



FOGYATÉKOSSÁG ÉS TÁRSADALOM

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EDITORIAL PREFACE

First of all, I would like to greet the readers of *Hungarian Journal of Disability Studies & Special Education (Fogyatékoság és Társadalom)*. As the new Editor-in-Chief of this prestigious journal, I would like to thank the great work of the founding Editors-in-Chief, in particular Prof. György Könczei. He had a vision of this journal, the first scientific paper in Hungary which focused on the complex, inter- and multidisciplinary field of social sciences and disability studies. Prof. Könczei built a journal which is nationally and internationally recognized, and which is one of the leading journals of disability studies in Central and Eastern Europe. Not only a prestigious journal, but a scientific community has been built by Prof. Könczei, a community, which is linked by the *Hungarian Journal of Disability Studies & Special Education*.

We also owe a debt of gratitude to Dr. Ilona Hernádi, who, as former Editor-in-Chief, ensured that visual culture was present alongside scientific content. Therefore, the new Editor-in-Chief has a difficult and an easy task ahead at the same time. The task is easy, because a rocksolid foundation has been built by the Editors-in-Chief: they created an internationally recognized journal, drawn a wide range of authors and valuable articles. But this task is still a very difficult one, because it is a complex challenge to meet the high standards set by my predecessors.

Therefore, my main goal as the new Editor-in-Chief is to maintain continuity and develop the journal. Disability studies are complex, critical multi- and interdisciplinary social sciences. Thus, this polemic nature should be maintained: our articles will critically examine the current phenomena of our societies through the lens of the persons with disabilities. Therefore, the journal will remain inclusive. We would like to follow the principle of “nothing about us without us”, therefore, we will also present the results on participatory research. The journal will remain a multi- and interdisciplinary one; the phenomena of disability and society will be examined by different approaches: by the approach of pedagogical sciences, sociology, psychology, medical sciences, political sciences, economics, jurisprudence, etc. – by the complex approach specific to disability studies.

The main goal of the Editorial Board is to develop the journal: we would like to be a forum for researchers of disability studies, not only from Hungary, but from all around the world. The foundations have been built, now there is a task to build the whole house.

This mission is mirrored by the current number: it is a result of complex research; there are articles based on sociology and economics, psychology and pedagogy, sociology and legal sociology, the multidisciplinary approach of the critical disability studies and even administrative sciences. This issue is a special one, because it

shows the collaboration of the most important workshops of disability studies in Hungary.

Therefore, I hope the readers will find interesting, thought-provoking articles and important scientific findings in this issue, and they will agree that although our journal is changing, like our societies, but we follow our basic values and traditions.

Prof. István Hoffman
Eötvös Loránd University, Faculty of Law
New Editor-in-Chief of *Hungarian Journal of Disability Studies & Special Education*

ABSTRACTS

ANIKÓ SÁNDOR

Self-determination Opportunities of Persons with High Support Needs

Based on the theoretical framework of Critical Disability Studies, the paper presents the characteristics of self-determination of persons with high support needs in different types of living arrangements in Hungary. It examines the available support for persons with high support needs in Hungary to ensure self-determination in different areas of life that are relevant to them. Within the qualitative, participatory paradigm, participant observations, interviews and focus group interviews were conducted. The study concludes that some elements of self-determination can be observed in all forms of living arrangements, typically as a part of the everyday routine, but at the same time, people with high support needs also experience very serious restraints and abuse. The practice of promoting self-determination is clearly influenced by the level of support needs and by the type of living arrangement. All actors are involved in systemic oppressive mechanisms, therefore the underlying power relations must be deconstructed.

Keywords: Disability Studies, self-determination, people with high support needs

ZSUZSANNA KUNT

Personal Assistance in the Context of Disability Studies and Cultural Anthropology

This article presents a concise summary of a section of a doctoral dissertation, which is a postmodern, critical, and reflective ethnographic work, positioned on the crossing point of Cultural Anthropology and Disability Studies. It discusses the connections of the two interrelated disciplines, introduces the cultural biographical qualitative research method in action, and the complex experiences of personal assistance. The present article at first shortly introduces the participants of the research, then points out the three main aims and the research methodology of the dissertation and finally shares a short synthesis regarding the findings of the doctoral research concerning the experience of personal assistance.

Keywords: participatory research, Disability Studies, Cultural Anthropology, personal assistance

ANDREA PERLUSZ

Inclusive School Leadership

The concept of inclusive school leadership was introduced into pedagogical professional thinking in the early 2000s, as a result of the realisation that the leaders of educational institutions have a decisive role in transposing inclusive policies, effective implementation of inclusive practices and inclusive school culture (Ainscow and Sandill, 2010; Mac Ruairc, 2013). The research presented in the study, launched by the European Agency for Special Needs and Inclusive Education in 2019 (Supporting Inclusive School Leadership SISL) examines the policies and institutional practices of the participating member states. The aim of the project is to present a policy environment conducive to inclusive institution-management, to describe the competences that can characterise a successful inclusive leader of an institution or the institution management, and to support the opportunities for training, further training and professional development by developing a self-assessment tool.

Keywords: inclusive education, inclusive school leadership, roles and responsibilities of the inclusive school leader, policy framework

NIKOLETT RÉKASI – CARMEN SVASTICS – CSILLA CSERTI-SZAUER –
GÁBOR KOVÁCS – VERONIKA KALÁSZ

Career Paths: Work Opportunities for Persons with Visual Impairment

The inclusion of persons with disabilities, and among them, persons with visual impairment in the labour market has been of increasing importance on the international and Hungarian employment agendas for decades. Various support services, including career guidance and labour market services, have proved to facilitate successful inclusion strongly. In this paper, we present the first steps of a Hungarian research project in which the milestones of the career paths of persons with visual impairment will be traced through personal narratives. We outline the current trends in the employment of persons with visual impairment and highlight career guidance and labour market services from a Disability Studies perspective. The paper provides a summary and theoretical basis for the design and implementation of the upcoming empirical research aiming to enrich domestic research and development in the given area.

Keywords: persons with visual impairment, career guidance, labour market inclusion, narrative life-story interview

GÉZA MÁTÉ NOVÁK – ZSUZSANNA KUNT – ZSUZSANNA HORVÁTH –
DOROTTEA VASS

A Forum Theatre-based Research with Youths with Multiple Disadvantages

Our research project gives an account of the functioning of forum theatre and its intra- and intersubjective level dynamic processes within the framework of a qualitative arts-based participative action research. During the intervention, information has been gathered on the tools of forum theatre that improve self-efficacy to highlight the techniques of participation in the creative work. The present article shows the theoretical and institutional framework of the project, introduces the participants, sheds light on the methods applied and gives insight into the findings and conclusions.

Keywords: forum theatre-based research, participation, school conflict management

VALÉRIA KISS

Protecting Dignity: Analysis of the Literary Representation of Legal Issues Related to Dementia

Dementia is one of the biggest challenges aging societies are facing in the 21st century. I examine how the topic of (1) preparation after diagnosis and (2) the theme of guardianship, care, and preservation of dignity appears in some literary works dealing with dementia. The extensive literature on Alzheimer's disease provides valuable empirical material for understanding the contradictions between black-letter law and social reality. However, the stories examined often reflect uncontrolled everyday biases, such as the idea of worthlessness of the lives of patients with dementia, the idealization of the love of family members and the uncritical acceptance of the resulting paternalism. At the same time, legal institutions seem to remain completely foreign, irrelevant, and meaningless to those concerned. The basic thesis of this study is that literary narratives can help understand dementia. Through these stories, legal professionals, or even law students, can learn about this condition which is a preliminary condition of good legislation and legal decisions alike.

Keywords: dementia, Alzheimer's disease, supported decision-making, substitute decision-making, guardianship, law in literature

ANDREA SZATMÁRI – ISTVÁN HOFFMAN

Support (Care) Service: A Supportive or a General Care Service for Persons with Disabilities?

The support care service has been institutionalised by an amendment of the Act on Social Administration and on Social Benefits in 2001. Prima facie, it seems to be a general care service for persons with disabilities. That seemingly general nature of the support (care) service is examined by our paper. First of all, the regulation on this service is analysed, and it should be stated, that it is a two-sided one: although there are general elements, it focuses mainly on the assistance to the access to basic public services. Secondly, the number of the persons who receive this service is compared with the data of the possible recipients of the service, the number of those persons who are potentially entitled to receive that service. Thus, the supportive nature of this service is dominant: it cannot be interpreted as a general service for the persons with disabilities, it is merely a special service which partially helps providing access to major public services.

Keywords: municipal social care, municipal social systems, analysis of the data on social care, centralisation, decentralisation, Hungary

FRUZSINA TÓTH

Power among the Powerless: A Theoretical Approach to Understanding How (Legal) Power Appears among Persons Placed under Guardianship

When a person is diagnosed with an intellectual or psychosocial disability, they may in some cases have their capacity to act restricted by court proceedings and a guardian appointed to act in their place in certain cases. In this way, the state can intrude into an individual's private life and control his/her daily life. In the following paper, I use a Foucauldian approach to power theory to examine how the institution of guardianship is reconstituted in everyday life, whether power appears at all in interview narratives and, if so, with what content.

Keywords: micro-power, Michel Foucault, guardianship, agency, narrative interview

Self-determination Opportunities of Persons with High Support Needs

1. INTRODUCTION

Based on the theoretical framework of Critical Disability Studies, the paper presents the characteristics of self-determination of persons with high support needs in different types of living arrangements in Hungary. The research design is based on a qualitative and participatory approach (according to this, the text was consciously formulated in first person plural) and the study was conducted as the doctoral work of the author.

The key starting point is that Hungary ratified the *UN Convention on the Rights of Persons with Disabilities* in 2007 (hereafter referred to as CRPD). The CRPD states that States Parties shall recognize the importance of individual autonomy, independence and choice-making [in particular: Preamble n), Article 3, Article 12]. Article 12 of the CRPD on *Equal recognition before the law* can only be interpreted in the light of Article 19 on *Living independently and being included in the community*. Gerard Quinn defines Article 19 as a window to Article 12 and Article 12 as an anchor of Article 19 (Quinn, 2013), so we conducted the research in the context of different living arrangements. Instead of independence, self-reliance or self-sufficiency, *self-determination* as a social and cultural concept can be a framework that is suitable for approaching the life situations of people with high support needs.

Persons with high support needs can be characterized as the most neglected and vulnerable group of people with disabilities. During the course of history, they were the first people who needed nursing, but did not need education. Then they became lives unworthy of life, whose killing is not punishable because they cannot be considered as human beings (Evans, 2010). Later on, they joined the educational system in Western societies, but they are still the ones who are often denied the services they need. It can be noticed that nowadays, society excludes them from the system of disability support services (Fornfeld, 2008; Dederich, 2008; Zászkaliczky, 2014). They experience oppression, such as marginalization, powerlessness and violence in their everyday life (Young, 1990). Therefore, when we talk about them, at the same time we raise the question of lower support needs, age, childhood, illness, ethnic groups and solidarity, that are fundamental issues affecting each and every member of society. Persons with high support needs expose elements of self-determination that would otherwise be hidden as we automatically fulfill the expectations that society latently imposes on us.

People with intellectual disabilities who are capable of self-reporting consider their self-determination to be significantly more important than their parents and teachers, while assistants believe that the question of self-determination is irrelevant in the lives of persons with such disabilities (Wehmeyer et al., 2000; Schalock et al., 2005; Martin et al., 2005). As Wehmeyer suggests, this idea can be derived from a misinterpretation of the construct of self-determination (Wehmeyer, 2005), and it is believed that the misinterpretations originate from the assistants' concepts of human, their understanding of what disability is, and their interpretation of their own role (Weingärtner, 2009; Theunissen, 2012; Emerson et al., 1994; Hellzen et al., 2004; Bigby et al., 2009; Walker et al., 2011). The topic is relevant because tens of thousands of persons are involved, who in general face numerous disadvantages in their everyday lives. There have been some case studies in Hungary that focused on this issue (Galambos et al., 2003), and the self-determination paradigm has been a part of scholarly discourse since the 1990s (Zászkaliczky, 1998). It is well known that the people living in institutions are mostly under guardianship and face significant limitations in autonomous decision making (Kozma, 2008; Verdes, 2009). However, in the first decade of the 2000s, Hungarian empirical research on the quality of life of the group was based more on a quantitative approach, and examined the life situation of families and the services available to them. It has been shown that families who raise children with high support needs, cannot maintain their former social and economic status, and they live in poverty and have a lack of social networks. Bass and Márkus have pointed out that due to the above factors the families do not have enough resources, which would allow for self-determination and advocacy, so it was necessary to explore the deeper layers of these issues through qualitative research (Bass, 2004; Márkus, 2005).

2. RESEARCH QUESTIONS

The main research question is: what kind of support is available today for persons with high support needs in Hungary to ensure self-determination in different areas of life that are relevant to them?

Further questions:

How do assistants support persons with high support needs in their self-determination?

What are the characteristics of self-determination of persons with high support needs in different living arrangements?

What characterizes the assistants' notion of what being human means and how do they interpret their own role?

