

## The Process of Becoming an Activist: Identity Transformations in Autobiographical Narratives of Women with Disabilities in Poland<sup>1</sup>

Kamila Albin D University of Warsaw

https://doi.org/10.18778/1733-8069.19.3.09

#### **Keywords**:

activism, women with disabilities, turning points, identity, autobiographical narrative interview **Abstract:** This article reconstructs identity transformations that manifest themselves in the biographies of female activists with disabilities. The empirical material was collected through autobiographical narrative interviews. The author identifies key stages and turning points for these identity transformations. She also analyzes the role of significant others in the process of identity transformations and becoming an activist. The analysis of narratives of women with congenital disabilities demonstrates that the incorporation of disability as an element of individual self-definition is an important factor contributing to identity transformations. In the analyzed narratives, disability represents a biographical resource and, like identity, is processual in nature. Although it accompanies the individual from birth, it undergoes reinterpretations at different stages of life.

#### Kamila Albin

PhD candidate in the Institute of Applied Social Sciences, University of Warsaw. A sociologist by training, her research interests evolve around disability studies. Her dissertation is devoted to self-advocacy and activism of women with disabilities in biographical perspective.

e-mail: k.albin@uw.edu.pl

1 This article was funded by the Polish National Centre of Science (NCN), grant no. 2021/41/N/HS6/01558 entitled "Activists, leaders, (self-)advocats. Experiences of activism in autobiographical narratives of women with disabilities in Poland".



© by the author, licensee University of Lodz, Poland This article is an open access article distributed under the terms and conditions of the Creative Commons Attribution license CC-BY-NC-ND 4.0 (https://creativecommons.org/licenses/by-nc-nd/4.0/)

#### Introduction

Despite the fact that activism of persons with disabilities can be traced well into the past, wider interest in social and political dimensions of disability dates only to the 1960s and 1970s. This was, above all, due to activism of organizations set up by persons with disabilities to represent their interests (Barnes, 1997).

In the UK, this activism was foregrounded in the social model of disability postulated by the Union of Physically Impaired Against Segregation (Union of the Physically Impaired Against Segregation, 1975/1997) and in attempts to reconstruct the system that treated disability as a medical phenomenon (Shakespeare, 1993). At the same time, in the USA, inspired by civil rights movements of minorities fighting for the recognition of their equal rights, the Independent Living Movement was born (Shakespeare, 1993; McDonald, Oxford, 1995).

As for Poland, due to, among other factors, economic and social transformations initiated in 1989, the emancipation of persons with disabilities proceeded slower than in the Western countries, and grass-root organizations of people with disabilities have little impact on public debate (Kubicki, Bakalarczyk, Mackiewicz-Ziccardi, 2019). It seems that the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), ratified by Poland in 2012, is a focal point around which the identity and activism of the Polish movement of persons with disabilities is constructed (Kocejko, 2018; Kubicki, Bakalarczyk, Mackiewicz-Ziccardi, 2019).<sup>2</sup>

Viewing activism from the above-mentioned perspective of organizations of people with disabilities, it can be defined as action-oriented attitude, often within the context of social or political movement. Although activism is primarily associated with collective action, individuals and their actions can also be analyzed within the framework of this concept if and when their actions concentrate on causes of which they are not the sole beneficiaries (Nepveux, 2015).

That is why I posit that the process of becoming an activist is part of the biographical transformations of an individual's identity.

The aim of this paper is to analyze the process of identity transformations that emerges from selected autobiographical narratives of women with congenital disabilities (n = 10).

An important element of identity transformation and the process of becoming an activist in the narratives of women with disabilities is the incorporation of disability as an element of individual self-definition. Disability here constitutes a biographical resource and, like identity, is processual.

<sup>2</sup> One such activity undertaken by organisations of people with disabilities, which is strictly related to the implementation of the UNCPRD in Poland, has been the Congress of Persons with Disabilities, held annually since 2015 (https://pfon. org/kongres/).

Although it accompanies the individual from birth, it is reinterpreted at different stages of their life. It seems that over time it becomes an important part of identity, as it is a focal point for the activism of women with disabilities at different stages of their lives.

Significant others (Mead, 1972) play an important role in these transformations. During the primary socialization (Berger, Luckmann, 1991), these mainly include the immediate family. In the first part of this paper, I will thus focus my attention on this group, since it is their perception of disability of a child that will be consequential for subsequent biographical processes. On the other hand, a key role in identity transformations is played by the disability community. Therefore, I will devote the second part of this paper to this aspect. It seems that identifying with a community is an important prerequisite of becoming its advocate.

Although this paper does not focus on the relationships between activism, gender, and disability, my intention is to illustrate more general processes with the narratives of women with disabilities. These processes lead an individual to a place where she becomes aware that she is an activist and that their personal troubles are problems of a wider group that she is part of.

Finally, it seems that research on the activism of women with disabilities makes this group more visible and their voices more heard, thus demonstrating that their personal stories of identity transitions and social engagement may increase their sense of agency and self-determination.

### Identity and biography

In the interactionist perspective (Blumer, 1969; Piotrowski, 1998), identity is not a fixed element, but is symbolic and processual, subject to constant transformation and redefinition that takes place through interactions with other social actors.

In line with this perspective and for the purposes of the present paper, I define identity in biographical terms as a reflexive project manifested in narratives constructed and ordered in the course of stories (Giddens, 1991). It is produced and sustained over time by the agent, who continuously interprets their positioning in the social environment, links the past with the future, taking into account all the consequential events, i.e. those that affect the self-understanding and development of 'the self' (Kumaniecka-Wiśniewska, 2006).

As the process of identity building and its anchoring in the biography unfolds, an individual has to do biographical work, which consists of recalling the past, repeating stories, interpreting and redefining the course of their life. In the course of biographical work, a transformation of the individual's relationship with themselves takes place (Schütze, 2008).

