

Personal Assistance in the Context of Disability Studies and Cultural Anthropology

1. PARTICIPANTS OF THE RESEARCH

Two persons took part in this participatory research which lasted for a year. One of them, who in the traditional sense can be called a *research fellow and a research subject*, and the other who can be called a *research leader*. The former is Zsuzsanna Antal (hereinafter referred to as Zsuzsa), engineer, mother, grandmother, tetraplegic woman experiencing disability. The other is the main author of the doctoral dissertation, Zsuzsanna Kunt, a special education teacher and cultural anthropologist. In the present research, disability is interpreted as a framework of analysis, which can help us to learn more about the structural, discursive and bodily dimensions of our social lives (Titchkosky & Michalko, 2012). In the spirit of discursive polyphony, the dissertation consists of two main voices: the dialogue between *Zsuzsa's* sentences and *my* sentences. The verbal quotes from Zsuzsa in the dissertation are marked with CAPITAL letters. Zsuzsa always uses uppercase letters in her correspondence with me and in the social media.

RESEARCH NEEDS CURIOSITY, OPEN-MINDEDNESS, DILIGENCE AND ENDURANCE. OCCASIONALLY WE HAVE TO LEAVE OUR COMFORT ZONES. [...]

WHEN I FIRST READ THE WORDS "DISABILITY STUDIES", I THOUGHT: "AT LAST SOMEONE HAS REALIZED THAT IT IS THE SCIENCE OF WHAT WE, PEOPLE WITH DISABILITIES, EXPERIENCE DAY BY DAY! PAIN, ASSISTANTS, ELECTRIC BEDS, PLEAS, HAPPINESS!" [...] IT HAD A GREAT INFLUENCE ON ME THAT THERE IS SOMETHING LIKE DISABILITY STUDIES. ALSO, ON MY PEERS. NOT EVERYBODY WAS POSITIVE ABOUT IT, HOWEVER. WHEN TALKING ABOUT DISABILITY STUDIES I ALWAYS EMPHASISE BRINGING THEORY CLOSER TO PRACTICE.

2. AIMS OF THE RESEARCH

The dissertation has three main aims.

Firstly, it attempts to give a comprehensive, analytical picture of the disciplinary interlacement of cultural anthropology and critical disability studies. Based on the Anglo-Saxon studies and research regarded as landmarks in the topic (Ingstad &

Whyte 1995, 2007; Kasnitz & Shuttleworth 1999, 2001; Battles, 2011; Hershenson, 2000; Ginsburg & Rapp 2013; Shuttleworth, 2000, 2001) it sheds light on their historical, theoretical, and pragmatic connections. Its intention is to draw attention to the possibilities of the duplex power of the combination of the two disciplines, that is forming society and sharing empowerment, while encouraging us to ask questions, find new ways of cognition, think and act.

Secondly, the dissertation aims to present in detail the process of participatory research created at the theoretical and methodological meeting point of cultural anthropology and critical disability studies (Bergold & Thomas, 2012; Reason, 1994; Király, 2017). It also strives for sharing the cooperation process of the two persons taking part in the research, the spaces and possibilities of their decision-making, and how the research method of *cultural biography* could be applied in particular situations. By sharing the methodological and research ethical dilemmas and risks, the chapter aims to contribute to the establishment of empirical research in the cross-section of the two disciplines in Hungary.

Thirdly, it aims to introduce the thematic focus point that Zsuzsa has chosen for the research. Here we deal with the history of the development of *personal assistant relationship*, the layers, resources and difficulties of the relations within the process of helping-cooperating.

THE TOPIC OF HELP. IT NEEDS TO BE RESEARCHED. IT MUST BE WRITTEN ABOUT. WHAT KIND OF PEOPLE HELP US, AND HOW? WHY IS IT SO, AND HOW FAR IT IS FROM THE GOALS, AND HOW I AM HELPED? THIS IS a VERY WIDE CIRCLE, IT NEEDS TO BE EXAMINED FROM VARIOUS ASPECTS, VARIOUS CONCRETE SITUATIONS [...].

THREE DISSERTATIONS COULD BE WRITTEN ABOUT HOW IMPORTANT ASSISTANCE IS FOR ME [...] FOR ME HELPING MEANS LIFE, THE ORIGO, THE STARTING POINT OF EVERYTHING ELSE.