How can the community of a group home be supported to extend options for self-determination for persons with high support needs?

3. METHODOLOGICAL BACKGROUND

Investigating self-determination is a major challenge in the case of people with high support needs. On the one hand, it can be questioned if self-determination is a measurable phenomenon (Haeberlin, 1996). On the other hand, the use of self-report-based indicators is not possible (Wehmeyer, 2005; Seifert, 2006). Thus, we applied a *qualitative* approach suitable for involving persons who typically communicated nonverbally, and we supplemented that information with the views of their trusted assistants. The *Grounded Theory* approach had the most important impact on our research (Glaser & Strauss, 2006; Corbin & Strauss, 2015).

We conducted participant observations within the qualitative paradigm, as well as focus groups and individual interviews, and prepared minutes and transcripts. The transcriptions were analyzed using the Mayring qualitative content analysis technique (Mayring 2015; Mayring & Gläser-Zikuda, 2008).

Our work is based on the participatory paradigm, with the aim to learn about the possibilities and limitations of inclusive research with persons with high support needs. Participation could be realised in small elements of the research process, mainly through an advocacy role. In the research, a person with high support needs, Richárd Zachareszku, took part from the planning to the analysis of the four-year research period. We met three to four times a month, and through our relationship, he influenced all observation situations and interviews.

The whole process of the research was accompanied by a reflective, non-standardized research diary, which included all relevant events, research reflections and self-reflections. The research diary is a tool of qualitative field research, which supports the analysis of the process and the methods used (Weigand, 2009; Frieberthäuser & Panagiotopoulou, 1997; Barnes, 1992, 1996; Fischer & Bosse, 1997).

The sample selection did not aspire to be representative, but rather, it wanted to ensure that the typical life situations of persons with high support needs are represented: one group lives in a small or large residential institution (in a group home or a residential home with more than 10-12 persons), the others live with their parents or siblings. In addition to the disabled persons, we also addressed close support persons (relatives, caregivers, educators, etc.). After weighing the results of the literature review, we did not use diagnostic tools based on the support needs and did not use available medical, special educational and psychological diagnoses. Following Beamer and Brookes and Seifert's sample selection criteria, we added our own criteria and worked with persons with high support needs, who:

- do not speak or speech is not their primary communication channel,
- live with intellectual disabilities, which in many cases are associated with physical disability or illnesses,
- have other labels such as "problematic behavior",
- require intensive support in their daily lives in all areas (Beamer & Brookes, 2001; Seifert, 2006); and
- are considered to belong to the group according to their environment.

In the first phase of the research, which lasted from January 2014 to June 2015, we included two group homes belonging to the same NGO. The selection was based

on nonprobability sampling. We chose institutions where people with high support needs lived.

The observation directly involved 7 persons living in the group homes. We conducted semi-structured interviews with 6 of their relatives or guardians. The support staff in the group homes participated in focus group interviews. Semi-structured interviews and focus groups were recorded at the beginning and at the end of the process, and the observations took place in the middle and at the end of the process. During the process, some of the participants died and some of them left their workplace, making it difficult to pinpoint the exact sample of this research phase. However, this was considered as the normal feature of the field and was supported by the continuous reconsideration of the methods used. The research design also included the participation in the team meetings and an internal, Disability Studies-based employee training organized at the end of the process.

The interviewees involved in the second phase of the research were mainly reached through institutions. We did not differentiate between the employees of the institutions in terms of their qualifications, but we included professionals and untrained persons as well, who perform some kind of occupational support, nursing or who serve as heads of these institutions. Interviews were conducted in small group homes providing services for 10-12 persons and supported living providers (5 interviews) and the staff of residential institutions providing services for 12 to 200 people (17 interviews). The gender ratio is determined by the field: at this stage, there was one male interviewee who had a leading position in one of the large residential institutions.

Besides the interviews with the staff, interviews were also made with relatives. We reached the persons still living with their families through the day-care system. With this technique, families who did not use services could not have access to this study. 6 interviews were conducted with parents or siblings of persons who live in their families of origin and 6 interviews were conducted with family members whose adult relatives are already living in one of the institutions.

The interviewees, also taking into account day-care services, were connected to 8 different institutions, some of which belong to a common service provider. One of the group homes was created specifically for persons with high support needs within the large institution itself. Some of the living arrangements operate in large cities, others operate in small towns or villages. To ensure that institutions and participants remain anonymous, we do not disclose any specific information about the size or location of the facilities.

4. RESULTS AND CONCLUSIONS

Our study has shown that some elements of self-determination can be observed in all forms of living arrangements. These elements are typically part of the everyday routine and are connected to fulfilling basic human needs.

It is extremely difficult for participants in the research to translate the meaning of self-determination into everyday situations. The concept is used actively and consciously by very few people, so it has little influence on the support as well. The misinterpretation of self-determination is the key obstacle in the process of support.

Self-reliance, decision-making, self-advocacy are aims that can hardly be interpreted in the case of persons with high support needs. That is why assistants think that self-determination is unavailable to this group and is not a relevant and meaningful principle.

All sections of the research confirmed that for persons with high support needs the self-reliance and possibility of choices *in eating, listening to music and playing* are the most important areas of self-determination. It affirms the theory of basal self-determination (Weingärtner, 2009) that these areas are linked to the everyday, most basic human experiences and provide opportunities for creating choice-making situations. Although at different levels, but in all types of living arrangements, these situations have emerged, or at least they were not hindered. The latter addition is important because effective support could only be provided if the creation and strengthening of these situations would have been the result of conscious, coordinated professional activity. However, the persons with disabilities have little or no opportunity to experience their own influence and to experience the consequences of their activities.

The practice of promoting self-determination is clearly influenced by the level of support needs. Most assistants say there is a kind of “border” in the field of communication and cognitive skills beyond which the concept of self-determination cannot be interpreted. Persons with lower support needs have broader self-determination options in every kind of living arrangement. Differences are reinforced by a variety of routines, such as categorisations and different labels for different support needs. Persons who cannot move are more likely to experience their vulnerability because physical barriers require their support to involve more resources. In that sense, they have less chance of self-determination. At the same time, with the lower level of self-determination, they are those who experience fewer restrictions because they cannot actively cause situations that are considered to be disturbing. In our analysis, we have come to the conclusion that this relationship may be subject to further research in the future, as it may help to develop alternatives to restrictive measures and relieve assistants. The level of support needs is not the only influencing factor. Self-determination is created in the dynamic interactions between the individual and the assistants. It is determined by the subjective significance and the desired level of self-determination, and the possibility of exercising it.

Assistants, regardless of whether they are family members or paid assistants, are involved in systemic oppressive power mechanisms. They are experiencing serious constraints in their work and do not have a voice in organizing and managing services. Therefore, they also prefer protection and continuous supervision and control over the activities of persons with disabilities.

We can conclude that the larger institutions are most likely to be characterized by the emphasis on the infant-status of adults with high support needs and the use of the very serious restrictive measures resulting from this attitude. Four groups were defined based on the observed restrictions, which are located along an interval. On one end of this continuum, there are severe physical restrictions, while on the other, there are useful, constructive social expectations. Small institutions and families are more prone to construct these positively-assessed, constructive expectations that are in accordance with our culture. In all arrangements, however, it is difficult to

maintain a balance between self-determination and restrictions on behalf of physical needs and emergency situations.

However, in this study, we cannot support the assumption that the restriction would be strongest in the family of origin, in the presence of parents or siblings. In this context, the social interpretation of self-determination and the importance of participation are the most common values. Families live together, mainly because of the lack of acceptable alternatives and the operational anomalies of existing services, not because they want to limit their children. However, it can be seen that even families, which support higher levels of empowerment find it difficult to organize social participation, programs, and they live more or less isolated. From this point of view, larger institutions are in a better position because they can use more resources to mobilize disabled people. However, persons with the highest support needs, especially those using tubes or wheelchairs, are often excluded from these recreational opportunities.

Types of living arrangements clearly influence how hierarchy develops and at the same time, the risk of power abuse in certain situations is inevitable. Experience confirms that this phenomenon is most noticeable in large institutions. In organizations where the number of employees sometimes exceeds 100 people, it is inevitable that this will develop and this will make it impossible to provide support for self-determination. Although small service providers (group homes and supported living) have been treated as one category, it can be observed that there is a difference between their operations. The most direct contact between the persons with disabilities, the workers and the relatives could be found in the non-governmental organizations providing supported living.

In institutions, the principle of self-determination is most desired by the management, while assistants believe that it is an unrealistic goal. In addition to the way they interpret their own role, this can be explained by environmental conditions. As long as there are service providers who respond to the lack of workforce by requiring restrictions on fulfilling basic needs (e.g. no need to bathe at weekends, workers buy their own nursing equipment, etc.), it is difficult to interpret the need for self-determination in relation to any actors involved. In smaller living arrangements, with more direct relationships, employees have more power to influence processes and are therefore more satisfied and more supportive.

The support staff working in institutions mostly interpret their role based on four pillars: education, protection, supervision and control. They believe that they work in the interests of persons with disabilities if they help them to accommodate themselves to institutional culture and keep them under constant control, thus preventing accidents or emergencies. In most cases this happens routinely, not consciously, and is not accompanied by professional reflection. In group homes and supported living, role interpretations are more in the direction of equality and partnership. The providers and users of these services have reported more dilemmas and questions about self-determination, which confirms that they have more differentiated understandings about the phenomenon and consider it an important professional principle.

We emphasize that, despite the uncertainty of the concept of adulthood, assistants consider persons with high support needs as valuable people. They talk about their relationships with deep emotional involvement and empathy. They think

of them as persons who have rights and who should be treated as we would like to be treated in similar situations.

In our work, we also assumed that in the context of group homes the key element in expanding the range of possibilities for self-determination is a complex assessment of personal preferences. To that end, we made use of the biographical approach. Through the method of biography, it is possible to map the subjectively relevant areas of self-determination. During the joint work, it has been proven that through the complex assessment of persons with high support needs and the support team and through the mobilization of their resources, the extension of self-determination is possible. Our research process has shown that workers are not familiar with the persons they are supporting due to fluctuation and the pressures of great workload.

Without changing the existing financial conditions and institutional structures, small elements of everyday processes have been developed to facilitate the change from the institutional culture to the paradigm of supported living services. In doing so, it was crucial to improve the frequency and quality of communication among different actors and to increase their involvement through individual time and attention.

The fact that parents and siblings are more likely to opt for full protection does not make the cooperation easier between them and other support personnel. Although staff members are typically more open to support freedom, they are afraid of responsibility. Facilitating the work of assistants is thus about finding a balance between restriction, responsibility, and self-determination.

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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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Inclusive School Leadership

1. INTRODUCTION

Integration in kindergartens and schools in Hungary started in the late 1970s, almost simultaneously with the integration initiatives and movements in Western Europe. Initially, social integration appeared as the ultimate goal of special education, and then it was defined in the 1980s as “the idea of educating children of different abilities and development in an integrated, common system” (Lányiné, 1987, 933). In the early period, the focus was on the possibilities of integration of children belonging to specific disability groups and the “inclusion” of these children, and then shifted to the conditions of public education necessary for integration. Hungarian legislation provided for integrated education as an alternative to special institutions in the 1993 Public Education Act. (Act LXXIX on Public Education) At the same time, it regulated the conditions for co-parenting by means of regulations (Csányi & Perlusz, 2001). The term ‘inclusion’ was first used in a socio-political sense to refer to measures that intervene directly from above to reduce exclusion, declaring that society values inclusion more than discrimination.

Inclusion means all the continuous and targeted interventions that make the eco-social environment inclusive by preventing the exclusion of specific persons and making them successful (Varga, 2015). In 2005, at the UNESCO conference in Salamanca, Spain, ninety-two governments and twenty-five international organisations addressed the Education for All programme, resulting in the Salamanca Declaration (Csányi & Zsoldos, 1994). This means that all children have the right to an education within the mainstream school, taking into account their individual characteristics, interests, abilities and learning needs. Since the 1990s, the concept of inclusion has also appeared in public education in Hungary.

In the early 2000s, Booth and Ainscow developed the conditions and steps necessary to make educational institutions inclusive (Booth & Ainscow 2002, 2011) and introduced the concept of the “Inclusion Index”, which is based on a situation analysis of the institution’s functioning and provides support for the inclusive institution development process. The Index for Inclusion looks at the development of an inclusive approach for the institution, the development of a programme for its implementation and the organisation of everyday practice. (Booth & Ainscow, 2002).

2. THE INCLUSIVE SCHOOL LEADERSHIP – A PROJECT PRESENTATION

The European Agency for Special Needs and Inclusive Education is an organisation that brings together the Member States of the European Union to promote

cooperation on inclusive education and to increase the quality and effectiveness of work in inclusive institutions.

The organisation, currently made up of 31 countries, was founded in 1996 on the initiative of the Danish government, and Hungary joined in 2006. Participating Member States delegate two people per country - one decision-maker and one professional representative. Through its thematic projects, the Agency addresses issues such as the financing of inclusive education systems, the organisation of support for inclusive education and, more recently, the support for inclusive management, which is the focus of this study.

