

# HUMAN RIGHTS IN CHILDBIRTH EASTERN EUROPE CONFERENCE

roditelji u akciji

Zagreb, Croatia, April 2015

## **Conference Papers**

Editor: Elena Ateva

Human Rights in Childbirth Eastern Europe Conference Zagreb, Croatia April 2015 Conference Papers

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### **INTRODUCTION**

By Elena Ateva

Women in Central and Eastern Europe face unique challenges in achieving the full realization of their human rights in pregnancy and childbirth. From restrictions on accessing healthcare for out-of-hospital birth, to the wide-spread use of informal payments to secure respectful treatment at birth, and legislation restricting C-sections, the rights of women are at stake in every aspect of maternity care. At the same time, women themselves have been spearheading the process of putting their rights on the agenda. In small groups, often even without a formal structure, women in Eastern Europe have managed to bring attention to the violations that they experience in childbirth, to engage researchers to study the topic, and to demand accountability through legal and political means. This is a superb manifestation of the power of women's voices.

This collection presents conference papers that were written as a result of the first Human Rights in Childbirth Eastern Europe Conference held in Zagreb, Croatia in April 2015. The program comprised of six panels of speakers from different backgrounds, including activists, lawyers, midwives, and doctors. They offer their unique perspective on human rights in childbirth through their research, activism, litigation or personal experience. Each panel begins with a personal story of a woman because we believe that it is the stories women share that ground our work in the realities of women's lives and experiences. Two workshops are also presented. They provided an opportunity for more in-depth exploration of specific issues.

I would like to thank Daniela Drandić and the whole team at RODA who worked tirelessly to make this conference a reality in a very short time frame. I would also like to thank the Human Rights in Childbirth Board and specifically, Nicholas Rubashkin, Hermine Hayes-Klein and Nicola Philbin, who provided invaluable input in the planning of this conference. Special thanks to the other members of the Steering Committee Zuzana Krišková, Janka Debrecéniová, Jette Aaroe Clausen whose wisdom and support I appreciated at every step.



This conference was organized under the auspices of the Ministry of Health and Office for Gender Equality of the Republic of Croatia. We appreciate the financial support of our donors, the Open Society Foundation, the City of Zagreb, Birthrights UK, and the Committees for Gender Equality in Krapinsko Zagorska and Osjecko Baranjska Counties whose contributions made it possible to gather activists, medical practitioners, and attorneys from the region and to produce these conference papers.

#### **ABOUT ELENA ATEVA**

Elena Ateva is a human rights attorney and an activist for women's rights in childbirth. She co-founded Rodilnitza, a non-profit organization in Bulgaria since 2009, to advocate for human rights in childbirth. In 2014, she joined Human Rights in Childbirth as the Eastern Europe Legal Advocacy Coordinator and later as a member of the Board of Directors. Previously, she has worked on domestic violence and trafficking in women issues in Bulgaria and the United States. Elena has worked on national human rights education campaigns in Bulgaria, focusing on the right to informed consent, the right not to be separated from your baby, and the right to privacy and respect during childbirth. She is particularly interested in utilizing UN human rights mechanisms for the protection and full realization of women's rights in childbirth.





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By Stefánia Kapronczay

Welcome everybody! It is indeed a **great honor** for me to offer opening remarks to the first Human Rights in Childbirth Eastern Europe conference. I vividly remember when I **received an email** from an enthusiastic American lawyer living in the Netherlands asking me about the case Ternovszky v. Hungary - he home birth case of the European Court of Human Rights. This lawyer was Hermine Hayes-Klein, who I am sure is watching us today. **Frankly, I was surprised** that people outside of Hungary, outside of a relatively small community of human rights lawyers and mothers, not only heard about the ruling, but also understood the importance of it. The court had ruled that the right to privacy contained the right of women to choose the circumstances, including choosing the place, of giving birth. Fast-forward several months later, I found myself with Anna Ternovszky, the woman the case is named after, in The Hague with many other brave and smart people from various backgrounds, from different parts of the world. That was the **pivotal moment** when the Human Rights in Childbirth movement was born.

When I look around today, when I read the list of speakers, I see again **people from various backgrounds:** mothers, activists, lawyers, human rights advocates, researchers, midwives, doulas, journalists, ob-gyns, neonatologists, and people representing international organizations, The diversity of the crowd is both hopeful and symbolic at the same time.

**The diversity is symbolic** of the many types of professions, of people who **demand a say** in women's choices about *whether or not to give birth and how to do so*. There are so many people who demand a say in decisions in women's choices over their own bodies. This is a diverse crowd. However, I must say that proportionally there are fewer doctors and politicians than the usual when it comes to being vocal about what women shall do with their bodies.

The topic of **human rights in childbirth is a newcomer** to the reproductive rights and women's rights agenda: a movement that has traditionally been more concerned with women not wanting to have children. However, the rights violations



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in childbirth are very similar to violations in other women's rights issues and are all deeply rooted in paternalism. Therefore, it is **difficult to say something new** about the phenomenon of paternalism and women's choices. I'll give you a few examples of what is going on in the other women's rights issues in our countries.

Even though the countries we represent here are among the developed countries, and many are members to the European Union, women still often face oppression and paternalism is part of everyday life and politics.

**1. Access to contraception** is often subjected to ideology-based policy-making.

The **percentage of seats held by women in national parliaments** is shockingly low in countries of the European Union (2014): Croatia and Poland 24 %, Greece 21 %, Bulgaria and Czech Republic 20 %, Turkey 14 %, Hungary 10 %. Women's choices are at the hands of legislative bodies mainly consisting of male politicians who decide the amount of control over female bodies. Predominantly male politicians view contraception in many countries as something **sinful**, and especially the need for emergency contraception is seen as something only women shall be blamed for.

2. Abortion has probably been for the longest time on the agenda of reproductive rights activists. The Center for Reproductive Rights published a report in 2014 under the title A Map of Progress. This map shows that since 1994 thirty-five countries have expanded the grounds on which women can access abortion services. Despite the progress, there are alarming tendencies in European countries that pride themselves on being the cradle of civilization. Starting with my home country, **Hungary**, has enshrined into the Constitution that fetal live deserves protection from the moment of conception. This and other public statements by state officials on abortion have created an atmosphere in which restriction of access to abortion can be realistically expected. In Spain, the government has eventually withdrawn its drastic proposal that would have made abortion illegal except in case of rape or when the mother's health is at risk. At the same time, there is an ongoing campaign calling on Spain's ruling Popular Party to withdraw a bill that would force 16 and 17-year-old girls to obtain the consent of their parents to terminate a pregnancy, even in cases in which the requirement could place them at risk of serious conflict, violence, or abuse. In Lithuania, in spring 2014 a draft was in front of the Parliament, which was another attempt by the state to regulate public morals at the expense of women's right to privacy, health and life. Although abortion is currently legal in Romania under certain circumstances, in the last few years there have been repeated attempts to impose excessive limitations on



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access to abortions at the expense of women's rights. In 2012, there was a draft bill that sought to make it mandatory for women seeking an abortion to first attend a "counseling" session. During this counseling session, women would have to see videos and images showing that abortion is in fact a termination of life, after which they would have to wait five days before finally being able to access an abortion. **Poland** is long known for its restrictive abortion laws, which are even made harsher in reality because of the abuse of conscience clauses. Public health insurance in **Bulgaria** does not cover any methods of contraception, nor abortion, unless it is performed for medical reasons.

#### 3. Violence against women

Domestic violence is probably the most brutal representation of the oppression of women. The ways in which authorities handle these cases and the reaction of politicians to those cases becoming public shed light on the real state of gender equality. **Turkey is notorious for its abuse of women.** Despite the topic being a taboo in the country, the brutal murder of a university student fighting off an attempted rape has triggered public uproar in which thousands of Turkish men have protested for ending violence by wearing a miniskirt.

This will also bring me to my point about why I find the diversity of this crowd immensely hopeful.

Whether we are talking about having a child or the way to have it, women often meet with judging, public disapproval, or shaming about their choices. Childbirth is no different in that regard. I have collected a couple of characteristics, all representations of paternalism that underline the similarity of this and other women's rights and reproductive rights issues:

- 1. Women wanting to make a decision about their life and their bodies are often labeled as **selfish**. "These reckless women do not understand that it is about the baby, they should consider the interest of the child!" Women are not only reduced to a mere vessel of future generations in debates about abortion, but our privacy and dignity is similarly infringed by disrespectful and abusive treatment in childbirth. Women's consent is too often not sought because the only issue taken into account is the presumed interest of the child. Presumed by strangers, like doctors and politicians, not the child's mother.
- 2. We will hear about the overuse of care, too many interventions in childbirth, from the presenters. One read of this can be the representation of paternalism, of the belief that **women are incapable of making decisions**. Women cannot



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even be trusted with birth, which their bodies is designed for. Therefore instead of supporting the natural process – be it in hospital or home - women's bodies are subjected to interventions. Too many times, these interventions serve the convenience of the caregiver staff and the doctor, at least partially.

- 3. The issue of gender equality and the **proportion of women in decision-making bodies in charge of critical policy-making** must be mentioned as well. Women rarely make it to the top of the hierarchy, to the committees and gentleman's clubs. Predominately male professionals set the rules of the game: for instance, in Hungary there is only one female doctor in the obstetrics and gynecology professional committee among the 18 members.
- 4. **Professionals enabling women** to make the choices they deem the best, are often penalized for their support. The sentence to two years of imprisonment and the deprivation of liberty of Agnes Gereb is a sad example of that. Agnes's freedom of movement has been restricted since 2010, and she was sentenced to two years of imprisonment in 2012 for not following the rules of a different profession than the one she practiced. This sentence, in which the words of the supporting expert witnesses were not considered by the court, has come after years of harassment for offering an alternative to women.
- 5. A frequent way to restrict women's choices is through **limiting funding** to certain procedures. The lack of financing of abortion services for example harms the most deprived women. The now-adopted Hungarian legislation on home birth also excludes state financing for home birth even if the woman has paid health insurance like everyone else. These policies send the message that "You might be allowed to have your choice, but the state will only pay for the right one!" Not only expressive regulations can contribute to the restriction of women's choice: informal payment pays a huge role in limiting impoverished women's choices when it comes to decisions about the circumstances of giving birth.

As I said in the beginning there is **hopefulness** to the diversity of the crowd in this room. As a lawyer and an activist, I would be less positive if there were only lawyers and activists in the room today. The diversity, both occupational and gender-wise means that we have already come a long way, made allies who understand the importance of the issues of human rights in childbirth. The issue is on the agenda of researchers; it cannot be swept under the carpet by professional committees of doctors. Even the WHO, which is not the most progressive institution in the



By Stefania Kapronczay

world, has issued a statement about the prevention and elimination of disrespect and abuse during childbirth, urging greater emphasis on the rights of women.

The fact that we have come a long way does not mean that we can lean back and enjoy our coffee break. I urge you to work on maintaining these collaborations in order to show decision-makers that these issues cannot be swept under the carpet anymore. I am positive that the professionalism, passion and solidarity of this crowd will eventually convince everyone that women's rights are human rights and this shall be the defining principle of decision-making. I wish you all a fruitful two days and make many connections to expand the circle of solidarity.

Thank you!

#### ABOUT STEFÁNIA KAPRONCZAY

Stefánia Kapronczay graduated cum laude from the Faculty of Law at ELTE as a lawyer, and has also completed a five-year master program in sociology in 2010. Kapronczay started working at the HCLU in 2005 and she was the Head of the Patients' Rights Program from March 2008 to August 2012. As program director Kapronczay lead HCLU's effort to stop restrictions on reproductive rights, criminalization of homelessness and foster the rights of persons with disabilities. Between August 2012 and July 2013 she was a scholar at Stanford University, attending courses on human rights and public interest work and graduating as Master of the Science of Law. Kapronczay was elected as the Executive Director of the HCLU in July, 2013. She was elected as the co-chair of INCLO in May, 2014.



## PANEL 1 HUMAN RIGHTS IN CHILDBIRTH

Women do not lose their human rights when they become pregnant and give birth. In the last few years international organizations have started to acknowledge the whole range of human rights at stake in childbirth, including the rights to autonomy, privacy, and physical integrity. The International Federation of Gynecology and Obstetrics and the International Confederation of Midwives recognize the human rights violations that women face in childbirth and announced the mother and baby-friendly hospital initiative. Researchers are advocating for a whole-system approach that firmly places the needs of women and their newborn infants at its center and provides skilled care for all.

Moderator: Willma Kolenc, Activist, Slovenia

Speakers: **Dr. Claudia Hanson**, Co-chair, Committee on Safe Motherhood and Newborn Health, International Federation of Obstetrics and Gynecology

**Dr. Alison McFadden**, Senior Research Fellow, School of Nursing and Midwifery, University of Dundee, Scotland





### **A BIRTH STORY**

By Willma Kolenc

My name is Willma, I'm from Slovenia and I'm writing you my story as a mother. I'm a mother of four and my first birth is the reason I'm a birth activist and my other births are the reasons I'm passionately in love with birth.

So what happened at my first birth?

I can tell you because even after 11 years I do remember it very well.

I remember, when I was admitted to the hospital I received drugs and because I wanted to know what I was receiving and what the drugs are for, that I was labeled as "difficult patient". That hurt my feelings. I felt humiliated.

I remember that the midwife was nice, however, when she was - without my consent or prior information on the procedure - manually opening my cervix and I cried out in pain, all she did was tell me "I have to do this, you know!"

I trusted her completely but I felt violated.

When my midwife allowed me to start pushing I pushed, but then she pushed my baby back in because she was not ready yet, she was not ready for my birth. She was yelling at me not to push and I wanted to be good, I wanted to please her. So despite the fact that I felt like vomiting because of holding off the need, the force to push, I tried to restrain myself, I tried not to push.

Then she performed an episiotomy. The pain was unbearable. I cried in pain and she said "I have to do this, you know!" Today I know she damaged my gland and nerve, consequently I have to live with constant pain in the perineum and I will live with this pain for the rest of my life. It makes me cry every time I remember this story.

Finally it was time to give birth and I had to push on command no matter if I had a contraction or not. I felt like my body is broken, defected, as I'm not good enough. I felt wrong.

After the birth they took my baby to be cleaned. It made me feel dirty, I felt I'm not good enough for my baby, like I'm too dirty to be his mom.



The sad part is that for some years I believed I had a wonderful birth and as a birth activist I see that every day.

Luckily I was brave enough to discover the truth about childbirth and I was even more courageous to experience three more births that I can describe as blissful, magical, orgasmic, respectful, peaceful...

PS: I'm also the founder of the International Home Birth Day - on this occasion I invite you to celebrate with us safe home birth practice every year on the 6th of June.





### FIGO MOTHER/BABY FRIENDLY BIRTHING FACILITY INITIATIVE

#### By Dr. Claudia Hanson

With its guidelines on Mother-Baby Friendly Birthing Facilities, FIGO aims to raise the attention of maternity staff, associations of obstetrics and gynecology, and health ministries to the neglected area of dignity in childbirth and respectful maternity care. This stands in the tradition of FIGO's strong advocacy for women's sexual and reproductive rights and FIGO's vision to strive for the women of the world to achieve the highest possible standards of physical, mental, reproductive and sexual health and wellbeing throughout their lives. The initiative is grounded in well-recognized international human rights declarations, such as the International Covenant on Economic, Social and Cultural Rights in 1976, The International Covenant on Civil and Political Rights in 1976, and others.

FIGO, a professional federation bringing together 125 professional societies of obstetricians and gynecologists worldwide, acknowledges with these guidelines the particular responsibility professionals organizations have to ensure that the rights of women and their babies are protected, especially during the sensitive time around birth.

In the Mother- Baby Friendly Birthing Facility guidelines, FIGO underlines that every woman has the right to a positive birthing experience and to compassionate care from knowledgeable, skilled providers who accept that each woman, family, and newborn is unique and deserves individual, dignified care. Our call for more attention to and assessment of facilities is backed by an increasing number of publications and reports from different settings in low, middle and high income countries alike, describing that the care provided to mothers and babies does not always adhere to minimum standards of respect and dignity.

We believe that every woman has the right to be treated with respect; she should be protected from unnecessary and harmful practices and should have access to the best available quality of care. The FIGO Mother-Baby Friendly Birthing Facility initiative links to several other initiatives and documents, such as that of the World Health Organization on "The prevention and elimination of disrespect and abuse during facility-based childbirth" [1], the statement of the Universal Rights of Childbearing Women of the White Ribbon Alliance (WRA) [2], and "The International



FIGO MOTHER/BABY FRIENDLY BIRTHING FACILITY INITIATIVE By Dr. Claudia Hanson

Mother-Baby Childbirth Initiative", promoting 10 steps towards optimal care for mothers and their babies [3]. FIGO's guidelines complement these initiatives, recognizing that FIGO's many member societies have a special responsibility to protect the rights of mothers and babies.

The guidelines aim to initiate a process of continuous improvement towards Mother–Baby Friendly Birthing Facilities. Ten criteria were developed (see also table 1): the free choice of mobility and positions of preference for labor and birth; non-discriminatory policies for the treatment of women with HIV, young women, minorities, etc. ; privacy; choice of birth partner; culturally competent care; no physical, verbal, emotional, or financial abuse; affordable or free maternity care; adherence to evidence-based interventions; non-pharmacological and/or pharmacological pain relief as required; and the promotion of immediate skinto-skin mother–baby care and breastfeeding in line with the baby-friendly hospital initiative. These criteria are not exhaustive, and others might be relevant in certain settings. However, our set of criteria cover many different areas and are relevant globally.

We are aware that for some aspects and indicators, no absolute thresholds or clear lines exist. For example, in many low-resourced maternity wards, curtains to ensure privacy might be the only affordable option, whereas in high-resource settings, separate rooms are the attainable standard. Caesarean section rates are much higher than necessary in many settings to ensure the highest attainable health of mothers and babies. Still, maternity wards and health workers operate in very specific legal, socio-cultural and health system settings. Such systemic factors may lead to higher levels than necessary, even if maternity staff in individual facilities are doing their best to only perform the absolutely necessary Caesarean sections.

We call upon maternity staff, maternities, associations of obstetrics and gynecology, and health ministries to start the process of striving towards and documenting adherence to the Mother- Baby Friendly Birthing Facility proposed criteria and indicators. Experience is needed to evaluate the relevance and feasibility of the indicators and assessment options.

We hope with these guidelines to initiate a positive discussion and change process. In this process, it is important to recognize that maternity staff, obstetricians, midwifes and nurses are part of an overall system which can only be changed in steps. Health workers need to be encouraged and see the positive elements in the promoted changes. Constructive discussions between patients' associations, rights activists, and maternity staff are an indispensable basis for a positive and sustainable change. By Dr. Claudia Hanson



#### Table 1

Summary of criteria and indicators for qualifying a facility as mother and newborn friendly.

Criteria	Indicators
Adopt preferred positions for women in	Written policy and implementation as
labor and provide food and beverages Nondiscriminatory policy for HIV-positive women, family planning, youth services, ethnic minorities, etc.	observed during care Implementation of guidelines for HIV- positive women, family planning, and youth services
Privacy in labor/delivery	Curtains, walls, etc observed
Choice of birthing partner	Accommodation of partners, including traditional birth attendant observed
Culturally competent care	Trainings, posters, policies, direct observations of care
No physical, verbal, emotional, or financial abuse	Written policy, display Charter of Human Rights, no abuse observed, exit questionnaires for mothers/families/ partners
Affordable or free maternity care	Costs clearly posted and in line with national guidelines
No routine practice	Evidence-based interventions in protocols and seen in direct observation
Nonpharmacological and pharmacological pain relief	Training on pain relief, direct observation of relief methods
Skin-to-skin mother-baby care and breastfeeding	Protocols/policies on combined care of mother and baby, immediate breastfeeding, observations of care

Set of criteria and indicators [4]



#### FIGO MOTHER/BABY FRIENDLY BIRTHING FACILITY INITIATIVE

By Dr. Claudia Hanson

#### **References:**

- 1. WHO. The prevention and elimination of disrespect and abuse during facility-based childbirth. 2014 [cited 2015 March]; Available from: http://apps.who.int/iris/bitstream/10665/134588/1/WHO\_ RHR\_14.23\_eng.pdf?ua=1&ua=.
- White Ribbon Alliance. The Universal Rights of Childbearing Women [cited 2015 May]; Available from: http://whiteribbonalliance.org.s112547.gridserver.com/wp-content/uploads/2013/05/Final\_ RMC\_Charter.pdf.
- 3. The International MotherBaby Childbirth Organisation. *The International MotherBaby Childbirth Initiative.* [cited 2015 May]; Available from: http://www.imbci.org/.
- International Federation of Gynecology Obstetrics, et al., *Mother-baby friendly birthing facilities*. International Journal of Gynecology & Obstetrics, 2015. 128(2): p. 95-99. Available from: http://www. ijgo.org/article/S0020-7292(14)00545-1/pdf.

#### ABOUT DR. CLAUDIA HANSON

Dr. Claudia Hanson is a global health expert with special interest in improving health systems and health care for mothers and their newborns. She has been a member of the FIGO Safe Motherhood and Newborn Health committee since 2009 and has been one of the key initiators of the Mother-Baby friendly birthing facility initiative of FIGO. Trained as an obstetrician in Germany and France, she has further post-graduate education in international health and epidemiology and has a PhD from the London School of Hygiene and Tropical Medicine on determinants of maternal mortality in Southern Tanzania. She has worked for 6 years in Tanzania in implementation and research to support district health systems and community interventions in the field of reproductive health and HIV/AIDS prevention, care and mitigation. Claudia is a researcher at Karolinska Institutet, Stockholm, Sweden and has an honorary lectureship at the London School of Hygiene and Tropical medicine. She has several research projects ongoing in East Africa to describe problems in access to care and evaluate interventions to improve uptake of services around birth. She is teaching in various MSc courses on maternal and newborn health and health systems.





### REALIZING THE RIGHT OF EVERY WOMAN AND BABY TO THE BEST POSSIBLE MATERNAL AND NEWBORN CARE: THE CONTRIBUTION OF THE LANCET SERIES ON MIDWIFERY

By Alison McFadden and Mary J Renfrew

It was a great honor to attend the Human Rights in Childbirth Eastern Europe and to present the Lancet Series in Midwifery. It was also a privilege to meet so many enthusiastic attorneys, human rights advocates, researchers, midwives, doctors, students and parents who are committed to improving the quality of maternity care across Eastern Europe.

During the two-day conference we heard many moving personal stories about giving birth in Eastern Europe. We also heard presentations of surveys of women's views and experiences of maternity care in Eastern European hospitals. The common themes in these birth stories and surveys, across several countries, were that women's and babies' rights are frequently violated; for example routine procedures carried out without consent, lack of respectful care, lack of privacy, and lack of autonomy to make decisions about their care. Women giving birth in hospital rarely have access to supportive midwifery care and there are very limited options for out-of-hospital care. This means that women and babies do not have access to evidence-based care that could improve their short and long-term health and wellbeing.

How can the Lancet Series in Midwifery help advocacy efforts for the right of every woman and baby to receive the best possible maternal and newborn care? The first paper in the Series "Midwifery and quality care: findings from a new evidenceinformed framework for maternal and newborn care" by Renfrew et al<sup>1</sup>, provides a new evidence-informed Framework for Quality Maternal and Newborn Care that firmly places the needs of women and newborn babies at its center. The framework is based on a definition of midwifery that considers skills, attitudes and behaviors rather than specific professional roles. It also considers the WHAT of care (effective practices), the HOW care is provided (organization of care, values and philosophy) and the WHO provides care. The Framework for Quality Maternal and Newborn Care was initially developed by 35 expert Series' authors from around the world



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including specialist midwife researchers, service user advocates, public health and policy experts, and clinical experts: midwives, obstetricians, pediatricians; health systems analysts, demographers, statisticians, epidemiologists, health service researchers, social scientists and health economists. The framework was then refined and tested based on a series of systematic reviews.

The main source of evidence for the WHAT of care (effective practices) was the 453 systematic reviews contributed by the Cochrane Pregnancy and Childbirth Group to the Cochrane Library<sup>2</sup>. Importantly, the rigorous methods used in Cochrane reviews are recognized internationally as the highest standard in evidence-based health care. Paper 1 of the Lancet Series provides a list of effective and ineffective practices (see Panel 2, pages 6-7). Examples of the 72 identified effective practices within the scope of midwifery include: continuous support during labour<sup>3</sup>, upright positions during the first stage of labour<sup>4</sup>, immersion in water during the 1st and 2nd stage of labour<sup>5</sup>, restrictive/limited use of episiotomy<sup>6</sup>, and skin-to-skin mother baby contact within 24 hours of birth<sup>7</sup>. These are all practices which have been shown to improve outcomes for women and babies.

In paper 1, we also highlight ineffective practices i.e. practices that appear to provide no benefit for women or babies and therefore should be abandoned. These practices include: perineal shaving on admission in labor, enemas during labor and amniotomy for shortening spontaneous labor. Fundal pressure/Kristeller maneuver which is widely-used in Eastern Europe and was the focus of much discussion at the conference was not included as either an effective practice or an ineffective practice. A Cochrane review of fundal pressure during the second stage of labour<sup>8</sup> found that there was no evidence available to conclude on beneficial or harmful effects of manual fundal pressure. We hope that you will use this robust evidence reported in the Lancet Series to advocate for women and babies to have access to effective practices and for abandonment of routine use of ineffective practices.