This paper will map key identity turning points in the biographies of female activists. Anselm Strauss (2007) defines them as significant changes occurring in human biographies under the influence of fateful events or difficult-to-predict changes in life concepts. Turning points lead to a reorganization of previous self-definition and a revision of the individual's conception of identity (Strauss, 2007). This radical change in self-perception is expressed in the phrase often found in autobiographies: 'I am no longer who I was before' (Bokszański, 1989: 135).

The processes of identity affirmation and formation that take place in the course of an individual's life never take place in a vacuum. The self-image constructed by an individual to a large extent arises through the process of negotiations with its environment and is based on how others perceive the individual. Significant others play a key role in these transformations (Mead, 1972). These are members of the closest family, peer groups, teachers, or other people who impact the course of their biographies, who are connected with the individual through strong and intense emotional bonds (Berger, Luckmann, 1991).

#### Methodology

Since the main interest of the study is to explore individual experiences of becoming an activist, and the subjective meanings attributed to them by the interviewees, the study is carried out within the paradigm of interpretive sociology. At the center of interest of sociologists conducting research in the interpretive paradigm lies the individual, understood as an agent capable of interpreting both social reality and themselves. Therefore, the researcher reconstructs the experiences of an individual, their ways of interpreting a given situation, and possible choices based upon this interpretation (Rokuszewska-Pawełek, 1996).

The research is conducted using the biographical method, specifically with the aid of the technique of autobiographical narrative interview (Schütze, 2008; Kaźmierska, Waniek, 2020).

Spontaneous narrative is a processual reconstruction of life experiences. It is not a mere sum of answers to the questions asked by the interviewer, but, rather, it uncovers both the different forms in which a human life may run and the ways in which individuals are entangled in social processes (Kaźmierska, Waniek, 2020: 15).

The principles that organize the life story emerging from the spontaneous narrative are called biographical process structures. Through these, an individual attempts to actively shape the course of their life. These structures include (Schütze, 2008):

 biographical action schemes – intentionally-designed actions taken to achieve an individual's specific plans (e.g. a career plan);

- 2) institutional expectation patterns moments and situations in which people act according to institutionally-shaped, normatively-defined and accepted life course patterns (e.g. pursuing an educational career or performing parental roles);
- 3) trajectories of suffering the experience of losing control over one's own life; it occurs when an individual is subjected to external events, independent of their will, which shape their biography; such an event could be, for example, the onset of a disability; the dominant sensation in the experience of trajectory is suffering;
- 4) creative metamorphoses of biographical identity unexpected, positive changes in an individual's life that lead to a creative transformation of biographical identity; it is the moment when a new line of biographical development is initiated.

The biographical method seems to be a promising methodology for disability research. As noted by Jolanta Rzeźnicka-Krupa (2009: 198), "the individual life stories of people with disabilities or their closest people shape a space in relation to which it becomes possible to analyse experiencing disability as an element of everyday life, the processes and mechanisms of coping with various limitations and difficulties, or the ways of understanding, interpreting and assigning meanings to various phenomena, events and situations that shape both the individual and social dimensions of living with disability". The use of an open-ended biographical interview format in research on the activism of women with disabilities seems particularly justified, as this area has not been the subject of broad and systematic academic inquiry to date, making it an open field for exploratory research.

In 2022, I carried out 10 interviews with women aged 28 to 51 working in the non-governmental organization (NGO) sector, informal collectives or unaffiliated, who self-identified as women with physical and sensory disabilities.

I conducted the interviews at a location chosen by the interviewee, usually at her home. Interviews lasted between 1.5 and 3.5 hours. Recruitment was carried out using the snowball sampling (Babbie, 2006) with the support of disability organizations and female leaders in the disability community.

The analysis of the collected material is inductive, meaning that theoretical generalizations are derived from the data collected during the research (Lofland et al., 2009).

The process of data analysis runs parallel to the process of conducting interviews (Hammersley, Atkinson, 2019). It begins at the time of the interview, when, during the phase in which selected issues are discussed in-depth, I share my initial interpretations with the interviewees so that they can discuss them with me, agreeing or disagreeing (Kvale, 2007; Silverman, 2017).

The analytical categories suggested in the latter part of this paper emerged in two ways. On the one hand, they were based on research questions, including the following ones: "What is the process of becoming an activist: what are the stages, turning points in the biographies of female activists?".

On the other hand, in distinction from quantitative studies, the data collected through biographical research are not a closed set of analytical categories defined by the scholar (Hammersley, Atkinson, 2019). That is why further questions emerged during careful reading of interview transcripts, including the following ones: "Which people are regarded by the women as the significant others: immediate family, friends, other people or organizations? What impact do significant others have on the transformation of identity as a person with disability and activist?".

By reading the narratives many times, I was able to isolate differences between individual biographies that inspire me to ask further questions, as well as similarities that enable me to draw generalizations regarding, for example, the ways in which activism manifests itself in biographical process structures and the role played by significant others in the course of biographies of women with disabilities (Kvale, Brinkmann, 2009).

#### The place of activism within biographical process structures

In the analyzed narratives, activism is framed in two ways: as a biographical metamorphosis and as a biographical scheme of action.

The first way in which activism can be present in biographical processes is when it is part of a metamorphosis whereby new possibilities open up in the course of an individual's life. The incorporation of activism as an element of identity is linked to the biographical work done by an interviewee.

The sense of agency initiates a new line of action in the individual's life. Such metamorphosis is suggested by the following passage from Maria's<sup>3</sup> narrative:

I think if we had met, like, ten years ago, you would have known me as a completely different person, because the fact that I am active in social causes comes from the fact that I myself once experienced a certain transformation (Maria, 28)<sup>4</sup>.

Secondly, for some of the female interviewees, becoming an activist represents a biographical scheme of action. At the narrative level, it manifests itself through phrases such as 'I have always wanted to' and emphasizing an interest in missionary or aid activities and a desire to take a 'meaningful' action:

<sup>3</sup> Names of participants were changed. Every quote is followed by pseudonimized name and age of study participant.