The Inclusive School Leadership project, launched in 2019 (Supporting Inclusive School Leadership, hereinafter SISL), is a precursor to the 2014–2017 project (Raising the Achievement of All Learners in Inclusive Education) which identified school leadership as a critical factor in creating a more inclusive education system.

In their summary report, they highlighted that the support of heads of institutions is essential to make inclusiveness work.

Besides Hungary, the SISL project involved Ireland, Sweden and Malta. The aim of the project was to examine how to improve inclusive school leadership through local and national policy frameworks and support mechanisms. During the SISL project, we examined the policies and institutional practices of the participating Member States in order to describe by the end of the project:

1. the policy environment for inclusive school leadership, i.e. the educational policy framework needed to develop and support inclusive school leadership in the education system,
2. the competences that can characterise a successful and effective inclusive head of institution, and
3. opportunities, tools and good practices for training, professional development, i.e. what supportive professional development opportunities are needed to train effective, inclusive school leaders?

The focus of the first phase of the research was the review of international and European policy documents and guidelines, and the systematization and interpretation of the data found in the literature. Data was collected from 21 countries on legislation and policies affecting school leadership, including inclusive school leadership, the roles and responsibilities of school leaders, their requirements (qualifications, degrees, experience and competences), and opportunities for professional development and ongoing professional support. The research shows that:

- At the international level, there is a limited amount of literature on inclusive governance and a lack of concrete recommendations. At the national level, these appear mostly in the context of special education institutions.
- Inclusive leadership roles are not sufficiently clear.
- There is a lack of training materials and programmes supporting professional development and the skills needed for leadership. The training of managers focuses mostly on management and administrative tasks instead of inclusive pedagogical strategies.
- There are also gaps in how inclusive school leadership is supported in participating countries.

- There is little specific policy regulation on inclusive governance (European Agency for special Needs and Inclusive Education, 2018).
- Three main elements were identified in relation to school leadership, linked to successful inclusion practices: transformational leadership, distributed leadership and instructional leadership. They focus on developing a shared vision, shared ownership and shared decision-making. When these three characteristics of leadership are combined in practice, they have a significant positive impact on student achievement, pedagogical quality and the development of the school's professional community. (European Agency for special Needs and Inclusive Education, 2018).

During phases 2–3 of the project, a model for inclusive school leadership was defined (*Figure 1*), using the results of “A model and a vision for inclusive education systems” (European Agency for Education and Training, 2015):



FIGURE 1. MODEL OF INCLUSIVE SCHOOL LEADERSHIP
(adapted from European Agency, 2018b, 15)

According to the inclusive school leadership model, the vision of the inclusive school leader (or leadership team) is that all learners – not just those with special educational needs or disabilities – should be provided with high quality educational opportunities in the local community, alongside their friends and peers (European Agency, 2015, 2019).

The model builds on the human rights approach to education, in particular the key principles of the Declaration on the Rights of the Child (United Nations, 1989) and the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006). Inclusive school leaders take responsibility for each and every student, valuing each one regardless of their abilities, needs and background. It creates an environment in which all learners can have the best possible learning experience and experience a sense of well-being and belonging to a community. The inclusive

school leader builds partnerships with the parent community and the school's external environment. Inclusive school leadership goes beyond the organisation to address inequalities through community building and full participation. It focuses on developing an inclusive culture in which all stakeholders are supported to work together, value equality and ensure that all learners receive a high quality education, including those most at risk of exclusion.

Transformational leadership is a popular theory of management science associated with Bass (1985), and is characterised by the leader's charismatic personality and ability to motivate others. Transformational leadership is important for setting the vision and inspiration for inclusion. It focuses on creating structures and cultures that improve the quality of teaching and learning, set the direction and ensure the development of people and (re)define the organisation (Day et al., 2016) This leadership role is often associated with the ability to create change and innovation that impacts on school culture (Stankevice et al., 2013).

According to the concept of distributed leadership, leadership – as the control, influence and initiation of change – is not only for the principal or the management of the school (deputy principals, workgroup leaders), but all actors have an impact on the culture, performance and values of the organisation, so everyone is directly or indirectly involved in leadership. Distributed leadership is therefore the awareness and knowledgeable application of this, the effective allocation of tasks, with the aim of supporting the development of both the people in the organisation.

Finally, the so-called instructional leadership towards inclusive education impacts on human resource development and organisational development. It highlights the importance of setting clear educational objectives, planning the curriculum and evaluating teachers and teaching. The primary focus is on the responsibility of leaders to improve the quality of teaching-learning (Day et al., 2016), which is why it is also called learning-centred leadership.

The results of the first phase of the SISL project have highlighted the need to give institutional leaders the knowledge to make decisions to put inclusive education into practice, but also the need for support and accountability for inclusion. Three factors have been described that support the creation of inclusive schools and the effectiveness of inclusive school leaders. These include access for example to suitable pay and status, to the necessary resources, training and professional learning opportunities in inclusive governance, the opportunity to engage with a wide range of stakeholders including communicating with policy makers to extend their powers. The second factor is autonomy (e.g. in making evidence-based decisions about the strategic directions of the school, in the flexible application of the curriculum, in adapting the assessment and accreditation framework to meet expectations and the needs of the local community and learners in appointing teachers and other staff, in providing expertise to support school development, in allocating funding and resources equitably). Finally, the third important factor is accountability in the areas of vision, values, definition of results, monitoring and self-evaluation (European Agency for special Needs and Inclusive Education, 2019).

In the third phase of the project, a self-assessment tool was developed and tested, which can be used by school management to help move towards inclusive leadership. Using the Self-reflection tool, school leaders are asked to reflect on their own practice using the questions.

The reflection covers the following areas:

- Identify the results of current practice and the main strengths and challenges.
- Prioritise issues to be addressed in order to implement inclusive practices.
- Identify policy support needed to support existing or inclusive practice.

The self-reflection tool is divided into three sections: reflection for school leaders, reflection for policy-makers and joint reflection. When using the self-reflection tool, school leaders can choose to do only step 1 or they can move on to levels 2 and/or 3.

The questions are structured around three key roles of inclusive school leadership:

1. Setting direction
2. Organisational development
3. Human development.

The tool contains seven columns. Column 1 contains questions for inclusive school leaders, which respondents rate on the scale below:

- to consider (column 2): this is a practice that has not yet been considered but should be.
- emerging (column 3): the practice is under consideration and implementation planning is underway
- in progress (column 4): the practice is partly implemented and steps are being taken to implement it more widely.
- implemented (column 5): the innovative use of good practice by the school is based on this and the implementation expectations have been met.
- sustainable practice (column 6): this practice is sustainable as an integral part of the whole school organisation and culture.

Each of the three sets of questions is followed by some summary questions to allow respondents to highlight areas of strength and areas for improvement, and to prioritise the activities needed for inclusive school leadership. In step 3, participants can identify policy support needed to support existing or inclusive practice that is missing in national/regional policy. This information can be used in dialogue with policy makers to develop policy to support inclusive school leadership.

3. THE SITUATION IN HUNGARY REGARDING THE SISL PROJECT

In Hungary, Act CXC of 2011 on National Public Education (Hungarian Parliament 2011) defines the terms of appointment of school leaders as well as the school leaders' main duties and responsibilities. More detailed information on duties and responsibilities of school leaders can be found in Ministry of Human Capacities decree 20/2012 (VIII. 31.) on the Operation of Educational Institutions and on the Use of Names of Public Educational Institutions. (Minister of Human Capacities, 2012).

The Government Decree No 326/2013 (VIII. 30.) on the Promotion of Teachers and the Execution of Act XXXIII. of 1992 on the Legal Status of Public Servants in Schools and all Public Education Institutions' (Hungarian Government, 2013) informs about the procedure of the appointments of school leaders in general.

Regarding quality issues, each education institution is obliged to conduct a self-evaluation every five years according to the national pedagogical-professional inspection system (Act CXC of 2011 on National Public Education and Ministry

of Human Capacities Decree 20/2012 (VIII. 31.) on the Operation of Educational Institutions and on the Use of Names of Public Educational Institutions). There are three types of institutional self-evaluation:

- a) the teacher's self-assessment
- b) the institution's management self-assessment
- c) the institution's self-assessment

Additionally, teaching staff and the parents' community of the respective educational institutions evaluate the work of the school leader in the second and fourth year of their mandate, which has a total duration of five years. The head of the public education institution is a professional and administrative leader. There are no direct references to inclusive leadership in Hungarian official documents, but the school leader may be granted an incentive supplement by the employer, taking into account for example the following: the development of the number of pupils at risk of dropping out of school, his/her role and effectiveness in the education of pupils with special educational needs or in the support of the inclusive education of pupils with special educational needs with other pupils.

In the handbooks for self-assessment and supervision of school leaders, the areas of leadership evaluation are following the Central5 (Central5: Central European Competence Framework for School Leaders) criteria, which were developed by the European Commission-supported International Co-operation for School Leadership project (2008-2013). Among these competencies in the field of learning-teaching, the idea of inclusion appears as a key competence: "School leaders strive to create an inclusive learning environment in their work" (Révai & Kirkham, 2013, 94).

As part of managerial supervision, experts analyze e.g. the management application, the pedagogical program, the annual work plans, and the reports at the end of the school year. This includes issues related to inclusivity, e.g.: How does the education of students requiring special attention appear in the management program? How do the principles, goals and tasks of the pedagogical program support the implementation of individual treatment? However, there is no question specifically related to inclusive leadership.

The proposed set of questions from the leadership interview during the on-site inspection of school supervisors also includes one question related to the topic of inclusion in the context of the leaders' responsibilities: What do you do to create an inclusive education and learning environment? (Educational Authority, 2019, 94)

There are several government decrees and local documents which inform about school leaders' possibilities and responsibilities regarding the "steering" of their school (setting directions, developing staff and learners). In terms of setting direction, these decrees refer to the national core curriculum, framework curriculum as well as the local curriculum, the local pedagogical program, and local "organisational and operational rules" (hereinafter: OOR) (Decree No 20/2012 (VIII. 31.) EMMI on Operation of Educational Institutions and on Use of Names of Public Educational Institutions).

3.1. Training for school leaders

The Government Decree No 326/2013 (VIII. 30.) on the Promotion of Teachers and the Execution of Act XXXIII. of 1992 on the Legal Status of Public Servants in Schools and all Public Education Institutions defines the conditions of an assignment to become head of an educational institution. To become a school leader, candidates must undergo a specialist examination for school leaders (Hungarian Parliament, Act CXC of 2011 on National Public Education 2011) This “qualification for head of institutions within the framework of teachers’ specialist examination” is a (2 years) special teachers’ further training, which includes basic legal, financial and management studies.

Besides this, looking at the continuum for professional development, all teachers as well as the school leaders are entitled to take at least 120 hours in the teacher further training system every seven years (Government Decree No 277/1997. (XII. 22.) on Teachers Further Training). The areas of competence that are required of school leaders are explained in the job descriptions.

3.2. Access, autonomy, and accountability of school leaders

In Hungary school leaders can contribute to development in education policy beyond their school through trade labour organizations or professional organisations as well as through the National Teachers’ Chamber. Possibilities within their schools, however, depend on local rules. The school board can give school leaders possibilities to set strategic direction and secure the commitment of all stakeholders. Furthermore, principals have the possibility to appoint teachers (Government Decree No 134/2016. (VI. 4.) on the National Maintenance Organizations and on the Klebelsberg Center).

On the other hand, the possibilities for adapting curriculum content are very low (10-20% of the National Core Curriculum). The same is true for managing school budget and allocating resources. However, school leaders are accountable for school outcomes (Hungarian Government Decree No 110/2012. (VI. 4.) on the Issue, Introduction, and Implementation of the National Core Curriculum, 2012) and professional examinations for school leaders also include topics on accountability.

4. AGGREGATED EXPERIENCE OF THE PILOT PHASE OF THE SELF-REFLECTION TOOL DEVELOPED WITHIN THE FRAMEWORK OF THE SISL PROJECT

The pilot study included online interviews with 10 heads of institutions. These included heads of primary, secondary and special education institutions. In addition, a focus group discussion was held with policy makers (8 participants). In this study, we report on the first experiences of using a self-assessment tool in the form of an interview with the heads of institutions.

We had all participants involved sign an Informed Consent. Prior to the interviews, the self-reflection tool was sent by mail, after which the questionnaires were taken in the form of an online interview. This format was well suited to the nature of the pilot study, as questions about uncertainties could be asked and clarified, and the face-to-face discussion also increased motivation. Interviews were conducted between May and July 2021. The average duration of the interviews was 60–90 minutes. The interviews were recorded and anonymized “minutes” were prepared from the audio files, which were used for the summary document. The audio recordings were then deleted.

All participants also completed the SISL pilot survey summary document translated into Hungarian.

4.1. General comments from heads of institutions on the self-reflection tool as a whole

(The number of mentions is indicated in parentheses.)

Participants in the piloting process were delighted with the topic processed by the tool and would consider it important to use the tool in practice (10 respondents).

The system and structure of the tool are considered good (2 mentions) and the wording of the tool is considered understandable (2 mentions). However, several respondents felt that the language of the tool is too technical, which makes the questions difficult to understand (7 respondents). The reason for this, in our opinion, can be corrected by simplifying translation, but there is no doubt that the novelty of the topic can play a role for the heads of institutions.

