

Eötvös Loránd University
Faculty of Education and Psychology
Doctoral School of Education

Thesis of Doctoral (PhD) Dissertation



Zsuzsanna Kunt

CONNECTIONS

**Personal assistance and cooperation reflected at the encounter of disability studies and
cultural anthropology**

Supervisor: Zászkaliczky Péter PhD

Budapest
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1. The participants and aims of the research

The present doctoral research is a postmodern, critical and reflective (Davies 1999, Nazaruk 2011) ethnographic work, positioned on a broadly interpreted crossing point of cultural anthropology and disability studies. It discusses the history and the results of the two interrelated disciplines, the possibilities of applying the research-methodological application of cultural biography shaped in the cooperation of two people, and the complex interaction experiences of personal assistance.

Two persons took part in the participatory research lasted for a year. One of them, who in the traditional sense can be called *rather* a research fellow and a research subject, and the other who can be called *rather* 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 phenomenon and a framework of analysis, by the help of which we can learn more about the structural, discursive and bodily dimensions of our life-worlds (Titchkosky and Michalko, 2012). It regards scientific texts as material, poetic, and political constructions, which are part of cultural, structural, material and linguistic processes (Clifford, 1999 [1986]), and where "the basic texture of the interpretation is [the participants' own experience]" (Zászkaliczky and Verdes), 2004, p. 270). 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 CONFORT ZONES.

The dissertation has three aims. The aims are combined to strengthen each other through the whole thesis, but they are formally focused: the three central chapters of the thesis are built around these aims:

- After the Introduction (Chapter I.), Chapter II. is one of the first attempts in our country to give a comprehensive, analytical picture of the history of the disciplinary interlacement of cultural anthropology and critical disability studies, of its theoretical and practical results by the synthesis of the Anglo-Saxon studies and researches regarded landmarks in the topic. (Ingstad and Whyte, 1995, 2007; Kasnitz and Shuttleworth, 1999, 2001; Battles, 2011, Hershenson, 2000; Ginsburg and Rapp, 2013; Shuttleworth, 2000, 2001a, 2002, 2004a, 2004b). 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 giving empowerment, while encouraging the reader to ask questions, find new ways of cognition, think and act.

- The aim of Chapter III. is to present in details the process of participatory research created at the theoretical, methodological meeting point of cultural anthropology and critical disability studies. It also strives for sharing the cooperation process of the two persons taking part in the research, the spaces of their decision-making, and how the research method of *cultural biography* could be applied in general, and of particular situations. By sharing the risks, methodological and research ethics dilemmas, the chapter aims to contribute to the establishment of empirical research in the cross-section of the two disciplines in Hungary.
- The aim of Chapter VI. is to present the thematic focus point that Zsuzsa has chosen. 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 BEING 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 THESISSES COULD BE WRITTEN ABOUT HOW IMPORTANT ASSISTANCE IS FOR ME [...] FOR ME HELPING MEANS LIFE, THE ORIGO, THE STARTING POINT OF EVERYTHING ELSE.

The aim of the analysis is to reveal how disability studies criticizes the *concept of help* of people with disability and the repressive practices it goes with, and by doing so disability studies gave birth to the idea of the innovative *personal assistance* which was introduced by the *Independent Living Movement* in the 1970s. Besides presenting the empowering results of the practices of personal assistance, the chapter also demonstrates its criticism and its reinterpretation through the influence of *feminist ethics of care*. Relying on the fundamental thesis's of *relational ontology*, this interpretation refuses the dichotomy 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 and 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, experiential systems in the everyday practice of cooperation in personal assistance.

2. The disciplinary framework of the research

The dissertation with the empirical and qualitative research at the cross-section of the methodology, attitude and theory of cultural anthropology and disability studies contributes to the foundation of empirical studies of the cross-section of the two disciplines in Hungary.

Disability studies is a critical social science dedicated to deconstruct the experience and notions of normality, impairment and disability, and their interrelations. It redefines these notions and concepts while exploring the hidden power mechanisms of disablism (Könczei et al., 2018).

