WE KNOW ALREADY HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH DISABILITIES (SUMMARY OF THE RESEARCH PLAN) WE KNOW ALREADY HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH DISABILITIES (SUMMARY OF THE RESEARCH PLAN) WE KNOW ALREADY HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH DISABILITIES (SUMMARY OF THE RESEARCH PLAN) WE KNOW ALREADY HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH DISABILITIES (SUMMARY OF THE RESEARCH PLAN) WE KNOW ALREADY HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH

FOGYATÉKOSSÁG ÉS TÁRSADALOM

HUNGARIAN JOURNAL OF DISABILITY STUDIES & SPECIAL EDUCATION

ELTE BÁRCZI GUSZTÁV FACULTY OF SPECIAL NEEDS EDUCATION

FOGYATÉKOSSÁG ÉS TÁRSADALOM

*Hungarian Journal of Disability Studies
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HUNGARIAN JOURNAL OF DISABILITY STUDIES
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HOW TO ESTABLISH A NEW DISCIPLINE?

Introduction to the Special Issue of the Periodical *Hungarian Journal of Disability Studies & Special Education (Fogyatékosság és társadalom)*

Early developments: Cooperative Research Institute

The first research

The first Disability Studies research was carried out in Hungary in the course of 1984, in the Cooperative Research Institute – lead by Director Antal Gyenes (member of the Imre Nagy government of 1956). The values it was based on would have qualified it as Disability Studies research. However, not even the researcher called it a DS research – we did not use this term that time. That research focused on *the vocational rehabilitation of people with disabilities in* (so called) *industrial cooperatives.*

In Hungary as DS scholars, we use several definitions for our discipline. The shortest, four-elements-one, that I call *essential* definition of Disability Studies, is as follows.

(i) It is a *critical social science*, that critically reflects onto the social world, and even onto itself (Critical Disability Studies).
(ii) It is based on the experiences and the narratives (own voices) of persons with disabilities.
(iii) It reconstructs and analyses hidden oppressive power structures in society (closely connected: the dominant discourse).
(iv) Its communication, values, views etc. are all based on reverence towards persons with disabilities.

That very early research of 1984 did not have all these four characteristics, only *the first* one and *the fourth one*.

In the following decades several interdisciplinary research projects were carried out.

Introducing new solutions: Eötvös Loránd University

Open Universities for Disability Studies

Since 2006, we, at Bárczi Gusztáv Faculty for Special Needs Education, organized three semesters of Open Universities for Disability Studies. The first focused on employment in the open labor market, the second on equal opportunities and the third on the Convention on the Rights of Persons with Disabilities (CRPD). We invited Hungarian and foreign professors (among others Amita Dhanda, Rosi Braidotti and Rosemary Garland Thomson, Tina Minkowitz). All of the three semesters were free of charge for everyone: persons with disabilities, professionals, employees of not for profit organizations. Attendance was higher than 100 persons each year.

The Hungarian language periodical

for Disability Studies and Special Education was founded in 2009. The periodical is based on voluntary work by the editors. An internationally recognized thinker of the discipline, and creative member of the International Disability Caucus (CRPD) Gábor Gombos served as a member of the Editorial Board for years.

Disability Studies Doctoral Workshop

In 2010 we founded the Disability Studies Doctoral Workshop that supports doctoral students, working on DS topics, based on DS values. We have 20 members – among them there are scholars with disabilities – and 7 of them already have PhDs. So DSDW has partly become a Disability Studies (Post)Doctoral Workshop.

Annual Conferences of Disability Studies

We have been organizing Annual Conferences of Disability Studies since 2013. Growing number of the attendance varies between 150–250. Internationally well known professors, e.g., Margrit Shildrick and Dan Goodley were already involved among other great researchers. Tom Shakespeare is invited to be one of the keynote speakers of the Sixth Hungarian Conference of Disability Studies in November 2018.

Hungarian Society for Disability Studies

was founded in 2015 as a Section for Disability Studies in the Hungarian Sociological Association.

Award winning participatory teaching

by teachers with and without disability has been carried out at our Faculty since 2015. Two institutes of the Faculty are involved in teaching and in *participatory research*. These are: the Institute for Disability and Social Participation and the Institute for General Theory of Special Needs Education.

A Fulbright scholar

Nancy Rice from the University of Wisconsin worked with us, while spending a semester at our Institute in 2017.

Taigetus II. research to understand the oppression of persons with disabilities

Teaching practice, as well as giving lectures at universities and international organizations led us to set up a research plan that was accepted and funded by the Hungarian Scientific Research Fund (OTKA, 111917K). This transdisciplinary research was carried out in the period of 2015–2017.

The PODIUM project to learn more about the process of deinstitutionalization

We participated in the Path of Deinstitutionalization – Urgent Moves programme and developed the 'Theory and Practice of Supported Living' inclusive seminar. This international, inclusive project was funded by the Erasmus+ programme and was carried out in the period of 2015–2018. Our work is not only innovative because it uses modern pedagogical tools such as project method, cooperative learning, and the team teaching model, but because the curriculum developers were the first to use the award winning inclusive methodology in higher education in Hungary.

Out of all of the above we introduce two fundamental elements of our most recent achievements in this special issue.

In the first part we articulate some results of our Taigetus research, and in the second part we present the PODIUM training development project. The authors are indebted to the Hungarian Scientific Research Fund and to Bárczi Gusztáv Faculty for Special Needs Education, ELTE for their valuable support.

György Könczei

FROM EQUAL OPPORTUNITIES TO TAYGETUS?

FROM EQUAL OPPORTUNITIES TO TAYGETUS? OTKA 111917K RESEARCH

GYÖRGY KÖNCZEI[1]

WE ALREADY KNOW HOW THE 'SUNNY SIDE' WORKS, LET US NOW TRY TO UNDERSTAND THE EFFECTS OF THE 'DARK SIDE' ON THE LIVES OF PEOPLE WITH DISABILITIES
(Summary of the Research Plan)

1. INTRODUCTION

Younger members of our research group – PhD-students and postdocs – do have a significant cumulative publication list. All of them are members of Disability Studies – DS – (Post)Doctoral Workshop (DSDW) that was founded approx. 5 years ago. The PI started his research on the field of DS exactly 30 years ago. Much more than 100 publications, membership in international boards, a successful Fulbright research professor year in the USA were integral parts of these 30 years. Furthermore, there were important projects successfully carried out during the last decade: the Disability History Touring Exhibit (that was shown in biggest Hungarian cities and even in the Palace of Council of Europe), three semesters of Open University on DS and 1st Hungarian DS Conference in 2013. The idea of our main hypothesis came up in DSDW. Are there counter tendencies of the positive developments (e.g. CRPD) in our postmodern age? Rising of Critical DS, as a critical social science discipline did have a relevant effect on our way of thinking.

So the research, in the era of biomedical technology, will be based on feminist disability studies. We shall analyze the issues of

> the giving birth to fetus being stigmatized as disabled ones,
> the reproductive autonomy of women living with intellectual disabilities and
> the chances of adoption of disabled children – between 0–6 years.

These analyses will be followed by complex legal and basic disability history examinations. Presence of exclusion besides inclusion tendencies will be shown in the course of human history. Our basic view is free of politics. According to our zero level presupposition deep-rooted prejudices, stereotypes and cultural narratives do have determinative effects on how persons with disabilities have a chance to live – and not 'daily politics'. The research will be a participatory one (Marton–Könczei 2009).

We are studying the *normal* and the *pathological* surrounding of the phenomenon of disability in the context of the power of the norm. Complex and long overdue questions regarding the appreciation and devaluation of disabled bodies are being mapped out. We are pointing at attitudes of exclusion dictating 'what lives are worth living and who should and who should not inhabit the world' (Hubbard 2006, p. 99).

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We are analyzing those power discourses, practices and policies according to which disability is exclusively equated with limitation, disadvantage, social stigma and lives not worthy of living (Canguilhem 1991; Foucault 1961; Davis 1995, 2006; Garland-Thomson 2002).

The results will be relevant geographically on Hungary in the time frame of January 1st 2008 and December 31st of 2013, except some elements of legal and disability history research.

1 Today, reproduction is almost entirely embedded in the discourse of biomedicine. The practice of prenatal screenings and pertinent legal regulations are aimed at doing away with the so-called 'genetic abnormalities'. At the same time, all of this is done with the intention of minimizing the 'social costs 'brought on by disability, cutting out undesirable conditions and normalizing bodies (Sawicki 1999; Tremain 2005, 2006; Parens-Asch 2000). Prenatal screenings are part of the dominant power discourse and mechanisms exerting destructive power over disabled fetuses and oppressing mothers.

Ultrasound and other control techniques expand the arsenal of exclusive practices (Foucault 1995) by making it possible to observe and normalize the body of the fetus even before birth (Saxton 2006; Hubbard 2006). The body of the expecting woman and her fetus are banished to the area of clinical discourse by the widespread use of prenatal screenings where based on the standard of normality the fetus stigmatized as disabled gets to be deemed deviant as an element of the functioning and maintenance of the terror of the able bodied (Sawicki 1999; Shelley Tremain 2005, 2006).

In the course of the research we are looking for answers to the following questions:

How do prenatal intervention strategies weigh on the everyday lives of those concerned, their processes of self-understanding, and the moral and legal systems and which ones of the determining social actors influence decisions to either keep or destroy fetuses diagnosed as disabled and what are their dominant attitudes?

2 It is a notorious fact that a lot of parents give up on keeping their child, expected healthy, but born with disability. It is well documented, that the adopting or fosterage rate of disabled children between 0–6 years, is lagging behind the rate of non-disabled children. At the same time, there are families those specifically want to take children with disabilities into their families. The Hungarian Child Protection Act – according to the modern family image – does not allow from 1st of January 2014, that children under 12 years get into institutional settings. At the same time, reflecting on the mentioned view of disability in the society, children with disabilities make up an exception to the rule. The regulation suggests, that their adoption is hopeless. Therefore, the governmental regulation is making a difference between the right to a family of non-disabled and disabled children, and that is contradictory to the basic human rights, and eventuates in institutional exclusion.

Goal of the research is to reveal the dominant discourse behind the regulation and to analyze the reality of society.

Our scientific results contribute to the recruitment and training programs of fosterers and adoptive parents, who consciously want to take a child with disability into the family. The expected results support the deinstitutionalization process from large social services into community-based settings.

Our research explores the life stories and decision making motivations of adoptive families, and is looking for answers of the following questions: How can those families make their decision not influenced by the medical model of disability, and why do they decide so? How do they become, either knowingly or unknowingly, followers of

the human rights model? What type of disabilities do the children have, who get into families? And, from the other point of view: why do families don't disclaim raising their disabled child in the family? What are their values and life stories? How does the wider family, the medical, social/child protective service, (special) educational system influences those families in their decision-making?

3 While motherhood is essential part of the stereotypical constructions of femininity there is a lack of data focusing on women living with disabilities. Also there is only a few gender-oriented analyzes in Hungarian disability research. The experiences and needs of women living with disabilities remain unobserved. Furthermore the Hungarian law system is not aware of the concept of discrimination by intersectional factors, thus it doesn't provide proper legal remedy for the women who are victims of multiply discrimination. While the struggle for social equality of women and men induced significant results in the 21st century, the situation of women living with disabilities barely changed. They couldn't achieve the same degree of political, cultural, social equality that the so called able bodied women won for themselves (USAID 2014; Connell, 2009).

Women living with disabilities are deemed to be asexual or hypersexual, dependent, in need of care or inappropriate to raise children, so in many cases their right for parenting or forming a family is denied (Llewellyn et al. 2003, 2010; Mayers et al. 2006). Violations of reproductive autonomy appears in many different forms: forced abortion, forced sterilization, limited access to supported reproductive technology and to the connected healthcare services, lack of information about sexuality in a broader sense and about issues related to childbirth and parenting (Steele 2008; TASZ 2012).

Desexualisation of the body of women living with disabilities is coming from the fear of the potential fertility of the deviant body. The birth of a child with disability appears to be a threat against the existing social norms. The forced sterilization or the selective abortion is the legitimization of the eugenicist interpretation as if they were their means of self-protection of society.

There are numerous obstacles in transition to adulthood of people with disabilities, especially of people living with intellectual disabilities. Among these obstacles the ones created by society have tremendous effect. The 19th article of the UN Convention on the Rights of Persons with Disabilities is focusing on independent living and community inclusion. There appears an expectation to society to provide the frame of transition to adulthood (UN 2006).

The criteria for social adulthood in general have become plastic. Transition to adulthood is getting more and more delayed to be achieved. In addition there is a great need of re-interpretation in the case of people with intellectual disabilities (Vaskovics 2000; Murinkó 2010). In their adulthood it is particularly important to use supported decision making in their lives and in their environment. Legal analysis is required for this. There is a wide range of Anglo-Saxon literature and also a number of good practices about supported decision making (Bach 2007a, 2007b). We are going to process these in terms of the ability of decision making in transition to adulthood.

Questioning the parenting ability primarily affects women living with intellectual disabilities. For them, sexual and reproductive health services are barely accessible. There is no available education in accessible language for them about childbirth and parenting. However we know from international research, that the child's well-being is not necessarily dependent on the parents' abilities and experience. Consequently, the intellectual capacity alone is not the main indicator of a successful parent grounds. Previous researches have shown that the major differentiating factor in the biography of people living with intellectual disabilities is the form of housing (with families, in big

institutions or community housing) (eg., Katona 2012). We don't have information yet about how and in what extent parenting is integrated in different forms of housing and what kind of possibilities and barriers appear.

We assume that we will find the less external barriers in the community-based housing in connection with the parenthood of people with intellectual disabilities. The chances of becoming parents depend heavily on the attitudes of key people around the women living with disabilities. In the preparatory phase of the present research our team suspects that obstructions of the parenthood of people with intellectual disabilities are caused by the helping attitude which complaints the dominant disability image in society. The opposite attitude that promotes the parenthood of people with intellectual disabilities is the supporting human right approach. In this part of the research we explore the differences in the process of becoming parents in the different housing forms. We examine what possibilities and barriers appear in the parenthood of women and men living with intellectual disabilities in the different housing forms.

Hypotheses

1 Ultrasound and other control techniques expand the arsenal of exclusive practices by making it possible to observe and normalize the body of the fetus.

Due to the normative and exclusive nature of scientific knowledge a huge pressure is put on expecting women after the positive diagnosis is arrived.

While the responsibility rests with them, women's autonomous decision making is largely limited by the pressure of society. Cultural narratives are alienating the mother's body from her fetus.

2 Significantly less children with disability between 0–6 years, are adopted and placed-out to fosters, than non-disabled children. Due to the operational mechanisms of the service system, the fosterage dominates over their adoption. This is, because of the dominancy of the medical model. Families, adopting and fostering a child with disability, are materially different from those, who take a non-disabled child into their family (parents' qualification, family structure, values of the family, etc.).

3 Barriers of transition to parenthood in the case of people with intellectual disabilities in institutional frame are defined by external rules. If they live in families the family treats parenthood as a taboo. In this aspect community-based housing forms are the least restrictive. Women are more affected by the denial of the parenting right. The possibilities of transition to parenthood are significantly dependent on the attitude of key people (professionals, parents, etc.). The obstructions of the parenthood of people with intellectual disabilities are caused by the helping attitude which complaints the dominant disability image in society. For them, sexual and reproductive health services are barely accessible. There is no support available in accessible language.

Methodology

In general terms:

– descriptive method will be used in order to summing up the results of Critical Ds and Feminist DS, frames of the legal regulation and main findings of disability history.

– both qualitative and quantitative methods will be used,

– wherever it is relevant we shall analyze professional protocols and statistics too.

1 Writing up and analyzing narrative interviews with 20 women (ten who decided to have an abortion after their fetuses were diagnosed as disabled and ten who gave birth to their children regardless of diagnosis)

2 We reach the families of our sample with snowball system, but we also use databases of NGO's, if possible. Families who have a child with Down Syndrome, can be entirely reached through their Facebook-group. In this case, we pursue a full debriefing with the method of a questionnaire. Also, we make narrative interviews with 15 families. We explore the impact of the medical and human rights model through document and content analysis in policy documents, financing models, educational programs. We do a secondary data analysis on statistical data and relevant publications, as well. Also, we organize 7 focus groups, 1 in every region, with the relevant actors of the process.