Several respondents mentioned that the number of questions was too high, which could reduce the motivation of the respondent (5 respondents), the wording was too complex and the questions themselves were too long (5 mentions). Several people mentioned redundancy, meaning a certain repetition of the questions.

On the scale of response options, they did not always find it easy to locate their own institution (2 mentions), and the mention of the category “Completed” was not considered to be a good one, as it implies closure and completion (6), but they all believe that there is always further development potential.

4.2. Reservations and challenges regarding the usability of the tool

What respondents identified as the biggest challenge was having to address issues related to institutional autonomy and they expressed doubts and difficulties in terms of cooperation with policy makers (3 respondents). The specificity of the situation in Hungary in terms of funding was reflected in the questions on this issue: respondents feel that self-financing is very limited.

All respondents consider that the tool can be used in their work environment, with its greatest strengths being that it can be used to create a long-term work plan

(2 respondents), to set the guiding principles for the institution (1 respondent) and to formulate new goals (1 respondent).

We quote two summary opinions from the interviewees in the pilot study: “An excellent opportunity to reflect as an institution leader on the approach, practice and process of inclusive school leadership based on a thorough analysis.”

“It consciously helps the head of the institution to think in specifics and not in generalities, otherwise it’s all for nothing.”

In our study we presented the first findings of a research and development project on inclusive institutional governance initiated by the European Agency, hoping that the idea and practice of inclusive institutional management itself will become an integral part of the professional discourse in Hungary in the near future.

5. CONCLUSION

The project titled Supporting Inclusive School Leadership (SISL), which is still new in Hungary, encourages Hungarian experts of the topic to think long-term. It is a challenge to place the topic in the professional discourse, in cooperation with policy actors, and to encourage the use of the self-reflection tool developed in the framework of the project to prepare school leaders and leaderships for the development of effective schools for all.

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Career Paths: Work Opportunities for Persons with Visual Impairment

1. INTRODUCTION AND THEORETICAL BACKGROUND

People with disabilities are one of the marginalised social groups whose fundamental human rights, such as the right to work, need to be emphasised and strengthened. The Convention on the Rights of Persons with Disabilities (CRPD) targets the issue employment and occupation in Article 27, where it states that people with disabilities have the right to work and also prohibits discrimination in the workplace. Employment, however, cannot be interpreted without the concept of accessibility (CRPD, Article 9). It is impossible to take a job without full accessibility, i.e. the physical and infocommunication accessibility of the environment. For people with visual impairment, it is not enough for instance to have tactile guidelines in the workplace itself, but a well-developed and comprehensive transport system is needed as a whole. Or it is not enough to provide a computer, the device must also be equipped with screen readers and/or screen magnifiers to enable work. According to the social model of disability, it is not the impairment that disables a person in the first place but the barriers of the environment. Viewing disability as a social construct makes the physical limitations of a person less of a problem, it is the exclusionary mechanisms in society that actually pose the obstacles (Könczei & Hernádi, 2011; Shakespeare 2006, 2013). In the context of the labor market, it is not the disabled worker who needs to be adapted to the working conditions, but it is the job that needs to be carved for the employee.

Although the social model gives an understanding of disability, the phenomenon is rather complex, so the question always arises: how can we grasp its essence as fully as possible? Goodley's (2016) answer to the question is to consider disability as the center of a matrix where besides being a social construct, disability is also a medical issue to cure (medical model), a social minority besides women, ethnicities or elderly people (minority model), a common cultural experience (cultural model) (Flamich & Hoffmann, 2015) or a form of social oppression undermining physical and psycho-emotional well-being (social relational model). As the phenomenon of

disability is by no means static, but dynamic and constantly changing, it cannot be forced into linear frames (Hernádi, 2015).

Disability Studies (DS) calls attention to the manifold aspects of blindness, as according to Paulson, blindness means “very different things, and moreover it is very different things, at different times, different places, and in different kinds of writing” (1987, 4). There is truly an abundance of definitions of blindness or visual impairment, it mostly depends on the actual context: at the doctors’, at school, in social service or at the rehabilitation centre. Although the definitions may not even have much in common, still, they are all based on a socially expected able-bodied *normality*. They rather demonstrate an expected functioning, how people should be able to see, than the true visual abilities of the person or what kind of support they need (Titchkosky, 2002). This idea comes up in Michalko’s (2010) theory of *Cool Blindness Time*, where he describes two different “time zones”: one for sighted people and one for blind people. They exist next to each other and rarely meet. When they do, it is almost always about the issue of how blindness could be cured or fixed and thus integrated into the world of sighted people.

2. ABOUT THE EMPLOYMENT OF PERSONS WITH DISABILITIES

In today’s society, paid work is generally considered highly important. It does not only provide a living but has crucial effects on the skills, mental health, social life and general well-being of the individual. It gives a framework to one’s life, defines adulthood, citizenship and social standing and provides the opportunity to develop a valued and positive identity as a useful and appreciated member of the work force in society (Rose, 2015). Unemployment at the same time not only causes poverty but also correlates with physical and mental ill-health, along with other socially, emotionally, psychologically adverse effects and a generally low quality of life (Bánfalvy, 2003). No wonder, employment is a crucial aspect in the social participation of persons with disabilities and several employment policies and programmes target inclusion in the labour market (Bánfalvy, 2020).

At the same time, according to the Analysis of the World Health Survey, the general employment rate for men with disability is 52.8% while for women with disability 19.6%, compared with 64.9% for non-disabled men, and 29.9% for non-disabled women (World Report on Disability 2011). In Hungary around 23% of the working age population with disabilities is working (Krekó & Scharle, 2020), which is considered rather low in the European Union as the average EU rate of employment for persons with disabilities is 50% (Lecerf, 2020). In general the disability employment gap between disabled and non-disabled persons has narrowed in recent years, especially for those with a tertiary education; the gender gap has, however, widened with female workers with disabilities working fewer hours (Eurofound 2018).

Labour market outcomes are influenced in general by a number of factors: among others education and productivity differentials; labour market imperfections related to employers’ attitudes, discrimination and prejudice; or disincentives created by disability benefit systems. Persons with disabilities are also frequently considered lacking the potential to become members of the workforce. Perception,

apprehensiveness, myth and prejudice continue to limit understanding and acceptance of disability, such as fears about the expenses of reasonable adjustment, job carving or digital accessibility (UN Disability and Employment). Nevertheless, many employers have found that persons with disabilities are more than capable in fulfilling the tasks and challenges at a workplace.

3. ABOUT THE EMPLOYMENT OF PERSONS WITH VISUAL IMPAIRMENTS

According to the WHO statistics, there are about 1 billion people globally with moderate or severe visual impairment and blindness. The most common causes are cataract, uncorrected refractive errors, age-related macular degeneration, glaucoma and diabetic retinopathy. In Hungary, according to the Population Census conducted by the Hungarian Central Statistical Office in 2011, there are 490,578 persons with disabilities. (Data is based on self-declaration.) Among them there are 9,054 people who are blind and 73,430 people have low vision (i.e. functioning vision to a degree but below the so-called good vision) including children below 14 and seniors above 60. This population is rather small compared to the group of persons with disabilities but the prevalence of visual impairment between the ages of 0–14 within the entire population increases in every ten years (Kiss & Pajor, 2021).

The employment rate of persons with vision impairment may vary greatly globally (24% in Australia, 28% in Canada, 32% in New Zealand and 44% in the U.S.; McDonnall & Sui, 2019). In Hungary, the employment rates of the economically active population of persons with visual impairment (aged 15–60+) are rather low: only 11.7% of blind persons and 13.7% of persons with low vision are employed while inactivity is over 86% and 82% respectively (Hungarian Central Statistical Office 2011). (The percentage of economically active but unemployed persons is also low.) Comparing employment rates of persons with vision impairment over time and place is rather challenging due to changing definitions of vision impairment, types of employment or research-related issues like small samples or methodological discrepancies (Lund & Cmar 2019).

Closely related to labour market success is the possibility to benefit from an appropriate career guidance process and employment service (Kenderfi, 2019; Borbély-Pecze & McCarthy, 2020; Török, 2020). While educational attainment of persons with vision impairment is relatively in line with the non-disabled population in Hungary (20% of persons with low vision and around 18% of blind persons have a secondary school certificate while 8.8% and 8.3% has a university degree, respectively; Hungarian Central Statistical Office 2011), the transition to the primary labour market is rather difficult and poses several obstacles. While there is general agreement in the literature that best practices in transition processes include vocational assessments, training in vocational and social skills, career education curricula, paid work experience, traineeship programs as well as collaboration among agencies and the involvement of families (Nagle, 2001), these are still unfortunately mostly lacking in their implementation.

4. THE IMPORTANCE OF CAREER GUIDANCE IN THE LIVES OF PERSONS WITH VISUAL IMPAIRMENT

More than a decade ago, the OECD and the European Commission (2004) published their report entitled *Career Guidance: a Handbook for Policy Makers* which highlighted the importance of guidance services in supporting lifelong learning and labour market integration. An analysis comparing the career guidance systems in thirty-six countries shows that making the right quality and quantity of services available as early as primary and secondary education can lay the foundations for a successful future career and positive labour market choices for young people. This is especially true for children and young people with special educational needs and adults with disabilities.

A career path can be seen as gaining a higher position within the work organization, but in addition to vertical advancement, expanding, deepening and personal development of professional knowledge or filling a new, interesting job can also be considered a career (Warr, 2011). The OECD and the World Bank define career guidance and orientation as a set of services that support individuals at any age and at any stage of their lives in making education, training and labour market decisions. Services include the provision of career information, career counselling, and career education including the strengthening of competences that support career management (Watts, 2013). Supporting persons with disabilities to build their careers is a priority for a number of reasons: their integration into the labour market is hindered and their career success is generally lower than that of their non-disabled peers (Kulkarni & Gopakumar, 2014).

5. TRENDS IN THE PRACTICE OF SUPPORTING CAREER GUIDANCE AND DEVELOPMENT

The processes that affect the careers of persons with disabilities and the social, cultural values and work environment that determine a place in life and in the labour market are rather complex and are rapidly changing over time. Thus, if we look at the situation of a person with disability from the aspect of employment and career opportunities, we find ourselves in a multidimensional, changing system of relationships (Sears et al., 2014). In addition to individual cognitive abilities, the planning of individual development and a career required must consider both social and economic circumstances, as well as socio-cultural endowments and the attitudes of the immediate environment (Brown, 2002).

Szymanski analyses the various theoretical approaches and processes influencing the working careers of persons with disabilities by integrating them into an ecological model. The model shows the embeddedness of the individual in specific contexts, e.g. family, socioeconomic status, education, and characteristics of the immediate work environment, such as organizational culture, work requirements,

physical and built environment, etc. Thus, individual career counselling must cater for all these to achieve the best possible outcomes in realising employment (Szymanski & Vancollins, 2003). In the procedures of implementation, complex and personalized individual counselling and process tracking is needed, according to the individual's situation. Within the framework of personal counselling for persons with visual impairment, the vocational rehabilitation counsellor, mentor, vocational counsellor can play a significant role in increasing career opportunities, from career orientation to job selection, job retention as well as long-term career planning and accompanying (Dávid et al., 2008; Sears et al., 2014; Cruden & Steverson, 2021). Domestic and international practice and the relevant literature from recent decades agree that the basic condition for successful long-term and adequate employment is individual case management, during which career counselling is provided within the framework of personalized, high-quality, complex labour market services. a successful career can thus be the result of e.g. the modernization of outdated skills and the associated well-designed process of individual development (Gere, 2009).

6. OUR RESEARCH PROJECT

The overall picture of the employment of persons with visual impairment in Hungary is rather mixed with average rates of education but lower rates of employment than the general population. This discrepancy raises the question: why do they have difficulties and what could be done about it? In our research project we would like to find some answers to that using the narrative life-story interview as a research method. The interviews with persons with visual impairment will serve to detect the milestones and important stations regarding their career paths (Rosenthal, 1993). This choice of research method fits to the critical aspects of Disability Studies as it puts the individual in the center and highlights the importance of not being normality-based. It also allows us to find our place on the matrix of disability models without explicitly fixing disability to one single concept. It is also not unknown in the field of DS to use the method of interview to examine the connection between work and visual impairment as French (2017) conducted a research in the UK with 50 people with visual impairment where she used in-depth interviews focused on their work experiences. Narrative life-story interviews give us a more detailed and complex path of life and hopefully we will be able to detect more details between the individual experiences and the struggles in employment.

7. DISCUSSION AND CONCLUSIONS

In the present paper we wished to present the importance of career guidance regarding the labour market position of persons with visual impairment from a DS perspective. There are carrier guidance and labour market services in Hungary, but these are not always available to many persons with disabilities for a variety of reasons: the services are concentrated in the capital and bigger towns, the interconnection of different actors is not always systematic, and service users tend to have insufficient information about the services provided.