3. METHODOLOGY OF THE RESEARCH

The principle of “nothing about us without us” and its message that “every person has the right to intervene in research that relates to her/his life” (Marton & Könczei, 2009, 6) is understood as a premise in this research. From the methodological repertoire used in cultural anthropology, our research has adapted the qualitative elements of *cultural biography* (Frank, 2000) and *ethnographic work* (cf. Biczó & Szász, 2008; Frank, 1995; Norris & Sawyer, 2012), supplemented by *narrative interviews*. Cultural biography is an analytical method that focuses on the person involved in the research (including power relations between participants) using ethnographic and life-history methods (Frank, 1995). As part of the biographical method, social media entries, comments, and articles, essays, statements, reports, and logs given to me by Zsuzsa during the research are used. Ethnographic material is made up of personal and telephone interviews and e-mails exchanged during the research process.

Voluntariness and informed consent were a prerequisite for participating in the research. Zsuzsa’s participation in the research design took place in the planning and scheduling of the research, in the narrowing of the research questions, in

the adaptation of the research methodology to the given situation, in the regular reflection on the research process, in the cyclic re-designing of the research plan, in the interpretation of the research findings, and in the dissemination activities (cf. Király, 2017; Reason, 1994; Lajos, 2016).

I KNOW WHAT IT IS LIKE BEING a CRIPPLE, IT IS NOT THAT I JUST HAVE READ ABOUT IT... NO ONE CAN THINK ABOUT REAL SOLUTIONS UNLESS ONE IS VERY NEAR TO THE SITUATION.

4. DIMENSIONS OF PERSONAL ASSISTANCE

The purpose of the analysis is to reveal how disability studies criticize the *repressive tradition of the practices of helping* people with disability. Besides presenting the empowering results of the practices of personal assistance (which was introduced by the *Independent Living Movement* in the 1970s), the dissertation also demonstrates its criticism and its reinterpretation through the influence of *feminist ethics of care*. Relying on the fundamental thesis of *relational ontology*, this interpretation refuses the dichotomic interpretation of dependence/independence, and focuses on the *relations* appearing in the very existence of personal assistance. The theoretical tool for this is the concept of *assemblage* (Deleuze & Guattari, 1987), which allows us to examine what cultural imperatives and fractures, boundaries and border crossings form and frame personal connections with people, with objects, with conceptual and experiential systems in the everyday practice of cooperation in personal assistance.

WE TRIED WRITING a JOB DESCRIPTION, BUT THIS WORK CANNOT BE DESCRIBED. IT DOESN'T MEAN ANYTHING, IF I WRITE: MANAGEMENT OF MY TECHNICAL INSTRUMENTS. HERE THERE ARE TWO OR PROBABLY THREE REAL PROFESSIONAL TASKS FOR NURSES: CATHETERIZATION, THAT IS REALLY a PROFESSIONAL TASK, THEN THE WASHING OR CLEANSING, AS THEY CALL IT, AND? FEEDING. THESE ARE COMPULSORY THINGS, BUT THESE ONLY MAKE MY LIFE BEARABLE. TO BE GOOD, ALL "COMPULSORY" THINGS MUST BE DONE WITH PROPER HUMANITY AND PROFESSIONALISM. I KNOW FOR CERTAIN THAT a COMPREHENSIVE JOB DESCRIPTION AND TICKING THE TASKS WOULDN'T WORK, BECAUSE SEEMINGLY EVERYTHING WOULD BE ALL RIGHT, ALL THE JOB IS DONE, YET THIS DOES NOT MEAN THAT I FEEL WELL.

If assistance is understood as something that we *do*, then it is immediately posited in cultural, political, economic, philosophical, and ethical context on which we should reflect (Bauman, 1993). The theoretical, practical, and legal framework of assistance has significantly changed during the past three decades, which is strongly connected to the impact of the activity of disability studies activists and scholars, the influence of the global Independent Living Movement and the unfolding of the theoretical framework of *feminist ethic of care* and *relational ontology*. According to these theoretical frameworks, the experience of assistance requires new theories

which do not value people in assistance relationships by their independence. Therefore, we need to deconstruct the meaning of dependence, and focus on the *relation* phenomenon, since it is impossible to exist without any relations to animate and inanimate objects (Benjamin, 2015; Sidorkin, 2002; Yannaras, 2011), therefore existing beings cannot be understood without their connections.

This means that we should overwrite our beliefs regarding the fictive autonomy of a human being, emphasizing that all our activities are relation-actions as well. These relations have material (objective and bodily), natural, discursive, cultural and structural dimensions. Due to these relations and their constant modifications, we are also in constant alteration. The interlocking of the different elements results in effective forces that either impede or create changes (re- or deterritorialization). Certain entities (money, emotion, etc.) flow through these interlockings, and they define the way of shifting and changing. Through our connections, and the constant flow of these connections we are always in the state of becoming (Deleuze & Guattari, 1986; Hernádi, 2014; Braidotti, 2006). Revealing these connections is the means that helps us to leave binarity, and to pay attention to polyphony, contradiction, uncertainty, and be able to examine entities and voices appearing in concrete relations without essentialism. Within the framework of relational ontology, the notion of *assemblage* – meaning connections/relations and the process of changes in these connections/relations at the same time – is a proper *theoretical tool* to analyze these connections. It helps us to:

- see each being as something that exists within relations (Gibson, 2014);
- leave behind binary thinking, to be able to notice not only the given being, but also its relations with other material, discursive, cultural, and psychological dimensions.
- realize that THERE IS NO INDIVIDUAL AT ALL WHO CAN LIVE WITHOUT ASSISTANCE AND COOPERATION.