3 Transition to parenthood (3): we use qualitative research method (semi-structured interview) (Kvale 2005), thirty-two persons with intellectual disabilities between the age of 30–40, both gender equally represented. Half of the samples are parents with intellectual disabilities, half are childless but fertile adult. If necessary we use alternative and augmentative communication tools (Brewster 2004; Cambridge and Forrester-Jones 2003; Barthel 2004). Primary analytical focus is the housing type (institution, community-based, family). Interviews are made with key persons too. In the absence of a descriptive list of all population we use expert sampling and snowball method. The interviews will be processed with thematic analysis and with Atlas ti content analysis software.

From Equal Opportunities to Taygetus 2014

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György Könczei[1]

New Examples and Approaches in Methodology for the Writing of the History of Disability

1. Introduction – the contextual framework

1.1. Discard or hold in high esteem?
A specific vantage point in research efforts in the context of the history of disability

In this paper our scrutiny regarding the history of disability aims to undertake the reconstruction of *patterns perceived in the context of both the acceptance and exclusion of persons with disability.* The continuous revisiting of this topic, broken down to research-related questions formulated time and time again, is an essential ingredient of the research effort, due partly to the changing components perceived in the development of society, partly to new findings rooted in the nature of science in development. The primary focus of our paper is related to specific methodological issues in the context of the history of disability.

1.1.1. A social issue to provide the background to our research effort

The social issue which necessitates the invocation of the history of disability as a vantage point to be provided – a background, as it were, to the whole concept of research – is *the oppression of persons with disability* in constantly changing forms at various epochs throughout the history of social as well as cultural development. This spectacularly visible phenomenon justifies the need for scrutiny while providing a context for the everyday relevance of that issue.

1.1.2. Our research-related question

The focus, in a nutshell, of our interest is this: *does social development point to the strengthening of the trend reflected in the acceptance of people with disabilities* (as is suggested by Kálmán–Könczei 2002) *or does the opposite seem to be the case?* Is the term 'social *development*' relevant at all in this context? Or would social advancement, perhaps, be a more relevant notion to use (Bloch 1965)? Or could it be the case that neither term might be considered valid? At the same time, our research-related question is not pertinent from the perspective of social philosophy; it

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is empirically determined by facts which, in the course of everyday events, both affect the lives of and inflict suffering on people with disabilities.

1.1.3. Our hypothesis formulated during our historical research

Our hypothesis based on previous works related to the history of disability (Könczei 1987; Kálmán–Könczei 2002; Könczei 2014) as well as relevant literature (e.g. Stiker 2007; Rose 2006; Adelson 2006; Dasen 1993; Braddock–Parish 2001; Longmore–Umanski 2001; Foucault 1988 and 1990; DHE 2007 etc.) is that *there is no such thing as linear 'development', one that is seen pointing towards an increasingly positive outcome.* Nor does the notion of 'spiral' exist in the history of disability. There have been various historical movements determining the lives of those affected by them. These movements have diverse, constantly changing patterns of *acceptance and exclusion*. Depending on specific historical periods, the patterns are different in form, providing a mixture, to a varying degree, of several so-called new models (see later in this chapter).

1.1.4. The methods of scrutiny and the notions thereof

Whether or not our research is capable of producing results is, on the one hand, contingent on the *strength of the method opted for,* and, on the other hand, on the degree to which those results are perceived to be in synch with actual facts. In what follows, a broad array of sophisticated methodological tools will be presented with the aim of penetrating both the scope and depth of the enormity of problems to be addressed.

1.) Our understanding of the history of disability allows for an interpretation according to which it is a descriptive and analytic discipline, admittedly free neither of social criticism nor its own set of values – a discipline cutting across various other fields of science.

2.) The fundamental principle applied in our scrutiny is the premise that the history of disability is the history of people with disabilities, particularly because 'man' is a term applicable only to a person with a history. That history *exists*. And because it does exit, the 'only' task to undertake through research is to reconstruct it. (Reconstruction can be achieved through diverse approaches. One such approach is to be presented in this paper). With all its initial results, our reconstruction effort laid out in this chapter does not claim to be more than a *fragmented* sort of achievement.

3.) If reconstruction is undertaken by looking back on the lives of people who lived sometime in the past, a historical view of this sort cannot be conveyed without including human figures, faces or destinies. By applying this *face-centred* (i.e. story-centred) method, we follow in the footsteps of Lyotard (1984) who replaced the traditional notion of history and the well-known, chronological etc. interpretation of history with *stories* by harnessing the findings of hermeneutics and post-structuralism. If, for example, we know that those who are oppressed are voiceless – as was explained by Gayatri Spivak: Chakravorty 2006 – the reconstruction of their voices will be undertaken from their lives and destinies (see, for example, Hottentot Venus later in this chapter).

4.) Stories about individuals or 'faces' are written, whenever possible, by following Hermann Gunkel's principle of setting in life *(Sitz im Leben).*

5.) By following Marc Bloch's teaching, 'throughout our research, in the dusty atmosphere of archives and the silence of museums, it has always been the person who once lived that we keep looking for'.

6.) While conducting our historical examination, the compartmentalization of our findings for the purpose of meeting the needs of all-inclusive development patterns should be avoided (Kámán–Könczei 2002).

Throughout the OTKA research, the 6-point methodological summary above has been the guiding principle for the historical aspects of that research.

Top of the list among *fundamental items of terminology* is the notion of *disablism*. It is an all-inclusive term to cover phenomena such as exclusion, expulsion, disability-based discrimination, negligence, abjection etc. It refers to the innocence of the person affected, while underscoring the *role of the social setting*.

The second fundamental terminological item is *models*. The most important models of disability are: the moral model, the medical model, the human rights model and the social model. Based on Könczei–Hernádi (2012), we understand them to be cognitive, thought-generated constructions which, in the course of history, are guidelines for thinking and acting in the context of our subject – disability and people with disability.

There is a third, albeit not very often identifiable fundamental terminological item among the initial research findings: *Weltanschauung,* 'world view', a word of German origin. In our case it provides a backdrop for historical observation. Certain phenomena with particular characteristics, partial processes and faces will, at some point in the future – not during our current research, though –, become part of the existing timeline elements.

2. 'SMALL PEOPLE' – AND MODELS

2.1. The dwarf syndrome

2.1.1. Changes in the role of the dwarf

Dwarfish people (the valid term used today is *people with a short stature*, sometimes referred to as *pygmoid people*) are probably the most *abused, most exploited* human figures in social history. The roots of stereotypes perpetuated in connection with these people are so deep and so easy to reproduce that they have, over long periods of history, continued to exist in a largely unchanged form. As has been the case many a time – cloaked in a variety of roles and changing attitudes – what we have *here* is the body of a human being; the interactions between a peculiar human body and the functioning of society.

Here is a list of the typical roles of pygmoid people in history:

circus act, entertainer, clown (a role often assigned to them during various periods in history);

object (e.g. a valuable property, an object of sexual gratification, a sports instrument in an attraction called *midget tossing,* which continues to be in existence even in the 21st century – see further details of this later);

miner – due to small body size;

smith, craftsman – particularly in northern mythology;

evil demon or its opposite: exorcist (also in the form of an amulet);

servant, slave;

mythical figure;

hero of a tale (e.g. Tom Thumb or the Seven Dwarves);

character depicted in works of fine arts, e.g. in paintings by Van Dyck, Velázquez, Toulouse-Lautrec, Pablo Picasso;

or characters depicted in various literary works (by Jonathan Swift, Walter Scott, Edgar A. Poe, Charles Dickens, Par Fabian Lagerkvist, Hermann Hesse, Günther Grass, J. R. R. Tolkien and others);

and occasionally featuring in films as a hero or character: The Wonderful Wizard of Oz, Snow White and the Seven Dwarves, The Hobbit, Twin Peaks, Freaks, The Station Agent, The Tin Drum, Smurfs etc.

2.1.2. Discrimination against people with a short stature and the imprinting of its effect in the course of history

Ancient Egypt

For people like Seneb the dwarf, (for further details, see Kálmán–Könczei 2002, pp. 35–37), the prestige is derived from the dwarf gods of the era as several of their gods (such as Ptah-Pataikos or Ptah-Sokar) are the depictions of the Creator God Ptah from different epochs. The power and force of God is symbolized through depicting him sometimes either with a scarabeus on the head or standing on two crocodile heads (Dasen 1993).

God Bes, the dwarf god and household deity that protected mothers, women in labour and birth, produces the same effect. This makes it easier to understand why Seneb, despite – or maybe *because of* – his diminutive human body, held twenty various titles (Dasen 1993, p. 127). As a court employee he held various offices. Moreover, he had clerical funcions as well.

In a publication, archeologist Zahi Hawass, finder of the statue of the dwarf Perniankhu, the *royal entertainer,* proposed a theory in connection with Seben. The statue dates back to the Fourth Dynasty of Ancient Egypt (2575–2467 BC). He was described as being 'the king's dwarf, Perniankhu of the Great Palace, who was prepared to entertain his Master every day' (Hawass 2010, p. 26). The assumption established on the basis of research findings in connection with the chronological proximity and the nearness of funeral sites is that Perniankhu might have been Seneb's father (Hawass 2010, p. 88).

Another source from Ancient Egypt is the Instructions of Amenemope, son of Kanaht, from around 1100 BCE. Chapter 24 (01.03) reads:

> '01 Do not laugh at the blind man
> 02 Do not tease the dwarf
> 03 Do not cause hardship to the lame'.

In the ancient Jewish society

the following was part of the duties of priests: 'No man […] who has any defect, may approach to offer the bread of his God […] a blind man or lame, who has marred face or any limb too long, a man who has broken foot or broken hand, or is a hunchback or a dwarf […]' (Leviticus, 21., 17–20).

What people with disabilities were denied in that culture and period was probably the most important social function. If the current volume is to view these phenomena from the vantage point of disability studies rather than cultural anthropology, it will be difficult to find arguments to prove that a ban of this kind is non-discriminative. What is known today as *ablism* – the dictatorship of ablism (see for more details in the following chapter) – was, apparently, the driving force behind this sort of

prohibitory attitude. However, a very serious consequence, its *effects on history,* can be attributed to the ban itself as there is no reason to assume that if a book is used for several thousand years by successive cultures and civilizations (the European, so-called Judeo-Christian culture), one of its fundamental contentions will have no consequences at all.

That would be a wrong assumption, because *the effects on history* are to be seriously reckoned with – they constitute a perilous *paradigm* which *inculcates into our perception of history* and into various segments of successive European cultures and the entire European civilization the idea, formulated in different languages, that *this not only can but must be done*. Here we need to anticipate one of the key findings of the historical aspects pertaining to our research: *The dominant discourse in a particular era does not come into being without antecedents. That being the case, the discourse itself can only be shaped with immense difficulty, given the fact that it is rooted in the effects imprinted and even engraved on top of one another by earlier historical periods*.

The institutional aspects of the freak show

The 'engravings' from various historical periods became even deeper during the first half of the 20th century – the period of *freak shows and picture postcards* – inflicting further damage on what has been turned by this post-modern age into a largely predestined future for dwarves. A woman with a diminutive body, somewhat vestigial hands and oddly shaped legs, not only became an *item on display* in a show during the World Exposition between 1939 and 1940 in New York City, she was also 'commercialized', her photograph having been sold as a picture postcard. The phrase used in the caption included the word 'sweet'. She was described as 'Mignon, the penguin girl'. A thought-provoking circumstance is the fact that she had by then reached 30 years of age, i.e. she was no longer a girl. Another interesting fact is that *no name was used* in referring to her. In addition to what Gayatry Spivak's works have taught us – see an earlier part of this chapter – i.e. that the oppressed are voiceless, here is a new conclusion to be drawn from the history of disability: very often they do not even have a name; there have been examples, particularly in some institutions, of names being replaced by *numbers*. These people are often called by that number, not their real name. Even their graves have that same number on them. As a footnote, the name of the woman in the above example was Ruth Davis. She was born in 1910 and is known to have been married twice. She had a son and is said to have died in 1960.

At that time, thousands of people lived a life similar to that of Ruth Davis, having to feature in freak shows and be shown on picture postcards. In addition, this period ended with the emergence of fascism and the outbreak of World War II, which *deepened those historical engravings* even further: in the 1940s Mengele, the infamous physician, one of the death factory masterminds and an aficionado of experiments, went into extreme lengths in performing both his experiments and his research by selecting the 'dwarves' from all over the Nazi empire (Koren–Negev 2005). Other historical imprintings, which had an effect on science, should also be noted. Other examples from these have also been drawn in this chapter. As a result of the 'protection' of the human material selected for Mengele's experiments, seven dwarfish people of Hungarian nationality – the entire Ovitz family – survived, which can be put down to mere luck. Another twist in the story is that one of the survivors, Perla Ovitz, bemoaned the death of Mengele. (The story is recounted by Barbara Duncan in the German language documentary entitled *Liebe Perla*).

The only reason making it possible for medical experiments to be performed on dwarfish people, while barring such experiments from being conducted on *humans,* was the assumption that pygmoid people were not humans. The fascist mindset was similar in eliminating persons with an intellectual disability and those with a psychosocial disability – a phychiatrical type of disorder – in the course of *Aktion T4* (see more details on this later in the chapter on adoption).

3. Women become sinful human beings – an accusation they cannot rid themselves of: cardinal points in the ancient and medieval narratives of adoption

3.1. Abandoning newborns

The Second Book of Moses – Exodus 2:3 – describes events that are fundamental in the Judeo-Christian narrative: the infant Moses is laid out in a papyrus basket by his mother. In this case the *imprinting* of *historical effects* mentioned earlier on is a phenomenon anticipating a course of action – with or without a basket – for people living in future societies as a *possible* and *valid* option to follow.

Based on ancient Greek traditions, historical imprinting carries with it the conviction that children with serious disability are *not to be considered human beings* (see later in this chapter). In this chapter the *effects of imprinting dating back to the Middle Ages* should also be noted. Those effects will invariably become part of the dominant discourse in future historical periods.

Thus in the ancient world of Greece the symbolic role of an institution was assigned to Taygetus. The following excerpt is by Plutarch, the famous biographer:

'Offspring was not reared at the will of the father... if it was ill-born and deformed, they sent it to the so-called Apothetae, a chasm-like place at the foot of Mount Taygetus in the conviction that the life of that which nature had not well equipped at the very beginning for health and strength, was of no advantage either to itself or the state' (*The life of Lycurgus* 16, 1–3).

Plato's attitude also falls in line with the above approach: 'those [....] who are born defective, they will properly dispose of in secret, so that no one will know what has become of them' (*Republic* 460c). Aristotle, the scholar, equally favours the practice of disposal: 'no deformed child shall be reared [...]' (*Politics* 1335b).

The relevant practice in Ancient Greece is summarised below in the following manner, based on Kálmán–Könczei (2002, pp. 40–42): *Before tossing a newborn off a cliff or exposing it,* the infant was presented to the father, who could decide to consider it unwanted. The custom of infants having to be examined by leading elder Spartans form the child's tribe was a practice observed mainly in Sparta. The custom of newborns being *tossed off cliffs or being otherwise exposed* was maintained despite the fact that the burying of the dead was an important ritual in the culture of Ancient Greece. (see, for example, *Antigone* by Sophocles). It should be borne in mind that being unburied is the harshest punishment of all; the souls of the unburied dead will never rest, therefore they will keep roving to the end of time. It is clear, therefore, that Ancient Greece was a civilization which considered newborn infants with a disability inhuman.

Ancient Greek culture, with all its outstanding, rich legacy that includes Acropolis, the Colossus of Rhodes, its brilliant philosophical questions, the institution of democracy

and the Septuagint, also left is mark through the effect it had on successive periods in history in the course of social development via the phenomena mentioned above.

3.2. Infants exposed and replaced, the witch's bastard i.e. the infernal origin

The Middle Ages, while being shrouded in mythology, was a period of cool and realistic ambience, also functioning as the myth of origin that perpetuated the subject of the infant born with a serious physical – occasionally mental – impediment. This phenomenon has been recorded in the German language via the term *untergeschobene Kinder,* while in English the term *changelings* has been used. A corresponding term has also been used in the world of Hungarian fairly tales (see more details, e.g. Kálmán–Könczei 2002).

The insinuative question, naturally, is 'how could, by any chance, two mentally healthy parents with perfect bodies have a child like that?!' Either the woman slept with the devil (i.e. the child was, according to the moral model, conceived in sin), or if evil, diabolical forces – witches or the devil himself – replaced the healthy baby with some witch's repulsive offspring.

What is the message conveyed by the myths of origin, rooted in our European mythologies, regarding the beginnings of disability? The message is that the woman slept with the devil, that the *proneness to sin* of the 'unruly, uncontrollable female body' is to blame for this undesirable outcome, and that serious disability is not human, therefore its product cannot be human, either.

