

13-14 July 2017

From Volunteerism to Activism

Volunteering among people with disability

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1. Abstract

This article examines the unique contribution of people with disabilities volunteer at self-help organizations for other people with disabilities, including the impact of volunteering on the lives and functioning of the volunteers. The article is based on qualitative research, which included 35 volunteers with physical, mental or cognitive disabilities. All of them work at 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 involved various organizations. They crossed from the role of merely extending services to the disabled and became activists for political and social change. Their practices suggest that the volunteers' self-identity as individuals with disabilities has shaped the way they help people. Therefore, understanding their unique approach to clients is a key factor in developing an organizational culture that promotes the integral recruitment of volunteers.

2. Theoretical background

Volunteering is an activity a person performs for the sake of others, freely given without material compensation (Cnaan, Handy & Wadsworth, 1996; Handy et al. 2000). The emphasis in volunteerism is that volunteering is not a onetime act of charity, but rather a personal, consistent and meaningful activity for the benefit of another person (a stranger) or a community that has some added social or personal value (Penner, 2004). The rationale behind volunteering for people with disabilities is their low employment rate. Volunteering, therefore, is an alternative employment option that grants a person the opportunity to be active and involved in the community, and to make an impact on society (Barron et al. 2009; Choma & Ochocka, 2005; Morton, Cunningham-Williams, & Gardiner, 2010). Additionally, it allows the individual to transform from being a recipient of welfare services to being an active citizen who contributes welfare services to the community (Bowgett, 2005; Cummins & Lau, 2003; Miller, Schleien, Brooke, Frisoli & Brooks, 2005).

The literature on volunteerism among people with disabilities emphasizes the employment motive behind volunteering (Grant, 2008; Roker, Player & Coleman, 1998; Trembath, Balandin, Togher & Stanliffe, 2010). Volunteers with disabilities want to gain work experience and they see volunteering as a bridge to the labor market. They expect that employment options that were previously inaccessible to them will open up during the course of volunteering (Butcher & Wilton, 2008; Held & Granholm, 2007). Also, they strive to explore their professional identity, gain practical

experience, make new contacts and meet professionals and, in doing so, improve their prospects for future employment (Miller et al. 2010; Reilly, 2005; Trembath, Balandin & Togher, 2009)). In other cases, for example, for people with more severe disabilities, volunteering is motivated by the need for flexible employment. Volunteerism is characterized by flexibility – in hours, roles and types of employment – which reinforces the perception of volunteering as adapting to a personalized framework and providing a meaningful leisure-time activity (Bates, 2002; Ferrari, Nota & Soresi, 2008; Patterson & Pegg, 2009; Van Asselt-Goverts, Embregts, Hendriks & Frielink, 2014).

However, from the volunteers' viewpoint, in the majority of cases they are offered positions far below their abilities. This generates frustration and undermines the importance of their volunteerism (Leipper, 2000; Miller, Schleien & Bedini, 2003). Even volunteer coordinators report that they struggle to understand the unique needs of each volunteer, and sometimes don't have volunteer positions that match their needs (Balandin, Llewellyn, Dew & Ballin, 2006). In this situation, when a suitable atmosphere is lacking, volunteers experience alienation and isolation, which only reinforces their repeated avoidance of volunteerism (Choma & Ochocka, 2005).

As we can see, the literature typically focuses on the problems that volunteers and organizations face. Based on social capital theory (Coleman, 1988; Putnam, 1995) this study focused on the unique insights the volunteers bring with them by virtue of living with a disability. According to this theory, social capital can be form of a disability and thus, increase the likelihood for someone to assist another person with a similar disability through the process of volunteerism (Campolieti, Gaomez, & Gounderson, 2009). Therefore, it is worthwhile to study the significance of volunteering in a peer group as well as the insights from assisting similar beneficiaries.

3. Methodology

The study's aim is to examine the significance of volunteering for self-help organizations for people with disabilities, with regards to the experiences, motivations, needs and challenges of the volunteers. Another aim is to examine the impact of a disability on volunteering by learning the volunteers' insights about assisting their beneficiaries as well as the organization.