<sup>4</sup> So far, in the Polish research concerning the experience of disability in narratives and related identity processes, scholars have most often been applying the concept of trajectory (see, e.g., Wołowicz-Ruszkowska, 2013; Giermanowska et al., 2015). Undoubtedly, disability is often perceived and told as a trajectory causing chaos and suffering. However, it seems that the trajectory potential of disability lies not only in the layer of biological impairment, but also in the ingrained social view of the stigmatizing nature of disability (Goffman, 1963). This has implications for the institutional patterns of expectations associated with disability and people with disabilities, as well as the processes of identity transformation experienced by these people.

You know, I've generally always been very fond of various activities that are, like, missionary, the sort of making sense of things, this is something that always motivated me. And in primary school I was the president of the study aid club... And... then in high school I was also the president of the study aid youth section (Justyna, 51).

In the narrative quoted above, activism manifests itself as a subjectively-constructed career pathway (Strauss, 2007). It becomes the core around which the narrative is constructed. It attributes meaning to sequences of events and life experiences. It consistently manifests itself at subsequent stages of life, from the school period, when Justyna acts as the president of the student council, to the professional choices made along the career pathway: working in the non-governmental sector or in aid institutions such as children's homes, social welfare homes, or working with groups particularly vulnerable to various forms of exclusion, namely the disabled, the unemployed, people experiencing homeless, or people who are addicted to substances.

The women emphasize their personality traits that they believe are important in activism. These include leadership skills, the courage to speak up on behalf of others, to represent the group, the courage to contest, which they explicitly call rebellion, openness to new activities, the willingness to continuously learn and develop their competences, and the desire to work with others.

I feel that my activism started when I was 18. Back then I belonged to a punk subculture. It was like I was already rebelling very strongly against the system, against the way the world was. But I have the impression that it was very much still such an immature rebellion... Well, it was just so vague. It wasn't about disability or women's rights, it was more about animal rights, against corporations or against the circus and animals (Hanna, 46).

The above-quoted narrative demonstrates how the interviewee reframes her activism, which she describes as immature in its initial phase. Hanna was born in a small town in the south of Poland, where she completed primary and secondary school. For her university studies, she moved to a larger city, where she subsequently got a job. It was there that she started making contacts with NGOs, including feminist and disability advocacy organizations. Over the course of years, the activist's identity crystalizes, Hanna does biographical work that involves successive redefinitions of her self-concept, discovering new elements of identity over the course of her life and new fields of exclusion that prompt questions about the rights of women with disabilities or queer people with disabilities. It is to these fields of exclusion and marginalization that the activist directs her rebellion and agency in the subsequent stages of her life.

Like, as I went on my internship, that's when I somehow became very aware of my identity as a person with a disability. Before, let's say, I didn't feel it very much somehow, because I hadn't known any people with disabilities. Until I was thirty years old. I was surrounded mainly by healthy people without any disability, mostly boys and men. [...] I didn't realize at that time that I was a queer person, too. Well, and after I moved to [another city – author] and took part in

self-defense workshops for women, I realized that this is my path. And from that moment my activism started. I started asking myself questions about the rights of women with disabilities. In the meantime, I discovered my identity as a queer person and became very involved in queer activism, mainly among [queer people with – author] disabilities (Hanna, 46).

#### The role of significant others in identity transformations

At the beginning of this paper, I posited that, as regards women with disabilities, the process of becoming an activist is linked to the discovery of an identity of a person with a disability. Although disability is present from birth in the analyzed narratives, it is generally not part of self-definitions created until the age of twenty or even thirty. This is particularly the case for women with sensory disabilities (sight and hearing), which can, to some extent, remain invisible to those around them. A person with a sensory disability may pursue strategies to control the flow of information about themselves by hiding the stigma, or controlling it by reducing its importance in social relationships (Żuchowska-Skiba, 2016).

Significant others play an important role in the biographical process of accepting disability as part of self-identification. During childhood and adolescence, these are primarily the immediate family, the parents and siblings of the person with a disability<sup>5</sup>.

Significant others transmit their definitions and a picture of reality that the individual accepts as objective (Berger, Luckman, 1991). They influence the formation of the individual's identity, self-esteem, behavior, choices made, and, finally, how they perceive the world and their place in it. It is their attitudes toward the child's disability that are highly consequential for how the child will perceive the disability itself and the opportunities and limitations associated with it (Babik, Gardner, 2021). Scholars believe that there is a gap in research on the role of the family in the process of psychosocial development of a person with a disability. Most research on relationships between parents and children with disabilities focuses on the negative effects of the onset of disability, such as parental stress (Maxey, Becker, 2016).

In the analyzed narratives, three types of the family's approach to the child's disability emerge: keeping silent about the disability, supporting the child and keeping it away from the disability (community), and raising the child embracing its disability. What follows is a discussion of these three approaches.

<sup>5</sup> In the autobiographical narratives, peers and teachers also take the roles of significant others. However, in this paper, I focus on the role of the family, because, as the narratives suggest, it is their practices and attitudes that have a significant impact on the perception of disability as part of identity.

### Keeping silent about the disability

At the onset of a disability, families are often shocked. There occurs a disorganization of biographical schemes of action, and thus the experience can be considered as a trajectory. The family may feel disappointment, confusion, and even shame about the child's disability. Their actions are then directed toward obscuring and/or invalidating it. Both in the immediate family and in the wider community, disability is an elephant in the room. It is a topic that is present, but at the same time dangerous to the *status quo* that is maintained.

And so they couldn't deal with it, so they would say: 'Listen, get your ears covered because people will see the hearing aid'. I was like: okay. You know, I fix my hair so they can't see the hearing aid so much, but still, you can see it. When the wind blows, when you turn your head, when this or that happens. So I pretended all through high school that I could hear, even though everyone knew I had hearing aids. But we didn't talk about it (Sabina, 43).