It is inevitable to always keep in mind that the contents, voices, resources, and difficulties of personal assistance are complex and many folded:

- HERE I AM THE EMPLOYEE, THE EMPLOYER AND THE SUFFERER OF THE JOB. THAT IS, IT'S ME WHO PAYS, ENTERS INTO CONTRACT, I DEFINE THE LIMITS, I GOT THE SERVICE, I CHECK OR DO NOT CHECK IT, SO THIS IS a SPECIAL SYMBIOSIS.
- personal assistance is not only giving and accepting assistance and help, and it is not a one-way activity;
- the individual using the service can have different roles during the relation, in which she uses different voices (Gilligan, 1982).

The research findings show us that to maintain a good personal assistance relation – amongst others – the following things are needed:

- appropriate, co-ordinated and co-developed/recognized knowledge, skills, attitudes and responsibilities, as well as relational ethics are needed from both sides, regarding each other and the cooperation;
- it is necessary to provide communication platforms that regularly reflect on cooperation;
- it is important to build and operate a dynamic web of personal assistants;
- certain resources (e.g. human resources, time, materials, infrastructure) are indispensable;

- reliable tools and aids are needed;
- there is a need for truly caring rights, legislation and also for social and individual responsibility;
- actors who have the proper legal, technical, infrastructural, professional, ethical, etc. knowledge, and who make all these accessible are essential in such relation.

The dissertation draws attention to the importance of collecting knowledge and experiences about a good personal assistant relationship:

- WHAT MEANS JOB AND ASSISTANCE TO THE PERSONAL ASSISTANT, THAT IS LIFE TO ME;
- it empowers both parties in the relationship – regarding their own life and relation;
- the co-operating participants' personality highly matters in this relationship;
- it may generate opposite experiences in the same relationship (e.g. counter-interest/willingness to help, caring/disgust, close-up/keeping distance, increasing vulnerability/reducing dependence, humiliation/ respect).

To accept or stop these effects both parties must develop strategies. It is imperative that both sides strive to reduce vulnerability and mutually reinforce each other. From the point of view of the user, the main difficulties of the personal assistance relation – among others – are:

- maintaining a personal assistance network from one's own funding is financially extremely burdensome;
- the number of available personal assistants is very low;
- IT IS VERY DIFFICULT THAT WE ALWAYS HAVE TO CONFORM TO DIFFERENT PEOPLE WHEN RECEIVING ASSISTANCE. WHO CONFORMS TO WHOM? WHERE IS THE BORDER WHEN WE WILL STILL BE OURSELVES? HOW MUCH DO I HAVE TO ALTER MY HABITS?
- sometimes the participants' most basic needs and the urgency of satisfying them are in conflict;
- no adequate technical tools are available to make hygiene activities more comfortable;
- the continuous training of assistants by the person using the service is wearisome work.

The dissertation concludes that personal assistance is not only important for tetraplegic people but also for example for people with other kinds of disabilities, for children, for chronically ill people, dying people, pregnant women, mothers and fathers with children, for the elderly, injured or ill people. It is inevitable to emphasize that THERE IS NO IDEAL ASSISTANT, AS THERE IS NO IDEAL ASSISTED PERSON, IT ALL DEPENDS ON THE SITUATION.

5. SUMMARY

The doctoral dissertation introduces disciplinary connections (cultural anthropology and disability studies), research methodological connections (ethnography and biography), and human connections (personal assistance). These connections are,

of course, inextricably linked with other symbolic, material, physical, structural and linguistic phenomena, which are also in the thematic focus of the dissertation.

The interconnection between cultural anthropology and disability studies, as well as the adaptation of cultural biography's ethnographic research methodology, has proved to be useful to get closer to the understanding of personal assistance relationships. During the research work, both theoretical and interpretive frameworks have emerged that help better *understanding* the complexity and connections of the relationships in personal assistance. We gathered knowledge and experience that can support organizations in Hungary (e.g. Freekey – constituted by persons with disability, academics, and allies) in establishing and developing personal assistance service, which empowers all participants of the service.

[Freekey is an innovative social enterprise in Hungary that believes the key to freedom and self-determination is personal assistance. You can follow us here: <https://www.facebook.com/freekey8>]

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