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Self-advocacy of a person with a disability in the dual role of paid worker and volunteer: Theoretical considerations and a case study

The changing models of disability influence the way people with disabilities participate in social life, and how they can transform their life and environment. Such participation may take the form of work and volunteering, as well as participation in self-advocacy movements. This paper aims to explore how a woman with hearing impairment perceives her dual role as a regular worker and voluntary self-advocate within one organization that supports those with disabilities. During an interview, she highlighted the role of self-advocacy in her personal and professional life, including the opportunities this gave her to thrive, as well as indicated the potential her work had for raising disability awareness within society. The results are discussed in light of the current literature about the meaning of self-advocacy for people with disabilities.

Keywords: disability awareness, hearing impairment, paid work, self-advocacy, volunteerism

Self-adwokatura osoby z niepełnosprawnością w podwójnej roli pracownika i wolontariusza: Aspekty teoretyczne i studium przypadku

Modele niepełnosprawności wpływają na to, w jaki sposób osoby z niepełnosprawnościami uczestniczą w życiu społecznym i w jaki sposób mogą zmieniać swoje życie i środowisko, w którym funkcjonują. Partycypacja społeczna może przyjąć formę płatnej pracy lub wolontariatu, jak również uczestnictwa w ruchu samorzeczniczym (self-adwokatury). Artykuł ma na celu przedstawienie, w jaki sposób kobieta z niepełnosprawnością słuchu postrzega swoją podwójną rolę: płatnego pracownika oraz samorzeczniczki w organizacji wspierającej osoby z niepełnosprawnościami. Podczas wywiadu, podkreślała ona rolę self-adwokatury w jej osobistym i zawodowym życiu, w tym szanse na rozwój, jaki daje ta aktywność, oraz wskazała na potencjał, który ma jej praca w aspekcie podnoszenia świadomości społecznej na temat niepełnosprawności. Wyniki są przedyskutowane w kontekście współczesnej literatury dotyczącej znaczenia self-adwokatury dla osób z niepełnosprawnościami.

Słowa kluczowe: niepełnosprawność słuchu, praca zarobkowa, self-adwokatura, wiedza o niepełnosprawności, wolontariat

Introduction

Illnesses and disabilities are health conditions affecting the body and mind, but also the key areas of social functioning, such as employment of personal relationships (Van Brakel et al. 2006). The model of disability perception has changed from medical to social and functional throughout the last century (Smart, Smart 2006), resulting in a modern biopsychosocial understanding of disability as reflected in the International Classification of Functioning, Disability and Health (ICF; WHO 2001). According to this classification, problems in human health and functioning might be classified as „impairments" at the body level, „activity limitations" at the performance of activities level, and „participation restrictions" at the level of involvement in live situations (WHO 2001). Often it is observed, that the restricted social inclusion is importantly affecting the person with a disability and their everyday functioning (Cardol et al. 2002), at a level comparable to the underlying health condition (Van Brakel et al. 2006). According to the ICF, the environment of the person with a disability and the society as a whole plays a crucial role in the „disablement" process. Creating opportunities for all members of society to participate in the social, family, and work life is crucial for the well-being and development of people with disabilities (Luu 2019).

According to the social role valorization theory (Wolfensberger 1983) playing socially accepted roles enables an individual to derive the same good things from life as others who do not have disabilities. One of the ways to promote inclusion and broadening opportunities for participation and playing respected roles in the society by people with disabilities is to raise disability awareness in the society. A form of engaging people with disabilities in a socially accepted role and, at the same time, raising disability awareness and reducing the stigma might be giving voice to the people with disabilities themselves through promoting their activism and self-advocacy (Kimball et al. 2016).

Self-advocacy is defined as the capability to act for one's own sake (individual self-advocacy, Ryan, Griffiths 2015; Stuntzner, Hartley 2005), but also as gathering together to act for a group (group self-advocacy) one is a member of, or raising awareness in the society about the group and the problems it encounters (public self-advocacy; Ryan, Griffiths 2015). Self-advocacy may be viewed as competence that should be learned by all individuals entering adulthood and is particularly important for people with disabilities (Nowakowska 2018; Vessey, Miola 1997). Kimball and colleagues (2016) found out that activist tendencies and advocacy skills are learned in early life by parental modelling. Test and colleagues (2005) suggest that self-advocacy consists of four important components: knowledge of rights, knowledge of self, leadership, and communication. Participation in the self-advocacy movement facilitates gaining such competencies and self-consciousness, to support coping in everyday life. The component of the knowledge of rights is especially important, given that people with disabilities are continuously striving to uphold their rights (UN 2006), an effort which is visible and ongoing, for instance, in Central European countries such as Poland (Jaglińska 2018; Żyta, Ćwirynkało 2016). Observable forms of this struggle are, for example, the increasing number of people with disabilities who are active in social life, including regular and paid work (Ferrari et al. 2017) and volunteering (Nowakowska 2020; Southby, South 2016).