Keeping silent about disability can result in not taking actions that would entail confronting the fact that a child has a disability. For example, the family does not seek institutional support, does not apply for a disability certificate or the benefits to which they are entitled.

If a person has a sibling, they are the ones who are often asked to help in day-to-day activities of the person with a disability, for example, in reading or mobility. Thus, in a way, the sibling takes on the role of a parent/carer. The situation described above is illustrated by Justyna's story.

My parents were very ashamed of the fact that I couldn't see, so I didn't move on my own for four years, but then again... some people would probably withdraw faced with situations like that (Justyna, 51).

Justyna comes from a small town where she attended mainstream primary and secondary school. She has two sisters. One of them becomes her assistant. She regularly takes her to school and, because her parents made her do so, goes to the same class with the interviewee.

And then my sister went with me and she didn't really want to walk me either, because she hadn't made herself the decision that we would go together to one class. When she was sick, [younger sister – author] would go with me (Justyna, 51).

The woman describes her family relations as 'difficult'. On the other hand, she states that this difficult situation motivated her to move away 400 kilometers from her family home to another city for her studies.

[...] in general, relations with my family were difficult for me at the time, and I'm very grateful to them that it was so awful, because, I don't know, if they had been nice to me and supported me a bit, would I have been able to, sort of, leave the nest and fly so far away (Justyna, 51).

#### Supporting the child and keeping it away from the disability (community)

This type of family approach is illustrated by the case of Daria. She is the only child of her mother, who plays a role of significant other in the biography of Daria. There exists a strong bond between the women. The mother, a lawyer and a single parent, is raising her daughter, who gradually loses her sight. She strongly supports her in her journey through education system. She finances her education at private schools, sends her daughter to the best secondary school in town, and records her textbooks on cassettes at nights. Importantly, she is not overprotective. She embraces her choices and multiple journeys abroad that the daughter undertakes during her university studies. Such an attitude seems to have a positive impact on self-esteem and a sense of self-worth (Riggio, Throckmorton, Depaola, 1990; McCormick, Kennedy, 1994). While investing in 'normalization' and seeking to position her daughter well, the mother wants to protect her from the presumed negative consequences of her disability. Recognizing it as part of her identity would mean pushing her daughter into 'a ghetto of the disabled' and marginalizing her in social life.

And so my mum has always had this attitude that 'my child is normal and she's going to do everything that other children do'. And she always, like, kind of stuffed my head with that feeling that you can do what everyone else is doing, but to be treated equally with everyone else, you have to be ten times better than them. Because you're disabled, you know you're dismissed right from the beginning. [...] And that's the kind of message that's been with me throughout my life. [...] I think it set me up mentally for a long time, right? It's generally worse to be among the disabled, that going to a school for the disabled is worse, and that, generally speaking, being consigned to one's own group is like ghettoization, and I've always tried to avoid that. Throughout school and throughout university, well, let's say most of university period (Daria, 33).

In her socialization process, the interviewee is, as it were, scared of disability. Thus, she assimilates a negative image of it. The adjective 'normal' often collocates in her narrative with words such as 'child', 'job', or 'people'. Being 'normal' often stands in opposition to being 'disabled'. To identify with this community would be tantamount to agreeing to be excluded from mainstream life. Over the course of her narrative, the interviewee several times invokes the metaphor of being 'shut in a ghetto'.

I wouldn't say that I somehow hid my disability, because you can't hide it, but, well, I tried, as it were, not to associate myself with the disability community or the community of the blind. [...] I remember in [university – author] in my first or second year I had a friend in the group who had a mobility impairment, she was in a wheelchair because she had cerebral palsy. And she said she just wanted to work with children with palsy. [...] I remember to this day, I had this thought at the time, that Gosh, how pathetic it is, that when someone is disabled, they immediately assume that they want to work with people with disabilities, that they don't have much ambition, that it's so terribly unambitious, that because I'm disabled, I have to work in the field of disabilities. And that's all, like, that's all I can do, right? And I also had this belief, quite strongly fostered by my mother as well, that, well, come on, you can do better, you can do what all normal people do (Daria, 33).

Out of fear of being dismissed, the interviewee avoids contact with other people with disabilities. She protects herself from her disability by attaching herself to a group of people without disabilities, which allows her to maintain a high self-esteem. At the same time, it leads her to denigrate other people with disabilities (Crocker, Luhtanen, 1990).

This narrative typifies a phenomenon that can be described as internalized ableism. Researchers in disability studies describe ableism as "an ideology of a fit body, a normal mind, an appropriate rate of thinking and an acceptable expression of emotions" (Campbell Kumari, 2015: 13). Ableism involves behaviors, beliefs, attitudes, and practices that privilege able-bodied people.

Arseli Dokumaci (2018) postulates the existence of a habitus of ableism. It is ephemeral; in our day-to-day activities we are not aware that it can be part of our thoughts and stories. However, it is deeply rooted in consciousness and bodily reflexes. The above-quoted narratives suggest that it is also present in how we think and talk about disability. Thus, a habitus of ableism is "embodied history, internalised as a second nature and so forgotten as history" (Bourdieu, 1990: 56). Pierre Bourdieu (1998) believes that key dispositions of habitus, such as tastes, interests, behaviors and attitudes, are transmitted within the family. It seems that this also applies to the habitus of ableism.

### Raising a child embracing their disability

In the narratives in which this type of parental behavior is exhibited, the family is presented as an agent of empowerment. It supports the child throughout her journey toward adulthood and independence. It accepts and supports decisions made at subsequent stages of life, such as ventures into study or travel:

There's even more fear [when you have a child with a disability – author], but still, parents would always tell me: you have to be independent, you have to act, you have to fight for yourself. And they always told me that, they always instilled that idea in me somehow. And they pushed me into this world (Karolina, 32).

