

SERVICE USERS INVOLVEMENT IN RESEARCH AND TEACHING: IS THERE A PLACE FOR IT IN EASTERN EUROPEAN SOCIAL WORK³

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SUMMARY

The article presents three major prerequisites for users' participation in research and teaching: a) the »narrative turn« in social sciences and particularly in social work, b) the impact of disability movements and other social movements in local contexts for the development of users' participation, c) the need for the development of an anti-paternalistic, strengths and resilience-oriented perspective of the professionals towards service users. In Eastern European countries which rather lack all of these three elements, users' participation and involvement in research and teaching still require a lot of cultural and professional changes. The article presents two case studies of users' involvement in research and teaching in Slovenia. In 2007 a group of

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³ The article is dedicated to the memory of Professor Tanja Lamovec Ph.D., one of the first mental health service users from Ljubljana who made numerous research, published books and taught social work students at the Faculty of Social Work between 1992 and 2006.

mental health services users were trained to become researchers in group homes for people with mental health problems in Ljubljana. They have proven, like most of the western studies on this matter, the need for participatory research in social work in order to gain a deeper understanding of the everyday experiences of service users. Since 1999 more service users, especially those experiencing mental health problems and with different impairments, were invited to give lectures and seminars to the social work students at the University of Ljubljana. The article analyses their experiences including the one of the "glass ceiling" in the dominant culture of the power-knowledge discourse.

When I introduced myself to the students as »a blind person«, I was labelled; their images of the blind became activated and I could not reach them during the teaching. They became very stiff. When I said I have serious damages of my sight, it was okay, it did not mean for them that I was an' invalid.

*Marino Kačič,
one of the first social workers with disability
who works with users in Slovenia, 2008.*

I was taken really seriously by the social worker. He took the time to talk to me and I found out that we had similar opinions. I had never viewed a social worker from this aspect.

A researcher, mental health service user, 2007.

INTRODUCTION

Service users' involvement is far from being an innovative topic in applied social sciences but it is certainly an innovative practice in Central and Eastern Europe. The region which is well-known by the former top-down socialist approach in social work and related sciences, has kept a strong dichotomy between the experts and the service users until the present times. In the common sense of local people from the region, there is a belief, that it is better not to show off in front of the professionals and that complaining can even worsen the person's situation (Zaviršek, 1995., 2001, Hessle, and Zaviršek, 2005.). The traditional dichotomy between the professionals and service users (until recently called »patients« and today commonly called »clients«) has been still alive in the claims that professionals have »expertise« and »knowledge« while the service users have only »experiences«. Experiences have been seen as too personal and emotional, and much too subjective to be able to provide an »objective truth. At the same time expertise and knowledge have been perceived as objective truth which could be generalised. This type of dualism constructs two different, seemingly homogenous groups of people, one of non-user and one of users. It has been widely expected that they share some intrinsic differences among each other and at the same time commonalities inside each of the groups of »professionals« and »users«.

The authors of the article claim, that it is very difficult to develop a service user involvement in the cultural traditions of Eastern Europe, since it demands a paradigmatic shift within the professional culture as well as the »eastern European mentality«, as it was called by the former Czech president Vaclav Havel (Završek, 1999.). Seeing service users as only as demanding and »with problems« is the major cultural obstacle which prevents the development of service users' involvement in research and teaching. At the same time there is a need for raising a general awareness of the importance of people's participation from the time they are children.

In UK - the leading country in user involvement - there is a duty to consult children and young people since the 1975 *Children's Act* and since the 1990s there exist a national regulation to involve service users in decision making. In Denmark, the educational regulations explicitly state that schools are expected to develop children's skills in learning to participate in decision making (McLaughlin, 2006.). Although most of the eastern European countries adopted and signed the United Nations *Convention on the Rights of the Child* by the United Nations' General Assembly, children and young people's rights are still not equally valued as the adult's rights. Children are still too often seen as incompetent and are not encouraged to stand for their rights. Something similar can be observed in the area of service users, who are still today too often seen and treated as »big children«. In some laws, as for instance in the one on people with intellectual disabilities in Slovenia, they are still officially called »children« (Završek, 2007.). McLaughlin (2006.) has emphasised that the Articles 12 and 13 of the UN Convention on the Rights of the Child have been particular important for user involvement in research and teaching. Article 12 promotes a child's right to express an opinion and for that opinion to be taken into account in any matter or procedure affecting that child, whilst Article 13 promotes the right to information and freedom of expression.