Self-advocacy groups for people with disabilities in the world had been formed most often by the environments of people with learning difficulties or intellectual disabilities (Goodley, 2005; Williams, Shoultz 1984), mainly due to the relative highest degree of oppression experienced by this group of people with disabilities. however, they can be formed out of any minority group as an answer to the need for self-determination. Participation in self-advocacy groups can have beneficial effects on the development of people with disabilities (Fenn, Scior 2019; Tilley et al. 2020). Anderson and Bigby (2017) basing on a grounded theory approach, formed a self-advocacy model, identified that participation in self-advocacy groups had the potential to create opportunities for positive changes in the lives of people with disabilities and to produce engagement in life and confidence. Multiple positive identities can be formed thanks to self-advocacy activism, e.g., an expert, an independent person, a business-like person, or simply – a self-advocate. Although the model was designed based on groups of self-advocates with intellectual disabilities only, potentially it can apply to various self-advocacy groups formed also by other people with disabilities or other minorities.

Self-advocacy groups most often function under the auspices of organizations supporting people with disabilities – associations, non-governmental organizations, or similar institutions; and these institutions are the primary contexts to understand the features of self-advocacy (Goodley, Ramcharan 2010; Petri et al. 2020). In literature, accounts from the professional staff and self-advocates can be found, however, no studies have focused on people who play several roles at the organization at the same time.

This paper aims to provide an exemplification of the self-advocacy features realized by a person with several disabilities, who is a paid worker at an organization supporting people with disabilities, and, at the same time, a self-advocate, performing this role as extra and often non-remunerated (volunteer) duties in the same organization. The goal of this paper was to explore the opinions the participant presented to discover the personal meaning of working for the minority group she belonged to within an organization supporting people with disabilities.

Method

Note on the research project

This case study is a part of a larger project focusing on the evaluation of the effects of the activity of a selected organization in one of the biggest cities of Poland. The name of the organization is not revealed due to the protection of the anonymity of the participant. The material from this interview has not been published elsewhere.

Participant information and rationale for preparing a case study

The study was conducted as a case study of a 30-year old woman who was an employee of a nongovernmental organization supporting people with disabilities and health problems in one of the biggest cities of Poland. The self-advocates in the organization were forming a group of self-help and a platform for exchanging views and finding solutions for their everyday problems, as well as, thanks to a project financed externally, acted as "social educators" who conducted anti-discriminatory workshops for various audiences (e.g., students, potential employers). The participant was diagnosed with a genetic disease at birth, which caused hair loss as well as hearing impairment starting in childhood. She started being active in the self-advocacy group 13 years prior to the study, and after years of being the beneficiary of the organization's work, she was offered a regular job in the organization. The interview was analyzed as a case study due to the unique role of this person in the organization – this was the only person who acted in both a role of the employee and self-advocate, crossing the boundary between the professional staff in the organization and its beneficiaries.

Procedure

The case study evidence was collected through a semi-structured interview. The interview consisted of questions regarding motivation to become a self-advocate, how it happened that the participant decided to become a self-advocate, how did she learn about the opportunity; what is most important in being a self-advocate for her, what is most difficult in being a self-advocate, what did she learn thanks to being a self-advocate, did anything change in her life thanks to the engagement and whether she would recommend becoming a self-advocate to other people with disability.

The study was conducted in the organization where the participant was working, in a separate room. Only the author of the study and the participant were present in the room during the interview. The interview was recorded (audio) and later transcribed verbatim for analysis purposes.

Data analysis

The method of qualitative data analysis employed in this paper was thematic analysis (Braun & Clarke 2006). Two initial themes were pre-defined before the first reading of the material: the personal meaning of the self-advocate role and the features of the dual role in the organization. At first, the material was read and extracts matching the themes of interest were highlighted. The second reading had the same goal. The third reading concentrated on forming sub-themes that emerged. Then, the sub-themes were re-named to adequately convey the meaning of the extracts, organized, and grouped. That resulted in four themes that will be presented in the Results section:

1. Working as a self-advocate as a form of opening up;
2. Soft skills: impossible becomes possible;
3. Sharing disability experiences with the public;
4. The special features of the dual role in the organization.

Ethics

The study conformed to the standards of the Declaration of Helsinki. The participant provided informed, written consent for conducting the interview, audio recording, transcribing, and using the material for scientific purposes. The interview schedule was approved by an institutional ethics committee board at «name hidden for peer review».

Results

The square brackets include text added by the author to clarify the context of the respondent's message.