An important issue raised during the conference was that many Eastern European countries report low rates of maternal and infant mortality allowing governments to deny that there are any problems with the provision of maternity care. This disregards the needs of all women and babies for skilled and compassionate care that improves their physical, mental and emotional health and wellbeing. The Lancet Series argues that women and babies deserve midwifery care that combines prevention and support, early identification and timely management of complications, respectful and compassionate care, helping to strengthen women's

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own capabilities, and promoting the normal processes of pregnancy, birth, and breastfeeding. This approach reduces the rates of unnecessary interventions. Midwifery care, as defined in the Lancet Series, is most effective when provided by skilled midwives who are educated to international standards, regulated and integrated into the health system.

There is no doubt that implementing the Framework for Quality Maternal and Newborn Care across Eastern Europe will be challenging. It will require tackling systemic barriers such as lack of understanding of what midwifery is and what it can contribute, lack of education and regulation of midwives to allow them to practice the full scope of midwifery, lack of collaborative team work, and informal commercialization of childbirth. However parents, health care providers, attorneys, human rights advocates and researchers can form a powerful alliance to advocate for change. The Lancet Series Framework for Quality Maternal and Newborn Care provides evidence and guidance to support this. Those struggling to have their voices heard in Eastern Europe can draw strength and support from the fact that global organizations and a range of countries are working to disseminate and use the evidence in the Lancet Series.

Various materials to support advocacy efforts and that can be used for teaching and dissemination are available through the midwives4all campaign (http:// midwives4all.org), Midwifery Action (http://midwiferyaction.org) and a series of films about the Lancet Series at http://www.youtube.com/user/midwiferyaction.

#### References

- Renfrew MJ, McFadden A, Bastos MH, Campbell J, Channon AA, Cheung NF, et al. 2014 Midwifery and quality care: findings from a new evidence-informed framework for maternal and newborn care. *Lancet*; 384(9948):1129-45.
- The Cochrane Collaboration Pregnancy and Childbirth Group. Reviews published in the Cochrane Library, Issue 6, June 2014. 2014. http://www.thecochranelibrary.com/view/0/index.html (Accessed June 4, 2014).
- Hodnett ED, Gates S, Hofmeyr GJ, Sakala C. Continuous support for women during childbirth. Cochrane Database Syst Rev 2012; 10: CD003766.
- Lawrence A, Lewis L, Hofmeyr GJ, Dowswell T, Styles C. Maternal positions and mobility during first stage labor. *Cochrane Database Syst Rev* 2009; 2: CD003934.
- 5. Cluett ER, Burns E. Immersion in water in labor and birth. *Cochrane Database Syst Rev* 2009; 2: CD000111.



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- 6. Carroli G, Mignini L. Episiotomy for vaginal birth. Cochrane Database Syst Rev 2009; 1: CD000081.
- Moore ER, Anderson GC, Bergman N, Dowswell T. Early skin-to-skin contact for mothers and their healthy newborn infants. *Cochrane Database Syst Rev* 2012; 5: CD003519.
- Verheijen EC, Raven JH, Hofmeyr GJ. Fundal pressure during the second stage of labor. Cochrane Database of Syst Rev 2009, 4: CD006067.

#### ABOUT ALISON McFADDEN

Alison McFadden is a midwife and health researcher at the University of Dundee. She qualified as a midwife in 1981 and, after 10 years practicing as a midwife in the UK and Malawi, Central Africa, she took up a post as a Senior Lecturer in Midwifery and Women's Health at Teesside University. During her 15 years in this post, Alison led 18 month and three-year degree Programmes of Midwifery Education and gained a Master's degree in Education. In 2006 she studied full-time at the University of York with Professor Mary Renfrew to gain a PhD in Health Sciences. From 2010 Alison has worked in the Mother and Infant Research Unit, first at the University of York and then from 2013, at the University of Dundee. Her research interests are inequalities in maternal and infant health and nutrition with a particular focus on the experiences and support needs of women and babies from low-income and marginalized groups. She is a member of the Executive Group and co-author of three papers in the Lancet Series on Midwifery. Her contribution to the first paper in the Series: Midwifery and quality care: findings from a new evidence-informed framework for maternal and Newborn Care.

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#### **ABOUT MARY J RENFREW**

Mary Renfrew is Professor of Mother and Infant Health and Director of the Mother and Infant Research Unit at the University of Dundee, where she is also Dean for Research in the School of Nursing and Health Sciences. She is a leading health researcher with a background in midwifery and nursing. She has conducted research in maternity care and in infant feeding for over 30 years, and her work has informed and influenced policy and practice in the fields of maternity care and infant feeding in the UK and internationally. She has advised WHO, UNICEF, and the International Confederation of Midwives, she has worked with the Cochrane Collaboration, and she is Principal Investigator for the Lancet Series on Midwifery, which is funded by the Bill and Melinda Gates Foundation.



## PANEL 2 RESEARCH AND ADVOCACY EFFORTS TO SECURE HUMAN RIGHTS IN CHILDBIRTH

From "breaking the silence" in Bulgaria and Croatia to monitoring and advocacy in Slovakia, activists and researchers have been busy bringing the violations that women face in childbirth to the forefront. European-wide grass-roots activism was indispensable in encouraging women to reveal the abuse they experienced in childbirth. Researchers started using a whole-systems perspective, incorporating women's views and experiences relating to maternity care across Europe.

Moderator:	Linda Roszik, Psychologist, Hungary		
Panelists:	Miglena Delcheva, Activist, Rodilnitza, Bulgaria		
	Daniela Drandić, Head of Reproductive Rights Program, RODA, Croatia		
	<b>Hartmann</b> , Political Activism Coordinator, Human Rights in Childbirth, Germany		
	<b>Dr. Nicholas Rubashkin</b> , Visiting Fulbright Researcher, Semmelweis University, Hungary		
	Zalka Drglin, PhD, Researcher, Natural Beginnings Society, Slovenia		
	Zuzana Krišková, Chairwoman, Women's Circles, Slovakia		
	Janka Debrecéniová, Lawyer, Citizen, Democracy and Accountability, Slovakia		
	Natalie Sedlická, Midwife, Jak Jinak, Czech Republic		





### **TELL YOUR STORY**

By Linda Roszik

My personal story shows exactly why it is so important to have women heard, to let those unpleasant stories come to the surface and get attention.

Couple of years ago I had a minor obstetrical surgery performed at a private clinic as the part of our IVF (in vitro fertilization) treatment. At the end of the procedure the most unexpected thing happened. As I was lying there on my back, half naked, legs apart, completely exposed - my doctor came to me and stopped at my side. No one else was there in the operating room. He smiled, and sad that he would like to express his support and good wishes – and as he said that he suddenly leaned over me and gave me two kisses on the cheek, one on each side. Since the operating table was high, in order to do so he literally had to lie on top of me with his (huge) upper body. I was completely powerless to stop him. As I was lying on my back the only "escape route" for me was upwards – that is towards him, however absurd it sounds. So my clumsy attempt to get out of the situation was trying to get up that actually resulted in moving towards him. But this was also the way for me to stop him from leaning on me completely, so the second kiss was at least somewhat... lighter.

This is not the end of the story, there is so much to it. First of all, right there, in the ward between other women his "supportive kisses" were casually mentioned as somewhat weird but "kind-ish gesture". So the process of normalization began immediately. It is much more pleasant to think that your doctor is supportive, even if a little weird, than to think that you were humiliated in a very vulnerable and powerless situation and you didn't do anything to stop it.

I had bad feelings about this all, but actually it took me 3 months to finally be clear about it, that I felt violated, that I was angry about what happened. And what made me realize it was the reaction of another woman. I told her about this doctor, other uncomfortable stuff (slightly sexual jokes etc.). When I told her about the kisses, her eyes went wide open and her jaw dropped in disbelief. She was shocked. This, her reaction was that finally helped me to say openly and confidently that what happened to me was wrong. That I was right to be angry about it. Even though I am a pretty brave and confident woman, in a situation when I was totally dependent on that doctor and needed his help I just couldn't be strong and stand up for myself. Not even right afterwards or the following months.

I am not saying this doctor was evil or intended to do harm. But he was completely blind to the situation, he was blind to and made use of his power, even if unconsciously. And most probably he never got a feedback from any of his patients. And this is our responsibility. About a year later I met this doctor on the street. He recognized me, smiled at me. As I walked up to him I started by asking him: "Do you know why I never went back to you?" I told him that his kisses were very inappropriate and that he should never do it again. He was pretty surprised



and told me defensively that "all right then, I will ask for permission next time." I told him to not do that, as most women in that situation (especially in an IVF procedure when they want him to help them have a child) will never refuse him, never say no to him. I suggested that he can express his kind support when he meets with his patients after the procedure, in his office, everyone fully dressed, women accompanied by their partners. Then he can ask if can give them a kiss. I'm not sure how well he understood it, but he apologized.

The good part of this story is that it made me realize that in a vulnerable, both physically and mentally challenging situation I want people around me who are respectful, gentle, and who are aware of the vulnerability of the situation. This is very important. This awareness helped me to choose wonderful birth companions who made me feel safe in every aspect. This made it possible for me to relax and give in to the experience, to have lovely and respectful births for our family, newborns and parents alike. I remember my birth experiences often, they are a great source of my inner strength.

Reassurance from my friend, and from women to other women generally, are just as important as feedback to doctors and caregivers so they understand the situation and what is going on in the situation better.

Let me finish with a quote from the American Journal of Obstetrics and Gynecology: "the influences of pain, pain relief, and intrapartum medical interventions on subsequent satisfaction are neither as obvious, nor as direct, nor as powerful as the influences of the attitudes and behaviors of caregivers."

So please, tell your story, and also tell it to your doctor, nurse and midwife.





### **ENERGIZING WOMEN TO SHARE THEIR STORIES**

#### By Miglena Delcheva

Rodilnitza, Bulgaria's NGO focusing on protecting women rights in childbirth, was founded in 2009 and officially registered in 2011. Since the first campaign in 2009 – NO to Violence in Childbirth – we have worked on a number of related topics as, for example, advocating for an improved Informed Consent process, First Contact Campaign (avoiding separation of mother and baby at birth); Why to Choose a Midwife (promoting the midwifery care model), and the right to have partner/doula at birth.

On November 25, 2013, Rodilnitza launched a new campaign – "Is it acceptable?" – questioning society's and general medical views on violence in childbirth, namely that some forms of violence are acceptable and even necessary for a better outcome or that there are situations where physical violence is needed to avoid or treat emergencies. A video slide show, created especially for the campaign, provoked the audience by pictures and questions on violence that would receive a "NO" in everyday circumstances but tend to be accepted as "YES" when referring to childbirth. The video went viral in a couple of days and many women started posting comments with their experience of violence in childbirth on Rodilnitza's wall on Facebook. This is how a campaign that started with a simple but powerful video continues now for more than a year, gaining public attention and comments, and reaching the attention of two Health Ministries.

<sup>1</sup> Is it Acceptable? - Challenging Violence in Childbirth, available at https://www.youtube.com/watch?v=6el\_UghVcuc



#### ENERGIZING WOMEN TO SHARE THEIR STORIES

By Miglena Delcheva

#### **ABOUT MIGLENA DELCHEVA**

Miglena Delcheva became a passionate birth activist after the homebirth of her first son in 2008. In 2009 she was part of the group of women who created Bulgaria's only NGO supporting women rights in childbirth – Rodilnitza – and since then has been actively participating in campaigns for humanizing hospital birth and informing society on women's rights to choose how, where and with whom they will birth, including the option of homebirth. In 2010, she completed successfully a national training as volunteer breastfeeding consultant and is providing free of charge breastfeeding support to new mothers. In 2011, she passed a DONA International doula training and is currently in her certification process. Her latest involvements have been to support the pan-European BBB study by translating and promoting it (reaching a third best rate of answers) and translating the Microbirth movie for a screening at the Bulgarian Midwives gathering in November 2014. In the meantime she continues working on Rodilnitza's annual campaign for stopping violence against women in childbirth and elaborating a strategy for improving maternity healthcare services.





### MOTHERHOOD, ACTIVISM AND COFFEE: HOW AN ORDINARY MEETING CAN HAVE A PROFOUND IMPACT

By Daniela Drandić

In November 2014 I had the pleasure of attending a home birth conference in Prague, Czech Republic, where I had the opportunity to meet and network with many advocates and maternity care providers from throughout Eastern Europe. During one of the coffee breaks, I struck up a conversation with an advocate from Bulgaria. Little did I know that from this seemingly unimportant meeting and discussion a regional campaign would spread and affect change in five countries.

Miglena Delcheva and I discussed the different issues facing maternity services in our countries and the ways we were working to affect change. Among other things, we discussed a Break the Silence Campaign that Rodilnitza had organized in Bulgaria, modeled after the sexual assault campaign "Project Unbreakable" in the United States. They invited women to describe in short their experiences during birth and take a photo of themselves holding up the short description, to be shared on social media. This campaign in Bulgaria had quite a large reach and put problems of maternity services and obstetric violence on the forefront of public discussion, and I thought that a similar effect would be had in Croatia.

Upon my return home I presented the idea to my colleagues, who were as I was, apprehensive about how well the idea would be received among Croatian women, for whom what goes on in the maternity ward is taboo and most often not discussed much less criticized. After all, if they and their child/ren left the hospital healthy, anything that happened in the process must have happened for a medically sound and scientifically justified reason. As the Sixteen Days of Activism against Gender Violence were coming up, which we usually marked with an online and social media awareness campaign on obstetric violence, we decided to make this year's campaign about **#BreakTheSilence**, or **#PrekinimoSutnju** as we translated it. We were prepared for the worst case scenario, which was to have only a few of our members and supporters send in their stories and have the whole thing end there. However, we failed to recognize the sheer power of social media, especially the social media of one of Croatia's largest parenting advocacy groups, which was 40,000 likes strong and growing.



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On November 25th we put up the first three stories on Facebook, my own, that of our social media editor and another member and invited other women to send their own stories in. We told women they could photograph themselves or hide their identity, it was up to them, but requested that they write the stories in brief and by hand. The response was lukewarm, with many women providing support and offering their own stories, while others stated that as long as mother and baby were "healthy" nobody should complain. Still others stated that doctors and midwives were overworked and underpaid and we should be happy with whatever care we got.

The next day we put up the few photo stories we had and had to start including other Facebook administrators to help moderate the onslaught of comments we were getting. We planned to continue this way until the end of the 16 Days, but on day four the stories were featured in one of Croatia's largest online news portals. In retrospect, we should have contacted them before the campaign began to ask them to cover it, but since we hadn't expected much of a response we didn't contact any media beforehand. That day, the story exploded. Over the next week obstetric violence and our #BreakTheSilence campaign were featured on the cover of every major newspaper and covered by every major news outlet, including online, print, television and radio. A taboo topic was becoming mainstream, the dams had broken and we were flooded with stories by email and telephone. Obstetric violence was THE topic of discussion. Within 7 days RODA's Facebook page had 5000 new likes, we had received over 500 stories and had appeared on every serious news show in the country.

Within a few days, RODA was contacted by the Ministry of Health who wanted to arrange a meeting about what to do on the issue. A seemingly benign action had led to the reaction from the state authorities we had been working for over the past twelve years! The meeting was fruitful and we left with four goals:

- 1. Start the Mother-Friendly Hospital Initiative in Croatia, with two pilot sites within the next two years.
- 2. Arrange for the publication of educational materials for pregnant women that would be paid for and distributed by the Ministry and written by RODA and maternity experts.
- 3. Arrange an obligatory communications course in the next two years for all healthcare professionals who work with pregnant women.

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4. Send inspection teams to all Croatian maternity wards to confirm the state of affairs and why women were being treated so poorly.

The Ministry admitted that the issues of obstetric violence were not new ones and that they had to be dealt with. This is what we had been waiting for! Inspection teams started their work in January and will complete by September 2015. Their preliminary results have unfortunately been quite telling, with practices, statistics and overall satisfaction varying from hospital to hospital, with many key statistics being reported to the Croatian Public Health Institute in one form while being calculated in the field in another form altogether. In September, we will know more and hopefully will have concrete statistics with which we can advocate for real change in the hospitals themselves.

(As a side note, when I spoke to Cristen Pascucci, one of the founders of the #BreakTheSilence Campaign in the United States and explained how successful we had been, she cried. She never expected her little social media campaign to have such an international impact.)

During the #BreakTheSilence campaign, we were contacted by a number of maternity care advocates from other countries in the region. The languages spoken in the countries of the Former Yugoslavia are quite similar and as such we were able to communicate easily. The issues in maternity care were also very similar across the region. We decided to find representatives from every country in the region and made a plan of action for International Women's Day, the week of March 8th 2015. Many Skype and Zoom meetings later, we had a plan of action set up with seven associations, each tailored to meet the needs of that organization and that country. The one thing we had in common was a name and hashtag that was the same across the region, #SlobodaPorodjaju (Freedom for Birth), a survey on satisfaction with maternity services (one of the advocates was a survey specialist who had worked for a global survey company – how fortuitous!) and a Walk for Freedom for Birth at the end of the week of March 8th.

The information collected through the maternity survey proved very valuable and every country used theirs as they saw fit. In Croatia, we published ours (it is available on www.roda.hr in English) and used it to form the basis of our CEDAW shadow report on maternity services in July 2015. Maternity services were in the media throughout the Former Yugoslavia during the week of March 8th 2015, and wheels of change began to spin in Serbia and Bosnia and Herzegovina especially. We had finally managed to move the issues from behind the closed doors of maternity units to the media, streets and cafes of the region.



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All this with no money, little time, lots of passion and driving forces for change, all beginning at an innocent conference coffee break in Prague. Unbelievable, isn't it?

What's more, many other interesting, organizational capacity building activities have come up from all this networking, including at least 3 EU and international grant applications being sent in the past four months, which have the potential to help our efforts have an even greater impact. Two Croatian hospitals are interested in becoming Mother Friendly Initiative Pilot Sites and maternity care providers are talking about decreasing episiotomy rates.

We didn't believe it was possible, until it was done. What are you waiting for?

#### ABOUT DANIELA DRANDIĆ

Daniela Drandić has been head of the Reproductive Rights Program at RODA – Parents in Action for the past four years. She is a Canadian expat and holds a degree from the University of Toronto. Ms. Drandić has organized conferences and public actions in the field of reproductive rights as they pertain to pregnancy and birth, and has successfully lobbied for changes in the maternal care system in Croatia, including the foundation of the Mother Friendly Hospital Initiative Working Group at UNICEF Croatia. She is a consumer representative at the Croatian Cochrane Centre and Country Representative for Croatia at Human Rights in Childbirth. Ms. Drandić compiled maternity hospital statistics for the website http://rodilista.roda.hr and will continue to work tirelessly to ensure that all women in Croatia have access to respectful, dignified and evidence-based care regardless of where they choose to birth.





By Katharina Hartmann

The Roses Revolution consists of the simple act of putting down a pink rose in front of the door behind which a woman gave birth suffering from obstetric violence. On the International Day for the Elimination of Violence against Women, November 25, women are invited to give expression to their suffering by this symbolic gesture.

Some women choose a real rose, whilst others prefer to use the Roses Revolution logo with the claim: Name it, each woman is a rose.



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The logo was created by Cuatro Tuercas after matriactivist Jesusa Ricoy Olariaga<sup>[1]</sup> had ideated the event in 2012 as a reaction against some very misogynistic cartoons about childbearing women in Spain.

I brought the idea home to Germany from the Human Rights in Childbirth conference in November 2013 in Belgium and I was intrigued by its simple beauty – a woman putting a rose down which represents herself, to regain the dignity others had denied her. What a powerful message and potential space for healing.

The first German Roses Revolution took place on November 25, 2013. After getting home from the HRiC conference, I had only 20 days to pull it together – so I basically just changed my own profile picture to the logo and put up a Facebook page<sup>[2]</sup>. On it, I put the description the event and then started to post affirmations like this: "Staff are not allowed to take your baby away without asking." People actively and respectfully started to comment and share these posts. I have no statistics for the first edition, but within a few days the page received 700 likes. Birth stories (which I had never asked for) started



By Katharina Hartmann

to arrive and groups of women formed to bring roses together at their hospital. Women wrote to describe the healing power they experienced by writing down their birth stories, by reading about other women's experiences and by putting the rose down. In short: the experience was encouraging enough for me to keep going.

For the Roses Revolution 2014, I was joined by Mascha Grieschat, a dedicated activist and owner of the "Just Birth" webpage (www.gerechte-geburt.de). Together, we send out a press release at the end of September, two months before the event, to over 50 different agencies, newspapers, radio stations, OBGYN's and midwifery associations, etc. Even though we had used the WHO Statement against Abuse and Disrespect in Childbirth, which fortunately had come out just in time, no one covered it. The only response we got from mainstream media was one of disbelief: violence is a too strong a word, of course birth hurts, we don't have that problem in Germany. But the Roses Revolution was picked up by the member magazines of our two major midwifery associations and by another big midwifery magazine, meaning that all midwives in Germany could know, if they had read their magazines, what the roses at the door steps were about.

As November 25 approached, we started to "revive" the Facebook page, which had been "sleeping" over the year, and posted this Call to Action:

"On November 25, bring a pink rose to the door behind which you experienced the worst – be it the door to the labour ward, the hallway or the hospital entrance hall. Please go only as far as feels right for you! If you like, put a short letter or your birth story next to your rose.

Important: In order to gain as much publicity as possible, please take a picture of your rose and post it on our Facebook page. If you wish to remain anonymous, please send the photo to us via private message and we will post it for you. Please use the hashtag **#rosrev** on FB and twitter."

We also prepared downloadable information for women to print out at home and bring to their mother-baby-groups, local cafés or wherever they wanted to inform other women about the Roses Revolution.

Just like the year before, women started to make appointments together to put their roses down in groups. Birth stories flowed in (some of which we were asked to post on the page, others just to be read and acknowledged by us) and messages of solidarity were posted. We were featured in an article in the Huffington Post<sup>[3]</sup> and a series of articles on obstetric violence was published on the blog of "Happy

By Katharina Hartmann



Birthday Deutschland."<sup>[4]</sup> Mascha also created a Wikipedia entry<sup>[5]</sup> and a YouTube video, explaining the event<sup>[6]</sup>. Another popular blog posted a video telling a traumatic birth story and illustrating the need for the RosRev<sup>[7]</sup>.

So the response via the internet worked and the traffic on our Facebook page was enormous: we jumped up to over 2,000 likes (1,300 new), reached over 100,000 users with our posting, had 17,000 interactions, received 1,800 comments (and controlled every single one of them for disrespectful language) and the roses and their stories were shared 1,000 times. We posted 41 different stories.<sup>(B)</sup> The real life event saw 58 hospitals (We have approximately 750 hospitals with L&D) in 42 different cities in Germany receiving roses, as well as one birth center and one midwives' office – proving that obstetric violence may happen in all birthing contexts. We were also contacted by women from Austria, Switzerland and Hungary, interested in organizing a Roses Revolution in their countries the following year.

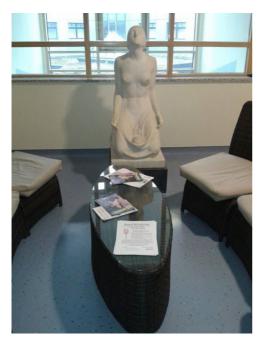
If we look at it closely, the Roses Revolution really consists of two parallel events: One real, where women go to their birthing places and put their roses down. The other is the virtual event on the Facebook page, where women post the picture of their rose and process traumatic birth stories. Both events are primarily meant to serve women's needs and to finally give a voice to those who were silent (and maybe even silenced) before. But both events also have a secondary audience: the virtual event on Facebook is also a public proof that obstetric violence really exists. With a community of women acknowledging it and being able to relate to the shared stories, it gets difficult to deny the existence of obstetric violence, because the stories show exactly, where and when the act of violence took place, what it consisted of and why it was perceived as such. On the other hand the real life event is primarily a private act of bravery and self-affirmation for the women and allows them to regain their personal dignity. But it is also an indicator for the care givers that something went wrong in their care and their need to reflect on their actions.

For some, this is the critical point: the Roses Revolution is a one way communication, as most, even though not all, roses are laid down anonymously. Some care providers may feel accused by them, but they cannot defend themselves. This misses the point that the Roses Revolution is not about the providers, but about the women. Maybe some care providers are able to humbly bear the burden and simply acknowledge the inflicted pain. Others may see it as a severe accusation and difficult to live with. But the Roses Revolution is not meant to be accusing. This closing part of a letter to a hospital in Eisenach sums it up beautifully. After relating her traumatic birth, the woman concluded: "And despite all of this, I have



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chosen one of the most beautiful roses for you. Because I don't want you to throw it away as you get angry over this letter. I want you to see and respect the beauty. Just like you should see and respect every childbearing woman. Because each woman is a rose."



Martina Klenk President of Germany's Midwifery largest Association, invited care providers to see the positive aspect of the Roses Revolution 2014: "Many midwives are irritated or shocked when they find such a rose at the door to their labour ward. Since the roses are placed anonymously, they lack the opportunity to talk about what was perceived to be violence during a birth. Nevertheless, the impulse to reflect on the kind of care given during childbirth is certainly right and adequate!"<sup>(9)</sup> For those care providers, who are unable to welcome this impulse, the Roses Revolution might be a means to build even more walls instead of opening up ways of understanding. But care providers need to understand that the Roses Revolution is for those women who are not (yet) ready to cope with

direct communication (and frankly quite often, even when they take place, those conversations do not contribute to the women's healing process as they are no symmetrical, honest interactions but are heavily influenced by fears of litigation on behalf of the hospital staff and administration). As one lady quite rightly commented on the Roses Revolution Facebook page regarding Ms. Klenk's statement: "Maybe some of the women concerned simply cannot or do not want to talk in person – maybe this anonymous way is the only way for them to talk about it at all. Because what if they have to justify themselves for their feelings? ..."