The so-called Elementary Rehabilitation Service Centres set up on a county basis employ social workers who, amongst many other tasks, provide career guidance and labour market counselling for persons with visual impairment. However, this often lacks authentic labour market statistics and a strategic approach and often focuses on the employment in sheltered workshops specifically created for people with disabilities. The Hungarian Institute for the Blind for instance offers candle and pottery workshops or broom and brush-making workshops as historically “classical” activities for people with visual impairment. Becoming a therapeutic masseur is also a rather typical job for persons with visual impairment, which can nevertheless be exercised as an employee in mainstream employment e.g. in baths. The possibility of becoming an entrepreneur and avoiding ableist organisational, workplace expectations is unfortunately little, as developing entrepreneurial skills and competences (e.g. drafting a business plan, managing finances, negotiation technique, contracting, etc.) – besides securing a start-up capital – is not part of vocational education and vocational rehabilitation services (Svastics et al., 2020).

Persons with visual impairment can also decide to continue their studies and pursue a university degree. Although the Hungarian Law on National Higher Education clearly declares the educational right of persons with disabilities to earn a degree and even supports accessibility in universities, real choices remain rather limited. According to Kovács (2011), the most inclusive university programmes are Humanities (e.g. foreign languages, History), Law, as well as some of the Social Sciences (e.g. social worker) and Computer Sciences. Based on governmental prescriptions, universities tend to have a support network for students with special needs, still students often struggle with technical-organisational, legal and personal issues (Fazekas, 2019). Information-flow, attitudes and personal obstacles as barriers are reflected in the fact that while Eötvös Loránd University of Budapest organised a course called *Special career management for students with disabilities* in 2016, only 11 students – four of them students with visual impairment – out of the 306 registered students with disabilities participated.

In the present paper we have introduced the first steps of an explorative research study on narrative life-stories of persons with visual impairment to gain an insight and understanding of career guidance and labour market services in their career paths. Our aim in the current paper was to provide an overview of existing research results and inspire the launch of further research and development projects regarding career guidance and career development for persons with disabilities. We believe that there is a strong need in reaching the successful labour market inclusion of persons with disabilities through new, comprehensive and human-rights based domestic research initiatives and services.

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A Forum Theatre-based Research with Youths with Multiple Disadvantages

1. THE FRAMEWORK OF THE PROJECT

The empirical part of the project element was carried out within the National Excellence Program called *School conflict management and bullying intervention possibilities by training-like and arts-based methods* (2018-1.2.1-NKP) in the spring and autumn of 2020 while creating the arts-based holistic program followed with research (Norris, 2000; Leavy, 2015; Novák 2019). Alternatives for handling conflicts, possibilities for prevention and intervention were developed for “specially different” (Deszpot, 2008) student groups with multiple disadvantages participating in talent programs.

The project was carried out through drama and theatre-based interventions, involving the students and the teachers of a secondary school in a two-day long forum theatre-based session and a pedagogical workshop. The main goal of the forum theatre was to generate situations requiring decisions within a protected group by interpreting the stage scenes performed by the creating group together with the youths, opening up possibilities for reflections and participation (Dennis, 2009; Duffy, 2010; Wager, 2014). This research allows participants to continuously re-write the storyline and re-direct the basic scene, in accordance with the series of forum theatre scenes. Thereby the participants can articulate their own opinions, experiences, and responses along the lines of the highlighted questions and the imaginary possibilities (Boal, 1979/2000; Oblath, 2017; Katona 2015; Sz. Pallai, 2002).

The aim of our empirical research is to map the experiences of the participants in connection with forum theatre, which focus on the relations of the oppressors, the oppressed and those supporting/observing this situation and in consequence of all this, the low-level self-efficacy of peripheral individuals.

At a participatory level, the aim of the project (and the research) is to detect individual and group dynamics and participatory opportunities within student communities and families through intra- and interpersonal processes.

2. PARTICIPANTS IN THE RESEARCH – CREATORS AND RESEARCHERS (DIVERSITY AND COLLABORATION)

The individuals participating in the research can be divided into four groups according to their roles in the forum theatre intervention (creators and researchers) and their roles at school (students and teachers). a group of 33 secondary school students, a creative forum theatre group of five members, five teachers and four researchers analysing the empirical elements participated in the research.

The group of the Creators of forum theatre scenes included individuals recovering from substance use, a psycho-drama group leader, the leader of the theatre therapeutic group, amateur actors and an expert/director in drama pedagogy.

According to their competences and qualifications, the members of the group of Researchers were quite varied: a cultural anthropologist, a teacher specialized in intercultural pedagogy, experts in movement and dance therapy, a researcher of pedagogy, a researcher of disability studies, a drama teacher, and an art therapist.

At the planning stage of the project, we thought that the different knowledge competences and competences of the members of the two groups would enhance the efficiency of both the forum theatre-based intervention and the research with their added values. The results seem to show that this variety proved to be fruitful for cooperative thinking and creative work. In accordance with the reflective paradigm of the research, certain role changes were provided between the roles of the researchers and those of the creative group. Due to the mingling of the roles, in the complex knowledge creating process of the research, the integrated knowledge contents experienced in the various roles became fertilizing factors that created more exactness.

Researchers became creators as for instance they ended up participating in a scene which was part of the basic scene of the forum theatre. The creators became researchers when on the second day of the intervention they interviewed one another on the creative process. The creators and the researchers were participating in the project by continuous self-reflection which is mirrored in the research diaries and in the interviews.

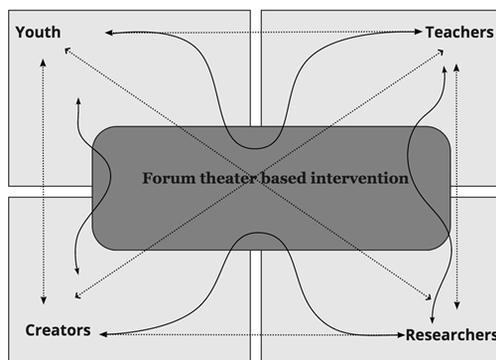


FIGURE 1. THE OPPORTUNITIES FOR THE PARTICIPANTS OF THE PROJECT TO BECOME INVOLVED IN THE SPACE/TIME OF FORUM THEATRE-BASED INTERVENTIONS

Our chart can be considered from several aspects. On the one hand, the four participating groups (Youths, Teachers, Creators, Researchers), their possibilities for relationship can be found in it, therefore it can be considered a matrix of dynamics. On the other hand, forum theatre based intervention, i.e. the project itself influences the matrix of dynamics and the opportunities for connections and therefore the focus points of the research analysis. Therefore, the relationship between the participants can be created within the framework of the project (in its real space and time) or outside of it. This latter category includes connecting and relative situations created outside the project, but at the same time, connecting aspects between the participants that were characteristic in the past. In this fashion the meeting and connecting possibilities of the four groups within the project (its real space and time) and outside of it are shown, which can be interpreted as a basis for our analysis.

3. RESEARCH METHODS

Our main research method within the arts-based research paradigm is the participatory drama and theatre-based action research (PAR – Participatory Action Research).

We intended to record the participants' own experiences with the forum theatre (the intrasubjective experiences) by interviews with individuals, groups and focus groups and the research participants' experiences with one another – connected to the intervention – (intersubjective experiences) through researchers' observations, video recordings and interviews. The research diary covered the observations of relationships of the participants (students, teachers, creative artists and researchers), the forms of their involvement and the level of their participation. The aspects of observation at the sessions and the interview questions were further fine-tuned by the observations made at the field research during the planning process (Lengyelne Molnár & Tóvári, 2001; Dobay et al., 2019). The creating group and the researchers reflected on their own experiences at a group interview after the two days of sessions. The interviews provided opportunities for systematic reflections (Griffith & Tann, 1992), which made it possible to elevate their presence to a more conscious level and support their self-assessment.

4. FINDINGS

With the help of interviews with groups, focus groups and individuals, our research group investigated the working of forum theatre as an applied theatrical pedagogical technique and the level of participation in the space of intervention created by it through the observational and reflexive diaries. Moreover, the opportunity of engagement and the elements of attention and cooperation were also investigated among the participating students, teachers, creative artists, and researchers.

During the analysis of the empirical research material, we found three main categories, which can help us understand the complex process of forum theatre:

- Participation – in which the impressions of the participating groups and the imprints of the project are analysed.

- Dynamics – in which the connecting possibilities between the participants are investigated.
- Context – in which the external factors affecting the project are investigated.

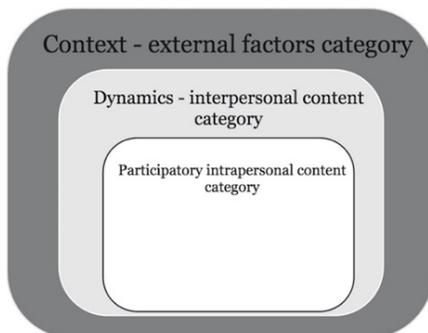


FIGURE 2. MAIN CATEGORIES OF THE ANALYSES OF THE EMPIRICAL RESEARCH MATERIAL

The category of Context covers those texts from the interviews, observational diaries and reflexive diaries which are related to the social, economic, political, constructed and natural environment of the intervention. Mostly those contents fall in this category which characterise the conditions of the framework and the realisation of the project: in space (institution), in time (2020, the time of COVID-19) and the participants (expectations).

"[...] the creators are waiting for us in front of the institute, we introduce ourselves, shake hands, put on our masks and enter the school; the receptionist tells us to disinfect our hands." (Researcher)

"Well, what can I say? I always have doubts, if I have to tell the truth now [...] we stumble into a lot of trashy things while we believe that they are good for the children. We force them into it as there is no other way. And then we often have to face it later that we say that poor children, it wasn't really what we wanted. But we don't do it with bad intentions, it is simply impossible to sort them out." (Teacher)

By Dynamics we mean the coding category in which the interpersonal contents and the opportunities for connections between the participants are investigated. Those sections of texts are classified in this category which indicate the interactions and the relationships of the participants of the intervention (students, teachers, creative artists, researchers) in a field of collective action and which can express cooperativeness, tension, partnership and opposition.

"[...] on arrival we waited in good mood, but the two classes sat down in different places – afterwards, during the exercises we couldn't feel any difference between them... the youngsters were sitting near each other, a little farther from the group of researchers." (Researcher)

"OK, several children, who otherwise aren't able to utter a word or do anything, could also take part in these games. So I was surprised at one or two people, yes. And they went up the stage, although B. is quite a shy child, he stepped up the stage and spoke." (Student)

The category of Participation includes all those intrapersonal contents which express the impressions of the participating groups and the imprints of the project. In these quotations the participants talk about the forms and the quality of their presence in the creative and research process.

The drama teacher/actor/actress/session leader/researcher demonstrates step by step that the experience shown to the youngsters about human characters through theatrical forms is not another person's experience and life but their own. Applied theatre and drama can reveal the phenomena of social life at dramatic, reflexive, symbolic and aesthetic levels at school – highlighting the necessity of human conditions – eliciting activity, devoted creative work and self-reflecting feedback through the gradually deepening learning process – and it can transform a “spectator” into a thinking-playing person.

Thus, by applying forum theatre we can achieve a double pedagogic aim: throughout multiple replays and role-plays, the spectators can easily find ways to cope with stressful situations (Novák et al., 2014). On the other hand, by applying this method we can make them participate in the creative work and involve them to the maximum degree (Boal, 1979; Sz. Pallai, 2002).

Below, the participation of the creative group, researchers, young people and teachers and the characteristics of their engagement are investigated in terms of self-efficiency through semi-structured interviews.

For the involvement code connected to the category of Participation we have taken the propositions made by Morgan & Saxton (1987) as our basis to describe the taxonomy of personal involvement, by which entering the “here and now” and the physical and verbal levels of the framework of the drama are distinguished (Gallagher, 2001). As a result of the research, the arrival, the readiness for accepting the story, the roles and the presence in the (fictitious) reality of the drama are emphasized. In the results of the research the following ideas are highlighted in connection with involvement.

“Well, if we go into the theatre, we usually buy the tickets, which are checked and then we take our booked seats. And thus, when we watch this play, we are obviously involved to the degree of our own thoughts [...]. So we respond, but in ourselves. But this interactive thing, I think, was what made it so approachable.” (Student)

“Well, when I am on stage, that's a completely different feeling. It's an awesome feeling. That there is nothing, only me, only the present. In conversations we usually talk about the past or the future. Hardly any word is said about the present. And when I am on stage, I feel that it's the present. It's me. I am here.” (Student)

While highlighting certain elements of the context of the forum theatre intervention, it became clear for us that the technical equipment of the school and the students' digital material culture influence the sessions. It became obvious for all of us that the corona virus world pandemic and the challenges it posed to the individuals and groups constituted the framework of the discussion of the intervention. Furthermore, the expectations of the creative artists, the researchers, the students and the teachers thematized the work during the process of intervention.

5. SUMMARY

Our research findings will be shared with the actors of the forum theatre-based intervention. All this makes a complex system of consequences accessible to the creative artists, the youths, the researchers and the teachers, by which they will be able to make their creative activities more effective and more reflective. Beyond the space and time of the world pandemic, forum theatre-based interventions and the findings of this research show these actors that there is a self-efficient alternative to stress and it is nothing else but hope in a more liveable world, in the power of cooperation or in the pleasure of a creative individual in a community.