The family representing this type of behavior toward disability spends time with each other, does recreation and sports together: they walk, cycle, swim, go on holiday together. The narratives of women from this group who have siblings talk about good relations with them. One interviewee, Emilia, metaphorically describes her family as 'a springboard to adult life'. For her, it is a space where she feels empowered and needed, for example by her younger brother.

[...] and at home I was actually given a springboard for adult life and I think I was equipped with such mechanisms and [...] I always felt that everyone believed in me. Grandmas, grandpas, parents. I also was a good learner, so I had a sense that I could cope. But I also had this feeling

that I was not alone in this, because apart from [the teacher – author] who was teaching me, my parents also helped me a lot, my grandmothers studied with me. My grandfather too. Really, everyone helped me, really, a lot (Emilia, 31).

As in the pattern of parental attitude described above, the family invests its time, and often also funds, in the child's education and additional extracurricular activities, for example learning in a music school, or support classes for independent living with a disability, e.g. mobility teaching<sup>6</sup>.

This type of support plays an extremely important role in the development of the individual. It increases the scope for independence and a sense of empowerment.

And the lady [the mobility teacher – author] taught me how to find my way, so I started to walk around a bit on my own after music school. It was a huge challenge then, well, but as I went from room to room, I felt as if the world was under my feet (Emilia, 31).

In this pattern of parental approach, disability is a topic that is not avoided. On the contrary, it is discussed. The family emphasizes that disability does not belittle the value of the child.

When that change happened, right? When I went to junior high school, I remember my dad telling me, sort of... Like, I could see that he wanted to support me somehow, but he didn't know how [to do that – author]. And he, for example, would tell me a couple of times things like: "Remember, you have nothing to be ashamed of", right? "You're not stealing anything, you haven't done anything wrong, this is who you are and that's it, and that's fine, and you've got nothing to be ashamed of", right? (Anna, 30).

The family is constantly learning about the child's disability and how to cope with it. Importantly, they do not try to 'protect' the child from contact with people who may have other kinds of disabilities. Thus, they do not discourage contact with other people with disabilities by scaremongering about negative consequences of embracing disability as part of the person's identity.

I have had [...] a mobility impairment, since birth. And so I've always seen myself as a bit different, but I've always tried to take some positives out of it. My parents brought me up in such a way that they always pushed me into the world. And it was always so obvious to me that you have to conquer the world, but in a positive way, don't strut around at someone's expense, don't push others with hands and feet, as they say, But really, fight for yourself and fight for others, too (Karolina, 32).

<sup>6</sup> The purpose of mobility training is to train a visually-impaired person to move independently and safely in both closed (built) and open spaces (Goldschmidt, 2018).

Because of Karolina's impairment, since early childhood, the interviewee, during her stay in hospitals and rehabilitation centers, has come into contact with people with various disabilities, with barriers and exclusionary attitudes that these people experience. The open-minded attitude of her parents and her contact with people with other disabilities seem to have equipped the interviewee with a high level of empathy, which, as an other-centered approach, directs the person's attention to the feelings, situation, and needs of others. It is crucial for the development of pro-social behavior, concern for others, kindness, and moral reasoning (Mestre et al., 2019; Portt et al., 2020). A sense of empathy may be associated with an increase in engagement with those with whom we stand in solidarity, identify ourselves, or empathize (Besta et al., 2019).

This narrative suggests that disability is a characteristic that, for the immediate family, marks a difference and significantly impacts the life, but does not necessarily devalue or discredit the future of the person who has it.

## The experience of disability community as a turning point in narratives of activists

As I suggested at the beginning of this paper, an important element of transformations within the field of identity and activism is the process of incorporating disability as an element of individual self-definition. The turning points in the course of these processes are the bonds established with other individuals or groups.

At my dorm there was [a blind friend – author]. [...] And at the beginning, you know, I would look at her as if she was some kind of an alien, because I didn't identify myself yet. But she was, for example, recording her notes for me, she was giving me hints on how to cope with things. And then I also saw how well she was doing, how she was walking around and doing research on her own (Justyna, 51).

For the interviewee, who is also visually-impaired and has chosen to study as far away from her family home as possible, her blind colleague provided support in studying at the university; on the other hand, she was an inspiration, or a role model, who defied stereotypes by her actions. She made the blind woman realize that a blind person can find their way when studying at the university (Jongenelen, 2017).

A person who is a role model can also be regarded as a catalyst for a biographical metamorphosis, opening up a new path of development. This can happen by empathizing with frustrations, anxieties, doubts, and showing a new perspective on a pressing issue.

So I met with the then chairman. We had an interview. About disability [...] Because he was the first person with a more serious disability, and a disability in general, with whom I was able to talk [...] to dispel my doubts. And he, for example, opened my head a little bit to other, like,

other perceptions, [...] during that conversation with the chairman I was telling him about what I would like to do in the future and he summed it up so nicely [...] And he said, you want to be a self-advocate for people with disabilities, right? And to be an advocate for our cause. And then I said: Oh, that's what I meant! Right? And really, he, in two words, like, he put everything I meant, and I couldn't express it so briefly and so emphatically (Anna, 30).

Here, the driver for positive change is an honest, open conversation with another person with a disability. Recognizing oneself as a self-advocate also plays an important part in the biographical work done in relation to one's identity. As a result of the conversation with the chairman of the non-governmental organization, which in retrospect proved to be a turning point, the interviewee recognizes her role as a self-advocate. She begins to identify with being a self-advocate and, as a result, speaks up for her cause and the cause of other persons with disabilities.

Similarly, a key role in identity transformation, and the subsequent turning point in activism, is the positive experience of the disability community and the creation of a sense of belonging (Gill, 1997; Dunn, Burcaw, 2013; Forber-Pratt et al., 2017).

The women's narratives suggest that many of them, by and large, were deprived of contact with other people with disabilities until they entered adulthood. In the analyzed narratives, other people with disabilities appear only during the university education period, for example in the dormitory, on the internships outside the usual place of residence, or on trips for recreational purposes, in which other people with disabilities participate.