This comment also explains why the event works: it doesn't ask too much of women and allows them to decide themselves on how far they want to go. Women are completely in charge and it is discrete and can be anonymous. Facebook also



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has a very low threshold, it is within everyone's reach and participation is only a click away. Via the Facebook page women also realize that they are not alone with their experiences. As another participant, a victim of rape before she became a victim of obstetric violence, wrote: "I am very thankful for the #rosrev as it showed to me that other women experienced terrible things as well and that it was not my fault, that it is not that I didn't function properly or that I was being fussy, as I had been always told by others." This sense of community creates a common place for healing and a sense of belonging.

Being set on a particular date, the Roses Revolution also provides a specific day of remembrance with an invitation to deal with the memories and speak up.

The real-life event works, because it has a powerful imagery to it: the fragility, yet immortal beauty of the rose, which symbolizes the women, the act of honouring oneself by laying it down, regaining lost dignity by doing so. For many participants, it is a highly challenging emotional grief work and some are realizing – sometimes years after the experience - how much they still suffer from the abuse. This means that the act of laying down a rose is quite an act of bravery for a lot of women, especially for those suffering from PTSD, as they experience shivering, sweating and even panic as they approach the hospital doors. Quite a few women said they felt like criminals doing something forbidden, but on their way back to the car experienced a hormonal rush, a flow of pride and the typical "I DID IT!"-feeling. These acts of bravery and personal efforts are then acknowledged by others on the Facebook page, strengthening the sense of community. Knowing that they help others by sharing their stories, or maybe even saving a woman from experiencing abuse by raising awareness of obstetric violence, is also a strong motivator to participate.

As we were certain that the Roses Revolution 2014 triggered off some things, we felt it was important to close the event with an indication on where to find further help. So on November 27, we posted a list of organizations helping victims of difficult births.<sup>(10)</sup> Many of these do great work as simple volunteers, as there are not enough public institutions dealing with victims of birth trauma and women too often reach out for help but don't get the support they need from professionals.

The past two years have proven to us that obstetric violence is an issue for German women. They are ready to face their birthing experiences and are willing to end the silence and start claiming dignified births. With a growing number of "proof", we as the facilitators are hoping to finally gain mainstream media's attention at the Roses Revolution 2015 and continue to explain to politicians and



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other stakeholders that obstetric violence is not the same as the fact that giving birth hurts. Obstetric violence is very real and it needs to stop – because each woman is a rose.

# **References:**

- 1. http://www.rosesrevolution.com
- 2. https://www.facebook.com/pages/Roses-Revolution-Deutschland/570332356372331?fref=ts&local e=de\_DE
- 3. http://www.huffingtonpost.de/michaela-skott/brich-das-schweigen-eine-rose-gegen-gewalt-inder-geburtshilfe\_b\_6214052.html
- 4. In German: https://www.happybirthday-deutschland.de/themenwoche/gewalt-in-der-geburtshilfe/
- 5. http://de.wikipedia.org/wiki/Internationaler\_Tag\_zur\_Beseitigung\_von\_Gewalt\_gegen\_Frauen
- 6. English version: https://www.youtube.com/watch?v=WR323nRgx2M
- 7. In German: http://walgesangmitstorchenbiss.de/es-sollte-der-schonste-tag-meines-lebenswerden/
- 8. 33 birth stories told by women, 1 told by a father, 1 story told by a midwifery student,1 told by an obstetrician, 1 story told by a woman unable to conceive, 2 stories about not (yet) being able to put a rose down, 1 "angry letter" (ranting about the state of childbirth and disrespectful care in general) and 1 call-for-letters from somebody working with traumatized women
- 9. "Vielen Hebammen sind irritiert oder erschrocken, wenn sie eine solche Rose vor ihrer Kreißsaaltür finden", sagt Martina Klenk. "Da die Rosen anonym abgegeben werden, fehlt ihnen die Möglichkeit eines Gesprächs über das, was als Gewalt während der Geburt wahrgenommen wurde. Trotzdem ist ein Anstoß, über die Art der Geburtshilfe nachzudenken, sicher gut und richtig!" https://www. hebammenverband.de/aktuell/nachricht-detail/datum/2014/11/25/artikel/ein-zeichen-gegen-diegewalt-an-frauen/ž
- 10. http://www.gerechte-geburt.de/links/verarbeitung-von-schweren-geburten/

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## **ABOUT KATHARINA HARTMANN**

Katharina Hartmann has been the scientific advisor of a number of birth related initiatives in Italy and Germany since she started to get involved with the Italian VBAC movement in 2008: As there was a lack of information, she started to study midwifery and general obstetrics books, researched C-section suturing techniques, investigated birth practices and pregnancy myths, attended conferences and explained her findings to others in understandable language. And she basically has never stopped doing this ever since. Her professional life includes a state examined teaching degree and teaching literature and modern languages. She obtained a PhD in Romance Philology within thetri-national doctoral school "Italianistica" of the Universities of Bonn (Germany), Florence (Italy) and Paris IV Sorbonne (France). This work led to a book on homosexual love poetry in late Renaissance Italy. The German birth advocacy community knows her as the "walking wiki" and the one to be asked when numbers and stats are needed. In 2013, she started the Roses Revolution against obstetric violence in Germany. Having moved back and forth between Italy and her native Germany for 10 years, she is settled in Germany now and enjoys life with her three sons and an amazing husband.





# BRINGING WOMEN'S PERSPECTIVES TO THE TABLE: RESEARCH AND ADVOCACY TOGETHER. ADAPTATION AND TRANSLATION OF THE LISTENING TO MOTHERS SURVEY IN HUNGARY

By Dr. Nicholas Rubashkin

Few health systems regularly monitor women's preferences and satisfaction with obstetric care, even though most professional and governmental organizations recommend that woman- or family- centered care be the standard. The Listening to Mothers (LTM) survey was the first American research to explore women's perspectives and satisfaction with prenatal and birth care. In his talk Nick will review how Listening to Mothers influenced the American discussion on quality of care, including recent efforts to reduce cesarean sections. He will briefly review the process of adaptation and translation into Hungarian of LTM and the Canadian Changing Childbirth survey (another survey grounded in LTM). Finally, he will share preliminary results and suggest how research can inform advocacy in Hungary and the region.

## ABOUT DR. NICHOLAS RUBASHKIN

Nicholas Rubashkin, M.D., M.A. obtained his MD and MA (Anthropology) from Stanford University and is an obstetrician of Hungarian descent who was born at home. Most recently, he was a visiting scholar at the Institute of Behavioral Sciences at Semmelweis University in Budapest, where he and his team surveyed Hungarian women regarding their preferences and satisfaction with birth care. The survey focuses on many issues particular to maternity care in Central/Eastern Europe, such as informal cash payments. In December 2013 Nick returned to hospital work in San Francisco, California and is currently applying to graduate research fellowships. He is also a board member of the organization Human Rights in Childbirth.





# WOMEN IN THE FOCUS. CONTEMPORARY BIRTH DESIGN THROUGH THE EYES OF THE RESEARCHER

By Zalka Drglin, Ph.D.

According to some indicators, Slovenia, a country with two million people and 21.111 babies born in the year 2013, is among those with good perinatal results; perinatal mortality in 2012 was 5.2/1000 births (Perinatal Information System). Maternal mortality in Slovenia from 1998–2002 was 12.5/100,000 live babies, 15.1/100,000 live babies from 2000–2002 and 9.4/100,000 live babies from 2003–2005 .That means 0 to 4 dead women per year. The average age of a mother at birth in Slovenia is 30.1 years, at first birth 28.4 years, and teenage pregnancy is not a problem (Perinatal Information System). Nevertheless, parents in the vulnerable period of transition to parenting too often find themselves in situations where many of their human and patient rights are violated and women suffer violation of their rights because of their maternal role.

This phenomenological overview of present day motherhood in its beginnings, and an analysis of how motherhood is viewed and experienced by women who pass through medical institutions, is based on an extensive national survey "Maternity Hospitals for Today." We first collected data about birthing practices in Slovenia from the women's point of view, using long (113 questions on 41 pages) questionnaires and deep semi- structured interviews to combine qualitative and quantitative methods; this was ten years ago, in 2005: we asked women about their experiences with maternity care.

We present some results which clearly show the discrepancy between established birth practices in Slovenia and the recommendations of the optimal use of procedures and interventions. The data from survey questionnaires talks for itself: 72% of respondents received an enema, 87% were shaved and 67% said a routine, non-stop CTG (cardiotocography) was performed. Routine vaginal exams are also an unwritten protocol. Eighty percent of women were lying on their backs during birth and delivery. Drinking was not allowed during almost 60% of respondents' labors and eating during birth was forbidden. Routine IV was used in 70%; induction with different drugs was performed in 30%; augmentation with oxytocin was used



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in 43%. Of all vaginal births reported in the questionnaires, epidural was used in 6.6 %, vacuum in 4%, forceps in 0.4%, episiotomy in 54% and fundal pressure in 60%. The cesarean rate was 13.7%. Eighty-six percent of maternity hospitals in Slovenia were Baby Friendly Hospitals (Wagner 2007).

Interviews (25 of them, with transcripts of more than 700 pages) about women's experiences of maternity care (as part of the survey "Maternity Hospitals for Today) represent a valuable source of information as they provide the basis for the clarification of certain blind spots in the understanding of the contemporary culture of childbirth in Slovenia. Together with my experiences in the consulting practice, working with women who suffer from different mental health problems, birth trauma included, we can deepen our understanding of the necessity of quality maternity care ensuring true autonomy of women (and midwives, of course).

In 2006 we organized an international conference to discuss the problems in maternity care in Slovenia and in 2007 we published the book Birth Machinery (in Slovene language) presenting some of the most intriguing results from the survey.

Women in Slovenia mostly give birth in one of fourteen maternity hospitals in the country; there are no free-standing birth centers. In the health care system, there is no official professional help available and/or protocols for homebirths and until last year Slovenia had no autonomous midwifery practice. If a woman has health insurance (and very few in Slovenia don't have it), maternity care is free and is divided among different health practitioners. Gynecologists take care of normal and high-risk women. In theory, five appointments can be done by a midwife, but this is never the case. Women don't know their midwife before entering the maternity hospital and one midwife is routinely responsible for two, three or more women during birth. Doctors still (informally) control midwives. In almost all maternity hospitals, only one companion is allowed to be present with a mother during labor; having older children attend a birth is considered an unacceptable practice by Slovenian health care practitioners. Doulas are having problems entering birth rooms, especially when a father-to-be would like to be there too. After a mother returns home with her new baby, a community nurse takes over the care of mother and baby.

Official data from Perinatal Information System for 2012 shows a decline in the episiotomy rate, which is around 35%. The C-section rate in 2010 is 18.9%, with differences among maternity units from 13.6% to 23%. The rate of spontaneous childbirth stayed the same – one third of vaginal births happen without induction

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or augmentation. Though no accurate data is available, the rate of epidural use during labor is rapidly growing.

Established birth practices have not been satisfactorily updated in line with the most recent scientific findings. Some frequently used practices are not of benefit during low-risk labor and birth, and some even harm women and/or babies. On the other hand, there are practices with scientifically proven benefits that have not been established in Slovenia. Knowledge about "normality," and the physiology of pregnancy, childbirth and the postpartum period is not very common and introduction of good practices to labor wards is slow.

Expectant women and families face additional problems. Women and their partners are not always properly informed about the advantages and disadvantages of individual interventions and/or treatments, care and procedures during pregnancy, labor, birth and the postpartum period, or about other alternatives and choices. The attitude of medical experts towards a woman during pregnancy, childbirth and afterwards, as well as towards her child and family, does not always meet quality standards. Many women and parents are not sufficiently informed about patient rights, and patient rights are not always consistently ensured. The medical paradigm is still dominant among doctors and midwives in Slovenia and childbirth is medicalized. We have just one midwifery department at the Health Faculty in Ljubljana, where a midwifery paradigm is slowly developing; the most acute problem is the lack of opportunity for students to practice a humanistic and holistic paradigm.

The only non-governmental organization in Slovenia dedicated to improvement in maternity care on a national level is called the Natural Beginnings Society, officially established in 2000. We are a small group of women with growing recognition and support. We work with individuals, couples and groups in pregnancy and postpartum; we educate by organizing childbirth and parenthood preparation classes, provide information about maternal (and family) mental health and by offering supportive care and healing, where needed, especially for depression, abuse and birth trauma. We also help to spread awareness about violations of rights in the health system. We are working at a national level to collect scientific data about pregnancy and birth practices in Slovenia and abroad. We write for a number of scientific and popular publications and collaborate with journalists and progressive health practitioners. In January 2010, the Slovenian translation of the International MotherBaby Childbirth Initiative (IMBCI) was published on the website of the International MotherBaby Childbirth Organization (IMBCO). In the same



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year, we popularized the movie *Orgasmic Birth* by organizing events with people around the country. We also organized workshops to educate doulas. Starting in 2009, our doula group began having regular meetings and every year we've had a special foreign guest: Ina May Gaskin, Marsden Wagner, Debra Pascali-Bonaro, Robbie Davis-Floyd. We also translated two guidebooks into the Slovene language: Gaskin's *Guide to Childbirth* (the first midwifery-based handbook for mothers-tobe to appear in Slovenian and Wagner's *Creating your Birth Plan*. In August 2010, the Natural Beginnings Society drew up a proposal for excellent maternity care in Slovenia, named "Our Common Goal: Excellent Maternity Care" (www.mamazofa. org/en/akcije/maternity-care-initiative).

The medicalization of maternity care is not perceived as problematic for all those who receive care and questioning routine practices invoke anxiety. Yet, the medical establishment is slowly recognizing the worth of civil initiatives by entering a space of respectful discussion. More women and parents-to-be are raising their voices to change the predominant model of contemporary "childbirth design" in Slovenia. We are still a long way from autonomous midwifery, and the survey results show that the average user of the health system cannot really imagine it.

At present, we in the Natural Beginnings Society are focusing on one of the key rights – the right to privacy, the right to form a private, e.g. family life at the very beginning without disturbance. In the project "Hug me Gently" we focus on the need for uninterrupted skin-to-skin contact of the mother and the baby along with the father's support in the first hour after birth. We collect birth stories to develop a database of contemporary practices for parents-to-be, health professionals and students of midwifery.

We look forward to a time when midwives will participate in the creation of the childbirth paradigm in Slovenia that suits the needs of each individual woman and is woman (baby and family) centered, when the dualities of woman/fetus and biology/sociology are rejected, as are the divisions between the physical and social experiences of motherhood. We are witnessing the difficult birth of a midwife paradigm and we are working with persistence and with love to raise awareness of the worth of midwives and of the holistic birth paradigm that are only just emerging in the Slovenian world of childbirth.

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# References

- Drglin, Z. 2007. "Vse najboljše za rojstni dan. Ranljvost in moč žensk v sodobnih porodnih praksah. In Rojstna mašinerija. Sodobne porodne vednosti in prakse na Slovenskem. Edited by Zalka Drglin. 105–156. Koper: Založba Annales (in Slovene language).
- 2. Perinatal Information System of Republic of Slovenia. 2009. IVZ 17. Perinatalni informacijski sistem Republike Slovenije.
- Ponikvar, B. M., A. Rudolf, B. Rudolf 2011. Perinatalni informacijski sistem Republike Slovenije, Primerjava podatkov med regijami za leto 2009. Ljubljana: Inštitut za varovanje zdravja (in Slovene language).
- 4. Ponikvar, B. M., S. Tomšič, A. Drev, Z. Drglin, et al. 2010. "Zdravje žensk med 20. in 64. letom. In Zdravje v Sloveniji. Edited by Ada Hočevar Grom. 55–61. Ljubljana: Institute of Public Health (in Slovene language). Wagner, M. 2007. "Evolucija k žensko osrediščeni obporodni skrbi." In Rojstna mašinerija. Sodobne porodne vednosti in prakse na Slovenskem, edited by Zalka Drglin. 17–22. Koper: Založba Annales (in Slovene language).

## ABOUT ZALKA DRGLIN, Ph.D.

Zalka Drglin earned her Ph.D. in Women's studies and feminist theory and is a cultural sociologist and researcher at National Institute of Public Health in Slovenia. She is an active member of Natural Beginnings Society, dedicated to improvement in maternity care on national level. She is a Transactional Analysis Consultant working on birth trauma, depression, anxiety. Zalka writes books, papers in scientific journals and articles for users, gives presentations on conferences and lectures to students, health professionals and pregnant women and others interested.





# WOMEN – MOTHERS – BODIES: WOMEN'S HUMAN RIGHTS IN OBSTETRIC CARE IN HEALTHCARE FACILITIES IN SLOVAKIA

By Janka Debrecéniová and Zuzana Krišková

The publication *Women – Mothers – Bodies: Women's Human Rights in Obstetric Care in Healthcare Facilities in Slovakia* is a result of more than two years of intensive efforts of two non-governmental organisations that promote the human rights of women in Slovakia: Občan, demokracia a zodpovednosť (Citizen, Democracy and Accountability), and Ženské kruhy (Women's Circles), as well as their close collaborators (the publication, including a full English summary, is available at http://odz.sk/en/women-mothers-bodies).

It is the first publication to discuss obstetric care in the country from the perspective of women's human rights. As obstetric care in Slovakia is concentrated almost exclusively in healthcare facilities and provided under the supervision of physicians – with no alternative options, for example, in the form of birthing houses led by midwives, or an official home-birth system organised by the state – the monopolised and institutionalised aspect of this care, coupled with women being particularly vulnerable during pregnancy, birth, and puerperium, makes it a specific phenomenon demonstrating a power imbalance that deserves consistent and critical examination. In this context, obstetric care in Slovakia is a topic that deserves and requires consideration from a human rights perspective.

The publication is divided into four chapters.

# 1. Human rights at childbirth: basic international and national standards

Chapter one describes the basic international and national human rights standards applicable to the provision and receipt of healthcare services during childbirth. Since these rights concern the reproductive health of women, they are also known as reproductive rights and include, in particular the right to human dignity, the right to the protection of health and the right to healthcare, the right to information and informed consent, the right to the protection of private and family life, the right to equality and non-discrimination, the right not to be subjected to



violence, torture and other cruel, inhuman, and degrading treatment, and the right to enjoy the benefits of scientific progress and its applications.

The duty to respect, protect, and fulfil the human rights of women is vested primarily with the State and its authorities. However, institutions and individuals providing healthcare are always also liable.

# **2.** Internationally recognised medical guidelines on the provision of birth-related healthcare

The second chapter is a summary of internationally recognised medical standards on obstetric care which are also relevant from the point of view of the protection of, and compliance with women's human rights. This chapter focuses on selected procedures and recommendations concerning the provision of healthcare to women during childbirth in the context of recommendations published by internationallyrenowned organisations: the World Health Organization (WHO), the International Federation of Gynaecology and Obstetrics (FIGO), and the National Institute for Health and Care Excellence (NICE). We consider these recommendations a good practice standard and essential part of respectful healthcare. Taking into account said standards, the following facts and guidelines served as our basic reference framework:

- Childbirth is an intimate affair. Women need to have their privacy ensured, they need to have the opportunity to be accompanied by a person of their own choosing, and medical personnel should give them as much information as they desire and need.
- Obtaining informed consent is essential in the provision of healthcare, with informed consent being one of women's fundamental human rights.
- The freedom of movement during stage one and two of labour is an effective means of pain relief. The best position to give birth is the one a woman has freely chosen.
- A routinely-performed episiotomy is harmful and needs to be eliminated. Perineal suturing must be performed using adequate pain relief.
- Uninterrupted skin-to-skin contact between the mother and her child should be allowed as soon as possible. Routine procedures that separate the mother and her child (including measuring and weighing) should be avoided



during the first hour after birth. Exceptions can be made if the woman herself requests it, or if her child's health conditions so require.

# 3. Birthing experience in a Slovak healthcare facility through the lens of women's human rights

Chapter three presents the findings of gualitative research whose aim was to explore women's birthing experience in Slovak healthcare facilities. The data were collected from July 15, 2014 to August 15, 2014. The research sample included women who had given a vaginal birth in the previous three years (June 2011 -June 2014) in a hospital in the Bratislava or Trnava region. A total of 15 interviews followed a chronological order: they were in the form of a retrospective narration regarding preparations for childbirth and a chronological description of the birth, as well as the stay in the hospital. Researchers experienced in qualitative research and human rights conducted semi-structured interviews in which women's point of view and their own research categories, language, concepts, reflection, and interpretation were explored. We primarily focused on how the women perceived the medical personnel's style of care and practices used during labour and delivery and the immediate post-partum period in the hospital. From the point of view of methodology, the interviews consisted of a descriptive component when the respondents described how their births had gone without giving any assessment, and, at the same time, we also wanted to know how they had imagined the birth would take place, as well as how they assess their birthing experience in retrospect. A research interview scenario is also available in English at http://odz. sk/en/women-mothers-bodies).

The findings were analysed and interpreted within the framework of WHO recommendations for good practice in normal birth, FIGO and NICE standards and guidelines, and human rights standards guaranteeing women's rights during childbirth. Findings indicate grave and systemic violations of all rights that are involved in childbirth:

- **right to privacy and intimacy** both in terms of spacial arrangements and of medical staff behaviour; grave violations of the right to choose circumstances of birth (e. g. regarding the birthing position);
- absolute lack of understanding of the concept of informed consent and informed decision-making on the side of the health personnel – it is exclusively the medical staff who takes decisions, "informed consent" forms are formally signed by all women at on admission;



- absolute lack of information and lack of access to information;
- right to dignity and autonomy degrading treatment, lack of basic respect (including direct humiliation, contesting of women's pain, lack of support and encouragement, accusations against the women; direct orders and intimidation, objectification of women, reducing their identity to "mommies", not introducing oneself to women, treating them like objects without talking to them, harassment, abuses of power);
- **torture, inhuman and degrading treatment** (e. g. the Kristeller manoeuvre, suturing without pain relief, the Hamilton manoeuvre) both physical and psychological violence;
- **separation** from/of the children, violation of the rights of the newborn;
- right to health;
- right to equality and non-discrimination;
- a lot of negative stereotypes about women;
- extreme normalisation of the violations;
- ignorance of internationally accepted standards (WHO, FIGO, NICE).

# 4. Information provided by healthcare facilities in Slovakia before birth

The fourth chapter discusses the provision of information by birthing facilities in Slovakia in a wider context, one that goes beyond obtaining informed consent with particular healthcare interventions from clients/patients. We argue that the sufficient information provided by individual facilities well in advance of an actual childbirth is not only essential for freely choosing a healthcare provider, but it also is an important condition for effective public control.

The monitoring exercise, performed between July and October 2014, the results of which are presented in this chapter, was also based on the acute lack of information given during the provision of obstetric care, as described by a number of women during the in-depth research interviews, the details of which are given in the third chapter. The monitoring attempted to identify the real options the women planning a childbirth (and the general public as well) have at their disposal in order to obtain information about individual birthing facilities, how these facilities ensure the provision of obstetric care, and how they fulfil the human rights of women. We wanted to find out what type of information women can obtain



prior to the actual birth in order for them to make an informed and free decision about a birthing facility and model of care, as well as how the birthing facilities are prepared to accommodate the wishes and needs women have with respect to childbirth. Therefore, we identified areas and issues relevant to women with respect to birthing, and made them the focus of our monitoring agenda. In terms of the content of the information provided, we focused on the information concerning:

- obtaining information from pregnant women before birth;
- provision of information to women before, during, and after birth;
- obtaining informed consent before, during, and after birth;
- women's privacy before, during, and after birth, and their companions;
- actual labour and delivery routinely applied procedures, practices, and interventions;
- feedback/assessment provided by the women who gave birth.

The actual possibilities to obtain answers to these questions were then examined through various monitoring methods (all the methods we applied focused, in principle and insofar as practically possible in the context of each particular method used, on all of the aforementioned areas of concern).

The first method involved examining the websites of all birthing facilities in Slovakia. The goal was to pinpoint the extent hospitals actively publish information about childbirth. The list of examined items is also available in English at http://odz.sk/en/women-mothers-bodies.

The second tool used involved correspondence with hospitals, and included the sending of (in principle identical) letters to all birthing facilities in Slovakia, written by women who were to give birth in the near future. The women *de facto* presented their birth-related wishes and demands, and requested a reply from the hospital (by replying to these letters, the hospitals would, in fact, also answer questions regarding the birthing options they offer). A sample letter is also available in English at http://odz.sk/en/women-mothers-bodies.

The third way of obtaining data for our monitoring was in the form of either official or informal requests for information (dependent on whether sent to an entity obliged to provide such information under the applicable Free Access to Information Act or not) to each birthing facility. The content of the official letter and the informal requests did not differ. Citizen, Democracy and Accountability was



the entity requesting the information. Sample official/informal requests are also available in English at http://odz.sk/en/women-mothers-bodies.