SUPPORTERS

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Protecting Dignity: Analysis of the Literary Representation of Legal Issues Related to Dementia

When he was alone, José Arcadio Buendía consoled himself with the dream of the infinite rooms. He dreamed that he was getting out of bed, opening the door and going into an identical room [...]. As in a gallery of parallel mirrors, until Prudencio Aguilar would touch him on the shoulder. Then he would go back from room to room, walking in reverse, going back over his trail, and he would find Prudencio Aguilar in the room of reality. But one night, two weeks after they took him to his bed, Prudencio Aguilar touched his shoulder in an intermediate room and he stayed there forever, thinking that it was the real room.

(Márquez, 2012, 143)

The newest edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) discusses dementia under the label of Neurocognitive Disorders. The diagnostic criteria for mild NCD include: (A) Evidence of modest cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual motor, or social cognition) [...]. (B) The cognitive deficits do not interfere with capacity for independence in everyday activities (i.e., complex instrumental activities of daily living such as paying bills or managing medications are preserved, but greater effort, compensatory strategies, or accommodation may be required (Simpson, 2014, 160). In laypeople terms, its most common symptom is memory dysfunction, loss of memories and the following disintegration of personality. As David Shenk (2003) puts it: “[...] as the disease relentlessly progresses toward the final dimming of the sufferer, it forces us to experience death in a way it is rarely otherwise experienced. What is usually a quick flicker we see in super slow motion, over years.” Dementia is one of the biggest challenges aging societies are facing in the 21st century. Not a stand-alone disease, but a clinical syndrome that can occur in many diseases, most frequently caused by Alzheimer’s.

The number of patients with dementia in Hungary is estimated at 200,000 (Vajda, 2020). Nevertheless, the awareness of laymen and professionals about the syndrome is still low. Related to this is the fact that most patients are not diagnosed in the early stages of the disease and do not receive specific treatment that could slow their deterioration. However, a more complex issue than a lack of knowledge is a true understanding of dementia, in which stories and literature can help us. Indeed,

dementia has a wide literature, for a review of the Alzheimer's literature see Block (2014).

Dementia is handled by the legal system through the concept of legal capacity. For Hungarian law, dementia is a condition with a partial or even total incapacity for sound decision-making in the advanced and late stages of the disease. As far as legal "treatment" is concerned, preserving the dignity of patients is a key issue. As dementia is usually long-lasting, Act V of 2013 on the Civil Code (Civil Code) § 2:39 which establishes preliminary legal declaration could be of paramount importance in case of early diagnosis. In addition, patients with dementia could typically walk through the relevant institutions of the Civil Code from the supported decision-making to the guardianship which partially and then completely restricts the ability to act. As the disease unfolds, respecting the will and preserving the dignity of the sufferer becomes more and more difficult. This is partly a regulatory issue, but largely depends on the functioning of the social care system. However, the proper functioning of this system must be secured by legal tools as the effective control over the activities of carers and guardians is also based on good regulation.

1. METHOD

There are several branches of law and literature research. The most basic division distinguishes between *law in literature* and *law as literature* approaches. The former deals with the analysis of the literary representation of legal institutions, while the latter uses the tools and insights of literary studies to understand legal texts and discourses. In his summarizing study, H. Szilágyi (2010, 5) states that the focus of the former approach is on the relationship between law and justice, and the aim of the analysis of literary reflections is often to critique black-letter law and to formulate moral lessons.

Although the short analysis presented in this paper can be classified as a part of the *law in literature* studies, its aim is not specifically to critique the relevant legal institutions (supported decision-making, guardianship, preliminary legal declaration) handling the decline in legal capacity. Dementia has become a widespread disease in 21st century societies, yet in a sense it remains a mysterious, unapproachable condition. With the loss of memories, an essential element of identity is damaged, so dementia raises not only health, social, or even legal issues, but leads directly to the philosophical problem of an individual's self-identity. It is also less and less comprehensible to family members and the patient's wider environment what the person is going through as the disease progresses. Lawyers, legislators, and law enforcers alike, generally lack the proper expertise on this condition, but the lack of real understanding is an even more fundamental problem. The basic thesis of this study is that literary narratives can help understand dementia. Through these stories, legal professionals, or even law students, can learn about this condition which is a preliminary condition of good legislation and legal decisions alike.

This kind of cognition is especially valuable because it brings the problem closer than studying the scientific literature on the disease, it brings real, emotional involvement and experience. On the other hand, as a reader, we can keep some distance, by reading these fictitious stories we have the opportunity to reflect more

emphatically on this particular area of human experience, which, once it becomes the story of our own family history, we no longer can contemplate in such a way.

These, of course, are not radically new insights. In connection with minority experiences, from time to time emerges a need to create a language for telling and narrating them, to have words for these experiences. These stories make the reality and social experience of minority members become more accessible to others. This insight is very important for feminist social sciences, such as feminist legal theory, but *Critical Race Theory* scholars also consider it of paramount importance and use the tools and methods of legal storytelling. The legal theories of minority consciousness usually rely more heavily on qualitative approaches than traditional legal and sociological research, placing much greater emphasis on telling stories and “counter stories” (Delgado, 1989). They need this because they are trying to show an alternative reading of reality, through the experiences of those who belong to a minority group. As Tamás Nagy put it describing the difference between European and American narrative legal theory: “The main purpose of the American school [of law and literature studies] is to give voice to minority groups ‘silenced’ by history, expressing the viewpoints and interests of traditionally marginalized, oppressed social groups”. This school seeks to describe the oppressive nature of translating social conflicts to the “neutral” legal language and wants to enable formulating other narratives about them (Nagy, 2015, 115).

2. RESULTS

The theme of dementia is slowly finding its way into the mainstream, or at least to works that reach the public. In 2020, Florian Zeller’s drama *The Father* was shown, an adaptation of a play. Anthony Hopkins, who plays the title role of a father with Alzheimer’s disease in the movie, won an Oscar for his portrayal, which also gave great publicity the movie and thus the theme depicted in it. However, many literary works deal with the subject of dementia (e.g. Bernlef, 1984; Bayley, 1999; Franzen, 2001; DeBaggio, 2002; Genova, 2007; Harvey, 2010; Cabré, 2011; Keaton, 2011; Enger, 2013; Thomas, 2014; Kawaguchi, 2019).

One of the central questions in these literary works is the relationship between identity and memories, the question of the disintegration of the personality, or even the appearance of some sort of *essential* personality that remains after the loss of the memories of a life. In addition, the authors are usually concerned with the topic of the family: the history of the parents and its impacts on their children, the relationship, conflicts, alienation between parents and children, the recollection of decisive decisions that may have dissolved in their daily lives back when they happened, but the struggle for memories makes their significance clearer, corrections, possibility of reconciliation, dissolution.

As for the legal issues related to dementia, they usually do not play a prominent role in these stories. The right to diagnosis, the right to self-determination at an early stage, and the right to appropriate treatment and care as the disease progresses, and the problem of alternate decision-making all affect the fundamental right to dignity. Legal language and evaluation do not usually appear in works dealing with dementia, nor do the actors of the legal system (guardianship authority, court,

guardian, or supporter). Dementia affects fundamental layers of personality and family relationships that seem to almost repel legal evaluation, making representation of legal threads in literary narratives meaningless, irrelevant. This shortcoming is instructive, it shows well how distant and ineffective the current legal solutions are in the everyday interpretation of the disease, whether for patients or for family members. However, this does not mean that the legal framework regarding legal capacity and the institutions of the social care system governed by the law do not have a role in resolving the problems of self-determination of patients with dementia. Moreover, a better understanding of the situation of patients and their families is key to developing better legal solutions reflecting their needs.

In the following I examine how the topic of (1) preparation after diagnosis and (2) the theme of guardianship, care, and preservation of dignity appears in some literary works dealing with dementia.

2.1. *Diagnosis and preparation*

In some works, the author presents dementia as a process in which the patient is “lost” from the very beginning, even at an early stage, their previous independence and agency immediately disintegrates, dissolves into the role of the patient, they are completely occupied by the frightening process threatening the basis of their existence. The concepts of education, up-to-date, readily available knowledge, early diagnosis, adequate health information and care do not appear articulately, although when we reflect on this, its lack is a very defining feature in the works. The protagonists’ rights to receive clear answers to their questions in the early stages of their illness are violated. This on a personal level entails uncertainty and fear, which is a prominent element in these stories. Reflecting on the legal consequences, it is not difficult to see that the patient’s right to self-determination is also violated. The naturalness of this is well illustrated by the fact that in many of these otherwise sensitive, complex works depicting the phenomenon of dementia, it does not provoke any criticism from any of the characters.

A good example of this is the protagonist of Bernlef’s work, Marteen Klein. Marteen lives in a closed and comfortable microworld with his wife, Vera, and their dog. The image of their life in the work is both monotonous and intimate, with few characters, the days are spent in a certain warm uniformity. Marteen is completely preoccupied from the first moment of the novel with the fact that this safe environment around him is confused, the days and hours lose their linearity, the episodes of oblivion interrupt the peaceful flow of time. In parallel, the past is becoming more and more alive for Marteen. However, there is no question of diagnosis, confrontation, disposition, preliminary declarations of law, at least for the protagonist, these issues do not seem to exist. These questions in *Out of Mind* are Vera’s questions, her problems. Vera faces the diagnosis, she is trying to find a solution, looking for a nurse for her husband.

Another example of this approach is Cecilie Enger’s work, *My Mother’s Gifts*: “It had been six months since Mom got into my sister’s car, deeply confused, without asking where they were going. Anne Johanne held her hand the whole time as she set off on the gravel road and rolled out the gate and drove to the nursing home where

a place was provided for Mom.” (Enger, 2013). The author describes the reaction of the narrator’s mother in the early stages of the disease as follows: “When Alzheimer intervened, Mother’s despair became unsheathed, she began to speak desperately to keep the frightening and ever-slipping world in place. And she kept writing, scribbled notes, letters, lists, dates. The sentences became shorter and shorter, the connections broke, significant episodes jumped through, everything was interrupted, and the meaning disappeared.” (Enger, 2013).

Facing the diagnosis and provided with proper information, the characters’ reaction changes: they try to find a solution. The protagonist of *Still Alice*, when she finds out she has Alzheimer’s, writes herself a letter beginning with five questions to her future self (“What month is it? [...] How many children do you have?”). In the letter Alice informs herself that if she cannot answer these, she no longer lives the life she wants. The letter then gives detailed instructions for suicide. However, Alice, the recipient, can no longer follow the instructions, even though she intends to. However, the final lesson of the novel is that Alice, who was diagnosed, did not judge her situation correctly, because as the disease progresses, memories are lost, the complexity of the personality disappears, but in the end some kind of core identity remains, and the foundation of dignity is preserved, Alice remains Alice (Genova, 2007).

The subject of the letter to the future also appears in the work of Kawaguchi (2019). The story of *Before the Coffee Gets Cold* is built around a specific, limited form of time travel. In a certain chair in a Tokyo cafe, you can travel to a specific point in the past or future and spend as much time there as you need to have a cup of coffee. One of the four stories in the work is about a married couple. The man, when he learns that he has Alzheimer’s, writes a letter to his wife, who, when she becomes aware of the letter, travels back in time to ask her husband for it. The trip gives them an opportunity to talk about the diagnosis and its effect on them, a discussion that did not happen at the time. Moreover, in the letter, the man describes what kind of treatment he wants in the future. This letter is no more positive than Alice’s: “You are a nurse, so I assume you have noticed by now that I have an illness that causes forgetfulness. I imagine that in parallel with the loss of my memory, you will put aside your personal feelings and take care of me with the indifference of a nurse. [...] You don’t have to stay by my side as a nurse either. I’m a useless husband, leave me! [...] I do not want you to remain my wife out of pity.” (Kawaguchi, 2019, 126). However, Kohtake, the wife does not feel caring for Fusagi a burden, on the contrary, she thinks it is the best solution.

These stories shed light on the fact that, having a diagnosis, the characters can control what happens to them later, according to their habitus. They both find themselves worthless without their memories and would free their loved ones from the burden of caring. At the same time, both stories show that their family does not see this as such, they consider them valuable, lovable even in the late stages of the disease, and they are convinced that the essence of the loved one’s individuality has been preserved. This message is, on the one hand, humane and hopeful, and, on the other hand, highlights that one of the main solutions of the law does not coincide with the moral guidelines that emerge from the stories. The essence of a preliminary legal declaration is that the will of the patient can be enforced even if she is no longer able to express it. If family members override this out of love, it is a paternalistic solution

that deprives the individual of her dignity. These briefly presented narratives highlight that a system based on preliminary legal declarations can lead to inhuman results – as characters encourage euthanasia, abandonment, and voice the worthlessness of their future self – if we do not have widespread knowledge of this symptom, and it is not generally accepted that the life of people with dementia is still precious.