Disability studies does not deal with the issue of separating, redrawing the normal and the abnormal, but it rather wants to describe its diversity in detail to create a theoretical context in which it is possible to describe social functioning in the light of disability, and the phenomenon and experience of disability in light of social functioning (Davis, 2013). Disability studies focuses primarily on the social, cultural, political, legal, and economic aspects of disability and the individual, public, and social experiences of disability (Davis, 2013; Goodley, 2011, Meekosha and Shuttleworth, 2009).

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 FELLOWS. NOT EVERYBODY WAS POSITIVE ABOUT IT, HOWEVER. WHEN TALKING ABOUT DISABILITY STUDIES I ALWAYS EMPHASISE BRINGING THEORY CLOSER TO PRACTICE.

Cultural anthropology is observative participation. The process of learning together with the people involved in the research, where the main aim is to get *thick connection* (Ingold, 2017). Cultural anthropology explores the systems of actions, forms and contents of relationship, symbolic and interpretation systems created by human relations (A. Gergely et al., 2010). Anthropological approach means the description of a culture from within, it seeks to reveal the individual's own viewpoint within the context of the society which the individual is part of; anthropology then explains this experience within the network of theories about social and cultural processes.

Postmodern anthropology began by recognizing that the anthropological research process and writing are not transparent and neutral practices, the researcher/author is not without body and position, but is inextricably part of her/his history and culture. Disability studies was born within postmodern movements, while anthropology let these postmodern movements flow through itself, while reformulated its own basic concepts from a critical point of view.

This "creative uneasiness" (Niedermüller, 2005, p. 3), the new interests and new social/scientific contexts made it possible for social sciences to criticize their own modernist past, emphasising that the research and writing process are not transparent and neutral. The researcher/author is not without position, but is inextricably part of his history and culture (Geertz, 2000; Boglár, 2005; Lajos, 2011, 2013a, 2013b).

The disciplinary curiosity of disability studies and anthropology strengthen each other in this dissertation, which helps to let ourselves open up to our questions and to the anxiety triggered by these questions, a state to which new questions and possible actions can be connected (Schieldrick, 2012). All these, however, do not suggest the melancholy of the impossibility of being able to find an answer, on the contrary, it emphasises the importance of asking questions, and actualizing the acts (Braidotti, 2006).

3. Methodology applied in the 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 and Szász, 2008; Frank, 1995; Norris and 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 me by the person participating in the research are used. Ethnographic material is made up of personal and telephone interviews and e-mails exchanged during the research process.

RECOGNIZING THE PROBLEMS OF AN INDIVIDUAL EVOKES ESSENTIAL PROBLEMS. THERE ARE FEW PROBLEMS THAT CONCERNS MANY EXCEPT ME. FOCAL POINTS CAN BE DECIDED AFTER TALKING WITH ONE PERSON, BUT IT IS ESSENTIAL TO NOTE THAT THERE IS A HUGE DIFFERENCE BETWEEN ONE TETRAPLEGIC PERSON AND ANOTHER TETRAPLEGIC PERSON.

Voluntariness and informed consent were a prerequisite for participating in 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 and Könczei, 2009, p. 6) is understood as a premise in this research. The cooperation 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 of the research process, in the cyclic redesignment of the research plan and in the dissemination activities (cf. Király, 2017; Reason, 1994; Lajos, 2016).

A four-focused critical (self) reflexive note system (cf. Borg et al., 2012; Bergold and Thomas, 2012; Nazaruk, 2011; Szivák, 2010) was an integral part of the process of the research. The research leader monitors her roles, their effects, her own stereotypes and the use of concepts. She reflects on the relationship between people involved in research and on their power relations. The research-leader raises awareness of and also records the difficulties regarding the research process and decision-making situations, as well as the potential links with theorizing. Finally, she draws attention to the social, structural characteristics of the research, as well as to the social and cultural embeddedness of the research and the participants. Awareness-raising and commenting on the research process is not only carried out by the research leader – all four reflection levels are regularly displayed in the ethnographic interviews, when the two participants reflect together and individually, positing themselves in the dimensions listed above.