The fourth form of obtaining data for monitoring purposes was an official request for information sent to the Ministry of Health of the Slovak Republic (the entity requesting the information was again Citizen, Democracy and Accountability). Our aim was to discover whether the Ministry of Health, in its capacity as a central governmental authority in charge of this agenda, has an overall overview of the fulfilment of birth-related human rights standards, whether it collects and systematically analyses the data on childbirth practices applied by individual facilities, and, in general, how it carries out its primary responsibilities in this area. The official request for information sent to the Ministry of Health and the Ministry's reply are also available in English at http://odz.sk/en/women-mothers-bodies.

The effectiveness, or the success rate in obtaining replies, considerably differed across the individual methods used to collect data for the monitoring. Generally speaking, it remains extremely difficult to obtain information about a particular facility before birth about the birthing procedures and practices it routinely applies, as well as about its preparedness and ability to meet the wishes and needs of birthing women, even if several methods of obtaining such information are combined, as done within our monitoring exercise.

Some of the most general findings:

- some information provided by the hospitals about standard practices used during childbirth were in direct contrast with internationally accepted medical standards (for example no freedom of choice as regards birthing position);
- some information provided by the hospitals about standard practices used during childbirth seemed to correspond with internationally accepted medical standards but were in direct contrast with experience reported by the women (for example, all hospital that replied claimed that they use pain relief for suturing perineal tears, but for some women this was the most painful part of their childbirth);
- some practices or procedures were "allowed" in some hospitals but "forbidden" in others (for example the possibility to drink during birth).

# WOMEN – MOTHERS – BODIES: WOMEN'S HUMAN RIGHTS IN OBSTETRIC CARE IN HEALTHCARE FACILITIES IN SLOVAKIA

By Janka Debrecéniová and Zuzana Krišková



# Conclusions

In conclusion, violations involve all human rights in childbirth, and are caused by individual healthcare professionals, healthcare facilities, as well as the State (in the case of our monitoring, directly represented by the Ministry of Health, especially with respect to its regulatory, coordination and control responsibilities). The considerable differences between medical guidelines generally accepted at the international level and the common practice applied by many Slovak healthcare facilities are also alarming. All the more so when combined with the fact that births conducted by health professionals in hospitals (being relatively closed institutional systems) are virtually the only option for women to give birth and receive healthcare guaranteed by the state.

We shall no longer turn a blind eye to the fact that Slovak birthing facilities violate the human rights of women. We believe our findings will help all stakeholders and responsible authorities to understand the core of the problem, encourage them to ask further questions and to subject themselves, others, and the entire obstetric care system – as well as wider social structures – to a critical reflection, and that it will contribute to measures, programmes, and policies set and designed to bring about a desired change. The change can also be facilitated by a dialogue and cooperation in partnership with those for whom obstetric care is primarily intended. If Slovakia genuinely wishes to meet its human rights obligations and commitments in actual practice – not through formal declarations alone – it must not ignore the violations of the human rights of women that occur in situations with such substantial impacts on their lives.



## WOMEN – MOTHERS – BODIES: WOMEN'S HUMAN RIGHTS IN OBSTETRIC CARE IN HEALTHCARE FACILITIES IN SLOVAKIA

By Janka Debrecéniová and Zuzana Krišková

# ABOUT ZUZANA KRIŠKOVÁ

Zuzana Krišková is a cofounder and current chairwoman of Slovak NGO Ženské kruhy (Women's circles). She studied financial management and has PhD. in accounting. After her first pregnancy and childbirth she became passionate about natural childbirth and later about human rights in childbirth which lead to complete switch in her career. In her work for Ženské kruhy she is focused on disrespect and abuse in childbirth. She believes that every doctor, every midwife or nurse are capable to provide respectful maternity care. In her future work she wants to address the "victim blaming" phenomenon between childbirth providers, doulas and activists.

## ABOUT JANKA DEBRECÉNIOVÁ

Janka Debrecéniová holds a law degree from the University of MatejBel in Banská Bystrica, Slovakia, a Magister Juris in European and Comparative Law degree from the University of Oxford, and a PhD degree from the Trnava University in Trnava, Slovakia. From 2000, she has been working for Citizen, Democracy and Accountability (www.odz.sk), an NGO based in Slovakia, as a legal expert, trainer and analyst, and from 2009 also as the Deputy Directress. She has been actively involved in many legislative and policy initiatives in the field of non-discrimination and the human rights of women. For example, she was a member (in 2007-2008) of a governmental committee that drafted a significant amendment to the Anti-Discrimination Act, and she later contributed to further legislative changes relating to this act. She has also been actively involved in various advocacy activities concerning reproductive rights of women, including in childbirth.





# JAK JINAK – ANOTHER APPROACH TO CHILDBIRTH CARE

# By Natalie Sedlická

Many changes in have happened in the past 25 years in the Czech health care system. However, there are still a lot of major fields for improvement in childbirth care. Birth care is based on secondary care (practice being led by doctors mainly, midwives are not allowed to register an autonomous practice, and information on the physiology of childbirth is not too common, nor widely spread). Primary midwifery care does not exist as such, nor does the autonomy of midwifery profession (women and midwives are suppressed in their rights and options). A project called Jak jinak (Another way) was presented and its complexity discussed. The project addresses ten pillars and fields that need to be improved. In the project, we aim to achieve systematic changes in birth options by introducing primary midwifery care based on the continuous midwifery model. In the scope of the project are legislative changes, health care standards, midwifery education, medialisation of normality of birth and much more. We summarised what we have achieved during the past year and spoke about the challenges we are facing as well as hopes, progress and views into future.

# **ABOUT NATALIE SEDLICKÁ**

Natalie Sedlická, MSc, is a midwife, providing women with complex care throughout the whole period of pregnancy and childbirth. She has studied midwifery at the Masarykian University in Brno with her final thesis being a comparative study of Czech and Dutch perinatal systems of care. She went to the Netherlands for continuing studies, where she also gave birth to her son Mathias. She has further studied psychotherapy, traditional Chinese medicine and shiatsu. Her thesis on psychotherapy focused on birth trauma and coping with it. She has completed Master of Science in Midwifery at the Glasgow Caledonian University with a dissertation on factors determining the quality of childbirth practices in the Czech Republic. She initiated and is a guarantor of a project Jak jinak (another way - in Czech birth care) in order to start building improvements into the Czech system of perinatal care.



# PANEL 3 CHALLENGES

There are a number of challenges that need to be addressed before women can enjoy the full range of human rights in childbirth. Informal payments for maternity care services pose a serious problem both for consumers and providers. C-sections are on the rise and we need to understand better what are the driving forces behind this increase. Is prohibition of maternal request C-sections protecting the rights of women and their babies? There is very little research and advocacy efforts regarding violations experienced by vulnerable groups, including minority women.

Moderator: Linda Roszik, Psychologist, Hungary

Panelists: Dr. Alberta Bacci, Obstetrician Gynecologist, Italy

**Dr. Nicholas Rubashkin**, Visiting Fulbright Researcher, Semmelweis University, Hungary

**Dr. Diana Dweik**, Department of Obstetrics and Gynecology, University of Szeged, and Semmelweis University, Hungary

Fleur Van Leeuwen, Assistant Professor Human Rights, Koç University Law School, Turkey

**Zeynep Oya Usal Kanzler**, Assistant Professor Human Rights, Koç University Law School, Turkey

Erica Schmidt, Birth House Association, Hungary

Mary Zwart, Midwife, Netherlands and Portugal

Volha Kusmierska, Midwife, Belarus





# **BIRTH RIGHT**

By Nicola Philbin

Hello, I am Nicola Philbin. I am British, but have lived away from the UK for more than 10 years now, and would really have to describe my nationality now more as 'international'!

One thing that this international life has given me is detailed experience of a range of maternity systems around the world. In the UK, I experienced midwiferyled birth, with excellent preparation and postnatal support, with my own three children. In Dubai, I experienced medical antenatal care, and a general lack of postnatal care and the factors led me to become one of the first doulas to qualify there, experiencing a very medically-led system with high cesarean rates alongside my clients. In the Netherlands, I have spent 5 years as a birth educator, working with clients in a system which offers the full range of experiences from safe comfortable home birth to high-tech hospital medical birth.

I now run Bright Owls Birth Services in The Hague, helping pregnant parents who find themselves in The Hague to prepare for their birth and becoming parents. I aim to help them to understand and explore their options, to work out the kind of birth they want and need for themselves and their baby, and how to find that within the Dutch system, and hopefully help them start their new family life with a birth experience that gets them off to the best possible start.

However, my seven years as a birth practitioner were preceded by 15 years as a telecommunications lawyer, and that is what brought me to the Eastern Europe Human Rights in Childbirth Conference - once a lawyer, always a lawyer!

I would never have dreamt, sitting behind my in-house lawyer's desk in Dubai 8 years ago about to have another baby that I would never come back from maternity leave, or be at this conference!

However, the issues I was involved in then as a lawyer still apply in my birth work - supporting others to understand and make risk assessments, based on the best available evidence, and then using that to make informed decisions about the right way to move forwards for them.



This interest led me to have coffee with Hermine Hayes-Klein in The Netherlands in 2011, the founder of Human Rights in Childbirth. I became involved in organizing the first HRiC conference in 2012, and then in the setting up of HRiC as a non-profit organization, and have served on the board ever since.

I don't think I could do the birth work I do, hearing so many stories of "I wasn't allowed" or "you must be induced" - yes these happen in Holland too - if I didn't also do the work I do to support HRiC, to help improve the care that my clients and others receive and the options open to them, through better recognition of human rights in maternity care.

But my motivation is most of all my own children - I want them to have access to the best possible start for their new families, in the years to come.

I will finish with a typo in the programme... Next to my name, it says "Birth Right Lawyer" rather than Birth Rights..... But I like it and will keep it! I am a "Birth Right Lawyer" - I believe that people should be able to Birth Right - to access the Right Birth for them and their babies, whatever that is, and wherever they find themselves in the world.





# HUMAN RIGHTS IN CHILDBIRTH: EXPERIENCE IN COUNTRIES WITH DEVELOPMENT PARTNERS

By Dr. Alberta Bacci

Concerns regarding high maternal mortality, and interventions to ensure safe delivery and appropriate management of complications, were the focus of programmes of United Nations organizations and development partners, since the Safe Motherhood Initiative, launched in 1987.

Issues regarding de-medicalization of birth, and holistic approach to childbirth, increasingly took a significant role in the WHO European Region, since the '90s. These approaches had to face challenges, in particular in countries where orders from Ministries of Health set a very strong and mandatory guidance on organization and even on specific clinical management details.

Taking into consideration and respecting women's views regarding childbirth was a key component of Making Pregnancy Safer strategic approach for WHO European Region, and it was included in intervention to improve mothers and babies health and well-being, carried out in collaboration by Development Partners in several countries. Results of assessments of quality of care including interviews to women and staff, which were carried out post interventions, show significant improvement in respecting human rights in childbirth.

## ABOUT DR ALBERTA BACCI

Dr Alberta Bacci, Obstetrician Gynaecologist, worked in different maternity hospitals in Italy since 1976. From 1987 she worked 4 years in Maputo Central Hospital, Republic of Mozambique. From 2001 to 2011 she was regional coordinator for the Making Pregnancy Safer programme in WHO Regional Office for Europe. Since May 2011 she works as independent consultant for mother and newborn health care, in several countries, with different UN organizations and NGOs. Her experience includes assessment of quality of care, and introduction and evaluation of maternal mortality and morbidity case reviews using WHO Beyond the Numbers approaches. She is member of the WHO Collaborating Centre for Mother and Child Health, Trieste, and faculty of the European School for Maternal, Newborn, Child and Adolescent Health, Trieste, Italy.





# THE PRICE OF A FREE DELIVERY: INFORMAL CASH PAYMENTS IN HUNGARIAN OBSTETRIC CARE

By Petra Baji, PhD, Imre Szebik, MD, PhD, Nick Rubashkin, MA, MD.

Informal cash payments are paid directly to providers for purportedly free health services in the Hungarian socialized insurance system. These payments are prevalent in the health systems of many Central and Eastern European countries. Cash payments are widespread at birth, and yet the role of these payments in birth has not been well examined. Unofficial cash payments in birth raise important equity issues for women and their families. The system of cash payments may create adverse incentives for providers, may allow only higher-income women to access certain options, and commodifies elements of birth care which should be free.

For these reasons, exploring cash payments in Hungarian birth care was a central aim of the "Mother-Centered Pregnancy Care" survey. The survey was administered via the internet to a representative sample of 600 women by the survey firm Ipsos. Women were asked the total amount of cash they paid for birth care, what percentage of this was informal, and what their intention was when they paid the cash; in total 9 questions in the survey were dedicated to informal payments. The survey asked women about a range of birth outcomes, including type of delivery, birth interventions, and also a measure of autonomy (Women's Autonomy in Decision Making scale; Vedam, S. et al, forthcoming).

At the Zagreb conference, Dr. Nick Rubashkin reported preliminary data from these 600 women. The final results will be forthcoming in peer-reviewed journals. This online survey is the largest to date in the region to explore the relationship between cash payments and interventions such as cesarean section and episiotomy and the first to explore women's sense of autonomy when paying for "free" care.



# THE PRICE OF A FREE DELIVERY: INFORMAL CASH PAYMENTS IN HUNGARIAN OBSTETRIC CARE

By Petra Baji, PhD, Imre Szebik, MD, PhD, Nick Rubashkin, MA, MD.

#### **ABOUT PETRA BAJI**

Petra Baji is an assistant professor at the Department of Health Economics, Corvinus University of Budapest. She obtained her PhD diploma at Maastricht University in 2013. Her research is focused on out-of-pocket payments and willingness to pay for health care services in Central and Eastern European countries.

#### **ABOUT IMRE SZEBIK**

Imre Szebik received his MD (1991), PhD(2004) and MSc in health care management (2008) from Semmelweis University of Medicine, Budapest, Hungary and his M.Sc. Specialization in Bioethics from McGill University (1999). He worked with the Biomedical Ethics Unit at McGill in 1997 1998 and 1999-2000 as a post-doctoral fellow. He was a post-doctoral fellow in clinical ethics at M.D. Anderson Cancer Center, Houston, Texas in 1998-1999. He works as a research associate at the Institute of Behavioural Sciences of Semmelweis Medical University. In 2014 a survey was conducted among Hungarian women regarding their preferences and satisfaction with birth care. Imre Szebik will discuss some of the results of this survey, he will focus on issues of informed consent and overuse of care in obstetric care.

#### ABOUT DR. NICHOLAS RUBASHKIN

Nicholas Rubashkin, M.D., M.A. obtained his MD and MA (Anthropology) from Stanford University and is an obstetrician of Hungarian descent who was born at home. Most recently, he was a visiting scholar at the Institute of Behavioral Sciences at Semmelweis University in Budapest, where he and his team surveyed Hungarian women regarding their preferences and satisfaction with birth care. The survey focuses on many issues particular to maternity care in Central/Eastern Europe, such as informal cash payments. In December 2013 Nick returned to hospital work in San Francisco, California and is currently applying to graduate research fellowships. He is also a board member of the organization Human Rights in Childbirth.





# NON-MEDICAL FACTORS IN THE BACKGROUND OF CESAREAN SECTIONS IN SOUTH-EAST HUNGARY

By Dr. Diana Dweik

Hungary has been showing just as high Cesarean rates as have evolved in many middle or high resource countries in the 21st century: in 2012 34.5% of all deliveries were Cesarean sections and there has been a steeply rising tendency for this since the political transition in the late 1980s, when the rate was 10-11%. Domestic and international debates concerning the reasons for this epidemic have highlighted numerous contributors to this trend: less risky procedures due to medical development; remarkable demographic changes in the pregnant population; widening of the range of indications for CS; threatening medico-legal environment. Beside these factors, the possible role of openly expressed and irrefutable demands of pregnant women has also emerged.

Cesarean delivery on maternal request (CDMR) is CS performed electively on maternal request in term following a physiological singleton pregnancy in the absence of any reasonable medical indication. The concept of large numbers of CDMRs in the background of skyrocketing CS rates of many 'Western' countries launched a new generation of studies that investigated the attitudes, beliefs, preferences, needs and fears of expectant mothers. Many of these studies, however, instead of affirming the assumption that large numbers of women are in favor of CS, called the attention to other issues possibly contributing to rising CS rates such as fear of childbirth (FOC), inadequacy of the information giving process, convenience and financial incentives of physicians, and anomalies of different maternity care systems, including women's limited access to midwifery care or their fears of receiving substandard maternity care. The widespread notion of obstetricians' respect for patient autonomy was also challenged by some studies.

Antenatal FOC is often, but not necessarily, characterized by a request for CS as mode of delivery. FOC has been shown to be responsible for more painful and prolonged labor and higher risk for emergency CS; however, there are studies that have not confirmed the association between FOC and birth complications. These conflicting findings and the unlike average FOC levels measured in different populations suggest that the concept of FOC needs to be interpreted within the specific cultural context.



#### NON-MEDICAL FACTORS IN THE BACKGROUND OF CESAREAN SECTIONS IN SOUTH-EAST HUNGARY

By Dr. Diana Dweik

Officially, pregnant women in Hungary do not have the right to choose elective or intrapartum CS as mode of delivery in the absence of firm medical indications. Nevertheless, the topic of CSs performed for non-medical reasons has been a revolving issue of domestic debates. However, the contribution of maternal choice to the rising Hungarian CS rate has never been assessed. It is also of interest to investigate how FOC may manifest itself in a maternity system where midwifery plays a secondary role and CS rates are higher.

# Survey of obstetricians' views on CDMR

The objectives of the first questionnaire survey were to assess the personal opinion of south-east Hungarian obstetricians and gynecologists on CDMR and to reveal their attitudes toward cesarean section vs. vaginal delivery (VD). In March 2010 structured, anonymous questionnaires were passed to each of the 137 obstetricians and gynecologists working in the 12 obstetric departments in the South East Hungarian Region by post. The questionnaires were completed by 102 physicians (74.5%).

Most south-east Hungarian obstetricians agreed that there was no need in Hungary for a legalized indication that would allow obstetricians to perform CS without firm medical reasons, but almost one-third of them would have welcomed such an option. However, the majority of the respondents felt ready to perform such an operation in case it was a legal option. Respect for patient autonomy was not a central issue for most of the respondents; therefore, we suspect other factors in the background of the finding that more than three- quarters of them would be ready to perform CDMR in case it was legalized.

Tolerant attitude of obstetricians toward the proportion of CSs is apparent and certainly has an impact on the societal acceptance of the phenomenon. More than half of the respondents turned the option of a legalized CDMR down; however, almost one-third of them would have supported such an option, indicating that south-east Hungarian obstetricians' opinion is not equivocal in this question. The contradiction between the theoretical willingness of the majority of obstetricians in this study to perform CDMR and the dismissive opinion of more than half of them on the legalization of it in Hungary is thought-provoking. The resistance of more than half of physicians to an explicit indication for CDMR might have been explained by the traditionally paternalistic doctor-patient relationship that still dominates the obstetric profession. It may also have reflected the official position of the Hungarian College of Obstetrics and Gynecology on CDMR, issued in 2003; however, their practice did not necessarily follow theory. By Dr. Diana Dweik



#### Pregnant women's childbirth preference and delivery outcome

The prospective follow-up survey of pregnant women aimed to unfold determinants of maternal childbirth preference and non-medical factors contributing to different modes of delivery in one of the five university obstetric departments in Hungary. We followed-up 411 pregnant women throughout pregnancy in order to unveil important factors in the background of preference for CS or uncertain childbirth preference. We also analyzed 453 non high-risk pregnant women's socio-demographic features, childbirth-related attitudes, fears and preferences and the circumstances among which subsequent deliveries took place and their association with delivery outcome.

This survey is a contribution to the ever growing body of evidence, that, given the chance, only small numbers of pregnant women would choose primary operative delivery in the absence of medical indications, since nine out of 10 respondents expressed (consistent) preference for VD as mode of delivery. Higher level of fear of childbirth was not identified among the important predisposing factors of an ambivalent or dismissive attitude toward vaginal delivery by multivariate analysis. Furthermore, logistic regression analysis did not reveal any differences between participants' main demographic characteristics according to their childbirth preference, apart from previous CS. More than half of maternal preference for CS or uncertainty regarding preferred mode of delivery could be ascribed to women having undergone previous CS. Certain attitudes, however, did differentiate between pregnant women with distinct preferences for childbirth. On one hand, nulliparous women consistent in their preference for VD were more likely to be insisting on their own sense of control. Both nulliparous and parous respondents consistent in their preference for VD were more likely to be convinced that birth is not necessarily about medical technology. On the other hand, the cognitive interpretations of perinatal events, along with mistrust in the power of nature, strongly determined the birth preference of not just many parous women with previous CS, but also that of a small but not negligible portion of nulliparous women. Our results call the attention to the appropriate and sufficient amount of information given to pregnant and postpartum women. Although we detected small numbers of women with explicit and consistent preference for CS throughout pregnancy, the possible normalizing effect of high Hungarian CS rate on nulliparous women's cognitive appraisal regarding childbirth issues needs to be considered. It seems that Hungarian CS rates seem to be high enough to gradually erode women's basic belief in the power of nature and to make them develop a certain tolerance toward CS, by depicting it as 'safe and simple'.



#### NON-MEDICAL FACTORS IN THE BACKGROUND OF CESAREAN SECTIONS IN SOUTH-EAST HUNGARY

By Dr. Diana Dweik

In the second analysis of pregnant women's data, although nine out of 10 non high-risk pregnant women preferred VD to CS in mid-pregnancy, one-third of the women ended up having CS. According to the results of the multivariate analysis women's increased scores on a FOC scale or childbirth preference were not independent predictors of the actual delivery outcome. This result supports previous observations that maternity care models where power inequality among professionals is obvious and private obstetric care complicates the scene, the effect of women's attitudes may be played down by other factors. Moreover, differently conceptualized childbirth and its effect on maternity care policies might be found in the background of different CS rates of countries, rather than individual maternal factors such as FOC. Younger maternal age and longer decision-toconception interval, however, turned out to be important determinants of CS. Among supplementary delivery outcome data neither private practice, nor timing contributed significantly to the model describing mode of subsequent delivery in our multivariate analysis. Two factors related to the attending obstetricians, however, played an important role, namely their power to decide upon CS in case of nulliparous and their age. Our results confirm that over-estimation of risks in pregnancy seems to drive both women and obstetricians to engage in even more risky procedures. It is not likely that Hungarian obstetricians are not susceptive of the patients' preferences, given the continuous personal care provided throughout pregnancy in the majority of the cases. Although having the power to decide upon CS can provide better time management for a professional, it also means that he/she bears all responsibility in an obstetric situation to deliver the 'perfect outcome,' which might lead to defensive acts. Older age and more experience of the attending obstetrician can also lead to certain cautiousness in doubtful cases. These findings further contribute to the already existing evidence that in countries with high CS rates the role of non-medical factors, more positively related to obstetricians than to pregnant women's preferences or fears, needs to be emphasized. A shift from the present Hungarian maternity care model toward a balance between medical and midwifery approach could provide women with the entire spectrum of information on maternity issues, which would improve patient autonomy and possibly lower the domestic CS rate.

By Dr. Diana Dweik



#### ABOUT DR. DIANA DWEIK

Diana Dweik, M.D., Ph.D., was born in 1976. Graduated from Faculty of Medicine, University of Szeged, Hungary in 2000. In 2003 she graduated as health economist, in 2008 as English-Hungarian medical translator and interpreter. Since 2007 she has worked at Department of Obstetrics and Gynecology, University of Szeged, Hungary as trainee in obstetrics and gynecology, which was interrupted for four years (2010-2013) when she was a full-time Ph.D. student. She defended her thesis titled 'Non-medical factors in the background of cesarean sections in South-East Hungary' in 2014. She is married, has four children





## **OUR RELIGION HAS DEFINED A POSITION FOR WOMEN:** MOTHERHOOD': REPRODUCTIVE POLICIES, LAWS AND PRACTICES UNDER THE CURRENT POLITICAL REGIME IN TURKEY

By Fleur van Leeuwen and Zeynep Oya Usal Kanzler

The former prime minister and current president of Turkey: Recep Tayyip Erdogan has been very clear about the invocation of women in society. Their role is at home, bearing and rearing children. He has been infamously quoted in international media, stating inter alia that 'women are not equal to men' and that 'You cannot make women work in the same jobs as men do (...) This is against their delicate nature.' These are not mere statements, many of his and his party's ideas have over the last years been translated into laws and policies. In our presentation we discussed a number of these laws: the ban on caesarean sections, the proposed new restrictive abortion law, and the laws and policies regarding family planning. Against the background of the notion that women should be stay-at-home moms who bear at least three children, we discussed the possible implications of these laws and we presented some actual heartbreaking cases. We argued that Turkey's reproductive laws and policies are in conflict with Turkey's international human rights law obligations.

#### ABOUT FLEUR VAN LEEUWEN

Fleur van Leeuwen (LL.M., Ph.D.) is a human rights professor and a mom of twin girls. She has been living and working in Istanbul, Turkey since 2009 where she is teaching at Koç University. Originally from the Netherlands, she worked for many years at the Netherlands Institute of Human Rights at Utrecht University. Fleur specializes in women's human rights with a particular focus on reproductive rights, violence against women, and human rights in childbirth. Under the name Havva Human Rights Projects (havvahumanrights.com) she has inter alia conducted research for the UN Special Rapporteur on Violence against Women, the Dutch government, the European Commission, and various research institutes. Fleur has frequently assisted NGOs, individuals and law firms in their complaints before international human rights bodies.