Working as a self-advocate as a form of opening-up

Being both a regular worker and a volunteer self-advocate allowed the respondent to become more open about herself and her disability. She also indicated that she could serve as a role model for others.

> „What is most important [in being a self-advocate]? I think that most of all, to have the conviction that I want that [to be a self-advocate] and, above all, that I have readiness and openness to talk about myself. That is not something bad or shameful because the fact that I can say I am a person with a disability, that I don't have hair, has nothing to do with my worth as a person. (…) I think what is crucial to me is that even though I tell people a lot about myself, I still feel comfortable talking about myself. (…) People, who meet me in the organization or outside it say that they can learn a lot from me".

Stress due to the stigma of disability is a source of distress; in the case of the participant, self-advocacy enabled her to enhance her self-esteem and sense of worth as a person. In turn, due to the positive image she built about herself, opening up did not cause discomfort. Despite sharing information about herself and her difficulties with others. This suggests that the atmosphere of the self-advocacy group is positive, creating space for showing own real self. She also mentioned acting as a role model for people from her organization and outside. This is similar to the idea of social valorization theory by Wolfensberger (1983), given that playing a socially accepted role of self-advocate enabled the participant to derive respect from others and feel dignified.

She shared a story when her readiness to talk about disability encouraged another person to open up.

> "The best way to learn is to talk about experiences and to encourage other people to do so. (…) Once I went to a rehabilitation camp (…) and one day I talked about a problem I have, the wig I wear every day, and how during summer I wear a headscarf. Because I went to this camp, I was afraid that when I slept in the wig, it was going to fall off (…). So I decided to wear a headscarf only and talk publicly about it. And I made a friend who had schizophrenia. If I could talk about my difficult experience, why couldn't she? And she followed my example [and talked about her experience of schizophrenia]. I think that it's the best example that social educators are to break [stereotypes], speak out, show people that regardless of disability, of constraints, everyone has the right to fulfill oneself in life".

Again, this quotation shows that self-advocacy enabled the participant to open up and be sincere in showing her difficulties. Moreover, her attitude resulted in encouraging other people to speak up, which is an example of disseminating a positive tendency for people to become less tense or ashamed about their difficulties, and as a result, enhancing their self-esteem. This information indicates the impact of self-advocacy on both individual development and encouraging others to speak out about their disability issues. It is especially important to accept oneself and to act confidently as an advocate against discrimination of one's minority group.

Soft skills: impossible becomes possible

The self-advocacy and work experiences equipped her with new skills, especially communication skills, and steered her towards self-development.

> „I learn all the time, every day. (…), I am constantly improving myself. I don't talk only about good things, but also about difficulties I encounter in the workplace. I can solve problems as they happen".

Therefore, the self-advocacy activity enabled the participant to develop also in the professional field, making it possible for her to exercise and learn communication skills, which in turn facilitated successful problem-solving. The respondent mentioned the support of the self-advocacy group, her husband, and colleagues who help her to thrive and overcome difficulties that once seemed impossible.

> „If it wasn't for this organization, my participation in the [self-advocacy] project, people who work here, my colleagues, my husband, who also puts in a lot of his private time here [in the self-advocacy group], I think I wouldn't be the person I am now, so open. I can overcome many things, play many social roles. The fact that I can be a paid worker, (…) this is my first paid work. I didn't work before due to health issues. I had a doctor's note that I couldn't, but, surprisingly, the impossible became possible".

This piece of evidence suggests how the feeling of being needed, as well as the opportunities provided by social inclusion, might positively influence the self-efficacy of a person with a disability and their coping skills. Similar to the previous quotations, the issue of playing various social roles is present here, suggesting that self-advocacy facilitated the process of checking out own capabilities in various roles, but also helped the participant to become a regular employee.

Sharing disability experiences with the public

The opportunity to share disability experiences with the public was the very essence of the choice the respondent made to enroll in the self-advocacy group.

> "Educators go outside to various institutions, and I like contact with people. I am familiar with that, so I thought that if I could share my experiences from primary school, high schools I attended. Why wouldn't I if I can, if I'm ready if I am willing to do so".

However, the respondent mentioned having difficulties in talking about experiences.

> "It's difficult for me (…) [to decide] what is worth saying, what would be appropriate to say for me to feel good with that, as well as for the recipient to feel good with it, for it all to go in a good, positive direction, to encourage these people [recipients] [to have contact with people with disabilities]. (…) I like talking about myself, but my main con-

> cern is that I could say something emotional or irritating. [I wonder] if I am talking about it in the right moment".