6. Summary

The Achilles' heel of the historical approach described in this chapter is, undoubtedly, its methodology. As the objective of the current historical review is to have a clearer view as well as an overview of all unknown historical periods, to approach the current methodology with a *critical mind* and to provide it with an additional *supplement* is of crucial importance. (An example for achieving the latter aim could be a chronological, pictorial summary – if this can create a clearer view – even if it cannot be published for technical reasons.) Most former methods thus clarified, along with those to be introduced as new ones, are to be considered new when compared with studies so far completed on the history of disability. During the 1990s and the early 2000s the first attempts to show human *faces,* i.e. the fates of individuals were made. Now the first additional steps have been taken by reconstructing some new faces such as *Saartjie Sawtche* (Sarah Baartman) the French boy from Lacourt, Randolph Silliman Bourne, Virginia Woolf. A greater depth of elaboration regarding the story will become possible in the future, when all the research findings will be included in one, more comprehensive work, in which previous errors will be rectified. This approach will offer a new methodological alternative, now at the embryonic stage: the juxtaposition of female faces – which have become faces with disability, due to the workings of society – with male faces, i.e. a more intense combination of feminism as part of the history of disability with the notion of gender, used as a complementary methodology.

A note on the question 'development or progress?', asked by the philosopher Ernst Bloch in 1965: findings so far have not really added a lot that question. What we do know now is that the history of disability is not a *story of salvation,* in which history, having encountered minor hitches along the road, is seen progressing towards the

glorification of people with disability and equal opportunity of a kind that is more complete now than previously. Based on the initial research findings, there is a strong likelihood that neither formula describing either the road *from Taygetus to that of equal opportunity*, or *from equal opportunity to Taygetus,* can adequately describe fundamental operational alternatives or basic stages in development. (Findings in other specific fields of research might, however, point to a different conclusion). It appears to be the case, though, that disability studies, together with the social model and the human rights model, seem to be strong enough safeguards to reduce the possibility of the future emergence of oppressive tendencies, unlike the hundred years from the recent past.

One of the findings of the current research is the introduction of the dwarf syndrome as a first step. The historical perspective is accompanied by other elements which are of relevance today, such as *dwarf-tossing* or *catch a dwarf*. Their significance lies in the fact that they underscore, yet again, the significance of *historical imprinting and historical engravings* – the subject of this chapter – as well as the *effect that they have on the dominant discourse*. In the 21st century, dwarf tossing is an occasional sports event held in some Anglo-Saxon countries. Strong men grab dwarfism-affected persons wearing protective helmets by the waist and by another spot on their bodies, then throw them parallel to the ground – like an object or a javelin or a shot put by a shot putter. With the crowd cheering, the winner is whoever has the longest throw. Bets are also allowed.

Catch a dwarf is an event with German origins. Rather than tossing dwarfism-affected persons, this event is held at parties where participants are invited to chase them (the event is known as *Liliputaner Action* in Germany). At one such party in 2013, the first prize to go to the winner was a plasma TV. The winner had to catch and lock up the 'dwarf'. A dwarfism-affected person was injured during the event, which caused a scandal.

Historical imprinting and *its effect on the dominant discourse* is to be interpreted in the context of CRPD as these two phenomena offer an answer to the question how it is possible to organize 'dwarf-tossing' and 'catch a dwarf' in states that have ratified the Charter of the United Nations. *Old elements of the dominant discourse, which have been present for hundreds of years or – in our case – thousands of years, appear to be stronger than new ones*.

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'Prenatal Screaming' Decision-Making Following a Prenatal Diagnosis of Down Syndrome

Abstract

Within the framework of the OTKA K111917 research entitled 'From Equal Opportunities to Taygetus?', we examined, through narrative interviews, how mothers took a decision after learning of the positive Down Syndrome diagnosis of their foetus, and who and what events influenced their decision to go on with their pregnancy or not. In our article, after a focused analysis of the narrative interviews we conducted 10 women about their life, our aim was to draw attention to the complexity and stratification of the social context and to pose questions. Our goal was to reveal the cultural background of the decision-making and the pieces of information which seem simple and unequivocal at first sight, in order to gain a clearer picture of the social and medical attitude and knowledge that surrounds mothers pregnant with a Down Syndrome foetus.

Key-words: feminism, disability studies, foetus diagnosis, power, risk, decision-making

1. Introduction

As part of the OTKA research, we conducted narrative interviews with six women who opted for abortion after their foetus had been diagnosed with Down Syndrome and with ten other women who decided to give birth to a child considered disabled. In this study we analyse only the interviews conducted with the women who decided to go on with their pregnancy. The concepts of prenatal screening, motherhood, the female body and normality are analysed within a feminist interpretation and within the framework of disability studies, since we are interested to find out what factors and/or people could influence women's decisions to continue with their pregnancy.

In the social discourse related to Down Syndrome different groups participate with sometimes overlapping or contradictory narrative content. Our current knowledge about Down Syndrome derives, on the one hand, from the knowledge and experience of people who live with the syndrome, their families, relatives and friends and on the other hand, from the scientific knowledge of professionals in different fields, health care workers, special education teachers, social workers etc. They use different discursive categories and deal with different contents of the lives of the people concerned. Besides, they also know about the economic, political, legal and historical dimensions of the life of the people with Down Syndrome, which is also part of the discourse. Apart from this, disability studies offer a new framework to structure and critically interpret the knowledge and therefore our study has a multi-disciplinary character as well (Yong 2007, p. 5).

The research tries to answer questions on the basis of critical feminist theory of disability studies and by conducting and analysing the interviews with women whose life circumstances were described above. When interpreting them we make use of the

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theories of anthropology, sociology, history and law, as well as the results of genetic diagnosis. The research and analytical method considers the life-story narrative as a discursive event and focuses on the continuous changes of the narrative subject, whilst at the same time dissecting the issues of reproduction, the evaluation and devaluation of female and disabled bodies, the parameters of normality and disability and the complexity of social constructions.

We focus in this study, amongst the various factors influencing the decision, on the reaction of the health care system, the relevance of the information provided at the moment of establishing the diagnosis, as well as the health of the foetus.

After formulating the research questions we briefly introduce the methodology and the sociological features of the interviewees involved in the study. In the following chapter we try to present the process of prenatal diagnostics and the different layers of its social interpretation by analysing the power dynamics of the agencies participating in the process. We draw attention to the doctors' ambition to exercise power and control in the Foucault sense during the scanning procedures and to the technicalisation of the pregnancy. We point out the changes in the mother's role and the possible impacts of the medicalisation of pregnancy or motherhood.

After describing the attitudes towards Down Syndrome in Hungary and the corresponding changes in the statistical data, we present the experiences gained from the ten narrative interviews in relation with the prenatal diagnostics and we compare it to the international experiences within the context of feminist disability studies literature. We also mention the Susan Wendell concepts of the 'healthy disabled people' and 'unhealthy disabled people' and their appearance. In our paper we talk about the experiences and decisions unfolding from the narratives. And finally we summarise our results and point out the layers of analyses of the present study which will be published in the future in separate articles.

2. RESEARCH QUESTIONS

Important questions of feminism are echoed in our research questions: how the subject is constituted in the Foucault sense, how power, knowledge and resistance create subject compositions? What is the balance between inscription, subordination and agency? We pose the question of what it means to a mother to expect a child regarded as disabled. What are the social/cultural factors determining our concepts and practices related to motherhood, a normal foetus, a high-risk pregnancy or social commitment? We ask the question of what is considered risky, normal, disabled or responsible behaviour.

As to agency and active subjectivity, we should mention that we do not consider agency as a normative concept, but much rather a dynamic force line in a given context. We depart from post-structuralist theories which profess that the individual is both the object and the subject of power, so agency exists only if there is a continuous movement between choice, inscription, active subjectivity and subordination, or only when it is possible to change the rigid power structure or re-interpret the normative experiences and attitudes.

All this happens in a complex discursive space where the agency of self-representation can exist only if the majority society 'listens' to the stories of women and is capable of interpreting these as a desire to break out from the power structures. In order to achieve this, it is necessary to widen the discursive space and one of the possible methods is to apply narrative interview-techniques through which we can listen to the voice of those affected.

In our research we were interested in finding out who and what events influenced women in their decision-making, whether the health care system provided them with sufficient, relevant and neutral information about Down Syndrome, the life of people living with the disability and what the available services are in our country? Our goal was to explore, understand and demonstrate the macro-level cultural and social mechanisms and the cultural context which could play a role in the decision-making of the expecting mothers. Our primary research question was in which cultural discourse, what information, attitudes, expectations and ideas influenced their decision of either continuing with or terminating their pregnancy, i.e. how the interviewees' stories relate or converse with the social discourse.

We would like to emphasize that neither as researchers nor as private individuals do we have the right to judge the narratives presented by the women, so we do not label their story, nor do we give advice, make proposals or pass judgements. We are merely gathering social reflections which point to the complexity of the questions and their cultural determination.

3. RESEARCH METHOD AND RESEARCH SUBJECTS

In our research we have used the so called narrative interview technique. Narrative analysis is a collective concept, which contains many methods of cognition. This is the least directive methodology of all the known interview techniques. Whilst the presence, gender, age and behaviour of the interviewer has an impact on the situation, it influences the thread of thoughts or use of language of the interviewee less than in the case of pre-formulated questionnaires (Creswell 2007; Curie 1998).
During the interview, after getting informed consent, we explained to the interviewees the main subject of the study and asked them to tell us their life-story. Thus the interviewees told their story in their own words and in the order and style that they considered important. In the second stage of the narrative interviews, after having listened to their life-story, we asked them to elaborate on some aspects of the elements and events they did not detail. With the consent of the interviewees we recorded the interview which later was transcribed (Hernádi–Kunt 2015).

Although within the framework of this study the interviewees became a group, the starting point of the research was that the interviewees were a complex and loose group of different women with different identities. We got hold of the interviewees by placing adverts in social media and also with the help of key people dealing with the subject. Participation in the study was always voluntary and anonymous. Our study did not gather the narratives of women living in extreme poverty or in multiple deprivation, but we consider it very important to carry out a similar research about this segment of the population, where the complex impact of intersectionality is even more marked. The interviewed women were not a homogenous group based on where they lived or their level of schooling, age, or marital status. Those invited for interview were open and interested women with good advocacy skills who were happy to make a statement, and for many of them it was not the first time that they had spoken about their life-story.

For each of our interviewees the Down Syndrome was established during pregnancy, except in one case where another type of health disorder was diagnosed, yet the baby was born with Down Syndrome. There was one woman among the interviewees who, after having learnt about the Down Syndrome diagnosis, decided to continue with her pregnancy, but in the end the baby did not have Down Syndrome as far as she knows. We regarded these narratives as nevertheless relevant for our

research, since we were investigating the circumstances of decision-making and in the case of this woman (whose child was not born with Down Syndrome) and who took her decision believing that the child would have Down Syndrome. We also included the other case, where the mother was informed about another type of disorder yet she decided to continue with the pregnancy even if her child would have to live with Down Syndrome. We also conducted an interview with a woman who took such a decision twice, since during two pregnancies she got a positive Down Syndrome diagnosis, yet she decided to go on in both cases, although in the end it turned out that only one of the children was born with Down Syndrome.

4. POWER STRUCTURES IN PRENATAL SCREENING

Throughout the whole research, and also in the current paper, we felt the need to understand the experiences of these women. Our research widens and surpasses the stereotypical definitions, construction and complexity of womanhood, motherhood, normality or disability. This construction and complexity can be most strongly perceived in the personal experiences narrated by the mothers. This article, therefore, gives 16 literal quotations from the narrative interviews.

Our research aims to show the similarities and differences of the self-representations unfolding from the narratives provided by the interviewees. The analysis of the interviews brought to the surface several similar features, but also some biographical strategies that differ substantially from one another. The similarities derive from the embodied experiences and the cultural narratives of motherhood, disability, femininity and normality. The differences are due to the individual lives and the variety of interpretations. The diversity of narratives outlined the complexity of the issue, whilst the *personal* and *cultural* aspects outlined the meeting points as well as the patterns of the power field.

The narratives of the interviewees acquire a political role if we interpret them as a method to review the cultural and social norms. Although the space of discourse in which the narrators place themselves is relatively narrow, their narration confuses and breaks down the established concepts of power.

According to Foucault power is a mechanism of disciplinary power. And this disciplinary power is achieved by surveillance. This means that the power becomes efficient by the tool of surveillance. There is no need for external control, because of visibility an internal urge makes us docile disciplined and normal citizens. And those who fail to comply the rules are stigmatised as irresponsible and dangerous to the society (Foucault 1990; 1982).

> '[...] the attitude of the health care workers. That was very bad. They tried to label us as irresponsible parents, because we were not ready to undergo the intervention. Whereas I think that we took this decision consciously. And everywhere we just got this, the worst. Whether we knew what it meant to have a disabled child and how horrible it would be.'

The technology of power described by Foucault infiltrates our everyday life: power is gradually extended over our bodies. The body is the object and target of power and the place of resistance at the same time. The supervision and control of the body is exercised in the institutions of the dominant ideology and prescribe what happens in everyday life to our body. We do not notice it and it influences every area of our life.

But when Foucault writes about docile bodies, he considers the body as if there was only one type, as if there were no differences between the embodied experiences of men and women. He does not reveal the disciplinary practices and activities which impact only the female bodies, forcing and shaping them in a way that they meet the social requirements.

In our analysis, apart from the linguistic discursive space, we focus on the embeddedness of memories, because although memories change and transform over time, they are always embedded and rooted in the body.

Our starting point is that by now the body has become the metaphor of danger and worries, 'it has become a property the ownership of which is a responsibility' (Csabai–Erős 2000, p. 142). The responsibility of the individual has become more and more pronounced in the acceptance of discipline, control and the avoidance of risky behaviours.

By discipline we mean the micro-mechanisms of power techniques of 'surveillance' (e.g. ultrasound exams) or *objectification* (e.g. doctors considering the foetus an object), *normalisation* (e.g. genetic screening) and *control* (Foucault 1990; 1982). In this situation the female and expectant female and foetus bodies become subordinated. We are interested to learn how reproductive practices under the auspices of bio-medicine influence the thinking and the behaviour of the individual.

Discipline means mostly the discipline of the female and pregnant female bodies. By discipline we mean the power dynamics that avoid risks, objectify and control pregnancy and which surround our ideas related to normality, femininity, ability, disability or a normal society.

> '[…] there are some minor anomalies, which can be anything, because there is a kidney pelvis dilatation. That is possible because he is a boy. And they said that we should keep on checking him [...] and so they did the ultrasound here and there, left side right side, I don't know.'

Observation and monitoring are partly due to the fast development of bio-medicine and technology. Medical science is capable of mapping the human genome, so it is possible to determine precisely the degree of our normality even before birth. In Hungary foetal tests are available and in some cases also compulsory. (Takács 2015)

Practices to discipline the female body and the concepts around normality can be interpreted only within a given cultural and social context. We want to analyse and understand this context. It is obvious to us that, e.g., the medical-biological decisions related to disability (what type of disability is tolerated in the foetus, what are those types where much effort is invested in order to eliminate it, in what cases is it considered important to intervene etc.?) are taken in accordance with cultural values.

'It is in the interest of society to have productive and healthy citizens, and therefore testing and termination of potentially impaired or unhealthy babies are required' (Shakespeare 2014, p. 130). Scientific knowledge has an exclusive and normative character, so there is a huge pressure on expectant women after the diagnosis. The responsibility to decide is theirs. But how independent is their decision-making under the pressure of the society?

> '[…] when they realised it, then many people blamed me, saying that everything is because of me […] anyway, always, before and during the pregnancy and also after birth, if a problem arose, I alone was responsible for that.'

>'And there are those compulsory tests, where you are supposed to go. Now, for example, I would probably not go.'

Health tests and services, as well as discourses qualifying a behaviour as risky, are the way in which discipline is exerted by society. These represent everything that society considers fit, normal, risk-avoiding and healthy during the pregnancy with regard to eating, exercising and behaviour.

This aim and worry is represented by the ever growing menu of prenatal tests offered. This is what Ettore writes about the issue: 'The workings of reproductive genetics expose the long-standing feminist unease that the medicalisation of reproduction, pregnancy and childbirth has more often than not been against the interest of pregnant women, making them objects of medical care rather than subjects with agency and rational decision-making powers' (Ettore 2002, p. 20). The appearance of genetic screening continues to raise new and important questions related to disability, normality, autonomy and valuable life. Tremain, making use of Foucault's bio-power concept, establishes that screening techniques have an excluding and normalising function. He states that the power 'ensures that impairments are generated in utero' (Tremain 2006, p. 36).