It is therefore not surprising, that the development of user-led research and teaching has first started in the western countries but in some eastern European countries in the late 1990s, the development followed very similar roots. This was best shown at the Zagreb seminar on user involvement supported by IASSW and directed by Kristina Urbanc in 2008⁴. In the article some of the commonalities and specificities will be presented.

THE DEVELOPMENT OF USER-LED RESEARCH AND TEACHING: A COMPARATIVE PERSPECTIVE

The development of user-led research and teaching in the western as well as in eastern European societies cannot be separated from paradigmatic shifts within research methodology and the political importance of the service users' social movements.

⁴ *Title of the project supported by IASSW: Service users as experience experts in social work education and research (2007. – 2008.)*

What anthropologists knew already for decades, namely that collecting stories from their informants in the fieldwork makes the »real« research, social workers were just about to discover. Since the late 1960s qualitative research in social sciences gained a strong importance and the so called »narrative turn« marked the beginning of the »story telling era« not only in social work practice but also in research. In order to understand people's every day experiences, struggles and needs, personal stories became a key focus for many researchers as well as a source in the professional teaching. Between the 1970s and 1980s a »new paradigm« in research emerged which raised the question of the power relations between the researchers and the researched (Ramon, 2003., Castillo and Graham, 2008., Videmšek, 2009.). Since 1990. the interpretative paradigm has been asserted as the main alternative to positivist research together with action research promoting user inclusion and co-operative investigation. Knowing the community and being able to »return« the research findings into the community, became not only the key principle in action research but also in qualitative research led by service users. Various types of action research, including user participation in the design and execution of the research activity itself appeared during at that period of time (Lyons, 2000.). The development of the new techniques of data collection and qualitative empirical material analysis provided conditions which started to enable the inclusion of users into research as researchers.

Another important source for the development of the user-led research was the raise of social movements like feminist and peace movement but especially those led by service users and carers, particularly in the field of mental health, psychical and intellectual disabilities (Oliver, 1992.; Winter and Munn-Giddings, 2001.; Rose and Lucas, 2007.; Videmšek, 2009.). Several of disability activists have importantly influenced the discourse on power relations in welfare services among service providers and receivers and contributed to some good practice principles based on a more equal relation among them. According to Thompson (2002.) social movements played an important role in ensuring that service user's views were taken into account as relevant in the policy and practice development and implementation, as well as evaluation of services. Service user's movements challenged the traditional model of professionalism whilst emphasising the expertise service users have regarding their experiences and rights. The results of the struggles by social movements in western as well as later on in the eastern European societies, showed that several social work issues have been inevitable connected with citizenship rights.

These two main sources opened the path for another struggle, the one for the inclusion of users in research in order to influence the power/knowledge of the research process in Foucaultian terms (Foucault, 1981.). Until present times there are several definitions of what are the characteristics of user-led research and to what extend service users are supposed to be involved in setting research agendas, planning, consultation, collaboration, doing the fieldwork and the interpretation of the findings. The authors of this article understands the user-led research as »one in which users are equal partners regarding the major decisions

taken about the research and the whole research process, while the research focus being driven by user's concern« (Ramon, 2003.:18). During the early period of user involvement it became clear that users have their own experiences that were neglected and overlooked in the past (Oliver, 1992.; Barnes, 1993.; Beresford, 2008.; Videmšek, 2009.). With their involvement, the users' perspective became one of the most valued qualitative methods that ensure account of their experiences and highlights the centrality of relationship between researcher and object of research. Service users started to be called »experts by experience« (van Haaster and Koster, 2005.).