2.2. Care and substitute decision-making

In novels about dementia, as the condition of patients deteriorates, it naturally occurs that family members begin to care for them. Later, when this is no longer enough or becomes too difficult, a qualified nurse is often admitted, and the patient is eventually placed in an institution. It is especially characteristic that the patient's decision-making right is not mentioned in connection with these steps. I have previously quoted an excerpt from Enger's work, about the placement of the narrator's mother in an institution. In the novel, the children look for a solution, their mother is not in a decision-making position. In an interview from the previously mentioned research, a father who is the guardian of his adult son who is mentally ill, described guardianship as not helpful, "a bureaucratic hurdle".

A similar picture emerges from the fictional stories and narrative life story interviews recorded in the research: the legal framework for substitute decision-making is very far from the ordinary realities of those involved. It is described as only natural that the individual, while able to do so, decides on issues that are important to her, just as when she is no longer able to do so, the right to decide (described rather as a heavy responsibility in narratives) slips into the hands of family members. In this case, the literature seems to bowdlerize, since substitute decision-making is an institution that exists in every legal system and is not free of conflicts, but these conflicts do not appear in the examined narratives. Not a literary work, but noteworthy is the movie *I Care a Lot*, which is about the potential of abuse in substitute decision-making. It is important to note that in the movie, a professional legal guardian tries to drain the savings of her elderly wards, so it is not about relationships between family members. Opportunities for abuse within the family seem to be taboo in this round.

3. SUMMARY

I hope that even if this short study raises many further questions, it sheds light on the extensive literature on Alzheimer's disease, and on the valuable empirical material they provide for understanding the contradictions between law and social reality. I also consider an important lesson that, at the same time, it would be wrong to set the picture described by literary works as a standard. The stories examined often reflect uncontrolled everyday biases, such as the idea of the worthlessness of the lives of patients with dementia, the fear of those involved, and the idealization of the love of family members and the uncritical acceptance of the resulting paternalism. At the same time, if we can believe the picture emerging from literary narratives and our research results so far, legal institutions are completely foreign, irrelevant, and meaningless to those concerned, the law in this field is so detached from the social reality that it is not able regulate it. a healthy strain between black-letter law and

social reality is the key to effective legal regulation, which would be much needed to preserve the dignity of those involved – potentially all of us.

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Support (Care) Service: A Supportive or a General Care Service for Persons with Disabilities?

1. INTRODUCTION

The supporting (care) service (*támogató szolgáltatás*) was institutionalised by Act LXXIX of 2001 by which Act III of 1993 on Social Administration and on Social Benefits (hereinafter: Szt.) was amended. The service was introduced actually in 2003, when the regulation about it entered into force. The introduction of this service was part of the disability legislation of the Millennium in Hungary. It has been linked to the regulation of Act XXVI of 1998 on the Rights and Equal Opportunities of Persons with Disabilities (hereinafter: Fot.). By that regulation – which has been amended several times during the last two decades – a new, specialised service has been introduced which focused on the social care of the persons with disabilities. Actually, this is one of the main non-institutional social care services which is entitled directly to assist the persons which disabilities. Therefore, it seems *prima facie* that it is the major basic home care service for persons with disabilities. This *prima facie statement* is analysed by this paper.

2. METHODS

Our research is basically a jurisprudential analysis. First of all, we would like to analyse the legal regulation on the support (care) service, especially the regulation of the Szt. and even the regulation of the executive decree of the rules of the Szt. [Decree of the Minister of Social and Family Affairs No. 1/2000. (published January 7th)]. Secondly, the major – available – data on the provision of this service are examined by the paper, especially the number of the potential recipients of that benefit and the actual number of the persons who are provided by this care. Based on these data and jurisprudential analyses the nature of this care is examined.

3. LITERATURE REVIEW AND ANALYSIS OF THE REGULATION OF THE SUPPORT (CARE) SERVICE

The support care service is institutionalised by Article 65/C of the Szt. *Prima facie*, it seems to be the general basic social care for persons with disabilities. It is stated by the first part of the first sentence of par 1 art 65/C. that “the support service aims to provide care for persons with disabilities in their residential environment...”. This first sentence states that this service can be interpreted as the general care service for the persons with disabilities, because that is the major basic (non-institutional) service to which exclusively persons with disabilities are entitled (another service, the day service for persons with disabilities can be interpreted as an institutional one) (Velkey, 2017, 144). However, another picture is shown even by the following regulation of par 1 art. 65/C. It is stated by the aforementioned rule that the support care focuses on helping access to public services and providing special home assistance while maintaining the independent life of persons with disabilities. Therefore, par 1 art 65/C. is a two-faced regulation: *prima facie* it is a general care service for persons with disabilities, but after that statement the special nature of the service is emphasised by the regulation. If we look at par 3 art 65/C of the Szt., an exemplary list of the services provided by support care is regulated by that paragraph. However, it is theoretically an exemplary list, but actually it is a very detailed regulation of them. These services have mainly *special* and *supportive nature*. The listed services focus on providing the access to public services for persons with different disabilities and the different services for the different groups of persons with disabilities. This supportive nature is confirmed by the executive decree of the Szt., the Ministerial Decree No 1/2000. (published on January 7th). title VI of the Decree has a detailed regulation on the services defined by the Szt. This list can be interpreted by the practice. Therefore, the *supportive nature* of this service as a tool for providing access to public services is emphasised by the literature as well (Kozma et al., 2020, 393–394; Laki, 2021, 87–89 and Cserti-Szauer, 2021, 36–38, Csák, 2016, 273–275).

DATA ANALYSIS AND DISCUSSION

To examine our hypothesis which has been based on the jurisprudential analyses of the regulation and the results of the former research, we examined the available quantitative data on the support care. As it has been mentioned earlier, the support care is persons with (severe) disabilities are entitled to support. As a first step, we analysed the number of persons with disabilities in Hungary (Based on the data of the 2001 and 2011 census and the 2016 microcensus).

TABLE 1. PERSONS WITH DISABILITIES IN HUNGARY (2001–2016) (KSH)

Year	2001	2011	2016
Persons with disabilities	577,006	490,578	408,021

As it can be seen, the number of persons with disabilities is declining in Hungary (the only exception is the number of persons with intellectual and psychosocial disabilities, which is constantly increasing) (Kiss et al., 2021, 2–4). These are the potential recipients of that service. Based on the regulation of the Szt., the services are provided to persons with severe disability are entitled to those services. In the practice, severe disability is linked by the Szt. and the executive decree to those persons who can be the beneficiaries of the disability benefit (*fogyatékosági támogatás*). Therefore, as a second step, we examined the number of persons receiving disability benefit (*Table 2*).

TABLE 2. NUMBER OF RECIPIENTS OF THE DISABILITY BENEFIT
(in December of the given year) (Source: KSH STADAT)

Year	Number of beneficiaries
2004	96,695
2005	101,360
2006	106,620
2007	109,169
2008	110,838
2009	112,647
2010	113,909
2011	114,625
2012	113,778
2013	114,009
2014	115,541
2015	114,066
2016	114,515
2017	112,887
2018	110,569
2019	109,262
2020	NDA

These data have been compared by the number of the actual recipients of support service (*Table 3*).

TABLE 3. NUMBER OF THE PERSONS WHO WERE PROVIDED BY SUPPORT CARE
(Source: KSH STADAT)

Year	Number of recipients of support service
2004	4,491
2005	10,531
2006	17,450
2007	18,590
2008	19,350
2009	17,841
2010	18,008
2011	16,912
2012	14,844
2013	14,344
2014	13,639
2015	13,356
2016	13,186
2017	13,306
2018	13,100
2019	12,718
2020	12,623

First of all, it can be stated, that the number of persons with confirmed severe disability is much higher than that of the recipients of care services, therefore, this service could not be considered as a general one. Secondly, it is clear by the analysis of the national data that the number of beneficiaries of the disability benefit is relatively stable, while significant fluctuations can be observed in the number of recipients of support service. In 2004 relatively few people received this service, because the regulation on the service entered into force on January 1st, 2003, but it became a mandatory municipal task on January 1st, 2004. The financing instruments were introduced by the national budget of the year 2003. Annex 3 point 11. b) introduced a flat rate budget support, which was 10 million HUF/year/support provider per service provider. On the one hand, the municipalities where a support service provider was maintained with at least 4 public servants employed since July 1st, 2003 received this grant. On the other hand, support was given to municipalities that maintained a provider which received support from the Ministry or from the Public Foundation for Equal Opportunities for Persons with Disabilities in 2002. The third case of budget support was the aid for larger municipalities: those municipalities which had at least 50,000 inhabitants could receive the flat rate support if they were permitted to establish a support service provider until July 31st, 2003. These providers were established in the course of the following years and the number of recipients of the service started to increase significantly after 2005. In 2008 the trend changed, because the municipalities were not obliged to maintain these services and the service lost its mandatory municipal task nature. The main reason for the transformation was equalising the geographical

inequalities. This service therefore became the task of the central administration and the financing of the providers changed as well. The service was supported by a centrally managed tendering system. The institutionalisation of the tendering system resulted in the reduction of the persons receiving the service, and their number stabilised around 12-13,000 after 2013.

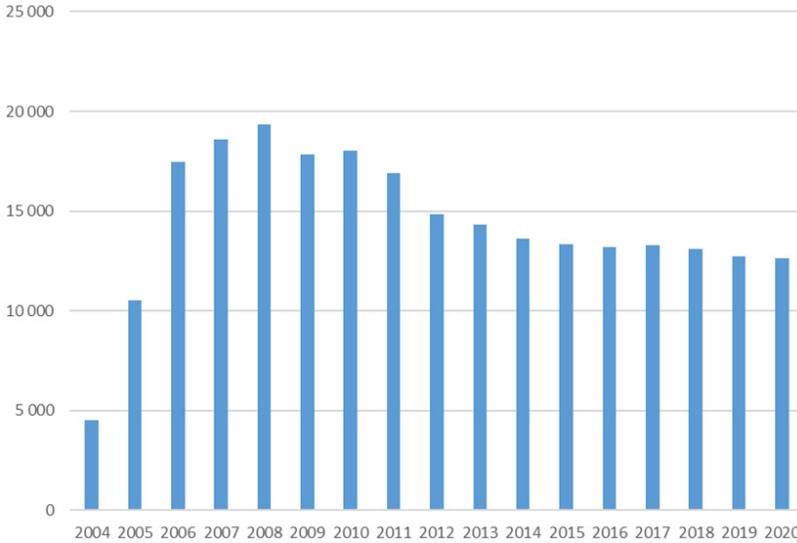


FIGURE 1. PERSONS WHO RECEIVED SUPPORT CARE SERVICE (2004–2020)
(Source: KSH STADAT)

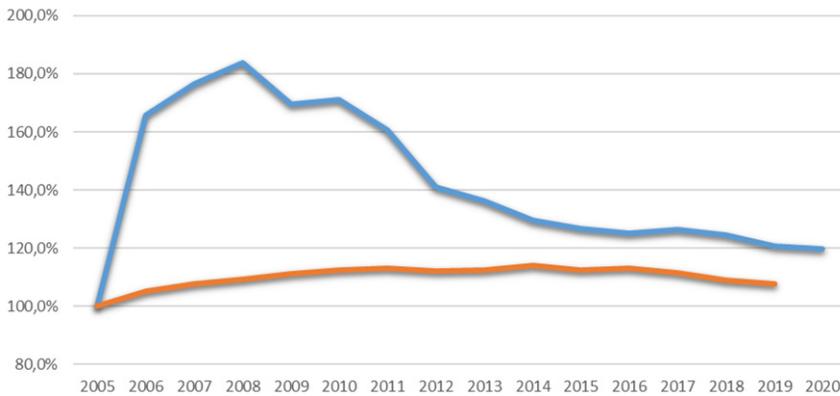


FIGURE 2. NUMBER OF RECIPIENTS OF DISABILITY BENEFIT AND SUPPORT SERVICE (2005–2006) (2005 = 100%)
(Source: KSH STADAT)

5. CONCLUSIONS

The data analysis confirmed the hypothesis based on the jurisprudential analysis of the regulation on support service. a limited share of the persons with severe disabilities received the support (care) service. It has been partially linked to the spatial distribution of the service providers, but actually it confirms that this service is merely a supportive service for persons with disabilities and not their general basic service.

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Power among the Powerless: A Theoretical Approach to Understanding How (Legal) Power Appears among Persons Placed under Guardianship

1. INTRODUCTION

In my study, I seek to answer the question of how the institution of guardianship is presented in the lives of people placed under guardianship, their families, their support networks, and their guardians. Guardianship is a legal institution that encompasses all aspects of life. The law is much more present in the everyday lives of the people concerned than it is for people who do not have to deal with it.

According to cultural sociology, the law is not an absolute, institutional system, but part of everyday life and everyday culture. In this interpretative framework, law is part of reality even if it is not consciously perceived or defined (Swidler, 1986). At the same time, we cannot ignore the fact that law is a construct of power. It allows or forbids, it controls, it sets limits. One of Michel Foucault's fundamental propositions is that power is constructed in everyday life, permeating the totality of society and life (Foucault, 1999). If we therefore consider law as part of everyday life, not forgetting that it is also a significant factor of power, we can build a theoretical analytical framework that can help us to understand what the legal institution of guardianship really means for the people concerned and how law intervenes in their lives.