Feminism and feminist disability studies tackle questions of the maternal body too and how that shapes identity. From Foucault's perspective motherhood, as a social institution of key importance, strengthens subordination, but it also offers the possibility of self-definition, empowerment and agency. Motherhood is an accentuated part of the stereotypical construction of femininity.

The sanctity of motherhood, the abledness of the nation and the new technologies are organically interlinked with control, supervision and normalisation. One of its pronounced manifestations is the medicalisation of pregnancy. The presence of medical gaze and the controlling attention permeate the days of pregnancy. To be sure of the perception of your own body has become a risky behaviour, which takes less account of medical results (Sawicki 1999; Parens–Asch 2000; Tremain 2005; 2006). It has become natural that women are referred for more and more tests and screening, whilst mothers' intuition and experience are becoming increasingly marginalized. Erzsébet Takács makes reference to the belief in the omnipotence of technology: 'the pseudo-objectivity of the 'foetal image' introduces a 'normless and valueless' reference - often the only possible one - that appears in place of reality and truth, as opposed to the experiences and intuitions of women who thus become false witnesses.

The authenticity of technology creates a 'reality' and a 'truth' which can contradict the internal experiences of the subjects… childbirth has become more a technique and less something where mother or foetus are important' (Takács 2015, p. 401). As a consequence of medicalisation women trust their own competence less and less. 'Pregnancy frequently is full of worries and fears, and women's faith in their own competence of giving birth and the wisdom of their own body are utterly weakened or even totally lost among the professionals and machines, not to speak of the natural experience of pregnancy and birth' (Varga–Andrek–Herczog 2011, p. 244).

The narrative of the interviewees reveals that, in hindsight, they feel that the successive tests made it impossible for them to enjoy their pregnancy. The medicalisation of pregnancy is considered a negative practice by them.

>'Because I was expecting a baby and I was also gravid. This word 'gravid' was something grave indeed, because you need to run here, to run there, that

you are pretty old, so have this checked! And this was horrible, a disaster. I wouldn't do it like this again. I wouldn't go to half of the tests, or even less, but instead I would just watch the telly or the moon or the stars or the sun or whatever. And I would be happy about the little baby who lived in my belly. I would not allow anybody to call me gravid again, because I was just expecting a little baby.'

The medicalised system and the quick sequence of tests prevent women from a well-considered and relatively free decision, since they can always focus only on the next examination.

'There was something like this, I think, that during the second genetic examination the blood test result was on the limit. It is weird that I do not really remember now what it was exactly'.

There is a fierce discussion taking place among researchers, activists, parents and the affected concerning prenatal screenings and how to approach selective abortion. The voice of those who support technical developments and welcome diagnostic procedures becoming more and more precise can also be heard. They consider it a good thing that there are procedures that provide information about the foetus. There is an advert on the internet where mothers are fighting to get the most sophisticated tests available free for every pregnant woman. Others, on the other hand, consider these tests dangerous. They think that these tests convey prejudices against people living with a given syndrome and the message is that it is not worth living with a disorder that can be screened. They are afraid that if tests become wide-spread, the possibility of individual choice will very soon become 'social necessities' (Wendell 1996, p. 156).

The participation of expectant women in genetic screening and their chance to decide on the basis of informed consent has not been fully investigated so far. The article published by Bekker et al. in 2004 tackles exactly this question. They underline that in the UK the primary goal is to provide women with the right to take a decision about whether they want to participate in prenatal screening of Down Syndrome or not. In order to achieve this, it is important that the gynaecologist and health care workers cooperate together with the pregnant woman and provide her with the most precise and full information and that they remain absolutely neutral about the women's decision. Making reference to other pieces of research carried out earlier, the authors establish that it is the women's knowledge of Down Syndrome and their attitude towards abortion which predominantly determine their decision. Hungarian studies are in total agreement with the opinion voiced by the pregnant women participating in the British research, namely that they did not receive sufficient information during their pregnancy about what alternatives existed to the diagnostic procedures. They felt that they were expected to say yes to the compulsory diagnostic tests and later they said that they could not assess the advantages and disadvantages of taking or rejecting the tests (Bekker–Hewison–Thornton 2004).

In the UK a variety of intervention methods have been developed to support pregnant women and health professionals in the decision-making process. The so-called decision-analysis is one such tool. It is based on the perspective model of decision-making and uses the subjective expected utility (SEU) theory. The SEU claims that individuals make decisions 'by balancing evaluations of the likelihood of outcomes occurring with their own preferences' (Bekker–Hewison–Thornton 2004, p. 266). The method aims to make the individual's values and viewpoints explicit with regard to the

expected result of the decision, and to support him/her in finding the balance between their own values and the possible risks. Decision-analysis is the technique used in the UK in the process of prenatal diagnostics, but hardly any research has been done to find out its efficiency. The Bekker–Hewison–Thornton study in 2004, nonetheless, targeted explicitly the role of decision-analysis methodology in the case of pregnant women who needed to take a decision concerning a prenatal Down Syndrome diagnosis they had received. The authors also draw the attention to the possible risks of the decision-analysis method with regard prenatal diagnosis. They expressed their worries that if pregnant women are encouraged to use the method systematically in order to evaluate their decision that can constrain the decision-making process. It can increase the anxiety of pregnant women and can lead to them regretting their decision. The above mentioned research showed in fact that women using decision-analysis did not feel that the consultation was more directive nor did it give them more concern, instead the perceived risk was more realistic to them and the decisional conflict was milder (Bekker–Hewison–Thornton 2004, pp. 265–266).

Both Hungarian and foreign studies corroborate that the decision-making process can be greatly enhanced if the health care service provides conscious, systematic and relevant information and if it ensures conscientious consultation possibilities.

5. Preliminary research results

In this paper we are presenting some preliminary research results. We summarise the focused consequences of the 10 interviews we conducted with women who after a positive Down Syndrome diagnoses decided to continue with their pregnancy and keep the foetus. In the analysis we focus on the reactions of the health institutions and the information that was shared, as well as the health status of the foetus, because these are the factors that potentially influence the decision.

The number of births in Hungary has not reached 100,000 in recent years, (Kapitány–Spéder 2015) and the number of those born with Down Syndrome annually is between 150 and 170. The data of the National Registry of Congenital Anomalies (VRONY 2015) show that this number has not changed in the last 15 years. Since 1985 a prenatal test has been available to screen for Down Syndrome. According to the VRONY database the frequency of Down Syndrome, including the cases diagnosed during pregnancy, is 1.64% (MoH 2012). According to the latest data 151 foetuses were diagnosed with Down Syndrome in 2013, all 151 were aborted. In the case of the 24 live-born children Down Syndrome was not diagnosed during pregnancy (VRONY 2015).

Hungary is essentially characterized by a strongly medicalised discourse concerning disability. Disability is something pathological with deviant difficulties, it is an individual non-compliance and a medical problem. The top priority is *prevention*. When this is not possible, then *cure* and, as a last resort, *elimination*. Complementing Titchkosky's and Michalko's interpretation, this discourse defines not only disability, but also disabled people, as objects (Titchkosky–Michalko 2009, p. 4). From the medical model perspective, the concept of disability is a bad 'thing', and it is a term attached to a disabled person who functions as the object of the interventions and professional policies. Those who exercise power in this model are the decision-makers at different levels. The leading actors are the professionals: doctors, health workers, researchers, politicians and the managers of institutions. At one level, apparently the function is to correct disability and to serve people living with disabilities by minimizing the negative impacts of disability in everyday life. At another level, it is to maintain

the basic structure dominated by professionals and, simultaneously, the allocation system of finances and to attach and delegate everyday power to the professionals.

Katalin Heksch also made a declaration concerning the general aversion towards Down Syndrome: '*The truth is that these concerns are not entirely unfounded in our country. Today in Hungary, compared to western countries, parents much less willing to accept a baby with Down Syndrome, and in our country a diagnosis at the foetal stage is almost synonymous with abortion and children born with a malformation are often left in the hospital. (In comparison, for example, 70 percent of British mothers accept the birth and upbringing of a child known to be ill)*' (Heksch 2016).

The stories told by the interviewees echo the prejudices and negative attitudes of society.

> 'It is very hard to cope with the, how shall I put it, with the negative attitude towards unhealthy children. Starting from the visiting nurse, well, everybody else too.'
>
> '[…] what I felt was, yes, that they are a millstone around the neck of society. This is what you can feel. You feel it with strangers.'

One of our interviewees, as a reaction to the negative judgments, is considering leaving the country:

> 'It seemed difficult then when I took my Down Syndrome child to the playground, what will he get there? Because I was convinced that they would not look at me when I walk through the street with him, everybody will, how shall I say, will look at us with aversion. At me and at him too. I can stand it. It would not be a good feeling, but not because of my child, but because of their attitude. It would be a bad feeling if they looked at him with aversion, if I felt that the others didn't feel like looking at him. But the worst of all would be, if he sensed that too. If, for example, I took the child to the playground and the other parent dragged his child away from him so that they would not play together. How could he stand that and how could I stand how he feels. One of the solutions, my husband said, is that if he is born with Down Syndrome then let's leave the country immediately. To a country where we know that the attitude towards not only the disabled, but also towards, say, the Roma or other people with different skin colour is better.'

5.1. Institutional and professional attitudes

Though from the Professional Protocol for Prenatal Screening and Diagnostic Procedures of Down Syndrome of the Ministry of Human Capacities in 2016 it appears that during the genetic consultation professionals are obliged to provide information so that the pregnant women can make informed decisions and that the advantages/ disadvantages have to be clearly explained (MoHC, 2016). However, listening to the life-stories of the interviewees, questions arose with regard to the quantity and relevance of the information and the neutrality of health care services.

Only one single narrative mentioned that the doctor outlined both the risks and the advantages during the consultation.

> 'So he explained the difficulties too of the Down Syndrome. And he also said that it shouldn't be like that by any means and I don't know what else. He

> represented a very honest medical attitude and it did help for sure […] there they did a perfect job and they were ethical too.'

In light of the Protocol of the Ministry, the calls for screening of the prenatal centres, as well as listening to the life-stories of the interviewees, questions arose with regard to the quantity and relevance of the information and the neutrality of the health care services.

The interviews showed that on the basis of the diagnosis the probability of Down Syndrome is the primary, in most cases the only piece of information that is shared with the pregnant woman. However, there are many examples where the results are not reliable and even a high percentage of probability does not mean a certain diagnosis.

> 'The chance that the child has Down Syndrome is 1 in 40.'
> 'And then they said that the probability that the baby has Down Syndrome is 99.9%.'
> ' And indeed the nuchal fold was thicker and he held his neck as if he a had a little scarf.'
> 'In the end, according to the integrated test the risk was 1 in 430, which is considered a medium risk and in theory they proposed to repeat the amniocentesis.'
> Doctors explain to expectant women what further tests are available, as a kind of information.
> '[…] and he took out a brochure about the additional tests which would have to be paid for.'
> '[...] that I should go on to the chorionic villi, or I do not know what kind of tests.'
> '[...] the doctor did not like something at all, so he said that he recommended the amniocentesis anyway. And I should decide what I want to do, but to him this child is suspicious.'

On the basis of the narratives we can see that after having been informed about the risks, the next step for the pregnant women is to gather more information about the received diagnosis.

> 'And at that time I have spared tasks for myself. I was walking with eyes wide open thinking what could be good for what.'

They rarely get the required information from the health care system. Only in few interviews did we hear about them receiving a brochure about Down Syndrome in the hospital.
 'In that little brochure they gave us in the hospital there were specific pieces of information and also web-sites.'
From the vast majority of the interviews it turned out that during the health tests, after being informed about the diagnosis, the women did not get information about the parents' groups, or about the everyday life of those affected nor was there a way to get in touch with the families.

> 'We had to find out everything ourselves. This is not good.'
> 'It is rather shocking what kind of a chaos there is. That there is no manual about what you have to do with a Down Syndrome child when he is one month

old or two months old or what can be expected. In short, what is that you have to do?'

The majority of the interviewees had to search in order to get hold of the information concerning the support services provided by the Down Foundation or the Down Nurse. Health services did not provide them with such help.

> 'It was my husband's idea, which was very, very good, that we should immediately get in touch with the Down Foundation and talk with somebody there.'
> '[…] my husband was the one who was checking the internet day and night and read everything he could. And then he conveyed the essence to me.'
> 'We got in touch right at the very beginning… It was us who looked up the information and searched and read a lot and looked around.'

The interviews reveal that it is possible and easy to gather a lot of information quickly on the internet, but at the same time it is difficult to find your way around the huge amount of data. It was mentioned as a positive fact in the narratives that in some cases there was a professional available who gathered and forwarded the relevant information to the pregnant mothers.

> 'He sent an email which included links to a great deal of articles, saying that these were worth reading. So, he filtered the internet a little bit for us, because everything is there of course.'

Almost every interview mentions that, apart from finding information concerning the medical diagnosis, it was important to find reports from peers.

> '[...] while I was mostly reading the parents' reports, my husband read medical case studies.'
> 'And there are the personal reports, many people write blogs and post videos.'

Before the internet it was difficult to access to these.

> 'And the internet did not exist at that time. I wasn't able to meet people sharing the same fate.'

Professional literature raises the amount and content of the information as a basic question, and so is the dilemma of whether or not, in the decisive moments of our lives, we take decisions exclusively on the basis of the information that we have and led by rational criteria (Gál–Szántó 2003).

Only one of the interviewees reported that she was asked in the first place about the continuation or termination of her pregnancy. We could find only one piece among the analysed interviews where the chosen gynaecologist did not give advice or make a judgement concerning the pregnancy, not even in the form of a question: *'I am here to help and not to express an opinion'*, the interviewee quoted the words of her doctor. From the other narratives it turned out that each woman came across a physician who gave specific advice or made a proposal concerning the continuation or termination of the pregnancy. The various positions of the different doctors are reflected in several interviews.

'[…] what happened during the course of the following weeks was nothing else but whichever doctor I met, except one, everybody thought that I was not normal. They were trying to make me see that I was an idiot. And I felt in their questions that they were trying to find out whether I myself was an imbecile or not.'

'I tried to contact the people I knew about – the obstetrician, maternity nurse etc. – who I knew would relate to me normally, even if I am ready consciously to accept a disabled child.'

The majority of the interviewees said that after having taken the final decision, although previously they experienced many questions and questioning, the health staff accepted the decision and were supportive afterwards up to the moment of birth.

'After each ultrasound examination they said that there was still a possibility to take a decision. We knew that! There is nothing to decide about, we said. Then after a while they stopped asking.'

There was also an interviewee who reported having positive experiences with regard to the reactions of the health care workers after the birth.

'[…] as far as I can remember, it was damn sweet of them, they even answered the questions which can arise under such circumstances and then…that was a pretty positive experience. In the hospital too and the staff there as well. They were pretty decent, really. So, I got only good words there. From everybody, even my midwife, when she learnt about it, she came to see me right away and that felt nice.'

The question arises again and again as to how much the obsessive desire for perfection of our society allows women to take an autonomous decision concerning reproduction. In addition to the rational choice theories, we found that the socio-cultural embeddedness of serious individual decisions, the negative social perception of disability in general, the wide-spread approach that disability is a personal problem and an abnormal condition, reduce the whole question to one of personal fate, on the other hand, it is shown as an economic burden (Barberic 2013; Goodley 2014).
In this sense, can we expect neutral information from healthcare workers in a society where disability is always perceived as negative or valueless and symbolises a digression from normality and where there is a consensus with regard to what is a happy form of life worth living? (Shakespeare 2014; Saxton 2006; Hubbard 2006; Parens–Asch 2000)

'And he told me that Hungary is not set up for idiot people, he literally said that, to walk arm-in-arm on the streets with idiot people.'
'and then he raised the issue of how much burden we will place on society and on the health care service, if he turns ill.'
'And then his reaction was more or less that: was it conceived right away? Then have it removed immediately. You will have a Down idiot child.'
'[…] it was dreadful how they treated me, how they treated my baby and how they treated the other pregnant mothers. I met several mothers-to-be there and when the subject of Down Syndrome was raised they told me how they were treated. And we did not meet those who were persuaded to have

an abortion. My gynae told me when I had the 12 week scan, this is the 6%, then I said to him that I was unable to do it, that I wouldn't like to have an abortion, because I feel that I don't have the right, that a child with Down Syndrome can become a grown-up and live a happy life. Then he said ok, but this won't be like you think that he will be so cute, but a bit stupid. In this style. But this was not the worst during the pregnancy. Then we talked about it, I don't know, for half an hour perhaps about how a Down Syndrome child looks like. And he said that his IQ level would be max seventy. He won't be able to live an independent life, I will always have to be dealing with him and I won't have energy for anything else. And that I won't have energy for other children either.'

