudes toward volunteering changed, as did the scope of their activity; they stopped seeing themselves as "volunteers" and started calling themselves "activists." Such a definition of "activists" is used in the literature to describe volunteers who are not satisfied with merely providing service, but who are wide-ranging partners involved, among other things, in planning, decision making and taking action for specific aims. This activity influences the community members themselves, the organizations around them and decision makers at various levels (Monikandam-Givon and Belit-Cohen 2012; Sadan 2009). Therefore, the definition of volunteers as "activists" signifies their political awareness vis-à-vis their disability and their view of volunteering as an engine for broad political and social change for the sake of people with disabilities. We could say that once volunteers' identity as people with disabilities is recognized as being valuable capital, they have an increased ability to replicate positive relationships that developed while volunteering and to reposition themselves within social (and other) organizations, with or without disabilities.

This brings us to a third important point in the study—encouraging volunteering among people with disabilities. This study demonstrates that external encouragement to

volunteer (through social workers or other external entities—a friend or the local special populations coordinator), motivated them to volunteer and did not reduce the scope of their volunteering or their motivation to volunteer; on the contrary, it increased their capital and their resources in various spheres. This understanding has important implications for recruitment of volunteers. Despite the tendency to think of volunteering as being based on free will, literature on volunteering highlights the need to encourage volunteers to step up and volunteer. Literature shows that inequality in volunteering stems from the fact that some individuals in society are being called to volunteer while others are not (Bonnesen 2018; Lee and Brudney 2009). One's likelihood to be called to volunteer is dependent on one's human capital; for example, whether the individual is educated, participates in the job market, is active in a religious organization, or is a child of parents who volunteer (Freeman 1997). Consequently, populations lacking in human capital are overlooked vis-a-vis their inherent right to volunteer. Therefore, our recommendation joins that of other studies which support the active recruitment of volunteers ("reaching out") and encourage volunteering through active recruitment with the help of people close to the volunteers (Arten-Bergman and Rimmerman 2009; Yanay-Ventura and Yanay 2008; Yanay-Ventura and Livneh 2010; Hager and Brudney 2011; Schervish and Havens 1997). Perhaps help organizations for people with disabilities can be the first to initiate this approach and encourage their clients to become volunteers. Such a call from help organizations for people with disabilities will not only show recognition of the contribution of disability to the organization but will also provide optimal conditions for this volunteering.

For these plans to succeed, we must identify what constitutes quality volunteering and create appropriate conditions for volunteers. The literature emphasizes that volunteers with disabilities feel that organizations for the most part tend to underestimate their abilities, offering them marginal roles that don't suit them and even offend them. Volunteers report feelings of alienation, claim they are not encouraged to participate fully, and see the organizations as being inaccessible to them (Roker et al. 1998). Other studies highlighted that volunteers with disabilities face various difficulties including lack of accessibility (Andrews 2010; Reilly 2005), low awareness of their physical limitations, prejudice (Bruce 2006), rejection by some of their colleagues and a lack of capable staff to support them (Miller et al. 2005). However, this picture does not reflect the participants of the present study. Interviewees described their volunteering as a space of self-realization and freedom of action. They raised ideas for social projects and described their future implementation, suggesting that they were given resources to fulfill their ideas. The language they used in the interviews reveals a high degree of autonomy; they described themselves as leaders, decision makers and in some



cases, team managers. Their status as reflected from the description of their tasks attests to the trust they had gained and the centrality of their roles. Most of them had been exposed to training within the organizations—classes and discussion meetings with colleagues. In terms of management, this means that it is important for organizations to provide volunteers with a broad framework for civil activism and social change. An effective management style, therefore, is one that grants them representation, access to resources and the means to fulfill the vision that brought them to volunteering in the first place. In this context, it is important to have organizational flexibility in advancing projects not previously found on the organization's agenda. These results support models developed for the effective management of volunteers (Yanay-Ventura and Livneh 2010; Yanay-Ventura 2014; Gidron 2010) and emphasize the chief role of volunteer management—the development of social entrepreneurship among them.

The study has several contributions and limitations. Its limitations stem from the research design. This method of data collection, as well as the relatively small number of interviewees, does not allow for a broad generalization of the findings but could be used as a foundation for a proposal for further research and ultimate implementation. The current study focused mainly on people with physical disabilities but lacks reference to other important disabilities, such as mentalhealth-related disabilities and a wide range of cognitive disabilities. The study dealt with the meaning of volunteering for adults with disabilities, and it is important to complement it by researching its meaning for youth with disabilities, who are at the stage of shaping their self-identity as people with disabilities. It is vital to attain a deep understanding of the role of volunteering in the optimal consolidation of these adolescents' identities as individuals with disabilities and as future useful citizens. The study's main contribution is in changing the paradigm regarding disability and in revealing its advantages in organizations that aid people with disabilities and for civil society as a whole. The optimal combination of resources granted by help organizations, encouragement from professional carers to become involved in social activism, and effective management strategies would allow people with disabilities to enhance their ability to use their capital. This ability would undoubtedly have a positive impact on the volunteers' quality of life as well as the wellbeing of the community at large, as was described in detail by the interviewees in this study.

#### **Epilogue**

This article, which deals primarily with volunteering among people with disabilities, can provide a wider theoretical and social model. What has become clear during the research is that beneficiaries who work in their own help organization are given considerable space for activism, which for them is a game changer. Their life experience has given them tremendous capital consisting of knowledge and help practices, capital which alters the relations between "those that know" and the "recipients of knowledge" and even reverses these roles. As has emerged in this study, volunteers are the ones that hold the organizational reins, thanks to their central role in providing service to people with disabilities. They crossed over from the limited role of help-providers to become essential social activists in the wider realm of civil society. A profound understanding of volunteers' personal and social issues has meaningful implications for empowering other excluded populations. Recognizing life experience as social capital invites society to become functionally dependent on people who undergo life's challenges. This recognition involves defining them as experts in spearheading social changes and as a result, as the "owners" of these changes. The fact that this capital is acquired in symbolic and tacit ways that cannot be revealed, or transferred, to others except solely by the capital owners, also summons us to embrace new ways of learning, such as learning with help populations instead of learning about them. This paradigm of "life experience capital" may have fundamental implications for the functioning of civil society and for increasing the capital inherent in the individuals within it.

#### Compliance with Ethical Standards

Conflict of interest The author declares that she has no conflict of interest.

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