I didn't come into contact with the community of blind people until I was probably twenty, when I went to that hapless university. There was a blind girl. [...] And she lived in the boarding house with a few other people who were also blind. And I started coming to see them, I started visiting them. The boys started to take an interest in me, too, and before no one would be interested in me. After all, I belonged to a different category, so, well, no one gave a shit about me (Emilia, 31).

American artist and disability activist Sunaura Taylor (2017: 17) emphasizes this experience of separation from people with disabilities: "A community of disabled people was something I did not have as a kid. Disability community is something many disabled kids, and disabled adults, lack."

At school, among non-disabled peers, women are accompanied by a elusive sense of otherness. It is dual in nature. On the one hand, it makes the person highly visible, while on the other, it makes them invisible (Taylor, 2017).

The feeling of otherness often remains unspecified, unnamed, or even abstract for many years. It is only through contact with other people sharing a particular characteristic, such as a disability, that this feeling becomes concretized and a group that was previously alien becomes a community of experience. [a]nd then I realized that I was very comfortable in that community. That I don't feel, like, different at all. That, like, nobody's pointing fingers at me, just... Like, you know, it's all about being accepted, that I felt good among my colleagues, my friends, but I always wondered at the back of my head what was wrong, right? That for example, you know, that these people had relationships, that they were often, you know, they were attractive, there was no attention paid [...] to how they, you know, looked or anything (Hanna, 46).

George H. Mead (1972) believed that we perceive ourselves through the eyes of others. The group we are in provides us with information from which we build an image of ourselves and, thus, our identity.

The newly met group becomes a positive point of reference in relation to which the individual forms basic judgements and evaluations about her own social position (Niedbalski, 2017). The interviewee finds friends and acceptance there. It is also where she becomes aware of and names her disability.

On the other hand, a positive experience of disability community can contribute to redefining the ableist and thus stigmatizing perception of disability inculcated by the family:

And that really started to change for me a little bit in my second or third year of university, when I went on a sea voyage [with blind people – author] for the first time. And it was actually the first time for me to come into contact with blind and low sighted people on a massive scale, because I just didn't have such friends before.

And I also met a lot of nice people, you know, parties and all that stuff. [...], I learned a lot of life tips from them [...], because I never had any, you know, classes in everyday activities. My mum taught me a bit, I did a bit of trial and error, but other than that I never had [this experience – author] (Daria, 33).

This woman finds positive points of reference among the group of blind people with whom she identifies herself as an active, curious, and sociable person. These positive role models shatter the stereotypical ideas she has been given about disability. Importantly, the group equips her with knowledge and resources that she had not had before, which help her to become more independent.

Another breakthrough for Daria came through the work for an NGO in the field of disability. The organization provides the individual with expertise, and broadens the perspective of the perception of the phenomenon of disability in general and of herself as a person with a disability.

So, during my university period I would always say that I'm blind and I need this or that. But, in general, I represent [only – author] myself and have absolutely nothing to do with other blind people. And I never asked for any, sort of, amenities, because I didn't want to step out of line. I wanted to be in the grey mass, I wanted to be treated like a normal person. And this work at the foundation was the first step which made me think of myself as a kind of representative

from a certain community and a kind of communicator of needs and in general of points of view, perspectives and so on (Daria, 33).

On the one hand, working at the foundation opens up new career opportunities for the interviewee, while on the other hand, it provides a space to speak on the topic of disability and related needs from an expert position, in training or accessibility audits. For the interviewee, this represents a milestone in the development of her advocacy work. As a result of the biographical work she has done in redefining disability and thus moving from seeing it as a disparaging characteristic to including it as a valuable and important part of her identity, in her advocacy work, the woman begins to contest the narrative of pity that society constructs around disability.

#### Conclusions

In the autobiographical narratives of women with disabilities, activism emerges as a polyvalent concept. On the one hand, it is associated with leadership competence and with fighting for the rights of a particular group. On the other hand, it carries a strong emotive content. Being an activist is associated with anger and rebellion.

As an element of biographical process structures, activism manifests itself both as a biographical scheme of action where it takes the form of a career path constructed subjectively, almost from childhood (Strauss, 2007), and as a biographical metamorphosis where it initiates a new line of activities in the individual's life.

Women's narratives suggest that disability is an important part of their identity. Often, it is the focus of their activism.

Therefore, an important part of the process of becoming an activist is discovering and incorporating disability as part of women's identity.

When analyzing identity from an interactionist perspective as a processual construct subject to constant transformation and negotiation in the course of social processes (Berger, 1963), it is important to consider the role that significant others play in these processes. During childhood and adolescence, these are usually members of the immediate family. It is their approach to disability that will have a significant impact on the self-perception and the perception of other people with disabilities, and, thus, how much intensive biographical work a person will have to do in order to consider disability as a positive component of their identity.

The analysis of the autobiographical narrative interviews uncovered three approaches of immediate families to the child's disability: keeping silent about the existence of the disability, supporting the child and protecting it from disability (community), and raising the child embracing the disability they have.

If we assume that identity is constructed and affirmed socially (Berger, 1963), it seems that both a strategy of silence and protection from disability understood as a negative phenomenon can cause an individual to internalize ableist beliefs about disability and other people with disabilities.

In order for disability to emerge in the biography as part of an individual's self-identification, positive contact with a person or group of people with disabilities is needed. This positive experience has the potential to 'dispel' negative beliefs about disability and redirect the individual's resources into activities for the benefit of the group with which they start to identify.

In this paper, I have only presented some snippets of the process of becoming an activist. The process seems to be much more complex. Of particular interest for further research is the relationship of activism and professional career, as well as the relations between activism, gender, and disability, and its positioning within the mainstream feminist movement.

#### Acknowledgments

I would like to express my gratitude to Dr. Wojciech Figiell for translating this text from Polish into English.

#### References

Babbie Earl (2006), The Practice of Social Research, Belmont: Wadsworth Publishing.