Influencing appears many times implicitly, in the form of a question.

'He immediately asked whether we want to keep the baby then? This is how he asked it. And I started to become upset already, how dare he ask this? How is it that he doesn't feel the responsibility of his questions?'

The conversation with the professionals and their negative attitude towards Down Syndrome is often evoked as something traumatic in the narratives.

'The doctor started to persuade me that I should have an abortion. This happened when […] probably before the 18 week test […] I asked the doctor to stop it. To stop this. But he repeated it three times. He practically begged me to have the abortion, because I should believe him that this won't do any good to the other child. In week 20 he asked me again whether I was sure, it wasn't too late yet to undergo it. With a baby who could be clearly seen already by the ultrasound. Whom I felt in my belly. And that I am supposed to know that we are fighting for the baby's life, so that I would not lose him. So I am not planning to take him away from me. This was one of the worst experiences. Otherwise, the doctor looked like, I don't know if I may say such a thing, but really, he looked like the Nazi leaders are depicted in films or books.'

In this case the interviewee connects the aggressive, inhuman treatment and trauma with the historical memory of genocide, torture, exclusion and humiliation hidden in the collective consciousness, this is how she strengthens remembrance itself. The hospital appears as the violent scene in the story, a memorial site by now. In order to understand this, we can use Pierre Nora's concept called *lieu de mémoire.* According to Nora, remembrance is rooted in the specific, be it a place, a gesture, a picture or an object. The creation of a memory place is the symptom of the lack of memory. Since there is no longer a real medium (*milieu de mémoire*) our memory creates places (*lieux*). These places are where memories pop up, come to the surface, where pain is still able to raise the problem of the embodiment (Nora 1999, p. 14).

5.2. Disability and illness

Susan Wendell makes a distinction between 'healthy' and 'unhealthy' disabled people. In relation to her chronic disease, she writes about her experience that the acceptance of disability is higher in the case of 'healthy' disabled people. Disability is often a stable, predictable and given physical condition, it does not necessarily

mean weakness and, at the same time, it ensures a highly rated health status as well. A predictable body is comforting, does not cause fright and is easier to adapt to. Disease is unpredictable and often associated with pain and suffering. It's hard to plan with it, you need to adapt to it. Wendell regards herself as an unhealthy disabled person, and the biggest challenge for her is the incomprehensibility of her disease (Wendell 1996, 2001).

When our interviewee was informed that she was expecting a healthy Down Syndrome child, she said that this piece of information induced her to continue with her pregnancy.

> 'It did play a role (in the decision-making) that we could see that he was a relatively healthy child… Because if we had seen that he was just a little kitten who didn't know what was happening, probably we would have given it a thought.'
> Mothers who learnt about the health problems of their child only after birth told us that the different diseases they developed apart from Down Syndrome significantly influenced the child's quality of life.
> 'His diabetes is a big drag […] I don't know what I could say concerning his independence. But only because of his diabetes. Otherwise he could easily live and independent life. But because of this, it is difficult to leave him alone. Because his life is in continuous threat.'
> 'Well, his illness (epilepsy) is shit, a big shit.'

Movements working for the rights of disabled people are rightly fighting to separate the different layers of illness and disability. Linking the two concepts together contributes to the medicalisation of the condition, where disability is considered a personal misfortune. This medical approach sends out a false message that people living with disabilities are *suffering* from physical and/or mental impairment or deviation. The healthcare system, therefore, is the primary framework where these people should be treated and cured. Disabled people consciously differentiate themselves from those who are ill. Wendell, nevertheless, underlines that legislators, employers or disability studies experts should not lose sight of the fact that there are disabled people who are ill. 'Moreover, some unhealthy disabled people, as well as some healthy people with disabilities, experience physical or psychological burdens that no amount of social justice can eliminate. Therefore, some very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it' (Wendell 2001, p. 18).
Our interviewees whose children recovered from their illnesses reported an improvement in the quality of life.

> 'And how wonderful it is that his heart is working well… Down Syndrome was not a primary issue then, but that he was ill and had to recover.'
> 'It gave me strength, as the tests were following one another, that he is a child in quite good shape. That he has no serious heart problems, he has a bit of an atrial septal defect though, but no need to take medicine so far and they said that this could even disappear on its own or, even if it had to be operated, there is still a lot of time till then. Well, this is still an open issue, but it doesn't set him back in his development. As far as we can see it now, there are no major health problems for the time being. This is good, and apparently he is quite a gifted young lad.'

Although it would have been of utmost importance for them, the majority of our interviewees were not aware of the health condition of their child in the foetal stage apart from the diagnosis of Down Syndrome.

> 'Everybody said to me that I would have a physically healthy child with Down Syndrome… Despite of all this he was born… ten weeks early, in fact with the septal defect… The absurdity of the whole thing is what would have been really important for us to know, we did not get any, not satisfactory, but any kind of answer, so what we expected was a healthy child to be born. That he will be mentally disabled to a degree that could still be accepted. Who is normal and who is not, this is a pretty relative thing.'

The words of these women support the fact that possible illnesses complicate the decision-making further.

6. Summary

In our article we presented the partial analysis of ten narrative interviews we conducted with women who decided to go on with their pregnancy even after having received a positive Down Syndrome diagnosis. We did it in the framework of feminist disability studies, separating the layers of the power mechanisms of the prenatal diagnostic procedure. We did not try to analyse the interviews in a holistic manner.

In the narratives we focused on the period between the diagnosis and the birth of the child, where the interviewees told their stories about their experiences of the health care system and where disability and illness were linked.

From the experiences related to the health care system, we focused on the content, amount and neutrality of the information, as well as its social and cultural embeddedness. With the help of these we shed light on the interlinking and complex issues of pregnancy, motherhood, normality, disability, risk-taking, biomedicine and the body. Based on Susan Wendell's thoughts regarding illness and disability, we were able to understand another complex aspect of decision-making. During our research we got an insight into the medical presence infiltrating the everyday life of pregnant women and the complex and multi-layered interpretation of normality within society. We pointed at the hidden tensions created by the need to take action and to the difficulties deriving from imbalances in accessible information.

In future we would like to concentrate on wider analyses of all the 16 interviews. We cannot analyse the different interpretation of prenatal diagnostic tests without taking into account the way pregnant women see the world and humanity or what their beliefs are. This is confirmed by the fact that women who received a positive Down Syndrome diagnosis during their pregnancy spoke about their religious belief, faith or relationship with God in their narrative. Therefore, in our next article, we will focus our attention on the relationship between abortion and the Christian faith and the interpretations of life, death and human existence. Discussing the subject, it will be necessary to tackle how feminist philosophies and disability studies deal, sometimes in a contradictory way, with the question of abortion. During our future work, apart from gathering experiences and interpreting the socio/cultural correlations, we will try to find the hidden *questions* as well. This is justified by the intricacy of our subject.

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VANDA KATONA[1] – MARIANNA SZÜCS[2]

PARENTING IN THE LIVES OF PERSONS WITH INTELLECTUAL DISABILITIES

Abstract

The questions of childbearing and parenting in the life of persons with intellectual disabilities are very marginal both in research and professional practice. Although international guidelines emphasize the total social participation and self-determination of persons with disabilities, protectiveness is more common at a local level in connection with sexuality and childbearing. Parenting capacity involves the complex interplay between children and their parents, home and community environments, and family and community services. Hence, our intention is to concentrate on these relationships and to conduct interactive pair interviews with people with intellectual disabilities and relevant people in their lives. In our research we are curious about the opportunities and obstacles in the lives of persons with intellectual disabilities to becoming parents in a variety of living conditions, as well as the characteristics of the parenting roles of women and men with intellectual disabilities.

Keywords: persons with intellectual disabilities, parenting, parent roles.

1. INTRODUCTION AND THEORETICAL BACKROUND

In our research we examine the possibilities of persons with intellectual disabilities becoming parents. In society we can find many stereotypes and prejudices and all too often we encounter taboo and silence. The questions of childbearing and parenting in the lives of persons with intellectual disabilities are very marginal both in research and professional practice. Becoming a parent is not a necessary condition in the transition to adulthood, but these days the experience of parenting is frequently a determinant element in establishing adult identity. The emphasis is on choice and self-determination. Although international legal framework emphasise the total social participation and self-determination of persons with disabilities (UN CRPD 2006), the topics of sexuality and parenting are extremely sensitive, especially for persons with intellectual disabilities, and protectiveness is more common at a local level (Foley 2002; Taylor Gomez 2012).

The question is how to predict who will be a 'good parent' or an 'adequate parent'.

Willems et al. examined the 'good enough parent' connotation regarding people with disabilities. According to their definition, the basic criterion of a 'good enough parent' includes that there is no abuse, that they do not neglect the child and that there is no legal case of child protection pending in the family. According to the carers interviewed in the survey, 51% of their clients would not be a 'good enough parent'. In the research it was considered a protective factor, i.e. a factor enhancing their ability to become a 'good enough parent', if the person with intellectual disability wanted or was able to follow the advice given by professionals, if there was a good social network around them and if they were accepted as parents by their environment. They

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considered it a success factor if the partner was not disabled, his or her IQ level was higher, capable of asking for help and if there was a strong professional background and support available for them. The greatest difficulty was the lack of acceptance and the bad socio-economic status. But they also emphasised that the interaction of positive and negative factors should be considered (Willems et al. 2007).

Many studies indicate that there is no systemic correlation between intellectual capacity and successful parenting (Aunos et al. 2008).

More and more frequently in the professional literature parenting is interpreted as a social activity in which it is not only the intellectual capacity of the mother or father that determines the quality of parenting. Parenting capacity involves the complex interplay between children and their parents, home and community environments, and family and community services (IASSID SIRG 2008). Hence, our intention is to concentrate on these relationships as well as on relevant people such as carers.

A number of studies examine attitudes towards sexuality and childbearing in the lives of persons with intellectual disabilities.

One of the areas examined was how much housing conditions determined the attitude.

Results differ, and while community-based living is found to be more liberal, ambiguity is typical in all types of residential facilities (Grieve et al. 2009).

Other studies indicate that there is correlation between the attitudes of care professionals and the gender of the person with disabilities. Professionals speak of the sexuality of persons with intellectual disabilities with a variety of gender stereotypes (Young et al. 2012).

Parental roles are closely linked to the female and male roles, so different expectations arise with regard to motherhood and fatherhood and the presence of disability just adds another strand to it.

In recent years, it has been difficult to reconcile the ideal of a 'super mum' lifted to mythical heights with the dominant social role of a women with disabilities which is characterised by eternal dependence and asexuality. Women with disabilities have to prove their competence to bring up children continuously, although in the case of non-disabled mothers this issue is never raised (Kálmán 2014).

The romanticized image of motherhood is hardly compatible with either the mother's or the child's disability. In a biomedical milieu the security of 'healthiness' is expected. In some cases, the mother is identified as responsible when a child is born with disabilities. For example, when the mother's alcohol or drug consumption continues during pregnancy. On the other hand, if the child is born with a disability, the mother has an outstanding responsibility to bring up a 'whole' person (Landsman 2009). If the mother is disabled, giving birth to a child is considered an irresponsible step by which a child with disabilities is born. Bringing up a child with disabilities requires a strong and responsible mother, and this competence is frequently questioned with regard to mothers with disabilities.

Educating children with disabilities requires intensive parental resiliance, mainly for mothers. The services and support are often incomplete, so parents should always be available and always be able to solve problems. The autonomy of the child is often influenced by whether the parent is able to give practical support. They have to make efforts in different areas like administrative issues, information-gathering, networking, advocacy and endurance. Parents have to become quasi experts so that their child with disabilities can get on in his everyday life (Saaltink–Oulette–Kuntz 2014).

All this, if the mother is disabled herself, means a lot of difficulty and effort.

Fathers with disability are rarely focused on in research. The fathers' breadwinning role can hardly be reconciled with such inherent features of disability such as

dependence, inactivity, asexuality or childishness. They are frequently unemployed or inactive, but other handicaps too provide a challenge to fathers with disabilities in the labour market. Although the model of a breadwinning father has lost a little of its dominance with the expansion of feminism and the socio-demographic situation, research about fathers with disabilities showed that the traditional, breadwinning image of a father often causes role-conflict especially in fathers staying at home with their children. Researchers drew the attention to the specific experiences of fathers with disability and also to the need for further investigation (Kilkey–Clarke 2010).

Based on these studies we are curious about the opportunities and obstacles in the lives of persons with intellectual disabilities regarding parenthood in a variety of living conditions, as well as the characteristics of the parenting roles of women and men with intellectual disabilities.

2. RESEARCH METHODS

We were working with qualitative methods, mainly with semi-structured interviews. In this study we analysed the parenting possibilities of 20 persons with intellectual disabilities (9 women, 11 men). Our interviewees were between the age of 21 and 47, their average age was 35,5. In this project we will additionally have 32 interactive pair interviews.

We conducted interactive pair interviews with persons with intellectual disabilities and relevant people in their lives.

We selected the pair interview method so that we could follow the interactions between the affected person and the helper, how they related to each other with recto the subject and what experiences they had while interacting. The key person (parent, helper) can help, among others, to bridge the gaps in communication or to dismantle mistrust towards the interviewer and sometimes can act as a sort of 'interpreter'. If we had held separate interviews, we could have acquired other types of information too, but parenting is a joint activity in which direct relations are decisive, so in our research work we concentrated on how their interaction reflected the attitudes related to the subject.

Based on the framework of disability studies second to the principle of 'Nothing about us without us', we worked with a parent couple with intellectual disabilities (Mercer 2002). They are insider experts, and they participated in the research process (testing the interview questions and analysing the results). Now we would like to present our actual results second to our main research questions.

3. RESULTS

3.1. What are the similarities and differences between parenting in a variety of living conditions?

We examined four types of living conditions: long-term residential institutions, group homes, supported living and family homes.

We found that the personal attitude of carers is more determinant than the type of accommodation. While large institutions are more regulated, regulation is typical in all types of living conditions, even the more liberal supported living. For example, contraception is compulsory in supported living but the choice is more personalised.

We encountered structural barriers to childbearing in all types of accommodation beside many uncertain, unclarified circumstances (e.g. guardianship). In Hungary the legal capacity of persons with intellectual disabilities or mental health problems may be restricted by the guardianship system.

> 'In the one hand, they are under guardianship. Guardianship does not directly limit childbearing opportunities, but it is highly likely that the authorities may take the child from them despite any possibility that they are capable of caring for a baby. On the other hand, supported living is officially a caring facility for adult persons and not for children' (care professional employed in supported living).

We detected additionally that protection and safety take priority over the self-determination mentioned in the observations of international studies (Bernert 2011).

3.2. What are the similarities and differences in parenting between women and men with intellectual disabilities?

In this part of our analysis we found that in many cases the 'disability role' exaggerates gender roles and concerns about childbearing. Yet greater emphasis is placed on protecting women, because in the most cases they have to take responsibility for contraception.

With regard to the role of parents, we detected uncertainty and unreal perspectives in more protected environments.

We also found women and men with intellectual disabilities living out their parenting ambitions in the role of 'substitute parents', for example as aunts or uncles.

> – 'I have accepted that I will not be a father, but I am glad to have a nephew' (31-year-old man).

Dolls also play an important role for women with intellectual disabilities.

> – 'I can't have a real baby, I'm sterile. I have dolls but I find it difficult to support them too' (34-year-old woman).

Women interviewees often plan to deal with children in a professional capacity. One of the professionals described the following dilemma:

> – 'She would really like to deal with children. But even if she had a nursing qualification, she probably would not get a job, so we are reluctant to allow her to try to study' (care professional, supported living).

Regarding parenting roles in the narratives we realised that several interviewees did not have a good example of parenting to follow, and that in their opinion good parents were ones who 'do not throw away or hurt' their child, or 'do not place them in institutions'.

Many interviewees interpreted parenting roles from a practical viewpoint, focusing on activities centred on the baby and financial considerations. The interviewees made little mention of parental responsibility and education.

3.3. What are the characteristics of gender roles in the narratives of persons with intellectual disabilities?

We asked the interviewees about the characteristics of women and men, and when they consider themselves, feminine or masculine.