4. Results of empirical and theoretical research

The doctoral dissertation incorporates three major, interconnected fields: the disciplinary area (cultural anthropology and disability studies), the research methodology (ethnography and biography) area, and the area of network of relationships (on personal assistance). These are, of course, inextricably linked with other symbolic, material, physical, structural and linguistic phenomena, which are also the thematic focuses of the dissertation. The results of the three areas are shown in the followings:

4.1. The encounter of cultural anthropology and disability studies

In the dissertation I collected and systematized the historical landmarks of the interaction between cultural anthropology and disability studies. These constitutes also the most prominent interfaces of this dissertation, as it follows:

- both focus on the individual and the individual's connections/relations;
- both are inherently participative;
- both are characterized by being both conceptual and active at the same time;
- both are characterized by a critical and (self) reflexive approach;
- their investigation position and knowledge are situated;
- both conducts, advertises and teaches social dialogue;
- both accept the parallel existence of multiple truths;
- both are characterized by the intent of familiarizing/disseminating diversity;
- both are open to learning new concepts;
- both help to re-learn our basic concepts.

According to my literature overview there are three main focuses of those researches which are realised on the meeting points of cultural anthropology and disability studies.

- The first group includes researches focusing on the lives of *people with disability*. These studies seek to comprehend and identify the individual- and collective life-experiences and activities, the way they use, create and internalize culture; these researches can be inspired by autobiographies (auto- ethnography) (Wilhelm, 2004; Wade, 2008; Peters, 2000, Albrecht, 2005).
- Surveys focusing primarily on interpretative-, behavioural- and custom-systems in a *given community* towards disability and people with disabilities. These include studies that investigate the local narratives of different cultural communities about the causes, meaning, and/or cultural activities, customs, and beliefs that affect the social status of people with disabilities (Ingstadt-White, 1995; Littlewood, 2006; Shuttleworth, 2004a, Scheer and Groce, 1988; Shuttleworth and Kasnitz, 2004; Reid-Cunningham, 2009; Armstrong and Fitzgerald, 1996, Hoffmann, 2017, Flamich, 2017).
- In the third group there are the *meta-studies* illuminating the process of researches done on the common ground of cultural anthropology and disability studies. They investigate the questions asked, methodologies, goals, participants, power dynamics and disseminating techniques of the studies themselves (Hammer, 2013; Shuttleworth, 2001).

4.2. Methodological lessons and implications of the research

The dissertation presents the collaboration of two people: one is the subject of the research, and also a co-researcher, the other is the leader of the research. They worked together in a one-year-long participation research. The methodology evolving from the practice of ethnographic work and biographic research of one person, and then employed in the methodology of two participants working together in the research process. The research process is interpreted as a learning process (Gelei, 2002; Ingold, 2017). This helps us to learn more about how an individual, whose experiences reflect social mechanisms and imperatives, encounters the everyday imprint and mechanism of our culture

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

There are ethnographic and biographic elements in the research, methods are complemented with narrative life-interviews (Angrosino, 2007), field notes and reflexive field logs. Confirming and verification the validity and reliability of qualitative research is present in all phases of research in the following ways (Flick, 2009; Steinke, 2000; Golnhofer, 2001; Mayring, 2016; Maxwell, 1996; Kvale, 1997; Gelei 2002):

- maintaining the dialogue between life and theory;
- confirming real participation from the planning phase through the process of analyses to dissemination;
- importing contradictory results to the research;
- applying reflective, disciplined subjectivity;
- research practise, self-knowledge, self-reflexion;
- documenting the research process, ensuring transparency;
- asking for and accepting feedback, criticism, maintaining the discourse about the research process;
- constant query and self-challenging during the research process;
- parallel application of different research methodology tools.

The dissertation points out that if we are able to reflect to our own ontologies, then we can construct theories on the basis of what we learned from the field (and not from previous theories). The critical energy of deconstruction can be shaped by reflexivity to a mechanism for generating a new way of thinking. This changes the relationship and hierarchy between ethnographic material and analytical sources (Paleček and Risjord. 2013). To achieve this, we need experimentation: experimenting with theoretical methodologies. At this level, one should again reflect on what one considers to be research methods and what not (Holbraad-Pedersen, 2017).