Today, the extent of users' involvement into research has become a question addressed by many researchers in western as well as in the eastern countries. The extent to which and in what ways service users become included in research has become a methodological question. Nevertheless, the idea of user involvement in research differs mainly in the degree of their inclusion in a particular study. There are three levels of user involvement in research which can be summarised from the existent literature:

- a) research within which users are members of the research team and are in the position of consultants (Barnes, 1993.; McLaughlin, 2006.);
- b) research where users are supported by professionals to carry out a research (Ramon, 2000.; Humphries, 2001.; Beresford, 2008.);
- c) research that are user-controlled and led (Wiltshire and Swindon Users Network, 1996.; Evans and Fisher, 1999.; Ajduković, Urbanc and Branica, 2008.).

What all three levels of user involvement have in common is the urge, that research should be done »with« people and not »on« people (Reason, 1994.; Videmšek, 2009.).

Looking at the history of the service users' involvement in teaching one of the major obstacles for its development was a strong professional limitation of seeing service users as being needy and dependant and not competent and with different abilities (Shultz, 2007.). If service users are seen as being not capable of solving the everyday difficulties, how can they be allowed to get involved in social work teaching and responsible communication with social work students? The paternalistic voices against service users involvement in teaching often repeated that an "unknown teaching situation might trigger trauma, stress, and can re-traumatise the person".

The conceptual opposition of these views was presented in the resources- are resilience oriented work with service users, which emphasised the knowledge of the other who is not only dependant but competent and strong at the same time. Resilience is most often defined as the psychic power to resist and as the ability to skilfully deal with strain without damaging oneself or as the capacity to emerge from the most heavy and damaging conditions in life with greater strength and resources than before (Eichenberg, 2006. in Shultz, 2007.). The results of some resilience research have emphasised particular personality traits of service users which can serve as protective factors while coping with stress: the necessity of seeking solutions, inventiveness, perseverance, flexibility, ability to change perspective, sociability,

etc. (Shultz, 2007). Most service users are able to master severe life crises, such as long phases of unemployment, the loss of loved ones, serious illness, forced migration etc. Many service users have to deal with multiple losses, like the loss of health body, of their native country and language, their profession and cultural identity or even social death. They have to deal with the "Otherness" ascribed to them on the daily basis. Some of them are able to develop – as the consequence of that - a great degree of strengths and learn to quickly assess situations and persons in order to survive in a society in which they often face hostility. Many service users have the ability to confront new challenges and difficulties and also the stress of being involved in an unusual and unknown environment of teaching.

Looking at the strengths and resilience perspective has become a prerequisite of inviting service users in teaching process in social work. Not only the importance of sharing personal stories but also the belief that it is part of empowerment processes if someone looks at the strengths instead of disadvantages of people experienced trauma and loss, encouraged professionals and teachers to make space for service users' involvement at the universities.

During the seminar on user involvement in eastern Europe mentioned above, it became very obvious, that many eastern European countries, like Macedonia and Bosnia and Herzegovina for instance, do not have any tradition of service users social movements which consequently delayed user participation in those countries.

In Slovenia the major shift towards the user participation in teaching were done by disability activists who started to publish critical books, articles and daily news reports based on their own personal experiences with mental health services and with social workers. One of the first critical books on mental health was published by a professor and a long term mental health survivor Tanja Lamovec in 1995. (Lamovec, 1995.a, 1995.b, 1995.c, 1995.d, 1996.a, 1996.b, 1997.a, 1997.b, 1997.c). She and people around her had pioneered politically aware user-led organisation that had not only set up the first advocacy service and a number of NGO's for and with people with mental health problems in Ljubljana, but had also challenged the power/knowledge of different professionals as well as educators and became continuously involved in social work teaching.

The lived example of stigma, discrimination and daily struggle for individual as well as collective rights with almost no support system in the community, pushed Tanja Lamovec to end her life with a suicide in 2006. Before she died she wrote a letter in which she bitterly concluded that the struggle was lasting too long and that she was unable to fight anymore. Some people had »read« her suicide as the collective accusation of the country she happened to live in and which failed to provide effective support network and services, while the others understood it as part of her mental health illness. Nevertheless, her personal story has shown once again, how difficult or even impossible it is to fight against the life-long oppression of mental health service users in one of the normative and discriminatory society of eastern Europe.