So far we have found that women often identify outward appearance (e.g. pretty, trendy) while men tend to emphasise character traits such as seriousness and determination with regard to their respective gender roles. Motherhood and childbearing did not feature as a dominant part of a woman's role in the interviews.
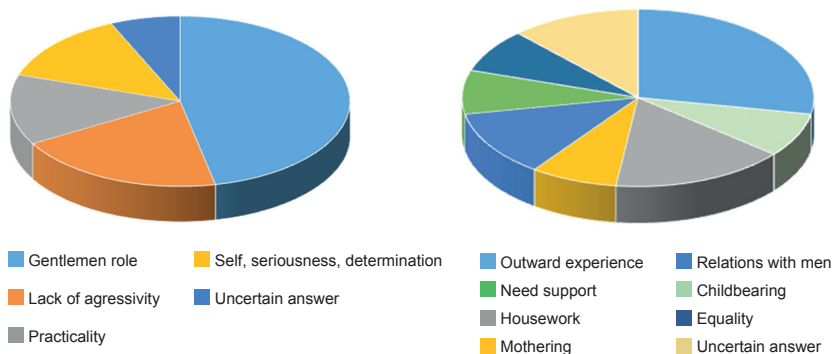

FIGURE 1. WOMAN'S AND MEN'S ROLE
IN THE NARRATIVES OF INTERVIEWEES WITH INTELLECTUAL DISABILITIES

3.4. What factors do the interviewees consider a problem when becoming parents?

3.4.1. Social hindering factors / hurdles

Each interviewee expressed what a financial burden it is for the parents to have children. Their income is significantly lower than the majority of employees and for 6 hours work per day they get, on average, 50 thousand HUF a month. Those under guardianship face several factors which hinder their becoming a parent, such as the fact that the guardian determines the amount of money they can use from their wages for what type of expenses. (We found a couple who had to cover the costs of their morning, evening and week-end meals from 8 thousand HUF, this is Ł 20 a week.)

Another obstacle is the fact that either a key person (e.g., grandparent) who could help them to bring up children is missing or is too old. In the society of the 'abled' the skills necessary to perform the role of a parent and the tasks related to the care of the children are taken for granted. It is an essential condition to be able to perform successfully things like managing household money, shopping, etc... In our experience, people with intellectual disability take a lot more time and energy to master and use these skills, compared to the majority society and without helper(s) it is almost impossible.

If it is impossible to rely on a helper (because of his or her advanced age) in bringing up children, then this frequently eliminates the desire to have children.

'…I would like to have children, but let me tell you that it makes no sense, partly because I am old, on the other hand Mom could not bring them up… you should not want a child if you cannot bring him up' (43 y. o. woman).

The lack of a proper parental role model (e.g., because of having grown up in an institution), hinders adequate preparation for the role of becoming a parent. Several interviewees explained their inability to become parents with the fact that they did not have a proper role model, since they had grown up in an orphanage.

'…I got into an orphanage at the age of eight. It happened because my parents were unable to provide anything […] they were like that' (43 y. o. man).

The difficulty of finding a partner and establishing a relationship on their own is an obstacle to becoming a parent.
    We came across several examples when people with mild intellectual (mental) disability found it hard to find a partner if the potential partners in their environment had weaker intellectual capabilities than they had. They also needed help in finding proper dating possibilities (internet).

'…they are not at the same level as I am. From this point, it would be quite one-sided… it could not become so deep' (36 y. o. man).

Societal attitudes also provide significant hurdles, especially if any of the above appear in the legislation or in the welfare provision system.

3.4.2. Obstacles deriving from the individual's intellectual disability

It is an individual obstacle if the person has disease awareness, i.e., our interviewees mostly regard their disability an illness, which is an excluding factor when becoming a parent.

'…I dreamt about having a family […] but I have given up this dream exactly because of my illness… I have to accept that I cannot have a family on my own' (31 y. o. man).

We found several cases where, despite the strong desire for a family on their own, they worried substantially that their condition, which they mostly regard as an illness, could be inherited, so the fear of repetition is also a significant obstacle to having children, which becomes even stronger if their partner is also has intellectual disabilities.

'I don't know. I gave it a thought that God knows if it is good or not good if an ill child is born and then… his mother won't accept him. Because if a child is ill, he won't be so much accepted, and then, if a child is born, it can happen that it will be disabled because the father is ill too' (43 y. o. woman).

Besides, we came across irrational suppositions and fears concerning the process of birth and its consequences.

'Because I am terrified of giving birth… it could happen that my kidney falls off due to the big effort' (24 y. o. woman).

It is noteworthy that some of the persons studied expressed intense concern that, if the mother's age was over 40 years, the child would come into the world with an impairment. Another age (in this case, e.g. 37 years) was also considered a hindrance to having children which, in the case of 'non-disabled' people, would not be a precluding factor in child-bearing.

> '…in theory it is risky to make a baby if you are above 40. Anything can happen. Disability or something like that' (24 y. o. man).

At an individual level we also noticed the lack of self-esteem and a very strong sense of incompetence with regard to performing parental tasks. The majority of the interviewees thought that they were unable to bring up a child.

Family members and mostly mothers and adult brothers have an important role in provoking this psychologically painful sensation. The latter in many cases at least make it possible for their family member with disabilities to acquire the joy and the sense of achievement of education by allowing them to act as aunt/uncles, something that otherwise they would not be able to experience as parents.

The background to this sense of incompetence is that they do not feel capable of doing many 'jobs', such as paying for the clothing, schooling, feeding of a child or financing their higher education, nor assuming the other responsibilities of bringing up a child, something that might derive from their previous socialisation.

Many expressed that for 5-7 years bringing up a child shortens significantly the time which the couple could spend on themselves or in common activities they both enjoy.

Another factor acting against having children is that many interviewees were afraid that they would not be able to dedicate the necessary attention or care to their children. Another argument they brought up was that they were unable to handle the problems that might arise and also the lack of knowledge, like e.g., what to do 'if the child starts to cry in the middle of the night'.

Dealing with older children seems easier for them, because in the case of older children they do not feel incompetent and skills like changing nappies are not needed, so this does not create anxieties in them.

Interviewees stated that for both partners a steady and satisfactory relationship is of greater value than the experience of becoming parents.

> '…it's better this way as we are' (43 y. o. man).

In our experience, for our interviewees engagement or wedding almost exclusively mean the appearances (e.g., buying an engagement or wedding ring, wearing a glittering wedding dress), and the motivation or the desire for having children derives mostly from the child's physical beauty.

> 'Q: Would you two like to have a baby?
> A: Yes, we would like to. Because always when we look at one, we see, oh, how cute they are and we would like one like that' (24 y. o. man).

It is worth mentioning that even for those who do want to become a parents and explicitly articulate their desire to have children, there is still some ambiguity.

> 'Well, I don't know, […] in today's world it is difficult to bring up children' (43 y. o. man).

3.5. The attitude of the helper to the relationship or to parenthood

3.5.1. For people with intellectual disability living in a family environment

The helper most of the time is the mother, in fewer cases an adult sibling. The relationship between the helper and helped is a very close partnership. Because in most of the cases they are relatives it is very difficult, in everyday life, for the helper to respect the independence of the member with intellectual disabilities of the family and one element of this is not forcing their own ideas on the individual with disabilities about his or her relationship. On the other hand, they also feel responsible for shaping the private life of their loved one, so they act as a protector, e.g., they also split punitively with their child's/sibling's partner, if they see that the partner is harming them.

Although, on the surface, they support that their child with intellectual disabilities to find a partner, and believe that the child indeed needs that, in their narratives they did not think it feasible for their family member to leave the safe family environment. Many times we found that they were happy to accept their child's or sibling's partner in their own home.

> 'Well, I'm saying to you that if you find somebody who can accept you as you are with this bloody awful nature of yours,… I promise I will accept her as a daughter' (37 y. o. man's mother).

We found examples where one of the parents considers a possible solution to be if they can find an institution where it is permitted for couples to stay together and where they can get practical help with their everyday activities.

> 'We have thought of them together, even if not independently… what we can see in these institutions is that couples can stay together. I can imagine something like that for him. Where… they have services. It is pretty cool that there are institutions like this' (48 y. o. woman's mother).

Without exception, the members of the family always pay special attention to contraception. It is quite remarkable that in a family the mother supported her son in his plan to undergo voluntary sterilization. It caused her substantial frustration that in the health institution they denied him the medical intervention that would have rendered him infertile.

> 'Once he came up with the idea completely on his own… that he was ready to go through with it. And the next time when we went to the hospital to get a date for the intervention, the chief nurse noticed in a medical document that er… independent life … and then she said, 'no way'. And she talked to me as if I had been a useless monster who was ready to persuade her own son to do mean and vicious things… I felt terribly humiliated. I left the hospital thinking now what? The hospital wants my son to increase the population? […] He is not under guardianship. So they should have accepted his request' (37 y. o. man's mother)

Pursuant to the points (1) and (1a) of Para 187 of the Act on Health (CLIV/1997), sterilisation, for family planning reasons, can only take place if the person concerned is over 40 years of age or has at least three children of his own. Since in the case the interviewee did not meet this criterion at the moment of filing the request, the hospital probably did not refuse to carry out the sterilisation because of disability, but acted lawfully. It became clear from the interview that the mother's frustration was caused by the fact that the hospital failed to inform her and because of the improper style of the communication.

There is a view that persons with intellectual disabilities will not be able to care for their children, therefore the upbringing would become the task of the already aging grandparents and/or adult sibling or, in the worst case, a children's institution.

> 'How could they have children? I'm not sure that is needed. Not sure. Because… a very good background is needed for that, a helping family. She should not remain alone by any means. Either she gives birth to a child or then… they put him or her into an institution. But if there is a safe place at home, well even then the probability is bigger that the child will also has disabilities. I do not know if I would have the courage once again. I don't know' (48 y. o. woman's mother).

The parents of adults with intellectual disabilities worry that, because of their age or being worn out, they are not suitable any more to bring up a possibly disabled grandchild. They think it is very irresponsible if an intellectually disabled person gives birth to a child just because they feel like playing with a doll, or if parents approve it because they want a grandchild. The examples of parents with intellectual disabilities having children is also a deterrent.

> '…I know that now it is very much encouraged that in a given case they could have children. I heard that, but then I gave it a thought that what if the parents, in fact, are in a condition that they are unable to bring up that child, if they are unable to provide schooling, then what? To give birth to a child just because they have the right to, then give birth to a child for an institution, furthermore… I have heard of a case where the child was mentally healthy and, as he started to grow, looked around in the family, then very ugly identity problems arose in him' (37 y. o. man's mother).

Even parents, who verbally support their children finding a partner, ignore or reject in a hidden way the possibility of childbearing. A young 24 year old person, for example, with a steady one-year-long partnership and plans to get married was not permitted to spend the night together with his partner in his parents' house. It became evident from the interview, and from the declaration of the young person's helper, that the parents opposed their child's sexual relationship in order to avoid unwanted pregnancy and not because of any religious conviction.

3.5.2. For those living in small groups in sheltered accommodation

In the sheltered homes we examined we found that the helpers have an attitude of acceptance towards the issue of having a partner, and helpers have a tight and well-functioning relationship with the residents.

This is especially valid in the case of long-lasting, steady relationships, where the clients consult their helpers even about personal issues and who comply with the norms and expectations of the institution.

> 'Everything is tidy and clean… they are really decent people. They keep their room tidy. They are both clients' (helpers' comments).

Yet both the management of the institution and the helpers have to be informed if a relationship is established as well as when they intend to live together.

> 'The manager and the helper have to know about everything, but is permitted' (helper of a 47 y. o. woman).

Having a child is possible in principle, yet the majority of helpers think that the high need of the person with disabilities for help does not permit it, since even parents with mild intellectual disabilities require continuous help.

> '…they need an incredible amount of help to bring up children. Everything that is related to schooling, hospital care, education or teaching. In their everyday routine, they need help in everything. Everything' (37 y. o. man's helper).

During our research we also found opinions that, because of the deficiencies of public social care system, both the families and the institutions have the right to decide whether they want to assume the upbringing of child with physical or intellectual disabilities.

> '…while there is no well-structured and usable system able to provide assistance in bringing up a child with physical or intellectual disabilities to born into a family, then you cannot take away from either the institution or the family the right to decide whether they are ready to bring up the child or not' (37 y. o. man's helper).

3.5.3. Supported living

In the Supported Living-Houses there is a possibility to provide a more independent life in separate houses to the adults with disabilities, still within a small group. In the different forms of supported living we examined couples, whose relationship was longer than one year, were enabled to live together. After having attended a training course, the couple can live in separate apartments or rooms but surrounded by a small group. This type of provision permits a higher degree of independence, whilst still receiving help, which is very favourable to creating and maintaining relationships.

People with intellectual disabilities can lead an independent life only with the assistance of their helpers. There is a partnership between the helpers and the residents of the supported living. In our experience the helpers are open-minded and their attitude is very supportive of relationships being initiated or even when the person with disabilities want to get married or have children, if their clients' mental and psychological maturity permit that.

The helpers' main principle is that they provide help only in issues where the clients need it or explicitly request it. Their view is that the main criterion for becoming independent is not whether they have children or not, but to be able to master the everyday routines and skill necessary to lead an independent life, like managing

money, doing the house chores or assuming responsibility for their actions with regard to other people.

As mentioned before, in this form of housing too there are structural obstacles and the helpers have uncertainty with regard to the existing frameworks. They consider it an important condition for having a child that at least one of the partners should be out of guardianship and have a place where to live at (e.g., a rented flat) and that the couple could receive practical help from home to bring up the child, to find a proper working place and to learn how to cope with the household chores.

Under current legislation, people under partially limited guardianship are free to contract marriage, but the marriage of those under fully limited guardianship is not valid [Civil Code point (1) para 4:10]. If a person under full guardianship would like to get married, then the limited guardianship should either be eliminated or a request should be filed to change the fully limited guardianship into a partially limited one. Guardians usually oppose very strongly the requests for eliminating the guardianship submitted with the assistance of the helpers.

Their main argument is what is going to happen if the person under guardianship becomes alone because of losing his or her partner in future. The reason of the resistance of the carers is not an unreasonable limitation of the rights of the persons with disabilities, but the fact that they want them to maintain a safe life, even if this contradicts or hinders the desire of becoming independent.

4. SUMMARY

In our research we examined the possibilities of adults with disabilities becoming parents. According to our results so far, we found that the possibilities both for having partners and for bearing a child are hindered by many social hurdles. The immediate environment and particularly the relatives of the adults with disabilities have a decisive role in whether or not they can overcome these challenges. By means of further interviews we will try to understand in detail the experiences of adults with disabilities becoming parents.

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> ”This is a life alternative you can take upon yourself, no question about it, you can find your joy and happiness in it…’

The Adoption of Children with Special Needs in Hungary

1. Introduction

This paper has been written with the aim of looking into the problem of families adopting children with special needs. Based on the theoretical foundations of disability studies, the issue to be addressed here pertains to *the characteristics of families opting for the adoption of children with special needs*. Our work has been guided by the paradigm of participative research: one of the researchers has adopted a child with Down Syndrome, while Éva Steinbach, another member of the research team, is a specialist who has taken a key role in supervising the procedure followed during the adoption of children with Down Syndrome.

Our aim is to deepen our understanding of the world of child adopting families, thereby changing the current situation so that in accordance with UN agreements on the rights of children, the highest possible number of children with special needs might be adopted by families rather than be transferred to institutional care. As a consequence of an amendment in 2012 to Act XXXI of 1997, the legislative approach in this country to the general principles on childcare is now in line with international trends by demonstrating preference for family substitution care to institutional care [Child Protection Act, section 7 (2)]. However, children with disabilities do not fall under the purview of this law.

New regulations introduced in accordance with the Act on Child Protection, effective as of January1st, 2014, have reshaped the balance between family care and institutional care, bringing about a shift towards family care. A guiding principle in the new statutory approach is that children under the age of 12 should not be transferred to institutional care; care must be ensured through an adopting family. However, this legal provision does, among other exceptions, not entail mandatory enactment in the case of children with disabilities who can still be transferred to institutional care.

Data – made public in the 2012 Yearbook on Social Statistics, published by the Central Statistical Office, the number of adoptable children, including those in the 'children with disabilities' category, along with adoptions officially approved and the adoptions of children with disabilities – shows that adoption percentages are generally between 35 and 39, i.e. every third child will be adopted by a family. As for children with disabilities, that figure is between 0.5 percent and 2 percent, *i.e. either only one out of fifty or one out of one hundred children will stand a chance of being adopted by*

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a family. The four-year period covered by the statistical information available shows that 39 'disabled children' were given a chance for a better life. It is to be noted that data on the adoption of children with disabilities has been available since 2009 (CSO 2013).