#### 'OUR RELIGION HAS DEFINED A POSITION FOR WOMEN: MOTHERHOOD': REPRODUCTIVE POLICIES, LAWS AND PRACTICES UNDER THE CURRENT POLITICAL REGIME IN TURKEY

By Fleur van Leeuwen and Zeynep Oya Usal Kanzler

#### ABOUT ZEYNEP OYA USAL KANZLER

Zeynep Oya Usal Kanzler (LL.M., Ph.D.) is an assistant professor in human rights at Koç University Law School in Istanbul, Turkey. She holds a law degree from Istanbul University, Turkey (1999), a Master's degree in European and Comparative Law (LL.M.) from Maastricht University, The Netherlands (2002) as well as a PhD degree in European Law from Istanbul University (2011). She also completed a human rights certificate program by European University Institute, Italy (2003) and conducted research at Lund University, Raoul Wallenberg Institute of Human Rights and Humanitarian law, Sweden as Svenska Institutet fellow (2006-2008). Before joining Koç University, Dr. Usal Kanzler worked as a lawyer at the European Court of Human Rights (ECHR) in Strasbourg over three years (2008-2011). Recently, she has conducted research at the Max Planck Institute for Comparative Public Law and International Law in Heidelberg. Besides her work at Koç, she works in expert capacity for various inter-governmental and non-governmental organizations, including the United Nations (UN) Women and the Council of Europe.





## DIVERSITY AND ACCESS TO MATERNITY CARE: SPECIFIC PROBLEMS AND NEEDS OF WOMEN AT A DISADVANTAGE (WITH A FOCUS ON ROMA WOMEN) -CONSEQUENCES OF A PIONEER PROJECT IN HUNGARY

By Erika Schmidt

The main aim of our project was to call the public attention to the fact that the current system of maternity care is basically patriarchal, in which women are oppressed and ruled by the law, and which results in discrimination and regular violence against women. Besides, we highlighted the specific problems and needs of women at a disadvantage who suffer from a cumulative effect of the system.

The Hungarian Roma ethnicity is not homogenous: their culture, socialeconomical-geographical status and circumstances greatly vary. Although there are general problems and challenges that Roma women may face in the maternity care system, the specific needs, demands and problems of the different communities have to be identified and stated with the help of representatives of the local community and stakeholders living and working in that area. We defined the first steps toward a culturally appropriate, women-centered maternity care for Roma women and discussed the possible ways of strengthening Roma women and their communities. We shared our experiences on the project and highlighted the main conclusions.

#### **ABOUT ERIKA SCHMIDT**

Erika Schmidt is a mother of three, activist, educator and lecturer, and a member and colleague of Birth House Association Hungary since 2011. She actively participated in the Hungarian homebirth movement, as well as in the "Justice for Agnes Geréb" campaign. At present, she is the director of the "Birthing Justice – Culturally Appropriate, Woman-centered Maternity Care in Hungary" project of the Association, and also responsible for international relations.





## **DEMOCRACY AND PERINATAL CARE**

#### By Mary Zwart

In 1967, I was for the very first time behind the iron curtain and visited a hospital maternity unit. I was very shocked and made myself a promise: whenever I can, I will support the change for women in the Czech-Slovac republic. That moment came when I met with Zuzanna Stromerova in Stockholm at the ICM conference in 1993. We started making plans for networking, inviting specialists, awareness raising among women and caregivers. The pittfalls were that teamworking was as such a new idea. Professionals were not used to have a team that made decisions. Women did not speak up, to have an idea and speak freely in public was new. Demonstrating for normal birth was not a world-wide idea yet

A lot has changed since then. Structures have been built. Communication is so much easier now. And so is access to scientific proof. If we look what should be done from now on: NGOs representing women, professionals, and doulas should inform goverments and insurance providers how the infrastructure of perinatal care sould be shaped. Goverments should provide finances to NGOs and implement international directives in this field. Eastern Europe is on the road to democracy and women in transition from woman to motherhood claim their rights which will help to implement it.

#### ABOUT MARY ZWART

Mary Zwart is a midwife, educated in the Netherlands and practicing since 1969. She became a nurse in 1971 and has been teaching midwifery since 1973. Mary remained in practice until 1996 in the Netherlands as a primary, independent professional. Mary has been an international speaker at the International Confederation of Midwives, Midwifery Today, and many international conferences. She remains involved in reintroducing the midwifery model of care in Brazil, Uruguay, Argentina, and in Eastern Europe. Since 2008 she has offered homebirth midwifery services to women in Portugal and in 2015 will be opening the first birth center in Portugal. She has attended over 4000 births.





#### By Volha Kusmierska

When I finished college and started my first serious job as a midwife I didn't't feel satisfied with the quality of service the hospital was providing to the women that were about to give birth. I was a young and humble midwife and I couldn't say anything, I could only obey what different doctors ordered. It was usually against to my best knowledge about physiology, natural birth and human feelings. All women were together in one room during their labor, without intimacy, without food and water, without anyone close (only in a few big hospitals a woman could have a birth with partner, but to make it even more difficult, only when they paid for it), without love and positive atmosphere, without right to choose a position to give birth and even without the possibility to defend her rights. I felt very strongly that I didn't want to give birth myself in such conditions.

For me giving birth is one of the strongest moments in woman's life that can give a lot of power, hope and love. But for many women this moment is full of indignity, helplessness, sorrow and shame. The moment which women want to forget.

Some women from Belarus, friend of mine made, this comparison, that during the process of birth in the hospital she felt like in India, where there are still castes, and she felt like at the bottom of society. The fear of changes is very strong. Some older midwives told me that during the whole period of their work, which usually lasts 25 years, nothing has changed in the hospitals where they work.

# So, how to speak about human rights in childbirth in a country where it is difficult to speak about human rights generally?

The common fear is so big that, of course, everyone can feel it almost everywhere, at work, at school, and in the hospital.

Some of you have probably heard Michel Odent speaking about birth rituals. In some primal tribes where people need to be aggressive to keep alive, there are often rituals with newborns. Rituals are very aggressive, for example the separation with mothers during the first hours of life. But here we speak about Belarus, a developed society living in the 21 century! I believe that the quality of giving birth



By Volha Kusmierska

and conditions for a newborn baby make difference for the whole society. Women and children need to be as comfortable as possible during the birth and right after, it would increase the standard of life and happiness in the world in the long term.

One more peculiarity of my country- if you ask people on the street or speak with the medical personal, doctors, etc., they'll most likely say that everything is OK in our system of childbirth. Most people will talk about new built beautiful hospitals, quite good statistics ( childhood mortality only 3,4 per 1000 live births for the last year, maternity mortality last few year 1 per 100 000 births. According to the Belarusian Ministry of Health it gives the country 6th place in the world...

The Cesarean rate is just under 30%, although it is growing every year. In my native country statistics are the most important, often even more important than the humans.

But if you would ask typical women how they feel after giving birth, are they satisfied?

I did. This is what they said to me:

- "I felt completely helpless, because I couldn't do anything while I was in the hospital giving birth. Each new problem felt like more pain in my body. I felt sorry for myself, because no one was considering me during the process of birth. I had no right to say anything and no one was listening to what I said."
- "I was crying like a child all four days after giving birth. I was begging my husband to take me from there (hospital)."
- "I felt like an unhappy person in the world, as if something most precious was stolen from me. When I was leaving the hospital I was planning that next time I'd rather die in my home, than come back here."
- "Prison for women, that's how I'll remember that place."
- "The medical staff looked at me like I was crazy, they talked to me in a very rude way, only because I chose not to take part in some of the useless procedures they offered me. I was urging them for most of the time not to interfere, while I was trying to fight for my rights."

So the first step for all changes is to acknowledge the problem.

Our birth activists notice that we need more doctors and midwives, who understand the importance of natural birth. Now we need to educate parents and



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disseminate the idea of natural birth and try to spread knowledge about its benefits and the disadvantages of medical interventions.

Usually when parents end up in a hospital their wishes are ignored and the general conditions are against them (untrained personal, common room for birth, insufficient number of midwifes). One possible alternative to have a normal birth or for example to have VBAC is home birth, which in most cases must be unassisted, because there are only a few midwifes in whole country that would assist a home birth.

Next possible steps:

- General appropriate information about childbirth, available everywhere.
- Organization to unite all birth activists.
- Birth partner rightful, free opportunity for every woman and in every hospital.

But what can we do with the political climate of fear, national character of Belarusians to never protest and to accept hardship? A lot of people would say that those factors are impossible to change in my country.

I'm personally very inspired by the example of neighboring Poland, where during the last 20 years of active work the Childbirth with Dignity Foundation (a non-governmental and nonprofit organization) changed the system and human consciousness in very positive way. In 2012 the Polish Health Ministry presented new standards in maternal care during childbirth, which have been gradually introduced in every hospital. Now common awareness and self-respect are so high that you can be sure you will receive what you wish during your birth.

And all this work started in March 2005 with the "You Have a Right to Ask" campaign





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When it comes to childbirth, women's rights are often ignored. These powerful posters set out to change that...

- You have a right to decide
- You have a right to ask
- You have a right to act

I'm sure this is a very good example for us how to act to make changes possible.

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#### **ABOUT VOLHA KUSMIERSKA**

When Volha finished college and started her first serious job as a midwife she didn't feel satisfied with the quality of service the hospital was providing to the women that were about to give birth. She also felt that she didn't want herself to give birth in such conditions. In 2009, Volha took part in workshops run by Polish specialists (childbirth educators, midwifes and doctors). Those people, mainly from the Polish Childbirth with Dignity Foundation, showed everyone the way how we can do something about the quality of childbirth services in Belarus. From then, Volha started actively educating women and couples about childbirth and topics connected to childbirth. With her husband, she started running birth courses in Belarus, taking part in home births, and also working a lot through her website. After she met Michel Odent and took part in a few his courses, she became a big supporter of the doula idea. She had experienced her own births in two countries (Poland and the UK) and worked in Belarus as a midwife. Right now she is concentrating all her strength towards creating an association or foundation for supporting women's rights in Belarus.





## WORKSHOP 1: COMMUNICATING WITH THE MEDIA

By Nick Thorpe, Journalist, Hungary

'Your unbounded courage and high ideals are changing the world! People in different countries are addressing issues of human rights as never before.' Letter from Sheila Kitzinger to Agnes Gereb, October 7, 2010

My name is Nick Thorpe, I'm the BBC correspondent for Central Europe, and the father of 5 children all born at home in Budapest. I've lived in Hungary most of the last 29 years, and my oldest son is now 22, so as you can work out it took me a while to start thinking about the connection between human rights and childbirth. Fortunately my mother did some of the thinking for me - I was born at home myself in Kent in south-east England in 1960, simply because my mother was strong-willed enough to insist she was not going back to the wretched hospital where my sister had been born in the middle of a flu epidemic 2 years earlier.

My first son Samu is sort of connected to the war in Bosnia - he was conceived in May 1992, when I was home from a spell covering the outbreak of war in Sarajevo. At that time, we already knew a rather remarkable woman in Budapest, Agnes Gereb, who had grown so disillusioned by her work at the university clinic in Szeged, where she had practiced as an obstetrician-gynecologist for 17 years, that she had started attending the births, first of her friends' babies, and then of anyone who came to her for help, at home. Samu was about the 25th baby born at home with her help. By the time my 5th son Jack came along 11 years later, he was something like the 2,500th birth which Agnes had attended at home.

I'd like to speak to you today wearing, or perhaps alternating 2 hats. The very subjective hat I wear as an activist, trying to stand up for gentle, active birth in Hungary. And the harder, more objective hat I wear everyday as a journalist, trying to cover the news. The two hats don't sit very comfortably on the same head, or at least, not on my head. Before I became a journalist, I was an environmental and peace activist in Britain. I loved organizing and attending demonstrations, writing leaflets, fighting for a cause I believed passionately in. I loved the comfort, the sense of solidarity of the crowd. As a journalist, I like crossing the front lines, listening to first one view, then another, and trying to report both fairly. And I love



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the loneliness, the distance of being a storyteller who is not, ideally, part of the story.

So I'll divide what follows into 3 parts. Our efforts in Hungary to campaign for active birth in the 1990s and early 2000s. A brief summary of what we achieved and have still not reached, and some lessons drawn on how to approach the media on childbirth issues.

From the start, a small group of women began to gather around Agnes Gereb, to learn from her. Agnes organized the first conference on alternative birth in Szeged in 1992, and invited speakers from abroad. She also set up a group called Alternatal. These were mostly women who had given birth with her, and found the experience so positive and empowering, they wanted to share it with other women. They started attending births with Agnes. It was then we heard the word doula for the first time in Hungary. Everything seemed possible in Hungary at that time. Some of the women began training in the established, very authoritarian - semi-Prussian, semi-Communist medical system, in order to qualify as midwives, then combine that knowledge with what Agnes was teaching them. Some of the women, including my wife Andrea, simply attended births with Agi.

Legally there was a kind of vacuum here. A law was still in force from the darkest Stalinist times, in 1951, according to which all births should take place in hospital, and any medical professional who knew of an impending birth was legally bound to get that woman to the nearest hospital. And if they failed, or refused, they were breaking the law as well as the regulations of their profession. That left us parents in limbo. No law specifically outlawed homebirth. But we weren't allowed to ask for professional medical help. Under Communism, the profession of midwife had been reduced to little more than a secretarial position, in a male-dominated, usually corrupt system. The midwife received 9 months training - on top of her training as a nurse. Her job was to write down the woman's details while the doctor arrived to do the cutting - the compulsory episiotomy. The doctor would then take the envelope with the money in it, either all, or most of it. Sometimes the midwife also had to put up with the sexual harassment of the doctor. There were so many routine interventions in the birth that many birthing women described their experience as tantamount to rape.

So we got organized. Alternatal wrote a project proposal for a 'Birth House' in Budapest, which would have multiple functions. It would serve as a teaching place for Agnes and the other midwives and doulas, and also a place where women could give birth whose home environment wasn't suitable for home delivery. Too many



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in-laws, too thin walls, or too many other children. Pets. Or because the couple lived far from Budapest. You should remember that at this time only Agnes was attending planned home births in the whole of Hungary, and there were more than 200 a year. She did sometimes travel to provincial towns and villages, but that might mean she wasn't back in Budapest in time for the next birth in the capital. Some of us also lent our flats to couples to give birth in. Occasionally 2 women were in labor at the same time, brought together in the same flat, one couple would be in one room, another couple in the next room, with Agnes attending both.

The plan for a Birth House was presented to Parliament in 1993, and got strong support, from both Liberal, Socialist and Christian Democrat deputies. Thirty million forints were voted for the plan from the 1993 budget. On that basis, Agi and her supporters bought a flat in Buda, and started kitting it out with nice carpets and cushions and so on.

Then the counter-attack began. The Board of Obstetricians and Gynecologists - the arch-conservative body of 12 elderly male professors who oversaw the profession - suddenly realized that an alternative model of childbirth was taking shape in Hungary, which would threaten their power over childbirth, and also their income. The going rate of so-called gratitude money in Hungary was - and is - about a month's wages. If you do 50 births a year - a nice little earner. If you do 100, or 200, you can buy a second house, a second car, and go on so many skiing holidays you're in danger of missing another fantastic money earning opportunity - the next birth.

So the obstetricians got together and started lobbying. They persuaded the Ministry of Health not to pay the 30 million forints - in today's terms about 200,000 Euros - which Parliament had already voted for the Birth House. They did that by finding all kinds of false technical flaws in the project. They did this for so long that the 1993 health budget was spent on other things. The beautiful sunny birth house that was already ready in Aranka Street in Buda had to be sold. The alternative birth movement was back to square one.

Or perhaps square minus one. Because the obstetricians weren't going to stop there. Agi and the midwives shrugged off this setback and just carried on attending births and training doulas. And the counter-attack continued. Doctors interviewed in the mainstream press insisted that women who gave birth at home were risking their own and especially their babies' lives. That Agi was a witch, a dangerous woman, a leftover from the Middles Ages. That the only safe place for birth was in hospital. Some of the more liberal minded doctors created the concept of 'home-birth in hospital.'



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They had wards re-decorated, put a beanbag in the corner, a couple of reproductions of Van Gogh or Matisse on the walls, and carried on inducing births and cutting.

So we organized the 'Melto Modon szulni' campaign, modelled on 'Rodzic po ludzku' - 'to give birth in a human way', which was a campaign in Poland. In Poland a small group of parents like us, facing a similar situation, organized that movement, and won a crucial ally in the early stages - the top daily newspaper Gazeta Wyborcza. That had been the underground Solidarity paper, and emerged after the fall of Communism as the best-selling independent daily. Very importantly, it already had - mid 1990s - regional supplements. In Poland, active birth activists designed a consumer campaign, in which mothers and couples assessed their birth experience in hospital with hearts and stars. Hearts for the subjective kindness of medical staff towards them, stars for the objective surroundings - the level of professional care, the hygiene or otherwise of the hospital toilets etcetera. Doctors and midwives were also encouraged to write their views, but from the first it was made clear that this was not an 'expert-led' campaign, but a grass-roots campaign to improve the atrocious standard of birth care in Poland. Women's experiences of birth were published in the national, as well as in the regional supplements. Questionnaires were devised, for women and hospitals. Some hospitals refused to cooperate, but most were reluctantly pushed into it, by the pressure of the women, and local journalists. Each year the results were published. And this gave hospitals an incentive to do better the next year.

A couple of us went to Poland from Hungary to study the Polish experience, then came back and launched what we hoped would be the same movement in Hungary. But from the first, we ran into a brick wall. The all-powerful Board of Obstetricians sent a letter to their members, ordering them to have nothing to do with us - not to speak to us, not to allow our questionnaires into their hospitals. On the positive side, the old trade union paper Nepszava gave us one page a week, paid for by the Ministry of Health.

We published a lot of women's letters. We aroused the interest of other media. We held press conferences, gave interviews. We put journalists in contact with Agi, with the midwives and doulas, and with women who had given birth at home.

At the same time, we started to organize summer picnics of children born at home and their families. I remember the first best of all, at Visegrad in the Danube bend. We even organized coaches going from Budapest, for those who had no car of their own.



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In the end, we published two books of results, in 1997 and 1998, working on a similar system of hearts and stars to Poland. It was a success of sorts, though we had to make do with very uneven data. We tried to make clear that we were not in any way against doctors or hospitals, we just wanted to encourage them to provide a better service, and more choice to women for birth care.

We gathered statistics, on which days of the week babies were born, and discovered that very few are ever born on weekends or on holidays like Christmas, or Easter, or New Year. That the caesarian rate in some hospitals was over 40%. That most babies are born at the beginning and end of the week, simply because most births are induced, to fit the doctors, and the hospital schedules, not the natural rhythms of the birthing mothers.

What happened in effect though, I think, was that it incensed the obstetric profession so much, that they intensified their own attacks against us.

In retrospect, I believe Agnes and her growing circle of midwives made a strategic mistake at this time. Even as the 'leading body of the profession' and indeed most obstetricians were attacking the whole idea of active birth, other obstetricians and hospital midwives, perhaps those with some experience in Europe or the US, realized that it was a good thing. In their own hospitals, they started to bring in genuine, if rather limited changes. They started to allow partners to be present. They reduced the number of interventions in very simple births. They let nature take its course a bit more. And several of these doctors made contact with Agnes, to suggest some kind of partnership. This was a time of new ideas in funding health care. Several private hospitals sprang up. Agnes received several offers of lucrative partnerships with similar minded doctors, which could have made her rich. She told them all to get lost.

She has a rather pioneering, even revolutionary nature, and she is not a woman of compromise. She knew how violent and corrupt her own profession was, and her fellow professionals were, and she wanted to build something new, something untainted. So no bridges were built with those people.

At the same time, our tentative attempts to make political allies in different parties, all came to nothing, even though we tailored our message to suit each group. We tried to explain to liberal and socialist MPs that birth is a basic human rights issue, to women MPs that it is a women's rights issue, to conservatives and Christian democrats that it is a pro-family and demographic issue. And to all of them that alternative birth in hospital, or at home, or in a future network of birth-



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houses would even be cheaper, without compromising the safety of mother and child. They listened to us. None rejected the arguments outright. But there was no political culture of cross-party lobbying in Hungary. No group of women's MPs in Parliament, for example, cutting across party lines. Hungarian politics has been and still is so polarized, on party political lines, that such a normal, democratic development is actually unthinkable to most deputies. To that extent, and many others, Hungary has a stunted, a deeply unsatisfactory democracy, to this day.

We also failed, often, to win over women's groups, who were more focused on the right to abortion, rather than on birth-rights. Though we used statements of the World Health Organization, especially from Fortaleza in Brazil in 1985, all the time, the WHO office in Budapest was also close to the medical establishment, and would have nothing to do with us. Other NGOs, Amnesty International for example, showed a little, but not much interest. In a word, we had no allies in Hungary, and with the benefit of hindsight, didn't work hard enough to build allies.

Abroad, it was much easier. We got to know British, Dutch, French, American professionals whose work we admired. Sheila Kitzinger, Michel Odent, Wendy Savage, Lesley Page, Elizabeth Davis and many more. They came to our conferences. Occasionally we attended theirs. But nothing changed in Hungary.

In the meantime, the obstetricians were working on the media, and on the prosecutors. More and more hostile articles started to be published. Doctors attached a little horror story to every birth. 'I saved your life' I saved your baby's life.' 'If you had attempted this outside hospital, you would both be dead - etc.'

The first prosecutions of Agnes and the other independent midwives around her began in 2000. In Hungary, as for example in Britain, every tenth birth which started at home ended up in hospital. In 2000, one of a pair of twins whose birth Agi attended at home, stopped breathing, and as a result had brain damage. A year later, she died. This was just what the medical profession had been waiting for apparent 'proof' that home-birth was dangerous. In vain did Agnes plead that the same outcome would have been likely in hospital. In vain did the parents of the child stand by Agi. Until that time, we had had a largely positive press - notwithstanding the articles written by doctors and their allies, attacking us.

This prosecution was followed by others, as the profession tried to criminalize homebirth. We became increasingly concerned about the legal environment in which she was working. The fact that while doctors attached to a hospital can never be sued - they can always hide behind their hospitals, and few individual



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doctors have ever been found guilty of anything - while Agi and the midwives were completely open to attack. So we started working with one Minister of Health after another, to draw up legal regulations which would cover planned births outside hospital. This led to serious disagreements among us. Agnes felt that she would be able to attend more births, with the least-possible outside interference, if no legal regulations existed - if the legal vacuum persisted. She was afraid that regulations, if drawn up, would restrict women's rights to choose. For example: no home birth for first babies, no home births over the age of 35, no home birth after a previous caesarean, no twins, etc. As an extremely skilled midwife, with several thousand births, in hospital and at home, she trusted her own instinct, and her own powers to encourage women, to overcome their own fears and barriers. One of her specialties was helping women overcome previous abortions as a barrier to birth. She was a brilliant advisor on breast-feeding.

She also trained and qualified as a psychologist, and helped women dissolve many traumas which prevented them from going into labor. But, we argued, none of the other midwives working with her had the same wealth of experience. The other midwives might not be able to take on, probably should not take on, the same wide range of birthing women that she could. Even bad regulations might be better than none, if it created a legal environment where alternative birth practices, in hospital and at home, could flourish. And also protect the midwives from prosecution - either by vindictive prosecutors who play golf at weekends with top obstetricians, or - God forbid, by embittered parents, when something went wrong - very rarely - at a birth.

In September 2006 the first and only baby died during a homebirth - a case of shoulder dystocia. And the father of the baby, who had been against his wife's wish to have a homebirth in the first place, got a tough lawyer who was determined not only to put Agnes in prison, but also to bankrupt her. After several years of court cases, they won, and in 2010 Agnes was sentenced to two years in prison for 'manslaughter through professional negligence.' In the meantime, another emergency case in which the mother had to be taken to hospital, led to her arrest in October 2010. She spent 77 days in prison. We organized demonstrations and vigils outside the prison nearly every day, and on the day after her birthday, December 22, we won her release into house arrest.

Since then, she has unsuccessfully appealed against the 2 year sentence, while the other 4 cases against her have continued. The most we could do, was to communicate with the Presidents of Hungary, first with Pal Schmitt, and then with the current President, Janos Ader.



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In the meantime, we had a partial success. Home-birth was finally regulated in the summer of 2011. As many of us had feared, the regulations were tougher than we had hoped for. But at least it gave the legal framework for a dozen or so independent midwives to work, to attend home births, and in some cases, to attend hospital births.

Another partial success came on October 8, 2012, when President Janos Ader issued his response to Agnes' appeal for clemency. Although he postponed any decision on quashing the sentence until all the cases against her have finished, he also made an unprecedented statement of support for her pioneering work.

'Thanks to the democratic development of our legal system, the legal order in Hungary – in accordance with European Union regulations – not only recognizes, but thanks to a new law adopted in 2011, by today also provides the choice of home birth, thereby recognizing the right to self-determination for women deciding to give birth to a child by allowing them greater room and more say in selecting the conditions in which they wish to deliver their child.

Dr. Ágnes Geréb has done a lot to expand the rights of women to unperturbed child delivery, thus she is recognized as the professional who introduced the option of allowing the father to be present at delivery in the hospital protocols and is also renowned for her professional activities aimed at the recognition of home birth.'

http://www.keh.hu/statements\_and\_letters/1677-Statement\_of\_the\_President\_of\_the\_ Republic&pnr=1

His office intended this as a moral rehabilitation, which would open the way to a legal rehabilitation in the future. In the meantime, after 3 years of full house arrest, the terms were softened to mean she can leave her home and travel anywhere in Pest county - that's the county around Budapest. But she is not allowed to teach, nor to attend births. So her hands remain tied, and Hungary is still denied the services of the country's most talented, and most experienced midwife.

