FROM EQUAL OPPORTUNITIES TO TAYGETUS?

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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)

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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.

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