2. Characteristic features of the adoption of children with special needs in the light of resources available in Hungary

Having already tackled this issue on the basis of foreign literature in an earlier paper (see: Sándor–Horváth 2016), this paper will, therefore, focus on those aspects of the issue which are characteristic of the current situation in Hungary.

The keyword 'adoption' in the data base of university libraries will produce 59 hits, whereas the combination of 'adoption/disabled' will display one hit (Bertók 2011). 'Disability/child protection' will produce one hit on adoptive parents (Kiss 2011). 'Adoption/family/children with Down Syndrome' (Tarró 1999) and 'adoption/physically impaired children' (Győri 2004) will produce one hit each.

It has always been Csilla Bertók's intention not to deal with the notions of 'foster care' and 'adoptive families' separately. Nor does she separate the intention behind adopting children with special needs form the situation when disability becomes an issue following adoption. A significant outcome of a survey based on questionnaires was *the finding that characteristically, families who were willing to go through with the adoption procedure had the intention to do so because they already knew the children about to be adopted*.

A search performed for the phrase 'disabled/disability and adoption' in the online catalogue of the Metropolitan Ervin Szabó Library produces 15 hits, while phrases containing all of the following words: 'Down Syndrome/physically impaired/deaf and adoption' will produce no hit. The only document to be identified as literature bearing relevance to the topic is an account by Neményi and Takács on discrimination in Hungary regarding adoption. The conclusion drawn by researchers is that only 1 percent of parents who wish to adopt children express willingness to adopt permanently ill or disabled children (Neményi–Takács 2015).

MATARKA (Hungarian Periodicals Table of Contents Data Base), a Hungarian language data base, produces no hit for word pairs containing any of 'disabled/Down syndrome/death/blind/mentally handicapped' alongside 'adoption/available for adoption' for the period between 1800 and 2016. A search for the phrase 'adoption' will produce 26 papers published between 2000 and 2016. Ten of them proved relevant, one of them being a paper by Neményi and Takács. Although one paper tackles the problem of children with Down Syndrome, it contains the findings of a research conducted in France in 2001 (Kibicher 2004). Six other papers tackles the problem of an additional difficulty posed by circumstances in which children with disabilities are to be adopted (Vida 2013), or the danger posed by a lack awareness associated, both nationally and internationally, with the procedural aspects of adoption (Andrási 2009; Bogár 2001; Marschalkó 2013; Neményi 2001), one paper putting forward the idea that it is less difficult for a single parent to adopt a 'sick' child (Kollár 2002).

According to Judit Deli 'the adoption of 65–70 percent of children registered in TEGYESZ (Regional Child Protection Service) as eligible for adoption will in fact go through. In other words, 30-35 percent of these children will be eligible for adoption, but only in a statistical interpretation. Generally speaking, 3-5 percent are either

not healthy or these are children with disabilities whose adoption, in the absence of adoptive parents, can at best be ensured by foster care' (Deli 2006).

The following point was raised by another specialist: 'Would it not be helpful for children not eligible for adoption if, just like in the case of foster care, positive discrimination was used by the government in the form of resources being allocated to families adopting children with disabilities, in order to financially support them? We are sure that many foster parents as well as adoptive parents would be willing to provide a permanent home for children with disabilities' Molnár–Radoszáv 2006). We have also come across Zsuzsa Mártonffy's blog on adoption, which featured observations (not meant to be academically in-depth) complete with findings from a 2015 research (Mártonffy 2015).

3. Research and our research methods

Our research effort focussed exclusively on adoptive parents, foster parents remained outside the scope of our research. Analysis was performed only in connection with parents *who were determined*, *prior to* the adoption procedure, to adopt children with special needs.

Our research was carried out in four stages: the exploration of

- international and
- Hungarian literature and of the pre-research situation
- questionnaire-based survey and
- narrative interviews.

This paper presents the details of the findings arising from narrative interviews. Narrative interviews constitute the most effective methodology to help interviewees talk about their lives as freely as possible and, by exploiting the fundamental principles of disability studies, are capable of achieving empowerment; by determining the extent to which an interviewee will spell out the details of his/her chosen topic and the manner in which he/she will talk about it, that interviewee will be in full control of the dialogue.

The interview was conducted with the participation of two interviewees (the adoptive mother and adoptive father) and two interviewers (one woman, one man – one of them was an adoptive parent). We are not aware of any similar interview, consisting of four persons, having been conducted elsewhere. Our request made to interviewees to participate in the interviews was accompanied by a letter in which we provided them with information regarding the survey. Between October 2015 and April 2016, a total of sixteen interviews were recorded with the participation of eleven pairs of parents and five mothers. Eleven interviews were held in the home of the adoptive family, one was conducted while the adoptive parent was at work, two interviews were carried out at a different location, while two were conducted in the researchers' office. This paper includes fourteen interviews, two interviews having proved inadequate to fit in with our target group, the reason being that in two instances parents who had gone through the adoption procedure were unaware of the fact that the child to be adopted would be one with disabilities.

The initial question during all interviews was identical: 'Please tell us about your life, tell us what was behind your decision to adopt 'disabled' children?' In the interviews, the word 'disabled' was replaced either by the name of the adopted child or by terms

referred to as a special type of need identified in terms of educational purposes such as 'a child with Down Syndrome', a 'blind' or 'visually impaired child' etc. A type-out containing the recorded interviews was produced by an individual who had previously signed a confidentiality agreement. Following the typing procedure, that very person was obliged to delete both the recorded material from the sound recording device and the written material. The interview tapescripts are approximately 15-20 pages long.

The texts needed to be prepared for analysis. A random check was run to ensure that the recorded interview and the typeout text were identical. This was followed by a procedure during which all materials were rendered anonymous. Events of the interviewees' life were then arranged in a chronological order, i.e. we created a *life version composed of events that had in fact been lived through*, something that in most cases is different from a *narrated version of events that had taken place in an individual's life,* the reason being that interviewees never give a chronological account of their life. Moreover, prior to the start of the analytical process, we discarded all events that took place following adoption as our research was aimed at the decision affecting adoption. In the text, we also separated life events from those other than life events. Finally, we set aside data and mottos from the text of the interview which enabled us to carry out a focussed analysis.

At one stage during the analytical process we used a special technique for narrative analyses originally created by Hernádi (Hernádi 2014) subsequently fine-tuned by Hernádi and Kunt in the course of the current research. By doing so, we used a sequence of accounts given by all interviewers with the aim of creating a common narrative through which the voice of parents could be heard, sometimes bringing forth very similar figures of speech while depicting characteristic, well-defined life events that are known to have built the road to adoption.

4. Research findings

4.1. Narratives constructed via accounts given by adoptive families

'I have no idea where to start. I should start at the beginning, shouldn't I? (I). In fact, without the beginning it will be impossible to understand what happened (E). At this point I should, perhaps, add that when I left school I worked … for four years in a social institution. My job was to look after new-born babies. There was this little boy whom I grew very fond of. I was thinking of adopting him but I was far too young back then, (I) and it was then that my boss took home a little boy with Down syndrome. As an adoptive parent, I reckon. I was, well, I was surprised and I was glad that there was this opportunity, thinking, well, that was for me, that's what I should do sometime in the future. Then, as years went by (B) I realized I had nothing to be apprehensive about. My first impression was, well, at that young age a child like this was, for me, just like any child in the neighbourhood. The eyes looked a bit Chinese, he had projecting ears, but he was an adorable child (G). Anyway, if I try to explain this in a more subtle manner, my first impression was that when you play ball with them, these children catch the ball just like any other children, they throw it back to you just like those others. So I did something that pleased me, something I like doing. (C) Well, yes, he thinks that's something of a benchmark, if a situation like this comes your way, up your street as it were. (A)… and then, well, I had a

feeling that I had a craving for motherhood. I had made up my mind by then (C) and I told him about my broad idea on this, that I would like to adopt a human being with Down Syndrome… we agreed, though, we both thought that first we should have two biological children, then we would adopt one. (B) Then I was asked if I wanted to adopt a child… if we did, we would only adopt a disabled child… I said it would have to be a disabled child because for some reason no one wants a disabled child… no one would want them. (Ö) Not even four days went by and the phone rang, it was about a child, still in hospital, just born (I). The paperwork wasn't ready yet but they immediately called us, Éva Steinbach telling me that there was this new-born baby. They were expecting us, so could we go and see that child. It happened so fast (N), there was this baby, you see, and she said she just couldn't' find a family that would take that baby. What about us, she said, (B) and then, right after that phone call we were on our way to the hospital. We saw the baby (A), they even let us feed the baby… it was so tiny, I was afraid to take it in my hands (G). You have to wait for as long as six weeks, we didn't know how it was gonna shape up, this was a delicate matter, you know. Then the six weeks was over.(B) When we were doing that course they told us, and that was what we saw, too, that when the parents sign the waiver document, that's when the clock starts ticking, six weeks from kick-off. That was a very long time for us. (D). The social inquiry report was done. They had the preliminary psychological examination completed and some, I don't know, some topical thing conversationally or what have you. What we needed to get done was that course, nothing else, really (A). The Ágacska Foundation people are absolutely professional, they really are. All the people in my group had this idea that they wanted to adopt a healthy, perfect child to solve their own emotional problems, get their trauma cured (H). Mind you, it wasn't really about the Down thing there, it was about adoption… healthy kids are different, for these other children it's different again, adoption, even if you tell them about it, they will react differently. Unless they are able to understand, somehow grasp it, OK, great, that's great. Yes, maybe, but I don't really believe this would work out that way. Whereas a healthy child will, if you tell them about it, they will comprehend. Anyhow, you need to tell these other children about it, full stop. How much of it they are capable of taking in is another problem (D). So initially it was family adoption, this is how we had this child with us. As long as we did not have the paperwork on this, almost for a year, the parents were in a position to change their mind (G). A disabled child, well, children like these can benefit from adoption because if they are raised by their natural parents, well, people in the family first have to deal with that situation, a difficult process to get through. But if the parents are determined to go for this option, it means that there will be only acceptance, no parental rejection… you can cope with that. This is a life alternative you can take upon yourself, no question about it, you can find your joy and happiness in it (A). And the child's contribution will be tangible, the feeling of togetherness. The child's share of togetherness. The child needs me as much as I need him or her (F). Anyway, I sort of feel the need to send a message to those who might want to do this adoption thing in the future, 'don't be afraid to adopt babies that are born with an impairment, Down syndrome or whatever else, they are a huge emotional treasure trove' (C)'.

4.2. The characteristic features and experience of adoptive families

Interviewees do not associate their child with the condition of being disabled, they do not even use the term except when referring to others talking about such children. Characteristically, their narrative is almost entirely void of any negative connotation being attached to their own child, whereas they give a detailed account of both the physical obstacles that make life difficult for them in their own environment and of the negative attitude of certain individuals. The main reason, however, why a negative frame of mind is alien to the adoptive parents of children with special needs is that due to their experience these people are rendered capable of coping with issues of disability and/or child protection, which they can exploit as a source of energy in dealing with everyday situations and tasks. That experience very often stems from a professional background: several adoptive mothers are (special educational needs) teachers, they work in the social sector or have health-care qualifications. And, although decision-making is the outcome of a joint effort by adoptive couples, it has been confirmed through various life narratives that during a relationship mothers make the final call on the issue of adoption as a result of their professional experience.

Those who have become familiar with the problem of disability, having gained that kind of experience in their own family, have a different set of skills to rely on. In several cases, either one of the parents has a disabled sibling or the adoptive couple has a disabled natural child who was born prior to the adoption. Consequently, disability is not an issue that families need to brace themselves for emotionally either at the start of adoption or at the initial stages of child raising. Having opted for adoption by their own volition, these families accept the fact that children with special needs will become family members not because 'they have been thrust into this situation by a stroke of misfortune.'

At the same time we need to understand that all this is true only of a particular kind of disability, most often the Down Syndrome, of which the adoptive parents were aware when they chose to go for it. In situations when a child has some unexpected impairment or illness, the parents have no alternative but to make their way through the process of acceptance. We had this experience in a specific case when events took an unexpected turn and the parents realized that the child was an autist. To further complicate an already complex image, in our dealings with some of the parents it was pointed out to us that they decided to adopt a child with disability because either due to their age or to their health condition the chances of having a natural child with disability could not be excluded. Paradoxical as it might seem, we believe that this might not necessarily be the case. What this does suggest, though, is that the situation of a family into which a disabled child is born is substantially different from one which is in a position to choose a particular, acceptable, well-known type of disability. This indicates both the diversity and the elusiveness of the notion of disability as reflected in our mind, while equally associable with specific knowledge acquired in a particular situation. Our interviewees have put an unequivocal interpretation on the health condition of their own adopted child, formulated in a context different from the 'health-illness' or 'ableness-disableness' paradigm.

Based on foreign literature, the assumption seemed realistic that either faith or the fact that people often belong to a religious community were key factors affecting the decision taken by families in showing a willingness for adoption. However, that correlation was not substantiated during our research. The topic of religion was not even mentioned by the majority of parents. An additional group of parents only mentioned it in passing. Not even during feedback did this group indicate that religion

played an important part in their decision to adopt a disabled child. Religion was a dominant part of the interview in only three cases, meanwhile the story of only one interviewee appeared to have a strong motivational value inherent in the religious conversion of that person and the events that ensued. In other families adoption, was the outcome of a decision – possibly arrived at as a result of previous experience or the notion of charitableness and social responsibility – related to the issue of disability and child protection.

It was mentioned earlier on that, unlike in the case of other types of adoption, the primary motivation of parents determined to adopt children with special needs is not driven by the fact that they are a childless couple. However, some of them have, due to infertility or a previous sterilization, taken part in an insemination programme during which they had to endure both the physical and the emotional pain accompanying it. The conclusion, therefore, that our interviewees are representatives of a particular, clearly distinguishable family model, cannot be drawn. Not one element of their openness to adoption can be singled out as a clearly distinguishable force of motivation that accounts for their attitude. These are families with one child, large families, couples and single parents, younger parents and people who decided to adopt a child after their natural, grown-up children left the family nest.

Characteristically, parents who go through with the adoption process with the aim of adopting children with special needs are proud to talk about adoption and will in the short term – certainly in the long term – earn the respect of people both close to them and of those who they are not very closely related to. Children with special needs will not have to face exclusion in the neighbourhood, nor will they be discriminated against in public education or healthcare. Another experience, seen through the eyes of parents, is that their children can have a positive effect on the behavioural aspects of the community.

Based on what we have seen in the context of adoption, in most cases adoptive parents who adopt children through a so-called open adoption procedure, i.e. when the child to be adopted comes from a family, speak positively of that family and see no reason why that family should be blamed for what is happening. Behind this attitude lies the assumption that parents who have decided to put their child up for adoption are doing this because this is how they think they can best serve the interest of that child who, as they understand it, was born with an impairment. Based on what we have seen, parents putting up their child for adoption often have other children being raised in that family. Those parents, therefore, are not unfit for parenthood. What happened is that they in fact could not cope with the impairment of the new-born child. Presumably, they did not have enough support from elsewhere to handle that situation.

Another interesting aspect of the conditions surrounding parents who have decided to put up their child for adoption is that some of them were expecting the baby with a considerable amount of enthusiasm, and these parents were particularly protective of the baby during the pregnancy period. In three cases among those that we have looked into, three babies were born via in vitro fertilization, and it was after the baby's birth that the parents decided to put the baby up for adoption. Social selection, manifested at two separate levels, is a key priority in our disability research. The first level is an initial step aimed at producing perfect babies via the genetic screening of the egg selected for fertilization. Were that process to end in failure, the second step is either intended to culminate in the termination of pregnancy or the initiation of a post-natal adoption procedure rather than the keeping of the baby.

None of the families interviewed regretted their decision to adopt; none of those families would be opposed to a second adoption. Finally, we make a note of the fact

that one of the interviewees was a parent with disabilities. The significance of this lies in the fact that there appears to be scarce knowledge about the subject of adoptive parents with disabilities, whereas in some cases – particularly in situations where the child to be adopted is deaf – the fact that the adoptive parent has had first-hand experience in the context of belonging to a particular culture can be something of an advantage.