Earlier this year (2015), her lawyers managed to have the first trial re-opened, on the grounds that a leading obstetrician is now willing to argue in court that her original conviction was unsafe. That she was simply attempting different ways to address a known medical nightmare - shoulder dystocia - which in hospital or at home, is one all doctors and midwives fear.

The situation of birth care in Hungary remains far from satisfactory. Hospital practices are somewhat gentler than they were 25 years ago, but women are still,



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on a daily basis, subjected to the humiliations and violence which we have fought against all that time. The caesarean rate is higher in Hungary than ever. And under the present government, empowerment of the citizens, grass-roots level democracy, is more restricted than ever.

After several years of mostly hostile coverage, media are becoming somewhat more favorable to gentle birth practices again. My advice for advocacy and human rights groups and individuals speaking to the media about birth issues would be the following.

- Get to know the specific media in question, and if possible the work of the journalist who will speak to you.
- For TV programmes recorded in advance, remember that only the briefest quotes will ever be used. Think ahead what you want to say, and repeat it in your answers to the questions, to increase the chance that your message will get across.
- For Live TV, dress smart, use humor, irony and common sense to get your message across. A few statistics or numbers are useful, too many are hard to follow, and counter-productive. If it's a panel discussion, research who you will be sharing the panel with. For all media appearances, know in advance what you want to say, and say it, no matter what questions are asked!

To finish with, would just quote one conversation with a top commercial TV editor, who I met to complain about his channel's coverage of Agi's trial. 'We are not asking for positive coverage,' I emphasized, just for fair coverage. 'Look, he said, 'in our news programmes, we only have villains and heroes. Agnes Gereb is now seen by the public as a villain. You're surely not expecting me to turn her into a hero are you?' As we were walking down the steps to leave the building I turned to him and said. 'Yes, I am.' But he hasn't.



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#### **ABOUT NICK THORPE**

Nick Thorpe is a writer and BBC journalist, born (at home) in Upnor, England in 1960. He studied modern languages in England, Germany and West Africa. He has lived in Budapest since 1986, and reported on the fall of Communism throughout Eastern Europe and the break-up of Yugoslavia for the BBC, Observer, Guardian and Independent newspapers. He has been Central Europe Correspondent for the BBC since 1996. He is also the author of 2 books The Danube – A Journey Upriver from the Black Sea to the Black Forest (2013) and 1989 – The Unfinished Revolution(2009), 9 documentaries and 1 short feature film, Vigilance about birth and war. With his wife Andrea he has 5 sons, all born at home in Budapest. Since 1992 he has taken part in the campaign for gentler, safer birth care in Hungary, for the legalization of home-birth, and for the defense of the independent Hungarian midwife, Agnes Gereb.





## WORKSHOP 2: SECURING FUNDING

## 2.1. FUNDING FOR CIVIL SOCIETY ORGANIZATIONS - THE STORY OF RODA - PARENTS IN ACTION

By Ivana Zanze

RODA was founded in 2001 when the government introduced austerity measures that drastically lowered maternity leave payments, and thanks to enormous volunteer efforts quickly grew to become Croatia's most relevant parents' advocacy group. Volunteerism remains RODA's cornerstone, but other models of financing and resource management have become equally important in making the organization sustainable. In this talk we explored the success and failures of a vibrant 200-strong volunteer organization with five employees.

#### **ABOUT IVANA ZANZE**

Ivana Zanze is one of the creators of RODA's Breastfeeding Support and Protection Program and since 2003 has been a RODA Peer Breastfeeding Counsellor. She is a member of the Breastfeeding Protection and Promotion Committee at the Ministry of Health of the Republic of Croatia, is a member of the Coordinating Committee of the Zagreb – Breastfeeding Friendly City Program and is an evaluator in the UNICEF Baby Friendly Hospital Initiative Program. Alongside Breastfeeding, she is actively included in all of RODA's activities including human rights protection. Through her years of work she has actively participated in numerous advocacy campaigns and initiatives and working groups for the preparation of strategies and legal initiatives. She is the Executive Director of RODA and the director of RODA's social enterprise, Rodin let LLC.





## WORKSHOP 2: SECURING FUNDING

## 2. 2. UPS AND DOWNS: SUCCESSES AND CHALLENGES IN MOVEMENT-BUILDING AND FINDING FUNDING FOR ADVOCACY WORK. A WORKSHOP FOR SHARING EXPERIENCES.

#### By Erika Schmidt

The Hungarian birth movement has a history made up of several stages. Our access to various kinds of funding has greatly depended on how the movement has been perceived by donors and also by the greater society. We talked about the role of communication with donors, how to convey messages about your mission, about the role of public discourse, national or international cooperation and also about the evolvement of feminist discourse on birth and birth rights in Hungary. I also presented the situation of the Hungarian non-governmental organizations, and our relation to the Government.

#### **ABOUT ERIKA SCHMIDT**

Erika Schmidt is a mother of three, activist, educator and lecturer, and a member and colleague of Birth House Association Hungary since 2011. She actively participated in the Hungarian homebirth movement, as well as in the "Justice for Agnes Geréb" campaign. At present, she is the director of the "Birthing Justice – Culturally appropriate, woman-centered maternity care in Hungary" projectof the Association, and also responsible for international relations.



## PANEL 4 LOCAL ACCOUNTABILITY MECHANISMS FOR VIOLATIONS OF HUMAN RIGHTS IN CHILDBIRTH

Are there local accountability mechanisms for violations in rights in childbirth? What are those mechanisms, and how can women become part of them and demand accountability? Researchers will highlight initiatives and tools that can be utilized to demand local accountability for violations of women's rights in childbirth. Attorneys from the Center for Reproductive Rights will talk about human rights fact-finding missions and their potential to bring meaningful change on a national level.

Moderator: Nora Schimcsig, Doula, Hungary

Panelists: Marie-Clare Balaam, Research Assistant, Midwifery Department, University of Central Lancashire, UK (Babies Born Better Survey Steering Committee)

**Dr. Imre Szebik**, Research Associate, Institute of Behavioural Sciences of Semmelweis Medical University, Hungary

**Dr. Marzia Lazzerini**, Director, WHO Collaborating Centre for Maternal and Child Health of Trieste, Italy

Dr. Milan Stanojevic, UNICEF Croatia

**Jette Aaroe Clausen**, Senior Lecturer in Midwifery, Metropolitan University College, Copenhagen, Denmark

Adriana Lamačková, Senior Legal Adviser for Europe, Center for Reproductive Rights

Jane Stojanovic, Midwife, New Zealand





# ONE COMPLAINT, ONE MOTHER, ONE HOSPITAL, ONE COUNTRY AT A TIME

#### By Nóra Schimcsig

I am a birth and postpartum doula, a HypnoBirthing® practitioner in Budapest, Hungary.

I also work as a breastfeeding peer counseler, and as a client centered counseler, supporting women who are afraid of childbirth or who suffered birth trauma. I manage Facebook pages and facilitate support groups, for example, for women who plan a vaginal birth after cesarean section.

I am also the founder of the Hungarian ICAN chapter. ICAN is the International Cesarean Awareness Network, a non-profit volunteer NGO of mothers, who want to prevent unnecessary cesarean sections by education, who support recovery after surgical childbirth, and support vaginal birth after cesarean (VBAC).

I am a single mother of a teenage son, and of course I have my own birth story to tell. Also, I could talk for a long time about how I got to do what I am doing now. This has all a lot to do with why I am here in Zagreb, to meet others who are also passionate about human rights in childbirth.

However, I believe that story would be very similar to the birth and doula experience of other Eastern European women. So I decided I want to tell you about another story of mine. The one that happened before I gave birth to my son, and before I got this calling to be around childbirth for the time of my life.

I happened to be an economist then. I realized I was interested in the way people organize themselves, and how those big groups of people: organizations, companies and institutions work. So I've studied psychology of decisionmaking, organizational behavior and development, and psychology of counseling. I've worked for ten years at a multinational company. An information technology company, that had no products, only services. A company that specialized in people. It understood customers and employees and management. I liked working there, I learned a lot and felt appreciated too. I worked at the customer service department in various positions.



By Nóra Schimcsig

I was an activist even then... I got elected to our works council, then to the European Works Council as a country representative, and later became Chair of the National Works Council of the company. (The works council serves as an elected body of employees in participatory management, together with the trade unions.)

In the last four years I delivered trainings to new hires about customer care. (It had the unintentional result of me becoming a terrible customer – I have expectations now.) This company understood that a happy customer is key to its' success. So we were interested in what the customer had to tell us. A complaint was not something to be avoided and the customer to be talked out of – but something we should be grateful for. Making a complaint takes precious time and effort, and many times the customer does not feel it would make any difference. But every complaint is a valuable piece of information, a feedback on how the company performs. Every dissatisfied customer who decides to take the time and tell us about their story does a great service to the organization, they help us to learn and grow and develop.

So when we had a customer who wanted to give us feedback, we listened carefully and documented. And then we analyzed those documents, and made changes to the ways we served our customers. Because we were passionate about becoming better and better and contributing to the world.

This company also had a non-Eastern-European culture. Meaning that we weren't so afraid to create documents and reports. Documents capturing reality as it is. The management understood that we could not make good decisions without data, without facts. The needed to know the facts. So we learnt that we weren't being punished just because the reality documented wasn't likeable. Reports weren't in the first place to blame someone – as it happens so often in my country otherwise.

This was a very important cross-cultural lesson... because later in the field of maternity care I learnt that our hospitals and professionals work in a split world of spoken and written realities. A dual world. For example, when a hospital birth happens on the **43**rd week of pregnancy, this won't be documented, because the hospitals' rule is not to allow women go past week **42**. So on the day a woman gives birth on the first day of her **43**rd week, all her documents will be corrected, because "there must have been some calculation error, and she was not, in fact, so much post-date"... This allows the staff to be "free" of supervisory board judgment, the hospital to be free of litigation risks – but also robs the woman of her reality, her evidence, and everyone involved, and the professions involved from the chance to learn by missing feedback. The statistics of the hospital will be distorted, unreliable, invalid. Is there a win at all?

By Nóra Schimcsig



A healthy person wants to learn from reality checks from time to time. A healthy organization should learn from continous feedback loops.

I so wish for our maternity care systems and organizations to understand the importance and the power of complaints and feedback. The opportunities they provide: we still have the chance to turn an unhappy customer into a happier one, but even more importantly, we could avoid mistakes in the future, we could make changes to the design of our workflows, the competence level of our colleagues, the staffing levels, the equipment... we could invest our little money so that it serves our communities better.

I am not sure how this can be achieved – maybe one complaint, one mother, one hospital, one country at a time. The rest will join later.





## BABIES BORN BETTER SURVEY: AN OPPORTUNITY FOR CROSS COUNTRY ANALYSIS OF CHILDBIRTH PRACTICE

By Marie-Clare Balaam

The Babies Born Better (BBB) survey is a pan-European survey which has been developed to collect the views and experiences of women who have given birth in the last 5 years. Designed to be distributed through social media and completed online the survey was launched in February 2014. It is currently available in 23 languages and has to date over 30,000 responses from women across Europe and beyond.

This paper will briefly explore the rationale behind, and the development of, the survey and consider the survey's potential to identify both excellent and poor childbirth practices across Europe. It will also consider how the results of the survey may act to support groups advocating for improvements in maternity care within their communities by providing accessible data and the ability to compare local, national and international conditions and practices.

The background: discovering good practice, engaging with women and developing networks

The survey came out of the work of the COST Action IS0907: Changing childbirth cultures and consequences. This was a 4 year EU funded networking project which involved over 120 participants from 26 countries. The Action's aim was to advance scientific knowledge about ways of improving maternity care provision and outcomes for mothers, babies and families across Europe by understanding what works, for who, in what circumstances , and by identifying and learning from the best.

One of the key underlying elements of the Action was the principle Salutogenesis. This approach supports a focus on the promotion of well-being for individuals and communities. In terms of maternity care, this means rejecting a focus on pathology and considering what factors promote positive outcomes. It supports an approach which seeks to explore which practices and approaches support good outcomes and positive experiences for mothers, babies and families and how maternity services can learn from these practices and philosophies. This underlying philosophy and an increasing awareness of the variety of women's experiences



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of birth and the range of childbirth cultures and practices across Europe led the Action to look for a way of investigating women's experiences of birth. The Action wanted to identify and locate where women had positive birth experiences and received excellent care. Mapping these results would allow us to identify where good practice was happening and then learn from this best practice to support positive change. However, while our focus was on positive practice, we were also aware that the survey would highlight places and situations where women had poor experiences of maternity care.

#### **Developing the Babies Born Better survey**

The survey was developed collaboratively with members of the Action from a range of countries and backgrounds. The intention was to use social media to maximize the survey's reach utilizing pre-existing social media networks and platforms used by women and mothers. The survey was developed to ask women about their experiences during their last birth along with some basic demographic data.

It is a relatively brief survey with 24 questions taking a variety of forms including simple yes/no responses, multiple choice questions and the opportunity to respond in a free text. This format was chosen to keep the survey easy to complete, to gather necessary demographic data but also to allow women the space to express their views in their own words. Respondents are asked their age, place of residence, resident status (migrant/non migrant), how many children they currently have, when they had their child/children, the gestational age of the child/children at birth and if they felt there had been any problems with the birth. They are asked where they birthed and who attended their birth. They are then asked to give 3 words to describe the best things about their care, 3 things that they would change about their care and 6 words to describe the care they received over all. They have the opportunity to enter free text about any issue that they wish to expand upon. Finally there is the opportunity to leave an email address if they are interested in being contacted by a researcher to take part in further more in depth research. Once the format of the survey had been finalized it was submitted to the University of Central Lancashire Ethics Committee. A steering committee and a network of national coordinators was established to oversee the management of the ongoing survey.

The survey was then translated into a range of languages by volunteers who included mothers, activists and academics. The translation process highlighted a

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range of issues that needed to be addressed. These included linguistic and technical issues as well as more philosophical ones as (childbirth) cultural differences emerged over the understanding of practices, expectations and understandings of maternity care. One example of this was the inclusion of the idea of 'stand-alone' and 'alongside birth centers', places where women receive only midwifery led care. While this concept is common in the UK and some other European countries, in other countries this option made little sense to women in their birth context as midwifery led care of this kind is not an option. However, the decision was made to leave these possible responses in all the surveys as it allowed women to see that there were options for birth locations which were different to those they saw in their own countries. It was hoped that this would act to raise awareness of different practices and allow women to question what they were offered as the norm within their countries. (Figure 1)

The survey was then posted online using Survey Monkey and can be accessed through a portal at http://www.iresearch4birth.eu/iResearch4Birth/en/ab2.wp (Figure 2) Dissemination of the survey was initially through a network of contacts from the COST Action, the COST Action website, the networks of the volunteer translators, the work of activists, and through the creation of a Facebook page https://www.facebook.com/iResearch4Birth?ref=hl and via Twitter. Since then dissemination has snowballed as mothers, activists, childbirth organizations and other social media users have spread the survey amongst their own networks.

### **Responses and data produced**

To date over 30,000 women have responded to the survey from Europe and beyond. Work has been done to clean and sort the data to ensure that it is accessible and maintains confidentiality for the women who responded. Initial data, up to August 2014, has been sent to National Coordinators to allow them to work on the data and disseminate the findings within their countries. In the autumn of 2015 the whole data set will be processed and distributed to the national coordinators. This will allow them to access a large quantity of data about the birth experiences of women in their counties and allow comparisons to be made between women's experiences across Europe.

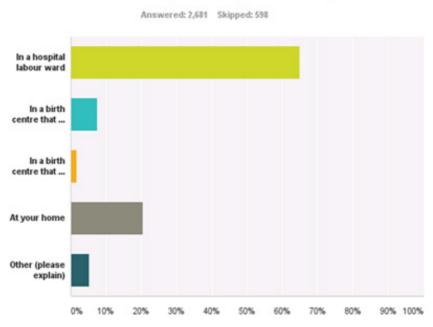
The philosophies underlying the survey and the policies of its management mean that this data is, and will be an accessible source for activists and academics working to improve the experiences of childbirth for women. This material will give



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activists access to the type of data that many are currently finding hard to access in a form that will be easy to disseminate. An ongoing commitment to engage with the women who have responded to us and the activists who have supported us will allow us to develop further research and continue to engage with mothers across Europe. The survey will be expanded in the future to other languages to allow more women to access the survey in their native tongue. Further research will allow more detailed cross country analysis of birth experiences and allow the identification of good practice and the opportunity to learn from these and conversely to highlight poor practice and seek to bring about change.



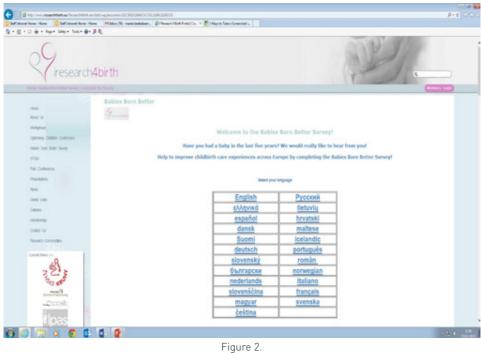
### Q12 Where did you have your last baby?

Figure 1. Place of birth including birth center

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By Marie-Clare Balaam





BBB portal

#### ABOUT MARIE-CLARE BALAAM

Marie-Clare Balaam currently works as a research assistant in the Midwifery department at the University of Central Lancashire, UK. Marie-Clare's background is in History and Women's Studies. She has worked as a lecturer and an academic and community based researcher. Her research interests are; migrant women's experiences of maternity care and childbirth in the UK and Europe, social support, and historical and socio-cultural perspectives on women's health particularly menopause. Her current research focuses on the experiences of asylum seeking and refugee women and social support for marginalized women. She is grant manager for COST Action IS1405 and on the steering committee for Babies Born Better European survey.





# ETHICAL IMPLICATIONS OF OBSTETRIC CARE IN HUNGARY. PROCESS AND RESULTS FROM THE WOMAN-CENTERED PREGNANCY CARE SURVEY

By Imre Szebik

Respect of autonomy and the ability of autonomous decision making during pregnancy and childbirth is an important value in our societies. Based on the Woman-Centered Pregnancy Care Survey conducted in 2014 Imre will reviewed how the rights and preferences of pregnant women were respected with regard to informed consent during their obstetric care. The frequency of interventions like vaginal exams, induction of labor, episiotomy, C-section and the consent procedures related to these interventions was reviewed as well.

#### **ABOUT IMRE SZEBIK**

Imre Szebik received his MD (1991), PhD(2004) and MSc in health care management (2008) from Semmelweis University of Medicine, Budapest, Hungary and his M.Sc. Specialization in Bioethics from McGill University (1999). He worked with the Biomedical Ethics Unit at McGill in 1997 1998 and 1999-2000 as a post-doctoral fellow. He was a post-doctoral fellow in clinical ethics at M.D. Anderson Cancer Center, Houston, Texas in 1998-1999. He works as a research associate at the Institute of Behavioral Sciences of Semmelweis Medical University. In 2014, a survey was conducted among Hungarian women regarding their preferences and satisfaction with birth care. Imre Szebik discussed some of the results of this survey, focusing on issues of informed consent and overuse of care in obstetric care.





# HOSPITAL CARE FOR MOTHERS AND NEWBORN BABIES: WHO QUALITY ASSESSMENT AND IMPROVEMENT TOOL

By Marzia Lazzerini, Alberta Bacci, Gunta Lazdane

### Introduction

The World Health Organisation (WHO) has developed several strategies and specific tools for helping countries to improve the quality of health care for mothers and newborn babies. In 2009 the WHO Regional Office for Europe, which provides technical support to 53 countries in the WHO European Region, released the first edition of a tool to assess and improve quality of hospital care for mothers and newborns.(1) A new updated version of the tool, including a specific chapter to assess the rights of women and babies, was produced in 2014, and is now available on the WHO/Europe website both in English and Russian.(2) These tools complement other existing tools to evaluate the quality of maternal care at the outpatient level.(3)

### Purpose of the tool and target users

The tool and its implementation can assist hospitals and health authorities towards providing quality health care to mothers and newborn babies. The tool adopts a participatory approach that facilitates wide involvement of hospital staff in a process of improving quality of care, (bottom-up approach) and in sustaining achievements over time. The tool can also guide and facilitate the implementation of all principles of "respectful care" for women and infants at facility level. (4)

### **Characteristics of the tool**

The main characteristics of the tool are listed below:

 It is based on international standards: evidence-based international guidelines and recommendations (over 150 references, reported for each chapter in the bibliography section). The tool includes a wide range of key items (about half of which refer to case management, the others to hospital support services, and to the organisation of care), which need to be evaluated to provide a systematic assessment.



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- 2. It adopts a participatory approach: the assessment is carried forward by an external international team of experts, together with a national team (usually identified by ministries of health (MoH)), and in dialogue with managers and health professionals from the facility under evaluation.
- 3. It aims at building capacities through a peer-review model: during the assessment, practical solutions are provided, together with training (if needed with explicit reference to the most recent literature), and lessons learnt from other countries.
- 4. It is action oriented: The final objective of the tool is to produce an improvement in quality of care; the assessment visit identifies the areas most in need for improvement and ends with the development of a practical plan for action.
- 5. It is suitable for use at facility level and also for countrywide assessments.

### Guiding principles of the tool

The ten basic guiding principles of the tool are shown in Box 1.

Box 1. Guiding principles beyond the tool

- 1. Coverage needs to be complemented by quality of care to achieve the desired health outcome. -->The tool is aimed at assessing and improving quality of care.
- Checking availability of basic equipment and supplies is necessary but not sufficient to evaluate quality of care; appropriate use of resources and case management also need to be assessed. --> The tool is divided into sections, evaluating availability and appropriate use of resources, case management, and key hospital policies.
- 3. Focusing on single key interventions is not enough; quality perinatal care requires systematic attention to all principal components capable of guaranteeing a continuum of care. --> The tool evaluates many different aspects of health care, at different times points (from access, to case management in hospital, monitoring, case referral, discharge and follow up) and across different services.
- 4. Safe childbirth is critical to the health and wellbeing of both the woman and the newborn child. --> The tool evaluates services and practices relevant to





# women's health together with services and practices relevant to the health of newborns.

- 5. Effective clinical management alone is not enough to ensure quality of care; holistic and culturally appropriate care is necessary. A health system should ensure all the rights of patients are met, not only the right to effective clinical management. --> Users' views, together with health staff views are collected by the tool through structured interviews. A chapter is dedicated to the assessment of satisfying/respecting the rights of women and infants.
- 6. A participatory approach is needed for raising awareness of problems and for building commitment. --> The tool is based on a problem-solving, participatory approach.
- 7. A blaming attitude and punitive approach causes denial and /or hiding of problems, decreases work satisfaction and motivation, and increases barriers to quality improvement. --> The focus of the tool is on the system, and not on the individual, with a non-blaming, supportive approach.
- 8. Assessment is the first step for triggering a quality improvement cycle and to be effective it should be combined with planning for action. --> The assessment is undertaken in an action-oriented way that facilitates the identification and prioritisation of problems and developing a plan for action. Matrixes for planning are included in the tool.
- 9. Both capacities and commitment are needed to improve quality of care. --> The assessment is also a training and motivating activity; international standards and best practices are presented during the assessment through a peer-to-peer approach to serve as models for improvement. Local capacity is developed as a result of the process at both facility and national level.
- 10. Health system factors need to be considered when planning quality improvement interventions. --> When applied over a representative sample of health facilities, the assessment indicates gaps.

### Main changes in the 2<sup>nd</sup> edition of the tool

Substantial changes were made in many chapters of this second edition (2014) compared to the first edition of the tool (2009) in order to update the tool contents in line with newer WHO guidelines and recommendations as well as with other international standards.





The tool now includes a chapter to evaluate specifically respect for mothers' and new-borns' rights at hospital level. This chapter is based on a large number of international references, and overall evaluates 62 key items.

Other new sections were created, and the overall format was improved.

### Structure and contents of the tool

The tool is divided into the following sections and chapters:

### SECTION 1: HOSPITAL SUPPORT SERVICES

- 1. Physical structures, staffing, and basic services
- 2. Statistics, health management information systems and medical records
- 3. Pharmacy management and medicine availability
- 4. Equipment and supplies
- 5. Laboratory support
- 6. Ward infrastructure

### SECTION 2: CASE MANAGEMENT

- 1. Care for normal labour and vaginal birth
- 2. Care for caesarean section
- 3. Management of maternal complications
- 4. Newborn infant care
- 5. Sick newborn care
- 6. Advanced newborn care
- 7. Monitoring and follow-up

### SECTION 3: POLICIES AND ORGANISATION OF SERVICES

- 1. Infection prevention
- 2. Guidelines, training and audit
- 3. Access to hospital care and continuity of care
- 4. Mother and newborn rights





### **SECTION 4: INTERVIEWS**

- 1. Interview with staff
- 2. Interview with pregnant women and mothers

### SECTION 5: FEEDBACKS AND A PLAN FOR ACTION

All the sections should be completed during the assessment, using the same methods in each facility. This allows for a systematic, comprehensive assessment of all domains relevant to quality of care.

### How to use the tool

This tool is mainly used in collaboration between WHO Regional and Country Offices and MoHs for country evaluations. Other agencies, institutions, and NGOs have also used it. General timelines for the activity and the number of facilities to be assessed are discussed at the initial stage.