The research also reflects on what dimensions influencing the research process: from the physical and mental state of the participants to the discourse about the content, evaluation and practice of the discipline. The dissertation presents the research as based on dialogues and as an

emergent process (Lajos, 2016, pp. 35–36), which is one of the surfaces of knowledge-creating (that is power-sharing) (Rappaport, 2008; Király, 2017). It maps the power circles of the two participants, the varied dynamics of them, emphasizes how complex the decision-making is in research situations, makes it clear in which situation the participants were *rather* involved in the phases of planning, implementing, processing, and disseminating. The research report highlights that the most serious challenge was to get rid of the deep-rooted practices of research planning and to take enduring flexibility and uncertainty accompanying qualitative participation research, especially in the following areas:

- planning and organizing time;
- narrowing research topic and questions;
- conveying research result;
- fitting research methods to the context;
- finding out forms and directions of the utilisation of the research;
- to comply with the different expectations concerning the research;
- solving research ethic problems (anonymity, getting the consent signature);
- ways of ensuring participation;
- strategies to ensure scholasticism.

In addition to accepting research uncertainties and difficulties, the dissertation highlights the range of tools available to the research leader to ensure real participation for the researcher – for example:

- sharing written and oral information on the planned course of the research;
- mapping out previous experiences as a research fellow;
- sharing knowledge and experience on participatory research;
- regularly asking explicit questions about the review of the research process;
- parallel use of different communication platforms;
- sharing comments on the research;
- regularly clarifying mutual research expectations;
- sharing professional and experiential resources about participatory research;
- continuously offer possibility to ask questions and to form opinions;
- creating and maintaining opportunities for engagement with collaborative research colleagues, information interfaces (e.g. conferences).

Throughout the whole process of research, special attention is paid to research ethics and to the proposals about research ethics connected to disciplines related to the research.

4.3. Dimensions of personal assistance

The thematic centre of the research is *connections of personal assistance* which draw attention to.

- Every individual has experience of assistance and dependence – these experiences are different, and lead to different life-qualities, THERE IS NO INDIVIDUAL AT ALL WHO CAN LIVE WITHOUT ASSISTANCE AND COOPERATION.

- If assistance is understood as something that we *do*, then it is immediately posited in cultural, political, economic, philosophical, and ethical space to which we should reflect (Bauman, 1993).
- To understand the universal nature of assistance we need to put it into the focus (more) intensely when forming theories both in cultural anthropology and disability studies.
- The framework of assistance (how we understand it and how we evaluate it) has significantly changed during the past three decades of disability studies, which is strongly connected to the Independent Living Movement and the feminist ethic of care.
- A *theoretical* framework of redefining personal assistance is offered by *relational ontology*, which:
 - emphasises that being is impossible without relations to animated and inanimate objects (Wildman, 2006; Benjamin, 2015; Sidorkin, 2002; Yannaras, 2011), therefore existing beings cannot be understood without their connections;
 - through our connections, and the constant flow of these connection we are always in the state of becoming (Deleuze–Guattari, 2009; Hernádi, 2014; Braidotti, 2006).
- 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 the proper *theoretical tool* to analyse the relations of phenomena and situations. It helps us to:
 - see all 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.
- Experience of assistance requires constructing frameworks which do not value people in assistance relationship by their independence:
 - therefore, we need to deconstruct the meaning of dependence, and focus on the *relation* phenomenon;
 - this means overwriting the fictive autonomy of human being, emphasising that all our activities are relation-actions as well;
 - due to these relations and their constant modifications we are also in constant shifting;
 - these relations have material (objective and bodily), natural, discursive, cultural and structural dimensions;
 - the interlocking of the elements results in effective forces that either impede or create changes (re- a deterritorialization);
 - certain entities (money, emotion, etc.) flow through these interlockings, and they define, the way of the shifting and changing;
 - unweaving 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.
- It is important to have such theoretical frameworks and practical experiences within which we can experience ourselves and our relations within the process of assistance.