5. SUMMARY

There is a shortage of information when it comes to research findings regarding the kind of world that adoptive families and adopted children with disabilities live in. In Hungary this subject is tackled mostly by dissertations and informative texts. As for research papers, the emphasis is mainly on child protection or the broader issues of adoption. Consequently, in these papers disability as a phenomenon is only dealt with perfunctorily.

Our paper is comprised of fourteen interviews giving an account of the process of adoption. These interviews provide us with an insight into a diversity of life stories and family models. In the course of our research we became increasingly convinced that all the families which had chosen to go in the direction of child adoption had some kind of previous experience on matters related to disability and child protection. As for the motivation of parents, neither faith nor religion was a definitive driving force behind their actions as these topics were either entirely neglected or were mentioned only in passing by the interviewees. None of the families regretted their decision to adopt. Based on the experience obtained in the process, none of those families would be opposed to a second adoption. Being fully aware of the course of action they were determined to follow, the ramifications of disability are in no way a challenge for them, although they need to deal with the consequences of secondary disabilities or chronic illnesses which were not visible at the time of adoption.

Our research findings seem to underscore the fact that children with special needs belong to a heterogenous group of children whose adoption in Hungary today will be met with difficulties. However, a group of people who do not shrink from the issues accompanying adoption are parents who display a *willingness* to enlarge their family via the option of adopting a child with special needs. All of this seems to justify the argument that recommendations stemming from professional considerations and expert opinion should be put forward so that a much higher percentage of children with special needs might be transferred to the permanent care of adoptive families.

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Pertinent statutory law

Act No. LXIV of 1991 pertaining to the announcement of the Agreement made in New York on the rights of the child on November 20th, 1989.

Act No. XCII of 2007 pertaining to the announcement of an agreement on the rights of individuals with disabilities and of the pertinent Optional Protocol.

Act No CXC of 2011 on national public education

Decree No. 149/1997. (September 10th) on childcare authorities, child protection and childcare procedures.

Act No. XXXI of 1997 on the protection of children and childcare administration.

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'The process is far more complicated than I thought'

Experiences of an Innovative and Inclusive Curriculum Development in Higher Education[6]

Abstract

In this paper, experiences of a three-year training development project, realised in the Path of Deinstitutionalization – Urgent Moves programme, are presented. The course titled 'Theory and Practice of Supported Living' is the outcome of the development, which includes many innovative elements. From these, we highlight the diverse cooperation with national and international higher education and non-governmental actors, and the inclusive higher education practice, which was given an award of excellence by Tempus Public Foundation last year. Our work is innovative not only because it uses modern pedagogical tools, such as project method, cooperative learning, and the team teaching model, but also because curriculum developers at the Faculty of Special Needs Education were the first to use the inclusive methodology in higher education in Hungary.

1. Introduction

The Path of Deinstitutionalization – Urgent Moves (PODIUM) project and the curriculum development carried out in this framework form part of the inclusive practices based on the 'Nothing about us without us' principle, which is the basis for diverse, innovative co-operation and team-work with people with disabilities and professionals. All authors of this study had experience from previous and ongoing participatory research projects (e.g. From Equal Opportunities to Taigetus OTKA Research), which supported their participation and cooperation in this project.

The background of the project was underpinned by several influencing circumstances that had an impact on both the design of the project itself and the selection of consortium partners. The leader of the winning consortium is Equal Opportunities of Persons with Disabilities Non-profit Ltd. (later FSZK), which in the spring of 2015 (in the project planning period) had already had the experience of the first phase of the deinstitutionalization process (transition from large institutions to community based services) implemented by the strategy[1] (implementation period 2012–2014). FSZK had previously participated in a LEONARDO Mobility Programme,

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as a consortium partner, in which a comprehensive training concept was developed for the further training of deinstitutionalization (DI) managers in the field of social adult training. The professional development realised in collaboration by Czech, English and Hungarian partners served as useful input in the preparation of the professional content of the PODIUM project.

During the granted period of 2012–2014 and the process of deinstitutionalization, resources were mainly directed towards the renewal of the physical environment and the improvement of housing services. Meanwhile, a clear need for human resources development emerged, on the one hand, among regional / local / institutional managers and, on the other hand, a more coordinated planning of community services was urgent (Losoncz 2017).

The PODIUM international program was created to contribute to the realisation of Article 12 and 19 of Act XCII of 2007 about the proclamation of the Convention on the Rights of Persons with Disabilities and its Optional Protocol. With regard to the national framework, the initiative is based on the implementation of the Strategy for the Development of Disability Social Inclusion Strategy (2011–2041), 2015–2020 (Bódy et al. 2015) and supports the long term realisation of the transition from large social institutions to community based services for persons with disabilities during the period of 2017–2036 [Government Decision 1023/2017 (I. 24.)]. (Cserti-Szauer–Losoncz 2017)

Partner countries and organisations participating in the project: Central Denmark Region (Denmark) (Adult Training Methodology Centre), Asociaţia 'Alternativa' Brâncoveneşti (Romania) (CUDV Draga (Slovenia) (complex residential centre near the capital city) MDRI-Serbia (Serbia), ELTE Bárczi Gusztáv Faculty of Special Needs Education and ELTE Faculty of Social Sciences (Hungary) (higher education institution) and FSZK Nonprofit Ltd. (Hungary) (consortium leader). The European Union's Erasmus + KA2 Strategic Partnerships Support Programme is carried out between 1 September 2015 and 30 April 2018.

The training structure developed under the LEONARDO program formed the basis upon which discussion and collaboration of consortium partners were initiated. The five project partners had jointly developed a core training programme, along which the participating organisations separately developed their adult training programmes, adapted to their own country and local circumstances.

In this adaptation period, using the core training material, the Danish partner developed a 'train the trainers' programme designed to prepare trainers for their later teaching tasks during the training. During the train the trainers course, six trainers from each partner organisation were educated. The expected result of the project is that, after training and adaptation, in all partner countries 20–20 people can run a pilot course for DI managers (altogether 80 persons). In Hungary, a pilot training for 30 students of higher education is also incorporated in the core training adaptation. During the pilotage, the quality and content of the training courses are continuously evaluated (by both trainers and participants). According to the project plan, after the pilot training, 'DI managers' involved in the project must demonstrate their newly acquired knowledge by solving practical tasks and then start their activities in the process of initiation. All partners are responsible for the dissemination of the project results in their country, and trained professionals start coordinating activities in institutions that joined the DI process (Losoncz 2017).

2. The Higher Education Pillar of the PODIUM project

2.1. Co-operation between faculties

The project, launched in autumn 2015, has a specific background. It had already been submitted to Tempus Public Foundation, the national agency for Erasmus + applications in Hungary, in the previous tender cycle of spring 2014. Although professional reviewers in their evaluation acknowledged the project design and underlined how much it fitted DI strategies that had earlier begun in the region, the elaboration of a training content and its trial in higher education were declared necessary in order to guarantee long-term feasibility (with a focus on human resources) of the DI procedure. FSZK invited two faculties of Eötvös Loránd University (ELTE), Bárczi Gusztáv Faculty of Special Needs Education and the Faculty of Social Sciences, to join the project.

At both faculties the focus of research has recently shifted from institutionalisation to equal access to community based living and employment services. Ágnes Lányiné Engelmayer (2002) and Péter Zászkaliczky's research on group homes (1998) are still fundamental documents of the Hungarian process of DI. Katalin Tausz (1997, 2015), György Könczei (1991, 1994) and Csaba Bánfalvy (1997, 2005) embed fundamental issues of social inclusion of people with disabilities into the context of social policy and occupational rehabilitation. Research results by Gyula Hatos (2015), Katalin Radványi, Enikő Regényi, János Csorba (2013), Eszter Márkus (2003), Anikó Sándor (2017) and Tünde Bulyáki (2016) improve the quality of life primarily of those most involved in the process, i.e. individuals with intellectual disabilities, high support needs and psychosocial disabilities (Cserti-Szauer–Losoncz 2017)

Thanks to the strong professional links of the two faculties and the traditionally good cooperation with advocacy organisations, besides the academic knowledge base, the practical experiences of these organisations as development partners are also incorporated in the course that was offered on Bachelor's level in the autumn semester of the 2017/2018 academic year. The involvement of the National Council of Associations of Persons with Disabilities (FESZT) and the Association of ÉFOÉSZ Veszprém County is an extremely credible value added during the training. (Cserti-Szauer–Losoncz 2017)

2.2. Training development project

Training development carried out in the framework of the PODIUM project is related to the current process of demolition of the institutional culture in Hungary and aims at strengthening the supported living service network from the perspective of training professionals.

In the framework of the PODIUM project, training developers seek to attract potential key people (Katona 2012) who may take an active part in planning and managing the life course of people with disabilities. Social workers as well as special needs teachers may be involved in the operation of supported living services.

The training development presented here responds to the ongoing process of replacing residential institutions, in the preparation of key personnel with the tools of higher education and adult education, in an international and multidisciplinary approach, in order to provide persons with disabilities access to the local community,

so that segregated services could be replaced by mainstream solutions. The development enriches the professional training repertoire of the replacement process in partner countries with higher education and adult training elements. As a result of the Erasmus + project, 80 DI managers in the partner countries and 30 higher education participants in Hungary are trained.

BA students of both special education and social work were offered participation in the pilot training, in a course titled Theory and practice of supported living. The professional content and design of the course supports the implementation of the Convention on the Rights of Persons with Disabilities in Hungary. This is why, the following principles, together with the experience of the core training program developed by the international consortium, were focused on during the development process:

- Practice-centred approach; theoretical foundations and additional information were made available online for everyone. Expertise on decision-making is in the focus.
- Inclusive methodology is used both during the pilot training and in future courses.
- A method of project and work is implemented, which has useful end results for the communities of collaborating students and instructors.
- In order to maximize the opportunity for cooperation, the course is announced jointly by the two faculties.
- Perspectives of people with psychosocial disabilities, besides 'classic' disability areas and expertise, are articulated.
- We work in a team teaching model, we use various co-operative techniques and group work, to underline the importance of collaboration of the special educators in team work.

The course was designed by three participatory co-teachers, four experts working in the non-profit sector, and eleven colleagues of ELTE Faculty of Special Needs Education and the Faculty of Social Sciences, and it was attended by 31 students. The 20 lessons can be divided into five modules, which modules are arranged around question raising professional papers, text collections and thematic source lists, connected as follows:

- Discussion of the course methodology – Freedom of Learning
- Independent Living Movement, Self-Determination
- Human rights model and rights, empowerment
- Supported living and community-based services
- The interpretation of professional roles in Supported Living services

Joint work is supported by digital interfaces (Moodle and Facebook); professional publications related to the development can be accessed on the ELTE Digital Institutional Knowledge (EDIT) site from autumn 2017.

2.3. Inclusive focus

The inclusive seminar is an educational method related to the values of disability. This approach strengthens the participation of individuals with disabilities in discourses about them, interprets participation in new areas such as, for example, the academic world, the education of university students in higher education, and the idea that

professionals in the education of people with disabilities should never talk about them without them. The method provides opportunities for the cooperation of disabled and non-disabled teachers and train special education students together.

Inclusive seminars are carried out in cooperation by persons with disabilities who are not qualified teachers (participatory co-teachers) and non-disabled, qualified university teachers. The methodology has been tested at several courses of ELTE Bárczi Gusztáv Faculty of Special Needs Education (e.g. H*istorical aspects of disability and special needs education, in upper grades Lifelong Learning and intellectual disability, Support of adults with disabilities, and 'From the cradle to the grave' – death, dying, mourning.*

Students' feedback show that these seminars are inspirational, support them in the process of professional path finding, and contribute to the selection of specialisations. Participatory co-teachers add values that nondisabled qualified trainers could not provide. The participation of individuals with disabilities guarantees that topics discussed during the course (and in the related inclusive research) are indeed relevant for the community with disabilities, which increases the validity of professional procedures.

In addition to the inclusive seminars, participatory co-teachers, as members of the training team, take part in planning the course content, prepare for the class, analyze the teaching experiences of the lessons, participate in the support of student project work and in the evaluation process.

The methodology has also been adapted to the curriculum development of the PODIUM project. The training team monitors the work with qualitative research tools (ELTE Bárczi Gusztáv Faculty of Special Needs Education website 2017).

In October 2017, the method was awarded the International Development of Higher Education prize by Tempus Public Foundation, and the inclusive work was acknowledged with the following words on the awards ceremony: 'The involvement of persons with disabilities as instructors in seminars, and their preparation for this task, present a new approach in the practice of higher education. The programme can be utilised in various ways and adapted in research areas focusing on human beings, and contributes to the sensitisation of students and instructors to the needs of persons with disabilities' (Tempus Public Foundation 2017).

3. Summary

Somogyi and Tausz, in their problem raising paper about supported living, say: 'Persons' with disabilities rights to freedom and dignity can only be fully enjoyed if they are considered autonomous beings: self-determination, freedom of choice, is a prerequisite for living with dignity. In other words: depriving a person of self-determination means being deprived of human dignity' (Somogyi–Tausz 2017, p. 3). Enjoying these fundamental rights constitutes the basis for realising the right to living a self-determined life and inclusion in the community.

At the end of the previous century, Independent Living movements evolved in Hungary and began fighting for the respect of human dignity and the right to self-determination. Looking back from 2017, we are amazed by the power and tremendous work of some advocating NGOs, rehabilitation specialists and committed politicians, which resulted in the creation of one of the most important legislative milestones in Hungary, the Act No. 26 of 1998 on assuring equal opportunities for persons with disabilities. They also became part of the National Disability Council, created the National Disability Program and participated in the development of services and

social consultation. It is, however, still unclear where enthusiastic and committed professionals and politicians had disappeared from the sides of those fighting for people with disabilities, and without whom it was finally not possible to complete the DI program of large residential institutions until the statutory deadline (January 1st 2010). The enthusiastic professional, methodological preparatory work at the turn of the millennium, slowed down for the second half of the 2000–2010 period, and gained renewed strength after the ratification of the UN CRPD. The Deinstitutionalization Strategy (2011–2041) and the subsequent (2017–2036) refer specifically to the self-determination of people with disabilities, identifying it as a target for projects funded under operational programmes and contributing to the development of access to community services.

The answer given by higher education to the declared policy challenges on the community inclusion of people with disabilities can be placed in the matrix system of education, research, development, forming attitudes, key personnel preparation and vocational competence concepts at all levels of training.

Applying the inclusive seminar methodology is recommended in the preparatory phase of the special needs teacher training program, with focus on courses on the provision of services for disabled persons. Students who choose to study special education are most likely to have increased sensitivity, interest, and commitment to supporting individuals with disabilities, their rehabilitation, self-determination, and social inclusion. But it is easy to see that this is rather at a cognitive level. At the inclusive seminars students are have an opportunity to directly experience partnership in interaction with people with disabilities, as well as in professional discussions with seminar leaders.

The training development, presented in this study, sought, both in the content and methodology, to include valid policy contents related to transformation. During the course, students elaborated topics from the full range of the topic of DI, which was presented during the project celebration. In each project students worked in close cooperation with participatory experts, and covered the following topics:

- creating supported living services for people with intellectual disabilities,
- the needs of persons with physical disabilities in the field of supported living,
- activities carried out by the group 'self-determined life – living in community',
- guardianship and supported decision-making in domestic judicial practice,
- after-care in state care for adults with special educational needs,
- how to create supported living services?

The link between practice and policy is justified by the fact that, due to the increased professional interest in the pilot training, the project day was opened by the Head of the Disability Department of the Ministry of Human Capacities. The main objective of the PODIUM project is to develop a curriculum that will help move from large residential institutions to community-based living services. While the majority of partners are directly involved, ELTE will target prospective special education and social professionals who will be potential participants in the process in the future. Our work is not only innovative because it uses modern pedagogical tools such as project method, cooperative learning, and the team teaching model, but because the curriculum developers at the Faculty of Special Needs Education were the first to use the inclusive methodology in higher education in Hungary.

The Theory and Practice of the Supported Living seminar both in its contents and in its methodology, perfectly fits the content of the special education program, the

community and values that the Faculty represents. Péter Zászkaliczky, the dean of the faculty, in his greeting on the website of the faculty, says:

'All that is, in the slogan of the faculty – With knowledge for an inclusive country'- so well described: With the professional, scientific knowledge and the know-how built on it, the members of the community of the faculty learn, teach and do research to contribute to the creation of a society that does not exclude anyone from any mainstream institution in which the information, goods and services are equally accessible, in which everyone is a part and a valuable part of the community.'

[1] Decision No 1257/2011 (VII. 21.) On the deinstitutionalization strategy for the replacement of social care facilities for persons with disabilities and government tasks related to their implementation

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