At least in the initial phase of a country-wide assessment, it is recommended that an international team of experts works together with a national team, to provide guidance and coaching and to build the capacity for quality assessment.

Key expertise (obstetrics, midwifery, nursing, and paediatrics/neonatology) should be represented in both the international and local assessors. Professionals with the ability to interview women and staff in their own language should also be part of the team.

Each facility is usually visited for one and a half or two days. Data collection uses multiple sources: visits to hospital services; evaluation of clinical records and clinical cases; reviews of other documents (audits, statistics, protocols, etc.); interviews with health professionals and mothers. At the end of the visit a feedback meeting is held at the facility, together with managers and staff. During this meeting a concrete plan of actions is developed (using a matrix provided by the tool) to improve quality of care.





### Practical outputs of the tool

The practical outputs of the hospital visit include:

- 1. A semi-quantitative systematic evaluation (utilizing a scoring system from 0 to 3) of the facility, to identify strengths and weaknesses;
- Development of an action plan at facility level developed with a participatory approach together with facility staff - the plan should include priority problems, identified feasible solutions/actions, responsible people and timelines;
- 3. Development of a National Action plan for countrywide assessments where an adequate number of facilities are visited, (this usually includes actions such as developing or updating national guidelines, organizing training sessions, revision of regulatory mechanisms etc.).

### **Country experiences**

Previous experience in the WHO European Region includes the following country assessments: Albania, Armenia, UN Interim Administration Mission Kosovo, Kyrgyzstan, Kazakhstan, Republic of Moldova, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan. Additionally, the tool (locally adapted versions) has also been used in other regions of the word, including the African Region, South East Asia, and Middle East. (2, 5-10) Overall experience with the use of the tool pointed out that substandard quality of care, and disrespect of basic patients' rights is a common problem even in the European Region. (2, 5, 6) However, there are also encouraging examples of significant improvements in quality of care following the application of the tool. (7)

### Conclusions

The tool and the process of using it can assist hospitals and health authorities towards providing quality health care to mothers and newborn babies. The tool can also guide and facilitate the implementation of all principles of "respectful care" for women and infants at facility level.

Requests for country assessment should be addressed to WHO Country Offices or WHO Regional Office for Europe Dr. Gunta Lazdane gla@euro.who.int.





### References

- Making Pregnancy Safer: Assessment tool for the quality of hospital care for mothers and newborn babies. WHO, Regional Office for Europe, 2009. Available at http://www.euro.who.int/\_\_data/assets/ pdf\_file/0008/98792/E93128.pdf.
- Hospital Care For Mothers And Newborn Babies: Quality Assessment And Improvement Tool http://www.euro.who.int/en/health-topics/Life-stages/maternal-and-newborn-health/ publications/2014/hospital-care-for-mothers-and-newborn-babies-quality-assessment-andimprovement-tool (Accessed on 25 June 2015)
- Assessment tool for the quality of outpatient antepartum and postpartum care for women and newborns. WHO Regional Office for Europe 2013. Available at http://www.euro.who.int/\_\_data/ assets/pdf\_file/0006/191697/assessment-tool-for-the-quality-of-outpatient-antepartum-andpostpartum-care-for-women-and-newborns.pdf (Accessed on 24 February 2014)
- Prevention and elimination of disrespect and abuse during childbirth. World Health Organization, 2014. Available at http://www.who.int/reproductivehealth/topics/maternal\_perinatal/statementchildbirth/en/Accessed on 25 June 2015]
- Tamburlini G, Siupsinskas G, Bacci A; Maternal and Neonatal Care Quality Assessment Working Group. Quality of maternal and neonatal care in Albania, Turkmenistan and Kazakhstan: a systematic, standard-based, participatory assessment. PLoS One. 2011;6:e28763. Available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3245221/ (Accessed on 24 February 2014)
- Mersini E, Novi S, Tushe E, Gjoni M, Burazeri G. Adoption of the WHO assessment tool on the quality of hospital care for mothers and newborns in Albania. Acta Inform Med. 2012;20(4):226-34. Available at http://www.scopemed.org/fulltextpdf.php?mno=29822 (Accessed on 24 February 2014)
- World Health Organization. Assessment of the safety and of the quality of hospital care for mothers and newborn babies in Gaza strip: mission report. 2009. Available at http://www. ochaopt.org/documents/ocha\_opt\_health\_cluster\_QoC\_MNH\_needs\_assesment\_2009\_07\_29\_ english-20090828-094926.pdf (Accessed on 24 February 2014)
- Doctors with Africa CUAMM. Mothers and Children First: the first steps Ethiopia. 2012. Available at http://www.cuamm.org/en/images/stories/mediciconlafrica/varie/etiopia\_def.pdf (Accessed on 24 February 2014)
- Doctors with Africa CUAMM. Mothers and Children First: the first steps Tanzania. 2012. Available at http://www.cuamm.org/en/images/stories/mediciconlafrica/varie/tanzania\_def.pdf (Accessed on 24 February 2014)
- Doctors with Africa CUAMM. Mothers and Children First: the first steps Uganda. 2012. Available at http://www.cuamm.org/en/images/stories/mediciconlafrica/varie/uganda\_def.pdf (Accessed on 24 February 2014)
- Tamburlini G, Yadgarova K, Kamilov A, Bacci A; Maternal and Neonatal Care Quality Improvement Working Group. Improving the quality of maternal and neonatal care: the role of standard based participatory assessments. PLoS One. 2013; 8(10):e78282. Available at http://www.plosone.org/ article/info%3Adoi%2F10.1371%2Fjournal.pone.0078282 (Accessed on 24 February 2014)





 World Health Organization. Kyrgyzstan making progress, but more to do in mother and newborn care, assessment shows. Available at http://www.euro.who.int/en/health-topics/Life-stages/ maternal-and-newborn-health/news/2014/06/kyrgyzstan-making-progress,-but-more-todo-in-mother-and-newborn-care,-assessment-shows. (Accessed on 25 June 2015)

#### ABOUT DR MARZIA LAZZERINI

Dr. Marzia Lazzerini is the director of the WHO Collaborating Centre for Maternal and Child Health of Trieste (WHO CC) since year 2011. She did join the WHO CC as a medical student, in 1996. Until year 2011, before moving full time to research, she has been working as a paediatrician in a third level hospital in Italy, as well as in low and middle income countries (Angola, Brazil, Mexico). In 2004, after a Diploma in Tropical Medicine and Hygiene at the Liverpool School of Tropical Medicine, she joined the Cochrane Collaboration, and since then she has been guite active in the area of evidence synthesis. In 2006 she attended a MSc in Methods of Clinical Research with the Cochrane Centre, and in 2009 she obtained a PhD in Clinical Research in Paediatrics, on a randomised controlled study later published in the JAMA. During time she has accumulated field experience in Sub-Saharan Africa (Angola, Malawi, Tanzania, Kenya, Mozambique, Eritrea), South America (Mexico, Brazil), South East Asia (Sri Lanka), as well as large experience in the WHO European Region (Georgia, Ukraine, Moldova, Kosovo Region, Kazakhstan, Kyrgyzstan, Uzbekistan). Her actual main area of interest in maternal and child international health include quality of care and respect of rights of children and mothers. As a director of the WHO CC she has coordinated in the last years the technical updated of standard based assessment tool for evaluating and improving the quality of hospital care for mothers, newborns and children, as well as the development of evidence-based training packages in perinatal health. In collaboration with WHO and other agencies such as UNICEF she is coordinating clinical trials in the area of Quality of Care in Mozambique and Sri Lanka.

#### ABOUT DR. ALBERTA BACCI

Dr Alberta Bacci, Obstetrician Gynaecologist, worked in different maternity hospitals in Italy since 1976. From 1987 she worked 4 years in Maputo Central Hospital, Republic of Mozambique. From 2001 to 2011 she was regional coordinator for the Making Pregnancy Safer programme in WHO Regional Office for Europe. Since May 2011 she works as independent consultant for mother and newborn health care, in several countries, with different UN organizations and NGOs. Her experience includes assessment of quality of care, and introduction and evaluation of maternal mortality and morbidity case reviews using WHO Beyond The Numbers approaches. She is member of the WHO Collaborating Centre for Mother and Child Health, Trieste, and faculty of the European School for Maternal, Newborn, Child and Adolescent Health, Trieste, Italy.





#### ABOUT DR. GUNTA LAZDANE

Gunta Lazdane is an obstetrician and gynecologist, Ph.D. and has been Professor, Head of University Department in Riga Stradins University, Latvia. Since 2003 she is working in the WHO Regional Office for Europe as the Programme Manager, Sexual and Reproductive Health in the Division of Noncommunicable Diseases and Promoting Health through the Life-course. She is assisting 53 WHO Member States in the European Region to improve sexual, reproductive, maternal and newborn health through promoting good health at key stages of life, taking into account the need to address social determinants of health and gender, equity and human rights. Dr. Lazdane has participated in many European and global conferences and congresses including International Conference on Population and Development in Cairo in 1994. She is the Chief Editor of the European Magazine for Sexual and Reproductive Health Entre Nous.





# CAN MATERNITY HOSPITALS IN CROATIA BECOME MOTHER AND BABY FRIENDLY?

By Dr. Milan Stanojević

Are maternity hospitals in Croatia really the sites of horrors that have been described in the media over the past few months? Recent reports have caused public and professional concern, and the issues concerned are not specific only to Croatia, being present in many other countries. International human rights documents are key to understanding violence in maternity care. Care that is not evidence-based and includes violence and insults represents the violation of women's basic human rights and is proof of gender inequality. This talk will presented the Mother Friendly Hospital Initiative, the partnerships that are necessary to make it a reality, and concrete steps that will be taken to make it a reality in Croatian maternity wards in the upcoming period.

#### ABOUT DR. MILAN STANOJEVIĆ

Dr. Milan Stanojević has been Head of the Neonatology Department at Sveti Duh Clinical Hospital since 2007. He teaches graduate and postgraduate programs at the University of Zagreb Medical School including Obstetrics and Gynecology, Basic Course on Ultrasonography in Croatian and English, foetal and neonatal neurophysiology, foetal behavior. Dr Stanojević was Secretary General of the World Association of Perinatal Medicine from 2007 to 2011 and served as vice-president (2011) and president-elect (since 2013) of WAPM. Since 2008 he has been a fellow of the International Academy of Perinatal Medicine and since 2014 has been a regular fellow of the IAPM. In 2011, Dr. Stanojević was awarded the William Liley Medal by the Foetus as a Patient Society and received the Ladislav Rakovac Award from the Croatian Medical Association in 2008. Dr. Stanojević has published 253 papers, has contributed to books and been editor, participates on the editorial boards of two journals and is a reviewer for ten journals. He is a National Coordinator for training programs at UNICEF Office for Croatia and has been involved in the Baby Friendly Hospital Initiative for the past 20 years.





# THE DANISH MISOPROSTOL CONTROVERSY PRIMUM NON NOCERE - FIRST, DO NO HARM

### By Jette Aaroe Clausen

Millions of women throughout the world have had their labour induced with misoprostol despite the fact that the drug is not registered as an induction agent. (Misoprostol has become available as registered drug for labor induction in some countries, but when it was introduced in the 1990s in the US, and later in other countries, it was used off-label.) No one knows when and where the first woman in Denmark was induced with misoprostol. We do not know what dosage she was given or if she herself knew that she was treated with a non-registered induction agent. The likelihood that she did not know this is, however, very high. A similar story can be told from many other countries around the world. In Denmark, as in many other countries, there are no legal requirements to report the use of off-label drugs to the National Health Authorities, and so it is not possible to identify public information on the use of off-label drugs, and it is not possible to determine when, where, and how these practices were initiated.

My point of departure in this paper is the use of misoprostol for induction of labour and the problems that follow, when a non-registered drug is introduced in maternity care and becomes a routine intervention. I will particularly stress the risk of unrecognised and unreported side-effects. Even though the lack of knowledge about serious side effects is acknowledged in the evidence based literature (Hofmeyer et al 2013; Wang et al 2015; Thornton, 2015) and the *underreporting of side-effects* has been acknowledged for a longer period of time (Hofmeyer et all 1999; Wagner, 2008; Gaskin, 2013) no effective actions have been taken to counteract this. Finally, I will briefly discuss how my colleague and I have worked for more than ten years to bring the problem of unreported side-effects to non-registered drugs to the attention of the Danish Health Authorities.

User groups (Timeo et les autres in France, Forældre og Fødsel in Denmark, the Madeline Oden Foundation USA), Medical suppliers (Searle (2000), and Pfizer) and Health Authorities such as the, Federal Drug Agency (FDA) in the US and the French Health Authorities have among others raised concerns about the off-label use of Cytotec.



By Jette Aaroe Clausen

Pfizer holds the licence to produce Cytotec and they have on several occasions stressed that they do not support the obstetric use of Misoprostol. During the public debate in 2013 Pfizer in Denmark issued a press release that they did not support the obstetric use of misoprostol. Pfizer in Sweden has done the same.

The Periodic Safety Report (PSUR) published by Pfizer (2011) stresses that obstetric use of misoprostol accounts for the majority of reported side effects; however no thorough and detailed analysis has been carried out as there is no formal stakeholder that has the obligation to take this responsibility.

The US Food and Drug Administration have issued a black label warning on Cytotec for pregnant women. A black label warning is printed on the package insert for prescription drugs The FDA can request that a pharmaceutical company places a boxed warning (a black line) on the labeling of a prescription drug, or describe it in words. It is the strongest warning that the FDA issues. Such a warning highlights that medical studies have indicated that the drug carries a significant risk of serious or even life-threatening adverse effects. Note that the black label warning in the Cytotec packet underlines that it should not be used by pregnant women who suffer from peptic ulcers (FDA, 2012). I have meet obstetricians that argue that this warning do not apply to low dose misoprostol that is used during labour. They bypass however the FDA has also issued an Alert (2008) and a patient information leaflet on misoprostol (2009). A patient information leaflet is published when the FDA wants to spread information directly to patients (pregnant women). The FDA writes, "This Patient Information Sheet is for pregnant women who may receive misoprostol to soften their cervix or induce contractions to begin labor. Misoprostol is sometimes used to decrease blood loss after delivery of a baby. These uses are not approved by the FDA. No company has sent the FDA scientific proof that misoprostol is safe and effective for these uses." (2009). The FDA furthermore stresses that there "can be serious side effects, including a torn uterus (womb), when misoprostol is used for labor and delivery. A torn uterus may result in severe bleeding, having the uterus removed (hysterectomy), and death of the mother or baby. These side effects are more likely in women who have had previous uterine surgery, a previous Cesarean delivery (C-section), or several previous births. "(2009).

Gaining access to misoprostol

In 2013 27% of all deliveries in Denmark were induced. Prostaglandin E2-drug (PGE2) (e.g. Minprostin®) has long been registered for induction purposes in Denmark. But in the beginning of the 2000s a non-registered prostaglandin E1-



drug (PGE1), misoprostol, was introduced, and since then has become the first drug of choice for 'uncomplicated' labor inductions. Minprostin is still used for women who have a previous scar.

How do Danish obstetricians place an order from the pharmacy for an unapproved medication that is not manufactured in doses thought to be safe in pregnant women? They do what doctors in many other countries also do; they cut Cytotec® (Wagner, 2008) into smaller pieces with a razorblade and apply these pieces vaginally as an induction agent.

Such a procedure is, however, not an innocent move to make. Pfizer manufactures misoprostol tablets that carry misoprostol within an inert vehicle designed to be used orally. The production process is designed so ensure that the amount of active substance is stable. In most countries Cytotec is available as either 200 mcg or 100 mcg tablets. High- dose misoprostol is associated with an increased risk of hyper stimulation. The Cochrane analyses on vaginal misoprostol (Hofmeyer et al, 20013; Alfiveric, 2014) recommend that dose should not exceed 25 mcg and the analysis on oral misoprostol says 50 mcg. As a consequence the misoprostol tablet must be divided. This process in some hospitals is carried out by hospital pharmacists and in other places it is done on site by doctors, nurse midwives or others who work on the labor ward. The above picture is from Portugal from 2014. Cutting a drug with a razor blade is not an effective means to deliver a consistent dosage, and it is indeed very difficult to understand why such a practice is carried out in a practice that in other domains is obsessed with safety, i.e. induction of healthy pregnant women for no other reason than to end pregnancy prior to week 42.

We do not know how many Danish women were induced with 'hand cut on the site produced' misoprostol, though it is likely a high number. Anecdotal evidence suggests that the onsite cutting of misoprostol tablets is widespread, but I have not been able to identify any formal statistics on this issue. We know from Swedish midwives who worked in southern Sweden that Danish doctors brought misoprostol to Sweden around the new millennium and that they cut it with a razor blade. We do not know what dose they used. Some Swedish midwives told me that these births became known as 'snit i hvidt' which means 'cut in white' a phrase referring to the high risk of an acute cesarean section. It is stunning that midwives in different setting report very different stories about misoprostol. There are stories like the one from Sweden, and Danish midwives reported frequent hyper stimulation and dark amniotic fluid in women who were treated with 50 mcg. Misoprostol. I have however also heard midwives, who work in highly medicalized environments i.e.



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hospital with 60% cesarean section, give a very different account. We never see hyper stimulation' they told me. I do not know the reason why midwives/nursemidwives have so different accounts on hyper stimulation. I would however not be surprised if hyper stimulation is understood very differently in low and high medicalized environments (augmentation with Syntocinon and cesarean sections).

The Danish Misoprostol controversy has raised a long list of problems. It is not in any way possible to go through them all here. I will however just briefly raise awareness of an important subset related to patient safety, namely the under reporting of side effects and the importance of Pharmacovigilance.

Much has happened in Denmark since the first woman was induced with misoprostol. For the larger part of the last 10 years of misoprostol use, hospital pharmacies produced off-label vaginal tablets. This method of production stopped in 2014 as a result of the public debate around the safety of these tablets. However, the public debate has not resulted in hospitals stopping the use of misoprostol inductions because many hospitals use tablets produced in India. I will return to this again later.

When misoprostol was first introduced into Danish maternity care it was used off-label and contrary to protocol. The Danish Society of Obstetricians and Gynaecologist (DSOG) published a new guideline on induction of labour in 2003. This guideline recommended 50 mcg Cytotec vaginal tablets despite the fact that the Cochrane Review on vaginal misoprostol highlighted that the dose should not excess 25 mcg (Hofmeyr et al, 1999).

Why did DSOG overrule the Cochrane recommendation? The answer is straightforward: they simply did not have access to 25 mcg tablets with misoprostol. At that time the only misoprostol product available in Denmark was 200 mcg Cytotec® tablets. Cytotec® was registered as a preventive treatment for peptic ulcer. Before they could use if for induction purposes the 200 mcg tablets had to be divided into usable pieces. A 200 mcg tablet needs to be divided into 4 pieces to arrive at approximately 50 mcg. Trying to divide it into 25 mcg pieces is extremely difficult not to say impossible. DSOG did not want to be stopped by the lack of supply and thus they acted pragmatically and took the 50 mcg solution. This practice was stopped in October 2004 when the Health Authorities intervened after a public debate. The Health Authorities send a letter to all Danish labour wards and stressed that they strongly recommend that the use of 50 mcg misoprostol should stop. They also asked all obstetric departments to begin to report side effects to the national registry (Sundhedsstyrelsen, 2004). Unfortunately, the Health



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Authorities did nothing to follow up, and we do not know to what extend the obstetric departmentc followed their recommendation. We know that the call to report side effects went almost unnoticed. Awareness about unreported side effects was once again raised in 2013. The president of the Danish Association of Obstetricianc and Gynaecologists has confirmed the underreporting of side effects. He stated in a public newspaper that "side effects and suspicious side effects should be reported. I do not know to what extend this is done, but my feeling is that not all side effects are reported." In a subsequent television interview he said, "The reporting of side effects does not have much attention in obstetrics".

The off-label production of vaginal misoprostol tablets in local hospital pharmacies was controversial from the very beginning, but in the early stages this was mostly discussed in close circles between pharmacists and the doctors who initiated the use of misoprostol. During the debate in 2012 and onwards a wide range of professionals became aware of this problematic practice and the issue was also discussed in the Health Committee in the Danish Parliament on several occasions.

The Danish legislation on medical safety does not intend to allow hospital pharmacies to circumvent safety measures laid down in the legislation that control the production and sale of pharmaceutical products (Kammeradvokaten, 2011). Some hospital pharmacies acknowledge this and refused to produce vaginal misoprostol products, but other pharmacies had fewer problems with that, and they began to supply tablets for more than one hospital, thus enabling the majority of labour wards to continue to use misoprostol for induction.

However, as the misoprostol controversy evolved from 2012 and onwards the National Health Authorities began to take a closer look at the local production sites. They also began to raise safety issues and emphasize a range of safety precautions that the pharmacies should follow. As a consequence the last pharmacy stopped its production in 2014.

The stop of local production of misoprostol tablets did however not stop the use of misoprostol for induction purposes in Denmark. What did Danish obstetricians do when they could not find supplies in Denmark? They took three steps 1) secured supplies of non-registered drugs, 2) secured the support from National Health Authorities 3) identified allies outside the field of obstetrics who would support the routine use of a non-registered drug.



The drug of choice was Angusta. Angusta is a 25 mcg misoprostol tablet. Angusta is not a registered drug in Denmark nor is it registered in any other European country. It is the first non-registered drug to be used routinely in a Danish Health care setting (see Table 1).

We do not know how Danish obstetricians became aware of Steril Gene in India and began to research this opportunity (http://www.steril-gene.com/tour/index. html). Sterile Gene is not a well-known medical supplier in Denmark. Sterile Gene is a small Indian factory that produces medicine for low income countries. Denmark is by no means a low income country, and to our knowledge, Denmark has never bought medicine under such conditions prior to this case. It is important to understand that non-registered drugs have much in common with off-label use but there are also important differences (see Table 1). Off-label drugs are *registered drugs* used for purposes that they are *not registered* for. Angusta is however not even a registered drug. In that respect one could say that the control with Angusta is even less than with off-label use.

When we first heard about Angusta in 2013 it was an unknown drug to us. We searched a range of medical databases without identifying any information, we have also asked professionals who work with medical safety, on a regular basis, if they could identify information on Angusta, and so far they have not been able to do so. If patient safety is a priority, which many obstetric departments would claim, you would think that the lack of information would be a barrier for implementation, but beware you are wrong. We know that currently obstetricians in other countries are considering to follow Denmark's lead. Anecdotal evidence suggests that Angusta is also used in Finland.

Doctors are not allowed to import non-registered drugs into Denmark. So before they could use Angusta they needed the blessing of the National Health Authorities. National Health Authorities might in special circumstances and to a limited degree, authorise the sale or dispensing of medicines that are not marketed. In such cases the doctor gets a compassionate user permit. Compassionate user permits are often used in situations when *specific patients* experience severe side-effects to a registered drug and there is no alternative on the market, or when there is no relevant drug on the market for the condition at hand. This compassionate user permit for misoprostol is controversial for several reasons 1) the drug is not registered in Europe 2) there is already a registered drug available on the market 3) the drug is used routinely and 4) it is used on a group of healthy individuals. Not exactly a situation that calls for the use of non-registered drugs.



Several Danish hospitals applied for a compassionate user permit to use 25 mcg Angusta for induction of labour and they got it. It is difficult to understand why they received this permission. Through a request for public information we have had access to all the applications from the hospitals and they contain hardly any information on Angusta. It does not seem as these hospitals were asked to issue any evidence to support their case. Those who did simply referred to the Cochrane analysis of misoprostol (which ironically notes that we do not have sufficient knowledge about side effects and that do not mention Angusta). The hospital applicants stressed that they wanted to use *oral* misoprostol instead of the *vaginal* misoprostol that had been the main offender of off-label use. They argued that women would prefer oral misoprostol to avoid vaginal examination (Ironically they did not explain how they would examine the woman, but the Health Authorities accepted their argument).

This use of compassionate user permits for non-registered drugs is controversial and is currently being discussed in the public and the question has been raised in the Health Committee in the Danish Parliament. At this time in history it is not possible to predict what the conclusion will be.

For the time being Danish hospitals continue to cooperate with an Indian pharmaceutical company to carry out misoprostol induction. However such a non-traditional practice does not have solid standing and the DSOG is aware of this vulnerability. They could not substantiate this controversial practice and sought allies outside obstetrics. They approached The Council for Expensive Medicine (Rådet for Dyr Sygehusmedicin (RADS))--despite the fact that misoprostol is not an expensive drug—to see if this regulatory body could produce a recommendation on misoprostol. For unknown reasons RADS accepted this task, and in the fall of 2014 they issued their report (RADS, 2014).

Even though DSOG went outside obstetrics to secure allies the RADS working group had nevertheless a majority of obstetricians as members. The head of the working group was an obstetrician who had been very active in initiating the use of misoprostol in Denmark. Furthermore, the working group had a midwife representative from the Midwifery Association and a pharmacologist. The work that Eva Rydahl and I have done has not been connected to the Danish Midwives association and we have not collaborated in this work.

I have discussed different forms of misoprostol induction agents, these different forms also have a range of other consequences. In the following I will briefly touch on challenges of monitoring side effects.