Babik Iryna, Gardner Elena S. (2021), Factors Affecting the Perception of Disability: A Developmental Perspective, "Frontiers in Psychology", vol. 12, 702166, https://doi.org/10.3389/fpsyg.2021.702166

Barnes Colin (1997), A Legacy of Oppression: A History of Disability in Western Culture, [in:] Len Barton, Mike Oliver (eds.), Disability Studies: Past, Present and Future, Leeds: The Disability Press, pp. 3–24.

Berger Peter L. (1963), Invitation to Sociology: a Humanistic Perspective, New York: Doubleday & Company.

Berger Peter L., Luckmann Thomas (1991), *The Social Construction of Reality. A Treatise in the Sociology of Knowledge*, London: Penguin Books.

Besta Tomasz, Jaśko Katarzyna, Grzymała-Moszczyńska Joanna, Górska Paulina (2019), *Walcz, protestuj, zmieniaj świat. Psychologia aktywizmu*, Sopot: Smak Słowa.

Blumer Herbert (1969), Symbolic Interactionism. Perspective and Method, Englewood Cliffs: Prentice-Hall.

Bokszański Zbigniew (1989), Tożsamość, interakcja, grupa. Tożsamość jednostki w perspektywie teorii socjologicznej, Łódź: Wydawnictwo Uniwersytetu Łódzkiego.

Bourdieu Pierre (1990), The logic of practice, Cambridge: Polity Press.

Bourdieu Pierre (1998), Practical reason: On the theory of action, Cambridge: Polity Press.

Campbell Kumari Fiona (2015), *Ability*, [in:] Rachel Adams, Benjamin Reiss, David Serlin (eds.), *Keywords for Disability Studies*, London–New York: New York University Press, pp. 12–14.

Crocker Jennifer, Luhtanen Riia (1990), *Collective self-esteem and ingroup bias*, "Journal of Personality and Social Psychology", vol. 58(1), pp. 60–67, https://doi.org/10.1037/0022-3514.58.1.60

Dokumaci Arseli (2018), *Disability as Method: Interventions in the Habitus of Ableism through Media-Creation*, "Disability Studies Quarterly", vol. 38, no. 3, https://doi.org/10.18061/dsq.v38i3.6491

Dunn Dana S., Burcaw Shane (2013), *Disability identity: Exploring narrative accounts of disability,* "Rehabilitation Psychology", vol. 58(2), pp. 148–157, https://doi.org/10.1037/a0031691

Forber-Pratt Anjali J., Lyew Dominique A., Mueller Carlyn, Samples Leah B. (2017), *Disability identity development: A systematic review of the literature*, "Rehabilitation Psychology", vol. 62(2), pp. 198–207, https://doi.org/10.1037/rep0000134

Giddens Anthony (1991), Modernity and Self-Identity. Self and Society in the Late Modem Age, Cambridge: Polity Press.

Giermanowska Ewa, Kumaniecka-Wiśniewska Agnieszka, Racław Mariola, Zakrzewska-Manterys Elżbieta (2015), *Niedokończona emancypacja: wejście niepełnosprawnych absolwentów szkół wyższych na rynek pracy*, Warszawa: Wydawnictwa Uniwersytetu Warszawskiego.

Gill Carol J. (1997), Four types of integration in disability identity development, "Journal of Vocational Rehabilitation", vol. 9(1), pp. 39–46, https://doi.org/10.3233/JVR-1997-9106

Goffman Erving (1963), Stigma. Notes on the Management of Spoiled Identity, Englewood Cliffs: Prentice-Hall.

Goldschmidt Mira (2018), Orientation and mobility training to people with visual impairments, [in:] Edwige Pissaloux, Ramiro Velázquez (eds.), Mobility of Visually Impaired People. Fundamentals and ICT Assistive Technologies, Cham: Springer, pp. 237–261.

Hammersley Martyn, Atkinson Paul (2019), Ethnography: Principles in Practice, Abingdon: Routledge.

Jongenelen Rik (2017), *Exploring Role Models in Disability Advocacy: the Case of the Young Voices Programme in Zambia*, https:// studenttheses.universiteitleiden.nl/handle/1887/64757 (accessed: 28.02.2023).

Kaźmierska Kaja, Waniek Katarzyna (2020), Autobiograficzny wywiad narracyjny. Metoda – technika – analiza, Łódź: Wydawnictwo Uniwersytetu Łódzkiego.

Kocejko Magdalena (2018), Nic o nas bez nas? Zaangażowanie ruchu osób z niepełnosprawnościami w monitoring wdrażania Konwencji ONZ o prawach osób niepełnosprawnych w Polsce. Studium przypadku, "Studia z Polityki Publicznej", vol. 5, no. 4(20), pp. 9–21, https://doi.org/10.33119/KSzPP.2018.4.1

Kubicki Paweł, Bakalarczyk Rafał, Mackiewicz-Ziccardi Marek (2019), *Protests of People with Disabilities as Examples of Fledgling Disability Activism in Poland*, "Canadian Journal of Disability Studies", vol. 8(5), pp. 141–160, https://cjds.uwaterloo.ca/ index.php/cjds/article/view/569/838 (accessed: 28.02.2023).

Kumaniecka-Wiśniewska Agnieszka (2006), Kim jestem? Tożsamość kobiet upośledzonych umysłowo, Warszawa: Wydawnictwo Akademickie "Żak".

Kvale Steinnar (2007), Doing interviews, Los Angeles: Sage Publications.

Kvale Steinar, Brinkmann Svend (2009), Interviews: Learning the Craft of Qualitative Research Interviewing, Los Angeles: Sage Publications.

Lofland John, Snow David A., Anderson Leon, Lofland Lyn H. (2009), *Analiza układów społecznych. Przewodnik metodologiczny po badaniach jakościowych*, Warszawa: Wydawnictwo Naukowe Scholar.