The data collection is based on a sample of 35 volunteers with disabilities made up of Jews (78%), Arabs (22%), men (42%), and women (58%) with different types of disabilities including impaired vision (28%), disabled limbs (26%), chronic diseases (15%), impaired hearing (11%), mental disability (11%), and cognitive disability (9%). The majority of participants are married (60%) and the rest are either single (35%) or widowed (5%). The vast majority (80%) is educated – about half (52%) with bachelor degrees and the rest with a high-school education (20%), post-high-school education (20%) or master's degree (8%). The majority of participants (78%) are unemployed and the remainder work in part-time jobs (14%). Only 8% have full-time jobs. Many of them volunteer four or five days a week (37%) and the rest work two to three days a week (28%), one day a week (20%), or less than one day a week, typically a few hours once every week or two (15%). All of them have been volunteering for more than a year. Many of them have volunteered for ten years or more (35%) and the rest for 7–10 years (22%), 4–6 years (20%), or 1–3 years (23%).

Participants were sampled from a variety of self-help organizations for people with disabilities in Israel. In most cases, the interviewees were volunteering simultaneously at more than one organization, fulfilling various positions, including regional accessibility advocates, workshop facilitators, lecturers, Braille instructors, and as musicians and actors in local ensembles. Half of

them serve in administrative roles, such as special-population coordinators, heads of various committees, and administrators in the organization.

4. Results

One of the major findings was the volunteers' scope of activity. The volunteers described many projects they initiated, typically at the same time as other projects and in several organizations. In some cases, this work took place amid a busy personal schedule. When they spoke about their volunteering, it was a curiosity how they managed to do all these things with their disability. In other words, how did their disability affect their volunteering? This presented a paradox, because when they talked about their personal life, their disability was very evident, and yet, within the volunteer setting they appeared to be free of any sign of restriction or disability.

This paradox was especially present in a woman we shall call Doris. She is a woman under long-term care and claims that 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. Doris was injured in a car accident during her military service and was left 100% disabled. As a volunteer, she has developed a rich career that includes delivering lectures at colleges and social organizations, focusing on handicap devices (that help move the paralyzed body), guiding groups of women with disabilities, editing a monthly newsletter, organizing conferences, developing and teaching a course on sexuality, and other activities.

Another woman, named Leah, began volunteering at the information desk for a health maintenance organization for the hearing impaired. In her work, she provides general assistance to the hearing impaired, gives advice about which hearing aid to get, and instructs people on how to use the hearing aid. She has also initiated, set up, and led support groups for the hearing impaired.

Guy, who has been crippled from birth, graduated high school, and completed a master's degree in computer science. Nonetheless, he remained unemployed because the labor market wouldn't hire him. Guy established an association that advocates for the rights of people with disabilities. Within a short time, the association became a social club under the management of nine disabled committee members.

Eli, who is totally blind due to an eye disease, volunteers as a special-population coordinator in the city where he lives. In his work, he makes activities accessible to people with disabilities, including enrichment classes, fieldtrips and lectures. He described how he started out in a small position in the social welfare department. He gained knowledge about people with disabilities through classes he took and developed a rich volunteering career.

We can see how similar these four stories are. Their specific disability determined the purpose of their contribution. Also, they had a wide range of activities and achievements. Unlike the widespread attitude that the lives of people with disabilities revolve around their limitations, the interviewees in this study describe rich volunteering careers in multiple disciplines. They see themselves as contributing citizens and have high self-esteem. Even their work as volunteers demonstrates their professionalism, such as vocational training. Many engage in social initiatives in order to improve their future opportunities.

In analyzing all of the 35 case studies, it was concluded that when people with disabilities volunteer at self-help organizations; their disability plays only a minor role. Their disability stops being a central factor in their identity; furthermore, they succeed in breaking out of the mold of being disabled and display additional qualities. As Eli told us, "When I'm volunteering, I'm no longer a *blind* man, but just a *man*." In other words, when people with disabilities work within their peer

group it not only takes advantage of their profound ability to identify with the beneficiaries, but also allows them to break out of the paradigm of being limited.