After 1999, another powerful disability activists group took the political arena, the YHD-Association for the Theory and Culture of Handicap (Pečarič, 2002.). In 2005 this was the very first organisation in Slovenia which started the Independent Living Programme and has been organising trainings for people wanting to become personal assistants for persons with disabilities in their homes (*Independent Living of Disabled People*, 2004.). Its president Elena Pečarič got in 2007. enough votes to run for the national presidential elections, but were constantly ostracised by traditional invalid organisations which remained on power from the previous regime. The members of user-led YHD organisation have become involved in teaching at the school of social work in 1999., while Elena Pečarič, a wheelchair user with severe muscle dystrophy, became a teacher at the school on the non-permanent basis since 2006.

These two leading and almost iconic figures in the Slovenian service users' movement show that it is not only enough to recognise the empowering effects of service users' involvement or the empowering effect the involvement has upon a particular person (Solomon, 1976.; Ress, 1991.; Evans and Fisher, 1999.; Flemming and Ward, 1999.; Videmšek, 2008.). Tanja Lamovec and Elena Pečarič did not need any additional empowerment for their pioneering work. In opposite, strong and empowered service users do not need more empowerment but respect and a place to be heard and taken seriously. They themselves often empower teachers and students to be more benevolent towards changes and empower them for a more critical thinking (Pečarič, 2009.). In the local context of Slovenia the involvement of service users in teaching would hardly be possible without these powerful persons. Therefore, the encouragement of user-led organisations and movements are of the core importance for user participation in research and teaching in eastern Europe.

MENTAL HEALTH SERVICE USERS IN RESEARCH PROCESS

Since the mid 1990s people with mental health problems in Slovenia were involved in research but their involvement were never documented and reflected. In 2001 the very first Roma student who got enrolled at the school of social work⁵ participated in a national survey on the living conditions of Roma ethnic minorities with the aim to embrace the perspective of the oppressed from the beginning of the research (cf. *Minority Protection in Slovenia: National Report. Open Society Institute, EU Accession Monitoring Program, Budapest. CEU Press, Budapest, 2001.*). It became very obvious that the involvement of the member of oppressed community has opened the opportunity for a more sensible approach in research and the verification of the research questions in an early stage of the research. The Roma researcher helped to understand how might a particular question sound in the ears of the persons who live in Roma community and prevented negative professionalization with the construction of kvazi-scientific »castles of truth«.

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Another more systematic user-led research was conducted in 2007. with mental health service users living in six different group homes in Ljubljana.⁶ Since group homes are a recent 1990s development among the community based services in Slovenia, the research wanted to explore the ways in which the residents of the group homes are encouraged to live an ordinary life, the level of their social inclusion and their quality of life. During the process of research 6 mental health service users were invited to become researcher and they went through a training program to learn some basic skills of interviewing and conducting the research. The qualitative research used mainly data collection of several focus groups (five focus groups with 6-8 people from different group homes) and interviews which were conducted by service user researchers (total 12 interviews with service users from different group homes). There were more men than women respondents, as more men than women are residents of the group homes included in the research. In the first phase of the research the service-users-researchers themselves were involved into focus groups which give them the opportunity to articulate the major issues about experiencing the lives in the group homes. Later on they were interviewing other residents with the use of a structured interview.

Throughout the research process, participation of service users had been changing. Sometimes they defined the theme of the research questionnaire, have chosen the group home where they wanted to conduct the interviews or took part in the focus groups. On other occasions they were involved as consultants, since they participated in the team discussions of what was heard and learned.

The Slovenian research confirmed the experiences of other researchers who already described the benefits of the user-led research: service users asked honest, direct and »right« questions, based on their own personal experiences and the answers obtained by informants-service users were honest and open which is not always true in studies done by researchers without lived experiences. On the other hand the obstacles mentioned by previous researches were confirmed, too (Butler, 2003., Lloyd, 1997., Ramon, 2003., McLaughlin, 2006.). Researchers spent a large amount of time for finding the service users who were willing to be researchers and needed time for an additional pre-research stage of developing and carrying out a training program for service users before they got involved in the research.⁷ During the study service users were offered a proper training before starting the research and lots of discussions, numbers of meetings, and peer supervision took place during the entire research process.

⁶ This research project was conceived, conducted and analysed in the framework of preparation of the doctoral thesis by Petra Videmšek.