- Experiencing and understanding the relations of personal assistance always happens in a given situation, relation, social, cultural space and both the reader and the researcher is a part of it.
- 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 PAY, ENTER 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);
 - to operate a good personal assistance relation the following 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 reflects 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;
 - It is important to know about a good personal assistant relation that:
 - WHAT MEANS JOB AND ASSISTANCE TO THE PERSONAL ASSISTANCE, THAT IS LIFE TO ME;
 - it empowers both parties in the relationship – regarding their own life and relation;
 - the co-operators personality highly matters in this relationship;
 - it may have opposites (e.g.: counter-interest – willingness to help, caring – disgust, close-up – keeping distance, increasing vulnerability – reducing, humiliating – respect);
 - to accept or stop these effects both parties have to develop strategies;
 - it is imperative that both sides strive to reduce vulnerability and mutually reinforce each other;
 - WE TRIED WRITING JOB DESCRIPTION, BUT THIS WORK CAN NOT BE DESCRIBED. IT DOESN'T MEAN ANYTHING, IF I WRITE: MANAGEMENT OF MY TECHNICAL INSTRUMENTS. HERE THERE ARE

TWO OR PROBABLY THREE REALS PROFESSIONAL TASKS FOR NURSES: CATHETERIZATION, THAT IS REALLY A PROFESSIONAL TASK, THEN THE WASHING OR CLEANSING, AS THEY CALL IT, 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 JOB IS DONE, YET THIS DOES NOT MEAN THAT I FEEL WELL.

- The main difficulties of a personal assistance relation from the point of view of the user:
 - keeping a personal assistance network from one’s own funding is financially extremely burdensome;
 - the number of available personal assistants is very low;
 - I THINK IT IS VERY DIFFICULT TO LIVE SO THAT I ACCEPT ASSISTANCE OF THE OTHERS CONFORMING TO OTHERS’ WILL AND PERSONALITY. WHAT IS THE LIMIT TO BE OURSELVES? IT IS VERY DIFFICULT THAT WE ALWAYS HAVE TO CONFORM TO DIFFERENT PEOPLE WHEN GETTING ASSISTANCE. WHO CONFORMS TO WHOM? WHERE IS THE BORDER WHEN WE STILL BE OURSELVES? HOW MUCH DO I HAVE TO ALTER MY HABITS?
 - sometimes your most basic needs and the urgency of satisfying them are questioned by the supporting relation;
 - no adequate tools are available to make hygiene activities more comfortable;
 - the continuous training of helpers by the person using the service is wearisome work;
 - it is not possible to complain all the time and teach everything to personal assistants.
- Based on Zsuzsa's experience, we gathered the main guidelines defined by the relations and contexts that characterize the *good assistant* and the *good employer*, in which there are contradictory features, emphasizing the complexity and variability of the situation and its polyphony. THERE IS NO IDEAL ASSISTANT, AS THERE IS NO IDEAL ASSISTED, IT ALL DEPENDS ON THE SITUATION.
- Personal assistance is not only important for tetraplegic people but also for example for people with other kind of disabilities, for children, for chronically ill people, dying people, pregnant women, mothers and fathers with children, for the elderly, injured or ill people.

5. Summary

During the research work, both theoretical and interpretive frameworks have emerged that help *understanding* the complexity and connections of the personal assistant relationship. We also gathered knowledge that can create a better *experience* of personal assistance.

The interconnection between cultural anthropology and disability studies, as well as the adaptation of the cultural biography's ethnographic research methodology, has proved to be useful to get closer to these inseparable understanding and living processes. The intent and results of the participatory

research process presented in the dissertation is to contribute to the development and availability of *good personal assistance*, and the empowerment of people using the services in Hungary.

Both of us aim to continue working on sharing and implementing existing results, both in science-based and in life-based forums. We intend to further process the existing rich empirical material of our collaboration and to generate and to participate in researches that work together with all actors in the personal assistant system.

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