Maxey Myles, Beckert Troy E. (2017), Adolescents with Disabilities, "Adolescent Research Review", vol. 2, pp. 59–75, https://doi.org/10.1007/s40894-016-0043-y

McCormick Cynthia B., Kennedy Janice H. (1994), Parent-child attachment working models and self-esteem in adolescence, "Journal of Youth and Adolescence", vol. 23, pp. 1–18, https://doi.org/10.1007/BF01537139

McDonald Gina, Oxford Mike (1995), *History of Independent Living*, https://www.ilru.org/sites/default/files/History\_of\_Independent\_Living.pdf (accessed: 28.02.2023).

Mead George H. (1972), Mind, Self and Society. From the Standpoint of a Social Behaviorist, Chicago–London: The University of Chicago Press.

Mestre Maria V., Samper Paula, Malonda Elizabeth, Llorca Mestre Ana (2019), *Bidirectional relations among empathy-related traits, prosocial moral reasoning, and prosocial behaviors,* "Social Development", vol. 28(3), pp. 514–528, https://doi.org/10.1111/sode.12366

Nepveux Denise M. (2015), *Activism*, [in:] Rachel Adams, Benjamin Reiss, David Serlin (eds.), *Keywords for Disability Studies*, London–New York: New York University Press, pp. 21–25.

Niedbalski Jakub (2017), Wymiary, konteksty i wzory karier. Proces stawania się sportowcem przez osoby z niepełnosprawnością fizyczną – analiza społecznych mechanizmów (re)konstruowania tożsamości, Łódź: Wydawnictwo Uniwersytetu Łódzkiego.

Piotrowski Andrzej (1998), Ład interakcji. Studia z socjologii interpretatywnej, Łódź: Wydawnictwo Uniwersytetu Łódzkiego.

Portt Erika, Person Staci, Person Brandi, Rawana Edward, Brownlee Keith (2020), *Empathy and Positive Aspects of Adolescent Peer Relationships: a Scoping Review*, "Journal of Child and Family Studies", vol. 29, pp. 2416–2433, https://doi.org/10.1007/s10826-020-01753-x

Riggio Ronald E., Throckmorton Barbara, DePaola Steven (1990), *Social skills and selfesteem*, "Personality and Individual Differences", vol. 11(8), pp. 799–804, https://doi.org/10.1016/0191-8869(90)90188-W

Rokuszewska-Pawełek Alicja (1996), *Miejsce biografii w socjologii interpretatywnej. Program socjologii biografistycznej Fritza Schützego*, "Ask: Społeczeństwo, Badania, Metody", vol. 3(1), pp. 37–54, https://www.worldcat.org/title/miejsce-biografii--w-socjologii-interpretatywnej-program-socjologiibiografistycznej-fritza-schutzego/oclc/922420696 (accessed: 28.02.2023).

Rzeźnicka-Krupa Jolanta (2009), *Niepełnosprawność i świat społeczny. Szkice metodologiczne*, Kraków: Oficyna Wydawnicza Impuls.

Schütze Fritz (2008), *Biography Analysis on the Empirical Base of Autobiographical Narratives: How to Analyze Autobiographical Narrative Interviews – Part One,* "European Studies on Inequalities and Social Cohesion", vol. 1–2, pp. 243–297.

Shakespeare Tom (1993), *Disabled People's Self-organisation: a new social movement?*, "Disability, Handicap and Society", vol. 8, no. 3, pp. 249–263.

Silverman David (2017), Doing Qualitative Research, London–Thousand Oaks: Sage Publications.

Strauss Anselm L. (2007), Mirrors & masks. The search for identity, New Brunswick–London: Transaction Publishers.

Taylor Sunaura (2017), Beasts of Burden. Animal and Disability Liberation, New York: The New Press.

Union of the Physically Impaired Against Segregation (1975/1997), Fundamental Principles of Disability, London, https://di-sability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf (accessed: 28.02.2023).

Wołowicz-Ruszkowska Agnieszka (2013), Zanikanie? Trajektorie tożsamości kobiet z niepełnosprawnością, Warszawa: Wydawnictwo Akademii Pedagogiki Specjalnej.

Żuchowska-Skiba Dorota (2016), Aktywność środowisk osób niepełnosprawnych we współczesnej Polsce, Warszawa: Wydawnictwo Instytutu Filozofii i Socjologii Polskiej Akademii Nauk.

#### Cytowanie

Kamila Albin (2023), *The Process of Becoming an Activist: Identity Transformations in Autobiographical Narratives of Women with Disabilities in Poland, "*Przegląd Socjologii Jakościowej", t. XIX, nr 3, s. 158–177. https://doi.org/10.18778/1733-8069.19.3.09

# Proces stawania się aktywistką – przemiany tożsamości w autobiograficznych narracjach kobiet z niepełnosprawnością w Polsce

Abstrakt: W artykule autorka rekonstruuje przemiany tożsamości, jakie manifestują się w biografiach aktywistek z niepełnosprawnością. Materiał empiryczny zebrano, stosując metodę autobiograficznego wywiadu narracyjnego. Autorka identyfikuje kluczowe dla tożsamościowych transformacji etapy i punkty zwrotne. Analizie poddaje także rolę znaczących innych w procesie przekształceń tożsamości oraz procesie stawania się aktywistką. Poprzez analizę narracji kobiet z wrodzonymi niepełnosprawnościami wykazano, iż ważnym elementem przekształceń tożsamościowych jest włączenie niepełnosprawności jako części składowej jednostkowej autodefinicji. W analizowanych narracjach niepełnosprawność stanowi pewnego rodzaju zasób oraz, podobnie jak tożsamość, ma charakter procesualny. Chociaż niepełnosprawność towarzyszy jednostce od urodzenia, cecha ta podlega reinterpretacji na różnych etapach życia.

**Słowa kluczowe:** aktywizm, kobiety z niepełnosprawnościami, punkty zwrotne, tożsamość, autobiograficzny wywiad narracyjny