⁷ Training was divided into three parts: introduction (of the persons involved; of the topics), getting the main information about the research and learning different research methods with special attention on interviewing and learning how to conduct interviews. A lot of time was devoted towards self presentations, to the questions how to handle difficult situations, listening skills, writing up and dealing with one's own emotions.

The user-led research showed a big deal of criticism upon the existent group homes which were supposed to increase the social inclusion of mental health service users. The user-led study showed that although located in the community the residential groups provided a minimal degree of integration (...users are still remaining on the margins with the emerging phenomenon of ghettoisation); and that residents' activities were organised within the welfare programmes and residential units and not in the community (visits to day centres, rehabilitation activities, attending chess clubs within the welfare organisation). For most residents, living in the group homes meant an accommodation for »an indefinite period of time« (people have been living there for up to nine years). Most residents came to the group homes from their primal families and not from institutions, meaning that the group homes actually did not implement deinstitutionalisation processes. The study showed that the residents could decide about their diet while social workers helped them to structure their menus. An interesting issue was smoking, where the element of infantilising the residents became very obvious, since the professional staff have decided on the daily amount of cigarettes for each resident. The most positive effect of living in a group home from the eyes of the residents was that they were able to make choices about certain things (time of getting up, daily activities and diet). For most of the residents group home was a place that offers some shelter, but was not seen as their home.

User involvement in research and teaching is a challenge to both, social work professionals and service users. It promotes some basic principles of social work »science of doing«, like the ethics of participation, empowerment and the co-creation of solutions (Videmšek, 2009.). By including those who have no social power, professionals enable them to express their views and take part in decision making which promote the principles of inclusion and diversity. By participating in research some service users took part in the socially valued activities (»now I am a researcher and not a mental patient«; »In the morning I tell everybody that I am going to a research meeting«). Some of the Slovenian service users reported becoming more respected by their peers, since they took part in research (you're lucky, you pulled yourself through; you're someone to be able to do this). Service users being involved in research are centrally challenging the stereotypes that people with diagnosis and those from oppressed communities could not become researchers and that the research is reserved for an elite group of people (Videmšek, 2009.).

BEYOND THE "GLASS CEILING": PEOPLE WITH DISABILITIES TEACHING IN SOCIAL WORK

As pointed before, one of the most important conditions for service users' involvement is the existence of the user movement in a local context. In Slovenia service users have been more often involved into teaching since 1996. which was the time when several user-led organisations became more powerful demanding their citizenship rights. The majority of service users

came from user-led mental health organisations and few of them were disability activists and people with intellectual disabilities working in sheltered workplaces. The article will present three outstanding figures most closely linked with social work training in Slovenia.

One of them was Luj Šprohar, a well known literature writer who became visually impaired in his young age. In the second half of 90's he was invited to teach social work students at new course »Theory of handicap« During his classes the students were fascinated with his teaching style and rhetorical abilities. He walked up and down in front of the class as not being visually impaired. On one occasion, when he wanted to leave the classroom in his quick manner, he bumped into the doorjamb and hurt himself. The students were shocked and ashamed since nobody supported him in finding the exit and left uninjured. Here the tiny line between paternalistic care and sensitive support became an issue. The students were too confident that "he sees much than he admits", that they were not sensible enough to help him when needed. On the other side, Luj Šprohar himself wanted to prove his independence and no need for any assistance. In order to overcome his disability he presented himself as an over self-confident individual and did not show any need for assistance.

This event taught the students and the teachers more than hours of teaching. It has shown an enormous struggle of people with impairments to become part of the "normal world" on a premise that they do not need any support, since independence is valued as the only condition of normality. At the same time it has shown the ignorance of the non-disabled world to acknowledge the need for assistance on the basis of equal relations, respect and diversity.

Not only social work students, the teacher as well were lacking the sensitivity for diversity and inclusiveness.

In 2005 a conference on violence against women with disabilities was organised at the Faculty of Social Work (Zaviršek, 2005.), but at the panel discussion no space was left for Elena Pečarič, president of the user-led organisation YHD who does not use the ordinary chair but a wheelchair. There was a big embarrassment of the organisers who promoted the unwanted topic to raise the awareness among social workers but failed to provide an inclusive environment for all. This event only showed the lack of experiences for ensuring the diversity on the every day basis.