Evidently, their volunteering creates a suitable psychological-social space that allows them to enter into a dialogue with themselves, with professional service providers, and with their general surroundings. Such a space changes their perception of their disability and themselves, and of the society in which they live. It also changes the “rules of the game” regarding the disabled, from exclusion to inclusion, as well as the range of opportunities available to them. In these self-help organizations, these volunteers have become knowledge experts and key players. Their volunteering activity yields them both knowledge and experience, which positively changes the quality of the relationships they form with others. Thus, volunteering opens up a new set of possibilities for defining themselves and a new outlook on the future.

It is also apparent that their self-identity as people with disabilities shapes the way they assist other people. Our basic assumption is that volunteers with disabilities, who assist others in a similar situation, possess unique capital that gives them insights into the appropriate way to assist others. And indeed, the volunteers frequently spoke about the added value they bring by virtue of living with a disability. The main value they bring is in serving as a role model of rehabilitation for other disabled individuals. When beneficiaries are exposed to volunteers with disabilities who are independent, autonomous, and satisfied with their lives, it contributes greatly to their rehabilitation. The organization also benefits, since the differences among its members foster tolerance and increase the ideological significance of the work itself. Such an organization learns from its volunteers how to extend services to different segments of the population, which improves the organization's functioning and increases its accessibility.

Finally, the volunteers frequently refer to themselves as “activists” and differentiate themselves from “volunteers.” They explain that although their work is unpaid and voluntary, they are autonomous in their roles and are not strictly managed. They claim that they've crossed the boundary, from extending focused service and assistance to engaging in social and political activity. They regard their self-management as evidence of an empowering organization rather than a weak organization. They emphasize self-management that involves “learning while doing” as well as the ability to come up with ideas and carry them out according to their best judgment. It follows, therefore, that effective management is of the type that grants them equal representation, access to resources, and the means to fulfill the vision that brought them to volunteering in the first place.

5. Discussion

The current study points to disability as a social resource. It also shows the unique contribution of volunteers with disabilities to the community and to self-help organizations. In the literature, one can usually observe numerous difficulties involved in such volunteering, including difficulties in finding suitable jobs, a lack of a skilled staff to support them, and feelings of alienation and isolation on the part of the volunteers (Balandin et al. 2006; Choma & Ochocka, 2005; Leipper, 2000; Miller et al. 2003). The volunteers who were interviewed in this study brought with them a different perspective, a contribution of volunteers with disabilities to social organizations. Their narratives contained almost no mention of difficulties, disappointments or feelings of unfulfillment. On the contrary, they viewed volunteering as an engine for political and social fulfillment and for increasing their own self-worth. They departed from the role of merely extending services to becoming activists for political and social change. For this reason, this study has been entitled, *From Volunteerism to Activism*. It is possible that focusing their volunteering activity on a peer group of

beneficiaries has had a positive effect on their volunteering experience. Organizations that assist people with disabilities have recognized disabilities as a resource and granted the volunteers a practical opportunity to make their voices heard. This stance, represented by the critical approach to disabilities (Oliver 1996), stresses that people with disabilities not only have equal rights, but are also experts who possess the ability to generate change. Such recognition is an essential condition for creating a space that enables successful mutual relations between the volunteer and the organization.

These insights suggest additional directions for social policy. First, we should consider recruiting more people with disabilities in order to benefit them, their beneficiaries and the organizations for which they volunteer. Second, we should create more psychological-social spaces in additional organizations, like the ones currently available to the volunteers in this study. We need to insure that the nature of these spaces encourage the volunteers to be self-directed, provide them with resources, and support their ideas. If these two steps are met, we can further promote volunteerism to activism, which can benefit both individuals and, in turn, society. These changes can have important implications toward the empowerment of people with disabilities.

6. References

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