In what follows, I will first examine the Foucauldian theory of power through the lens of a cultural approach to legal studies, and then I will compare this with interviews with those affected by the institution of guardianship. The interviews were conducted within the framework of the ongoing research project: *The Restricting of the Legal Capacity of Adults in Hungary*, led by Prof. István Hoffman [OTKA FK132513].

2. LAW AND POWER: ORDINARINESS AND ABSOLUTENESS

The starting point of the cultural turn in jurisprudence is that law should be analysed as part of culture, in which law itself is a cultural factor. This turn puts the social theoretical approach to law on a completely new footing. On the one hand, it argues

that law is not a separate subsystem but, on the contrary, an integral part of culture. This tradition of research goes back to Eugen Ehrlich's notion of living law, which distinguishes, especially at the periphery, between written law and the law used by individuals and communities. As Ehrlich puts it:

“Living law is not laid down in legal documents, yet it rules over life” (Ehrlich, 1977, 72).

Living law is thus a factor shaping social functioning and individual action, even in contrast to existing law. It can be understood by studying everyday legal texts, which are the source of the norms of living law, and not law books. Ehrlich's concept of living law and his work are not only the foundations of European sociology of law, but also one of the inescapable theoretical roots of modern cultural legal studies. (Ehrlich, 1977).

The cultural turn, therefore, shifts attention from the study of macro-social processes and institutional functioning to the everyday manifestation of law, in which the actor is at once an active, forming and reflective agent. Thus, instead of looking at the functioning of large social institutions, it examines the way in which “structure, culture and the actor interact to form each other” (Fleck et al., 2017, 11) and, at the same time, how they construct the realities of everyday life (Fleck et al., 2017). Sally Engle Merry in her paper – *Getting Justice and Getting Even: Legal Consciousness among Working-Class Americans* – examines the everyday legal problems of the American working class and finds that when a problem or a situation of harm arises, even the recognition of the problem as a right is a significant problem, which fundamentally calls into question the principle of equal access, or more precisely, its enforcement (Merry, 1990).

But the law also has a significant power dimension. In the Foucauldian approach, we can interpret law as a factor of power while remaining within a cultural framework, namely approach the law itself through the aspect of everyday life. In this interpretation, power emerges in the interactions of everyday life, manifesting itself in symbols, privileges, statuses, rather than a separate and distinguishable entity within society. (Ewick & Silbey, 2003).

Understanding the nature of power is the heart of Foucault's entire oeuvre, and I am just about to highlight his thoughts on bio-power. In several of his writings, Foucault explores how the organization of power is transformed from control over territory to control over the body. In his work on “governance”, he examines two ways of organizing power. The second of these is linked to the emergence of the modern administrative state. It is in this period (18th century) that the focus of governance shifts from the territory to the body of people, exercising power over their well-being. The exercise of power is rationalized and institutions such as the police, the prison and the hospital appear, covering all aspects of life. Thus, the point contact with power ceases to exist and becomes much more embedded in the experience of everyday life. The historical change of power, according to Foucault, has moved towards atomization, that is, power dynamics are increasingly understood at the individual level (Sik, 2009). As Foucault notes in *The History of Sexuality*, the meaning of power and with it, of law changes in this era, “power is exercised not by law but by normalization, not by punishment but by control” (Foucault 1999). This type of government is the era of the emergence of liberal states, one of whose mottos is that the purpose of government is “the right ordering of things” (Foucault 2000b).

This does not mean, as Vikki Bell points out, that for Foucault, the emergence of the liberal state would mean that the individual becomes completely free, free from power dynamics, but on the contrary, it is a myth of the free person. In the case of the liberal state, since the system itself, based on indirect democracy, the structure of the state is an obstacle to complete freedom of action, even for a politically active man (Bell, 1996). In Foucault's interpretation, law becomes part of everyday life, power is transformed into a kind of technique. As he writes in *Discipline and Punishment*, in terms of the technique of the exercise of power, the medieval demonstration of force based on violence and spectacle is replaced by constant control (Foucault, 1990). In this way, anyone who does not fall into the categories of normality can be controlled, he writes in *The History of Madness*. Anyone whose behavior does not fit what is accepted by society is placed beyond normality, his or her life is more constrained. Power thus appears as control through normativity, embedded in everyday life, in all aspects of life (Foucault, 2004).

Thus, Foucault interprets law within these frameworks of the concept of micro-power, but, as Alan Hunt points out, he fails to take into account the role of the state and power groups, and thus cannot interpret law according to its weight (Hunt, 1992). Foucault argues that in the power logic of the technique of discipline that weaves the fabric of society, law is rather formal and external. As a critique of this, Hunt argues that law is not the opposite of discipline, but rather its primary source (Hunt, 1992). "Power spreads through individuals, not through them, it finds its resting place in them" (Foucault, 2000a, 155). [Translated by the author. In Hungarian: "A hatalom az egyéneken keresztül árad szét, nem pedig rajtuk keresztül, bennük jut nyugvópontra."]

The legal institution of guardianship fits perfectly into this approach. It is through the guardianship system that an individual's capacity to act, and hence his freedom, is limited. By placing an individual under guardianship, he is removed from the "normal", and the state or society is given the right to control him.

3. INTERVIEW IMPRESSIONS

3.1. *The method*

In the following I will analyse how the legal institution of guardianship appears in some of the interviews. The interviews were conducted within the framework of the research project entitled *The Restricting of the Legal Capacity of Adults in Hungary*, in which we are interested in how the institution of guardianship appears in the life stories. For this purpose, we will conduct narrative life story interviews with caretakers, persons under guardianship and their supporting family members and friends. Our aim with this threefold split is to examine the legal institution of guardianship from as many aspects as possible, thus building a complex picture of its impact.

The interviews are narrative life-course interviews, a construct that is one of the least intrusive interview techniques. While most social science methods are more or less intrusive, the narrative life-course interview attempts to minimize this by reducing the role of the interviewer as far as possible and focusing on the role of the interview subject as far as possible. The interviewer simply explains the focus of the

research and asks the interviewee to tell the story of his or her life. From then on, the interviewee leads the interview process, deciding how long he or she wants to talk and what he or she wants to say (Vajda, 2006).

In this approach, the narrative itself is the basis of the analysis, the social construction itself, which gives us the ability to reconstruct a kind of social structure based on the social reality and experiences of the individual (Kovács, 2011). Based on the narrative life story interview, we construct a hermeneutic case reconstruction, in which, following Rosenthal's approach, the analysis of the life story consists of two major parts, a hermeneutic case reconstruction of the lived life and a hermeneutic case reconstruction of the narrated life. For the analysis of the lived life, biographical data will be collected and arranged in chronological order. We then form hypotheses on it, considering the socio-historical context. The narrative life story is then examined. The text is broken down into sequences, but not transformed; everything is analyzed in the order in which the interviewee told it (Rosenthal, 1993).

However, this is not done here. In this paper, I present below some of the statements from the interviews, which could potentially support the cultural concept of rights and Foucauldian power theory described above. Thus, the analysis is methodologically unsupported, and this will be remedied in a later phase of the research. So, in this paper I will only report impressions from the interviews.

3.2. *Entries – interview narratives*

Nine interviews have been conducted so far during the research. The aim of the research is to interview people under guardianship, their guardians, and their supportive relatives, in order to get the most complex picture possible of the effects of incapacity. The following quotes are written without punctuation. The reason for this is that when we describe live speech, we are already interpreting it by punctuating it. To avoid this, narrative life history interviews should be handled with as little interference as possible, leaving out punctuation. In the following, I will try to show what this can mean in everyday reality, using a few examples.

Kristóf, a 20-year-old young man from Budapest, whom his father wanted to place under guardianship, because of an injury he had suffered at birth, which required nine brain operations. His parents will therefore start a guardianship procedure, a lawsuit, against him when he reaches the age of majority. *Kristóf* does not consider himself mentally or psycho-socially disabled at all, and he says that he wants to live an independent life. He describes his own situation as follows: “that’s why my father will keep me on a very short leash, because for them, living with this illness in a normal environment is not possible, they don’t look kindly on it, but I would like to live like a normal person.”

It is interesting to note the juxtaposition of normal and not-normal, which is a feature of his language throughout the interview. *Kristóf* perceives that by being placed under guardianship he would fall outside the “normal” members of society, he would not be an equal member anymore.

He perceives the attempt to be placed under guardianship as an attack he is unprepared for. Although it is clear, that *Kristóf* is perfectly capable of understanding

the legal process, he is struck by the fact that they argue about Kristóf without arguing about him at all.

“Why this guardianship was initiated is still unclear to me, because the fact that I was not informed about it, or only found out about it afterwards, is a dark hole, and neither the guardianship office nor my father and mother explained why it was necessary.”

So even restrictions covering all aspects of life can start without the person concerned knowing anything about it, they are going over their head. Suddenly, the law intervenes in his life, looking at him as an external, offensive instrument.

László, seventy-five years old, who is both the guardian and the supporter of his own son. His son suffers from a psycho-social illness and was placed under guardianship as a young adult. *László*'s son is in his forties at the time of the interview. *László* has a university degree, he is an intellectual freelancer and currently working in a high-level position. His experience of being taken into care by someone is very similar to *Kristóf*'s. The proceedings will start when his son is once back in psychiatric care.

“The doctor suggested, it was an official suggestion, that he should be put under guardianship, we found out afterwards, because she didn't tell us and then the guardianship office started to hearing us and I said I didn't think we should, but they said it was ex officio and then the court ordered it because it was an official procedure that he should be put under guardianship [...], we even had a lawyer several times to say no.”

Here again, the legal process is initiated without the person concerned, or without their family member being aware of it. *László* says several times during the interview that he and his son didn't want this guardianship, they had explicitly objected to it, but that they did not take it into account in the proceedings, only the expert's report. This is what he says about the guardianship: “my experience of guardianship itself has been negative, it has not helped but has been a hindrance”; “the institution of guardianship does not really help [...], it does more harm than good.”

Not only does the law go over their heads, but it does not reflect the real problems either. *László*'s son needs help in making certain decisions, and the family needs financial and social support, but this institution is lacking these. As *László* puts it, guardianship is just an administrative burden, it interferes with their daily lives and ties them together, it transforms the father-son relationship into a formal one, and it is not a help but a handicap.

Klára is in her forties, she has been a professional caretaker for eight years, in and around a small rural town. She makes a statement about the institution of guardianship in a mostly technical sense, mainly about how she buys to her client and how she helps with finances.

“70% of my work is spent going into town, I have checks, I plan what I'm going to do and I write a weekly report on what I did.”

Making joint decisions, the possibility of enabling does not even appear in the interview. At first glance, this is due not only to the outdated institutional system, but also to the fact that *Klára* has 40 caretakers in two settlements, far exceeding her strength.

She also speaks in a very technical way about guardianship and court proceedings, just describes it without reflection. *Klára* is there in the everyday lives

of the wards. The scope of her intervention is more or less depending on the degree of limitation of her client's ability to act. She mainly talks about the financial problem and tasks, but also another thread appears: placing the people under guardianship in the institution as soon as possible.

“As soon as I receive the ward's application we will start applying for an institutional placement.”

“The homeless shelter has indicated that he [a homeless person] will lose his money and also the homeless shelter has indicated to the guardianship authority that they wish to place him in custody.”

The institution can dominate the wards' all areas of life, their freedom of choice is even more limited, their independent living is de facto lost. Of course, in some cases, institutional placement is the best solution, but strikingly, without any critical tone, it appears as a natural part of the process, as something inevitable in Klára's interview. It does not even appear if these people would be able to live independently, to make free decisions, or what kind of institutional help exists to live a freer life, it does not come to light.

4. CONCLUSIONS: LAW AND POWER IN EVERYDAY LIFE

I think that, although the above analysis is just a superficial summary of first impressions, two aspects could be the subject of further investigation. One is the way in which guardianship transforms human relationships and everyday life, and the other is the way in which the legal process intervenes in people's lives and how they experience it.

The real purpose of the legal institution of guardianship is to intrude into the life of the individual, and by limiting capacity to act, freedom of choice is infringed. At first sight, it seems clear from the interviews that the restriction or threat of restriction of capacity is a change in the level of everyday life, a diversion of life paths or a change in family relationships. The power over the body is seen as a limiting force that does not help but regulates and disciplines.

In Klára's interview, it is striking how this is normalized, how this intervention can be spoken of in purely technical terms and thus how what is actually happening, the fact that the freedom of the individual is violated, ignored. With this normalization, the intervention loses its scale, it becomes more and more neutral.

The legal process, in Kristóf and László's interview, is also a sudden event. Although they are the subjects of the procedure, it starts abruptly, the law looms over their heads. Of course, this can be a feature of law, criminal proceedings obviously start with the accused not consenting, or we can start a lawsuit for damages without asking the person who caused the damage. However, in the case of incapacity, there is no harm on the other side to justify it. Both Kristóf and László define the procedure almost as a punishment, the singling out of the “normal” of the individual. One may ask whether the very legal procedure by which the Hungarian legal system limits capacity is appropriate or whether it is worth reconsidering.

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