Marino Kačič, a social worker and a trauma counsellor became another person with visual impairment who was continuously involved in social work teaching since the late 1990s. He became visually impaired after a heavy accident in his youth and his disability was the major reasons which brought him to the school. After finishing the diploma course in social work he worked as a volunteer at a mental health crises help-line. During a public lecture in 1994 he recalled one of his experiences: "Some people wanted to talk to me, when they called and I knew them over the phone during a long period of time. Sometimes I told some of them that I don't see, having an accident when I was a child when a mine got activated in my hands when we played. Then, most often there was a long silence on the

other side. People didn't know what to say. For some people this was a revelation but some never called again." (personal notes, Darja Zaviršek, 1994.).

In the last ten years he worked with relatives of people with disabilities and became the editor of an on-line journal for people with visual impairments (RIKOSS⁸). In 2006. he started to teach on a non-permanent basis at the Faculty of social work at the department of disability studies (today Department for Social Justice and Inclusion in the areas of Disability, Gender and Ethnicity).

In his long-term experiences of teaching social work students he found out that the students were more silent during his classes than during some others. They remained very formal and more careful than in front of other teachers: "Often they appeared very stiff to me!" (personal communication, 2008.). This was especially the case in the times when he introduced himself to the class as "person who is blind", which was for him a gesture of openness and the way of starting the learning process at the same time. Soon he discovered that the shock by the students, who experienced only segregated schooling and rarely knew a person with disabilities themselves, was too big (the law on inclusion of children with disabilities in ordinary schools has passed in 2005. but is until today modestly implemented). The students with little experiences of diversity were not able to move beyond the label "that he is blind". For some of them he could not be disabled and a teacher at the same time, while for the others, their silence was an expression of having very little life experiences and did not know what to say. In Marino's observations he needed rather long time until the turning point happened and the students started to communicate with him, feeling more relaxed: "I wondered how to shorten this time-period. I learned for myself to use some tricks for that. For instance, I ask them to help me with something. Now I have noticed that the time-leg is getting shorter. Sometimes it took me hours of lecturing and seminars before I broke the silence and discomfort." (personal communication 2008.).

He discovered that the word "blind" is a bigger problem for the non-visually impaired people than the fact that he has been unable to see. When he started to teach in front of the class without mentioning the fact that he is severely visually impaired, some of the students often even did not notice it until the end of the first class. He passed as a non-disabled person and the majority of the students comfort their unease with the belief that he "do sees something" ("I can't believe it, I'm sure he must see something!"). Marino Kačič reflected on that: "When I introduced myself as a blind person, I was labelled; their images of the blind became activated and I was losing time. When I said I have serious damages of my sight, this does not mean being 'an invalid' in their perception. The word 'blind' itself is a big problem!" (Kačič, 2007., 2008., 2008.a)

At the same time he also needed to involve the students in the assistance and in the understanding of his barriers and needs: "After introducing myself I asked them to help me to find the chalk. I wanted them to get involved in a situation of mutuality, to interact, and

⁸ Available on: <http://www.zveza-slepih.si/rikoss/index.htm>

also to raise their understanding of who I am and what are my needs. It is important to make them sensible of my needs, too" (personal communication 2008.).

All of these examples show that what the non-disabled teachers take for granted, a person with disabilities has to work through, developing different strategies to be accepted and successful. The barriers of the teachers with disabilities are enormous: they need to make sure that the "level" of their disability is still "acceptable" for the students and at the same time had to be seen as a person with impairments in order to get support and assistance needed; they need to break all sorts of stereotypes and deal with the students resistance to be accepted as the respected and trustworthy authority.