Raising awareness about disability in various groups is at the same time pleasant and causing worry. The worries concentrate mainly on how the participant will be perceived by the audience of the meetings conducted by self-advocates. The quotation regarding how the respondent wonders whether she talks about a difficult matter in the right moment for the audience shows how she takes the perspective of the people who are meeting participants. She was ready to invite other people with disabilities to become "social educators". She mentioned the therapeutic value of such an activity.

> „I'm fully convinced to invite people [with disabilities to become self-advocates], who can work (…) but everyone who has time and wants to can become a social educator because (…) it's great therapy, to say, for a person who is an educator, but also for the recipient of the [anti-discriminatory] workshops".

The anti-discriminatory workshops conducted by the self-advocates enable them to speak up and share experiences, as well as interact with the audience. Understanding the group of people with disabilities probably can help the workshop recipient become more tolerant toward „otherness" as well as toward their own difficulties.

The respondent also indicated that raising disability awareness by self-advocates could be complemented with contributions from those without disabilities, e.g., via conducting anti-discriminatory workshops together.

> „It would be balanced cooperation (…) Conducting [workshops] together, doing something together, organizing workshops".

The opportunity to speak out and share experiences with the public outside the organization was very important for the respondent in taking up the responsibility of self-advocacy. What was highlighted by the respondent was the idea of cooperation between people with disabilities and those without to combat stereotypes. This might be a fruitful idea for people to socialize and work together toward a better co-existence in the social world. Such joint initiatives are often goals of anti-discriminatory workshops. The respondent probably recommended involving the audience in conducting the workshop for the self-advocates and the audience to mutually explore the perspective of the „other side" of the workshop.

The special features of the dual role in the organization

The respondent also stated that it is important for her that her opinion is valued in the workplace. As a regular worker, she felt like an extraordinary person who understood other people with disabilities better due to her experiences.

> "[What is important in self-advocacy is] the fact that I can be a partner at work, that my opinion is important, that it counts. I also have an outlook on various things. At work, my colleagues understand me and other self-advocates [beneficiaries of the organization], but they don't understand them as well as I do. I understand what the other person feel".

This indicates how crucial it might be to encourage people with disabilities in supporting their minority group. The understanding that can be provided by a person with a disability to another person with a disability is invaluable, making it possible to tailor the support suggested by an organization more effectively.

Discussion

This brief piece of evidence highlights the opportunities of both the regular and voluntary self-advocacy work of a person with a disability to develop skills useful in personal and professional life, as well as to promote disability awareness within society. This is congruent with the results present in the literature regarding the positive aspects of participation in self-advocacy initiatives by people with disabilities (Anderson, Bigby 2017; Fenn, Scior 2019; Tilley et al. 2020). The respondent raised several very interesting topics of the impact of her dual role and contributed to a better understanding of the perspective self-advocates have of their work. For instance, she mentioned that she is a worker who understands the beneficiaries of the organization she works in due to her experiences as a person with a disability and a self-advocate. Employment of people with disabilities generally might have beneficial effects on their personal development (Schur, 2002), and employment in organizations supporting people with disabilities might be a gateway for broad inclusion of people with disabilities, and encouraging them personally, as well as the people who are only beneficiaries and not workers of the organization, to participate more fully in planning therapeutic programs.

The respondent thanks to her engagement in the self-advocacy group gained the opportunity to work, establish meaningful relationships and feel self-efficacious and needed, which might be viewed as a form of social role valorization and deriving good things from life thanks to playing a socially respected role (Wolfensberger 1983). Both of the roles played by the respondent (employee and volunteer self-advocate) are still not obvious when considering people with disabilities (Saunders, Nedelec 2014; Southby, South 2016). The evidence provided by the study suggests that both of them might be a valuable source of personal development, including the development of self-esteem and soft skills. It is also interesting that to date most self-advocacy studies concentrated on the benefits of self-advocacy to people with intellectual disabilities (Goodley 2005). This brief piece of evidence shows the meaning it may have to a person with the genetic illness and hearing impairment and suggests that for people experiencing different types of disability the impact of self-advocacy participation may also be important and encouraging positive life changes.

The main limitation of the study is the fact that it bases on qualitative evidence gathered from one person only. However, due to the uniqueness of the role played by this self-advocate in the organization (employee and self-advocate with a disability), it helps to understand the perspective of a person who is involved both professionally and privately in the activism supporting people with disabilities and their full participation in social life. Participation is one of the key concepts in public health (Van Brakel et al. 2006). Creating inclusive environments might contribute to the well-being of people with disabilities and making it possible for them to take control over their lives, make decisions about themselves, and truly self-advocate – realizing the human rights that are guaranteed by United Nations conventions (UN 2006), but inherent for all people. The phenomenon of self-advocacy and the impact of working for one's minority group, specifically among people with disabilities in general and people with hearing impairment, is worth further investigation beyond a case study due to the scarcity of existing data on this topic.

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