For social work students people with disabilities offer not only the teaching content but also a lived experience of interacting with a person with experiences of whom they only know from books. It encourages the processes of de-pathologisation of the disability in a society where being disabled is a huge stigma and people with impairments are still called 'invalids' (Zaviršek, 2007.). It is a learning process where students themselves can easier disclose their own vulnerabilities and share personal stories. On one of the occasions, a social work student who took the intensive disability study course for 2 years already, disclosed that both of her parents were deaf only after the seminar given by the person with disability. Being taught by a disabled teacher offered a safe space for many students to talk about their traumatic events. One of the students disclosed that she is unable to have children, and told to the class that it was for the first time to talk about it. In these examples the teacher with disability expands the boundaries of normality and while using his/her vulnerability as a teaching tool, symbolically permits sharing the vulnerabilities and traumas of the students. Another important benefit was expressed by the students themselves; they felt that teaching by a person with disability has a greater level of authenticity and truth than they experience among some non-disabled teacher: "When he says this, then we know it is true! Other professors often just go like 'bla bla bla'. He goes in the centre of the thing" (interview with students, 2008.). Sometimes disability itself means a guarantee that the issues discussed from personal experiences do not need lots of justifications and counting on the research of the others. It is the personal experience that gives the validation of what is told.

The most responsive students have been those who have their own experiences of impairment and disability and can therefore more easily relate to what have been told or experienced. They are a step ahead of those students without the experience of disability. Some of the students recalled that having a disabled teacher helped them to go to the practice placement and doing interviews with other people with disabilities.

People with disabilities and service users who are involved in teaching challenge the hierarchies which are very common among Slovenian social work students. In their view being disabled and a teacher is a contradiction, which gets torn apart after experiencing a disabled teacher. There are also many bitter experiences which show that people with disabilities still have to struggle enormously because of prejudices and oppression.

Both, Marino Kačič as well as Elena Pečarič mentioned the phenomena of the “glass ceiling” when they described their experiences during their social work teaching. The students’ non-cooperation, non-responsiveness, silent resistance, the refusal of doing work, absentism from classes, talking to each other while the lecturer were giving the lecture, were the most common responses. Marino Kačič recalled the situation: “I noticed that they were standing up, leaving the class silently, going in and out. I left them to do this for a while. Then I asked a person, ‘do you leave for good or you intend to come back?’ This was a shock for them. They thought I did not notice. Then they stopped. They tested my boundaries” (personal communication, 2008.). The feeling of the “glass ceiling” was also related to the fact that the students needed a very long time before they accepted their authority as teachers and that the lecturers themselves needed to invent several strategies to cope with the barrier which they were confronted with. Some of the students expected that having a disabled teacher will help them to pass the exam easier: “One of the students wrote an essay, and among 15 pages that were required, three of them were blank pages. She thought I will not notice it” (Marino Kačič, personal communication 2008.).

Another experience of these type was when Elena Pečarič on one occasion asked the students to formulate some questions after she finished talking and the students turned to the non-disabled teacher and started asking the questions instead of asking Elena directly: “What did she meant by this, when she said that [...]?” (participatory observation, 2007.). The student repetitively followed the oppressive pattern of people who speak or look at the personal assistant instead the person on a wheelchair while asking something the person with disabilities. It is the communicational discrimination and the oppression of the gaze while ignoring the visual contact with the person with disability. Elena Pečarič experienced being objectified, not valued as equal partner and not taken seriously. The student expressed an intentional or an unintentional refusal to interact with her directly.

But having “the experience” is not enough for a good teaching. Most of the people with disabilities emphasised the need to have a “reflected experience” in order to reflect on the personal one: “I’m always including my personal experiences in what I teach but this is not everything what I do, personal experiences have to be only a part of the complex teaching.” (Marino Kačič, personal communication 2008.).

CONCLUSION: THE LESSONS TO BE TAUGHT FOR THE EASTERN EUROPEAN SOCIAL WORK

As it was discussed above, there are three major prerequisites for users’ participation in research and teaching: a.) the “narrative turn” in social sciences and particularly in social work; b.) the impact of disability movements and other social movements in local contexts for the development of users’ participation; c.) the need for the development of an anti-

paternalistic, strengths and resilience-oriented perspective of the professionals towards service users. In Eastern European countries which rather lack all of these three elements, users' participation and involvement in research and teaching still require a lot of cultural and professional changes. The article presents two case studies of users' involvement in research and teaching in Slovenia. They have proven, like most of the western studies on this matter, the need for participatory research and teaching in order to gain a deeper understanding of the everyday experiences of service users and to challenge the dominant discourse of power-knowledge.

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