### Pharmacovigilance - the monitoring of possible rare but serious side effects.

*Primum non nocere*, is a Latin phrase, it means first do no harm. Non maleficence is a fundamental principle in bioethics. There is no such thing as a free lunch, and drugs are potent agents that may cause harm. The World Health Organization stresses that the expected benefits from a treatment or an intervention should outweigh its potential harm (WHO, 2011). The problem of iatrogenic effects should have a high priority in midwifery especially as pregnancy and birth have become highly medicalized.

Before a drug can reach the market it must be approved by national health authorities. The patent-holding company bears the responsibility to demonstrate safety and efficacy. It should be noted that the monitoring process is heavily dependent on the company that holds the license to a registered drug. In the case of Cytotec it is Pfizer. In the case of Angusta there is no company that holds a license in Europe and thus it is an open question as to who carries the legal responsibility.

Many countries provide public and free information on *registered* drugs. However, these databases do not contain information on non-registered drugs. Without knowledge of possible side effects it is not possible to decide if a patient that receives treatment is likely to benefit from it, i.e. have a better outcome than the spontaneous process would result in.

The main function of pharmacovigilance is to ensure that medicine is safe and effective. Knowledge about effects and side effects is developed through a difficult, expensive and time intensive process. Development, approval for marketing and manufacturing, of pharmaceuticals is a supremely regulated activity, especially compared to many other parts of health care. Pharmacovigilance is a complex system of interrelated rules that govern a broad range of activities.

The development of medical products can be divided into several phases (see Figure 1). The initial studies are pre-clinical studies carried out on animals and followed up by experimental studies. In the final stages it is considered good practice to test drugs in randomised trials, where the presence of a control group allows to identify side effects that cannot be explained by chance alone.

There is a range of different trials:

• **Phase I** trials involve healthy volunteers and are carried out to determine safety and dosing.



- **Phase II** trials are used to get an initial reading of efficacy and further explore safety in small numbers of patients who have the condition that the drug aims to target.
- **Phase III** trials are large, pivotal trials to determine safety and efficacy in sufficiently large numbers of patients.
- **Phase IV** trials are post-market surveillance studies.

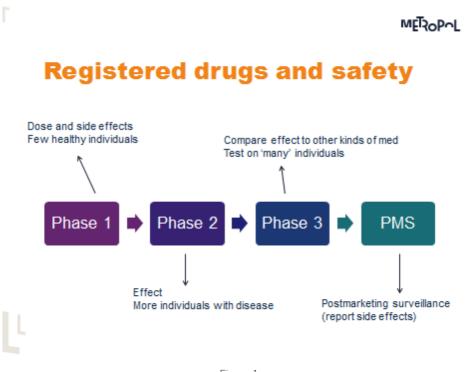


Figure 1: Developing knowledge about effects and side effects

The later phases of this process use randomized trials that are trials with a control group.



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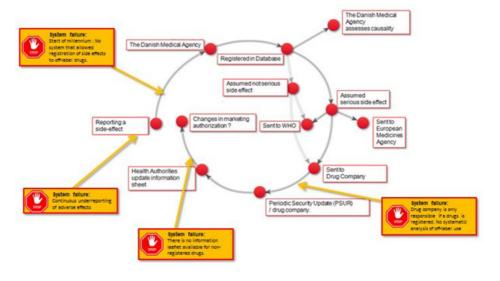
Randomized studies do *not* have statistical power to measure rare effects, and furthermore you cannot measure outcomes that are not known or that you cannot even imagine. A well-known example of a medicine that caused devastating unanticipated expected effect is thalidomide. Women who had thalidomide gave birth to children with multiple congenital defects, especially limb and heart defects. The case of Thalidomide demonstrated that drugs could have devastating unanticipated effects, and this realization led directly to the development of more structured drug regulations. A pivotal aspect of establishing drug safety is reporting of side effects.

Post-marketing surveillance is a method that can be used to develop knowledge about serious and rare side effects that cannot be monitored in trials. Postmarketing surveillance refines, confirms or denies the safety of a drug after it is used in *everyday* practice. Post marketing surveillance uses a number of approaches, including spontaneous reporting databases. The first and second misoprostol controversy identified important issues concerning the reporting of side effects to non-registered drugs (see Figure 2)

The first misoprostol controversy (2003-05) made us aware that misoprostol induction was initiated despite the fact that we did not have a national reporting system capable of monitoring side effects to drugs that were used off-label. You would expect that this would make the health authorities more aware of the reporting problem, but the second misoprostol controversy (2012 and forward) made us painfully aware that we had been far too optimistic. As the Danish Health Authority issued compassionate user permits for Angusta they did not, however, investigate the problem of legal responsibility. Sterile Gene has a different legal responsibility than Pfizer because they do not hold a standard license that allows them to sell Angusta. They are only allowed to sell Angusta to Danish obstetricians because obstetricians/obstetric departments hold a compassionate user permit. This changes the legal situation on several accounts. Sterile Gene do not seem to have a legal responsibility to monitor side effects nor do they have legal obligation to develop an information sheet that meets the standard for registered drugs and they do not have to update the patient information sheet. This is how we understand the situation at the moment. There are, however, many unanswered legal aspect that is still unanswered; keep in mind that Angusta is the first unregistered drug that was made available for routine use (see Box 1)



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### Generating knowledge through Pharmacovigilance



Identifying barriers in the reporting system with a special emphasis on non-regulated drugs.

Licensed medicine, which is sold in Europe, carries a *product information sheet* and a *patient information sheet*. The company that holds the license to sell the drug has the obligation, in cooperation with the national health authorities, to keep this information current.

The fact that doctors can only use Angusta because the Health Authorities have issued a compassionate user permit has to be kept in mind. The legal framework on which this practice rests is different from registered drugs. This may have implications for safety, patient rights and compensation in case of severe outcomes. It may be more difficult to prove that a side effect is related to the drug in cases where one cannot refer back to a product information sheet. However, this is highly dependent on how the legal system works in different countries.



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### From here and forward

The introduction of misoprostol into Danish maternity care was a silent process advocated for by unknown doctors. It went unnoticed until two midwifery students began to work with this issue during their bachelor in midwifery studies in 2003. I was their supervisor and after having become aware of this widespread practice I contacted the national health authorities. The national health authorities proceeded to take only minor actions; it would be fair to say that in many respects that they just silently approved of bending protocols in many directions.

It was not until 2012 when women began to report side effects to the press that this matter was brought to the public attention again. Following these public reports, we managed to keep the process going by bringing a range of cases to the Health Committee of the Danish Parliament. Also critical to this process were two investigative journalists who researched and reported on misoprostol in more than 60 articles in *Berlingske*, a Danish newspaper.

The legal obligation to report side effects to off-label medication is an important step, furthermore women have the right to be informed about the use of a non-approved drug and this has been stressed by the Health Authorities and the legal advisor to the Danish Government (Sundhedsministeren, 2013; Kammeradvokaten, 2012) but sadly has not been implemented in practice to any great extent.

For the optimist the Danish misoprostol controversy illustrates that changes are possible. The pessimist will, however, draw attention to the fact that changes did not come from within the health care system or from the health authorities. Changes were brought about by concerned citizens who did not let the matter rest; promoting change is a long-lasting and ongoing process and at times the process will go on for years.

Meanwhile, Eva and I struggled to keep the issue in the National Health Authority's attention. We await the Authority's response to these urgent questions:

- 1. Why has unsafe pharmacy practices persisted in this area?
- 2. Do women have the right to be offered registered drugs?
- 3. What role and legal obligations do midwives have in the induction process?
- 4. Do women who are treated with off-label drugs or non-registered drugs have the same rights for compensation in case of birth with severe outcomes?



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We are also currently waiting for a new report from the Counsel of Expensive Medicine (RADS). In spring 2015, Eva and I submitted a critique of their Angusta recommendation (2015). We raised a number of issues, both legal and clinical. The RADS recommendation draws heavily from the Cochrane analysis on oral misoprostol (Alfiveric, 2010). We questioned this Cochrane analysis' conclusion that misoprostol lowers the risk of Caesarean section (Rydahl and Aaroe Clausen, 2015). As a consequence of our submission to the Cochrane Collaboration and a critique published by Jim Thornton (2015), an English obstetrician and well-known researcher, the Cochrane analysis is currently being reassessed.

I do not know if Eva and I are to be thought of as optimist or pessimists, I note however that we have continued to work with these issues. We are highly motivated by the wish to secure safe birthing practices and secure that women themselves have a say. Before I close I will just sum up, some of the changes that the Misoprostol controversy has brought about.

- It raised awareness about the use of non-registered drugs in general. The Health Authorities issued a national report on reporting of side effects where they specifically mentioned off-label use.
- It raised awareness that midwives and obstetricians should not take for granted that the drugs they used were registered drugs.
- The use of 50 mcg Vaginal misoprostol was stopped by the Health Authorities
- The production of misoprostol off-label tablets diminished over time and stopped completely in 2014.
- The legislation on hospital pharmacies was revised.
- A system that allowed the reporting of side effect to off-label use was put in place in 2005. Midwives were given in 2013 the legal obligation to report side effects to the National Health Authorities. They hold the same obligation as doctors.
- The Health Authorities published in 2013 a plan on the monitoring of the use of medicine to induce labor (Sundhedsstyrelsen, 2012). The Health Authority set a deadline, spring 2016, when they will access the result of this process.
- The Health Authorities set out to:
  - 1. Monitor and secure the quality of off-label drugs



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- 2. Provide evidence based information to women
- 3. Secure surveillance of the use of drugs for induction of labor
- 4. Secure that adverse effects and unintended actions are reported.
- 5. Secure that a reported incident is followed up.

### **Different types of medication**

- **Drug**: The term "drug" means [any] articles intended for use in the diagnosis, cure, mitigation, treatment, or prevention of disease in man or other animals.
- **Registered drug:** A drug that is marketed by a stakeholder that has a license that meets international legal standards for drug safety.
- **Off-label drug:** An approved drug being used by a physician for a purpose that it is not approved for.
- **Non-registered drugs:** A drug that has not been registered in Europe or any other system with similar standards.

. Box 1: Different types of medication.

Questions you might want to consider?

- Is misoprostol used for induction of labour in your country?
- In cases when misoprostol is used, what is the product name? Is it a registered drug? Is it used off-label? Or is the drug non-registered?
- Is it possible to report side effects to non-registered drugs in your country? If yes who holds the responsibility to analyse the data?
- Who is allowed to report side effects? Doctors? Midwives? Nurses? Women? Family members?
- Do women have the right to be informed about off-label and/or use of non-registered drugs?

### THE DANISH MISOPROSTOL CONTROVERSY

Primum non nocere – first, do no harm

By Jette Aaroe Clausen



### **Bibliography**:

- Alfirevic Z. Oral misoprotol for induction of labour. Cochrane Database Systematic review 2000; (4):CD001338
- 2. Alfirevic Z, Aflaifel N, Weeks A. Oral misoprostol for induction of labour. Cochrane Database of Systematic Reviews 2014, Issue 6. Art. No.: CD001338. DOI: 10.1002/14651858.CD001338.pub3.
- Aaroe Clausen J, Rydahl E. 2015. Analyse af RADS Vejledning om Prostaglandiner til igangsættelse af fødsel [Analyse of the RADS Recommendation of Prostaglandin for Induction of Labour]. Submitted to the Health Committee in the Danish Parliament. Accessed at http://www.ft.dk/samling/20141/ almdel/suu/bilag/278/1503679.pdf
- FDA. FDA ALERT- Risk of Use in Labor and Delivery. 2009. http://www.fda.gov/DrugSafety/ PostmarketDrugSafetyInformationforPatientsandProviders/ucm111315.htm Accessed 07/05, 2015FDA. 2012.
- 5. FDA. Cytotec- misoprostol tablets. http://www.accessdata.fda.gov/drugsatfda\_docs/ label/2012/019268s047lbl.pdf
- Gaskin IM. 2013. Cytotec and the FDA Midwifery Today. Accessed at http://www.midwiferytoday.com/ articles/Cytotec\_FDA.asp
- Hofmeyr GJ, Gûlmezoglu AM. Misoprostol for induction of labour: a systematic review. Cochrane Database Syst Rev. 2003;(1):CD000941.
- 8. Hofmeyr GJ, Gülmezoglu AM, Pileggi C; Vaginal misoprostol for cervical ripening and induction of labour (Review) The Cochrane Library 2013, Issue 1
- Kammeradvokaten [The legal Advisor to the Danish Government]. 2011. Anbefalinger af anvendelse af lægemidler uden for deres godkendte indikation. [Recommendation on the use of medicine outside the registered indications]. Advokatfirmaet Poul Schmith.
- 10. Marsden Wagner. 2008. Born in the USA: How a Broken Maternity System Must Be Fixed to Put Women and Children First University of California Press.
- 11. Ministeriet for Sundhed og Forebyggelse [Ministry for Health and Prevention]. 2013. Notat: Redegørelse om anvendelse af Cytotec (misoprostol) til igangsættelse af fødsler [Note: The use of Cytotec (misoprostol for induction of labour]. http://www.ft.dk/samling/20121/almdel/suu/ bilag/301/1249234.pdf 8.8.2013
- 12. Pfizer. Periodic Safety Update Report on the active substance misoprostol. 2011. ATC code A02 BB01 for the period July 1th 2008 to June 30th, 2011.
- Rydahl E, Aaroe Clausen J. Feedback April 2015 IN: Alfirevic Z, Aflaifel N, Weeks A. Oral misoprostol for induction of labour. Cochrane Database of Systematic Reviews 2014, Issue 6. Art. No.: CD001338. DOI: 10.1002/14651858.CD001338.pub3. Page: 427-2[]
- 14. Searle. 2009. Important drug warning concerning unapproved use of intravaginal or oral misoprostol in pregnant women for induction or labour or abortion. Letter to health practitioners. August 23.





- 15. Sundhedsstyrelsen [The National Health Authorities]. Igangsættelse af fødsler med Cytotec [Induction of labour with Cytotec]. 2004; Available at: http://www.sst.dk/~/media/Sundhed%20 og%20forebyggelse/Graviditet/Anbefalinger%20for%20svangreomsorg/igang\_foedsler\_cytotec. ashx Accessed 29-03, 2012.
- 16. Thornton J. Feedback April 2015 IN: Alfirevic Z, Aflaifel N, Weeks A. Oral misoprostol for induction of labour. Cochrane Database of Systematic Reviews 2014, Issue 6. Art. No.: CD001338. DOI: 10.1002/14651858.CD001338.pub3. Page: 326-27
- 17. Timeo et les autres. France. https://timeo-asso.fr/content/index.php?mact=News,cntnt01,detail,0& cntnt01articleid=17&cntnt01origid=70&cntnt01returnid=39
- Oden M. The Freedom to Birth. The use of Cytotec in labour: a non evidence based intervention Perinatal Education spring; 2009; 18(2)48-51 accessed at:http://www.ncbi.nlm.nih.gov/pmc/articles/ PMC2684033/
- 19. Sundhedsstyrelsen [National Health Authorities]. Plan for overvågning og tilsyn med Regionernes brug af medicin til igangsættelse af fødsler [Plan for surveillance and monitoring of the Regions use of medication for Induction of Labour]. 30 August 2013. http://www.jordemoderforeningen.dk/ fileadmin/Nyhedsbreve/Planen\_til\_ministeriet\_sags\_nr\_2013070690\_2\_.pdf Accessed 09/15,2013
- 20.Wang L, Zheng J, Wang W, Fu J. Hou L. Efficacy of safety of misoprostol compared with the dinoprostone for labor induction at term: a meta-analysis.J Matern Fetal Neonatal Med. 2015 Jun 11:1-11. [Epub ahead of print]
- 21. World Health Organisation. 2011. WHO recommendations for induction of labour.

#### ABOUT JETTE AAROE CLAUSEN

Jette Aaroe Clausen has a background in midwifery. Jette is currently a senior lecturer in Midwifery at Metropolitan University College, Department of Midwifery, Copenhagen, Denmark. Her areas of interest is medicalization, iatrogenic effects, place of birth and woman's Involvement in decision making and legal issues. Jette is also engaged in international work on human rights issues in maternity care with a special focus on European maternity care practices. Jette completed her Ph.D. at the Center for STS Studies, Faculty of Art, Aarhus University under the topic: How does materiality shape childbirth practices? An exploratory journey into evidence, childbirth practices and Science and Technology Studies (STS). The point of departure is a non-essentialist take on technology which means that technology should be studied in practice. She explored the relationship between technology in use in everyday birthing practices and field study as her methodology. Jette has also worked with quantitative research i.e. she is one of the authors of a Cochrane meta-analysis on planned hospital birth versus planned home birth. She is currently engaged in research on the side-effects to off-label use of medication, with a special emphasis on Misoprostol used for induction of labor.





# MATERNITY IN NEW ZEALAND: PROTECTING WOMEN'S RIGHTS IN CHILDBIRTH

By Jane Stojanovic

### Introduction

This paper was written to provide just one example of one of the maternity systems where women's human rights are protected. It outlines the maternity system in New Zealand (NZ) and describes the ethico-legal framework that protects childbearing women from breaches of their human rights. Protection for women in childbirth comes from four sources; NZ law, the Ministry of Health, midwifery and medical organizations with their ethics and standards of practice, and health consumers who act as advocates for women.

The maternity system in New Zealand is not perfect and we strive constantly to improve it, however, it is a system that is appreciated by its consumers. Maternity care in NZ, including medical, midwifery and hospital care, has been government funded and free to women since 1938. (1) Home birth, although a small percentage of births, has always been legally available, and midwifery or medical care for women having a homebirth is free in the same way as a hospital birth.

The framework that protects health consumers consists of national statutes that reinforce personal autonomy for all citizens, with extra protection for health and disability consumers. There is statutory protection of all citizens from discrimination and coercion. The Health Practitioner Competence Assurance Act 2003 (HPCAA) established separate regulatory councils for registered health professionals such as medical doctors, nurses, dentists, midwives and others. (2) Each council's prime duty is to protect the public by regulating their profession. Also established by the HPCAA, the Health Practitioners Disciplinary Tribunal (HPDT) "hears and determines disciplinary proceedings brought against all registered health professionals, including doctors, midwives and nurses." (3)

The midwifery profession in New Zealand is strong and autonomous. Their professional organization, The New Zealand College of Midwives (NZCOM), is an active member of the International Confederation of Midwives. NZCOM has both midwife and consumer members at the highest levels of the organization, and has established a Code of Ethics, Standards of Practice, and Midwifery Competencies



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which reinforces each midwife's responsibility to work 'in partnership' with women and promotes consumer representation. There is also consumer representation on the Midwifery Council of New Zealand and on the Health Practitioner Disciplinary Tribunal. All women have the opportunity to access midwifery care during pregnancy, birth and until the baby is six weeks old.

### **Maternity in New Zealand**

The Social Security Act of 1938 introduced free Maternity care in NZ, including medical and midwifery care at home or in hospital. Some private obstetric care can be paid for by the woman but midwives, general practitioner doctors and hospitals are not allowed to charge the woman for maternity care. The free maternity care is provided from the beginning of the pregnancy until six weeks after the birth of the baby and includes access for the woman, by phone or in person if needed, to a midwife or doctor twenty four hours a day. Midwives are able to care for healthy women throughout their childbearing journey without the woman needing to be seen by a medical practitioner.

National referral guidelines were established by the Ministry of Health in consultation with midwifery, medical, obstetric, pediatric and other key professionals. These ensure that the Lead Maternity Carer (LMC), who can be a doctor or a midwife, refers women or babies requiring extra specialist support to the appropriate specialists at the appropriate time. (4) The model of primary maternity care is a case-loading model where LMCs are contracted by the Ministry of Health to provide maternity care in a manner that gives as much continuity of care to the woman as possible. (5) Doctors and midwives are not differentiated as LMCs – They are contracted at the same rates for the same services.

Midwives practice autonomously and by law are able to prescribe appropriate medications, order diagnostic tests such as ultrasounds and laboratory tests, cut episiotomies and repair perineal damage under local anesthetic, and use intravenous therapy as necessary. The LMC manages the woman's pregnancy birth and postnatal care, attends the woman in hospital under his/her care and can refer the woman or baby directly to specialists as required. LMCs are self-employed and paid through their contract with the Ministry of Health. Midwives and doctors are also employed to work in hospitals where they support the LMCs and care for women under specialist care. New Zealand women report high levels of satisfaction with their maternity care. (6)



## The Legal Framework Protecting Women in Childbirth

National laws established by statute or Acts of Parliament are the backbone of protection for women in childbirth and all other health and disability consumers. I will only discuss some of the most important but there are also others that impact on issues such as privacy, quality of care and hospital standards.

The Crimes Act 1961 states that every practitioner has a "duty to have and to use reasonable knowledge skill and care". It also defines what constitutes manslaughter which includes acts of commission or omission that lead to a person's death including negligence on the part of health practitioners. (7) The New Zealand Bill of Rights Act 1990 ensures that "everyone has the right to refuse to undergo any medical treatment." (8)

The Health and Disability Commissioner Act 1994 came into place after a group of health consumers suffered as a result of medical research. (9) The Act established a Commissioner (HDC) to investigate complaints from, and to act as advocates for, health and disability consumers. This organization established by regulation a Code of Health and Disability Consumers Rights 1996 (the Code). (10) The HDC can lay charges in court against health practitioners where breaches of the Code have occurred or can ask the practitioners' regulatory council to deal with less serious breaches, especially if they are because of health or competency issues. Usually the HDC works with health practitioner regulatory councils such as the medical council and the midwifery council to investigate breaches. (11) Serious complaints to the councils from consumers must be investigated by the HDC and may be taken to the Health Practitioner Disciplinary Tribunal. The Code applies to all health practitioners including alternative health practitioners and details 10 rights for all health and disability consumers (12):

Right 1: the right to be treated with respect

Right 2: the right to freedom from discrimination, coercion, harassment, and exploitation

Right 3: the right to dignity and independence

Right 4: the right to services of an appropriate standard

Right 5: the right to effective communication

Right 6: the right to be fully informed

Right 7: the right to make an informed choice and give informed consent



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Right 8: the right to support

Right 9: rights in respect of teaching or research

Right 10: the right to complain

The Health Practitioners Competence Act 2003 is another key piece of legislation in the protection of women in childbirth. (13) Based on similar Canadian law it established the regulatory councils for all registered health practitioners. Each health discipline has its own council but they must operate as the Act dictates. The Act was passed "... to protect the health and safety of members of the public by providing mechanisms to ensure that practitioners are competent and fit to practice in their profession."

The Midwifery Council of New Zealand regulates the competency of midwives setting minimum competency requirements for ongoing midwifery practice, regulating the undergraduate and postgraduate education of midwives, controlling midwifery registration and maintaining the register – all of its responsibilities are to ensure public safety by ensuring that all midwives are competent to practise. [14]

Other health practitioner councils work in similar fashion, the Medical Council, the Nursing Council, and others, because they have all been established by the HPCAA. Having a midwifery regulatory council enables the midwifery council to be self-regulating and prevents midwifery from being controlled by other health disciplines such as medicine and nursing. The Council is self-funded and consists of government appointed midwives and a consumer. The first competence required of midwives is that they are able to work in partnership with women.

The HPCAA also established the Health Practitioner Disciplinary Tribunal that is the disciplinary authority for all registered health practitioners. Health practitioners can be brought before the tribunal by either their regulatory council or by the Health and Disability Commissioner for breaches against the Code. Membership of the tribunal is tailored to each health discipline so that practitioners are judged by their peers. Each tribunal consists of a lawyer, a consumer and three 'peer' practitioners so a midwife appearing before the tribunal would be judged by experienced lawyer, a woman consumer and three midwives all of whom have been appointed by government. The pool of midwives appointed as members of the tribunal are nominated by the midwifery profession. The Tribunal has the right to penalise practitioners by censoring, imposing monetary penalties, imposing conditions on practice and suspending practitioners' ability to practice. (15)



### The Midwifery Profession – Ethics, Standards and Consumers

The New Zealand College of Midwives was set up by midwives in 1989 in an effort to gain autonomy after being a minority group within a nursing professional organisation. (16) The organisation represents midwifery at a national level and has set a Code of Ethics and Standards for Practice that emphasise women's autonomy, right to informed choice and working in partnership with women. (17) NZCOM works with the Ministry of Health to help fund midwifery scholarship. Midwifery postgraduate education is provided in various universities in New Zealand up to doctorate level. Among other support NZCOM gives to the midwifery profession it functions as a conduit for professional indemnity insurance for midwives (paid through membership fees) and offers legal advice and representation to members.

The midwifery profession is enormously grateful to NZ women who lobbied members of parliament and supported midwifery in 1990 to change the law that for the prior twenty years had enforced medical control of birth and required midwives to always work with a doctor. Helen Clark, a sympathetic woman Minister of Health (later NZ Prime minister) supported the 1990 law change and amended 12 Acts of Parliament to give midwives the ability to work effectively. Because of their debt to NZ women NZCOM has consumer representation at all levels of the organisation and promotes and supports the inclusion of consumers in all areas of health governance.

## Conclusion

This paper has outlined the structure within New Zealand that supports the human rights of women in childbirth. The structure reflects a culture in which women are valued and have the same human rights as every other citizen. Personal autonomy is valued and demonstrated by the right of citizens to informed choice to the degree that every citizen has the right to refuse any medical treatment, and has the right to be treated with respect and consideration of their own knowledge of self.

It has been said that where there are strong women there are strong midwives. New Zealand was the first self-governing country to extend the vote to women in September 1893 (18) and perhaps that statutory demonstration of respect for women is why we have a strong midwifery profession and a legal framework that protects women health consumers.



This paper has been written to demonstrate that there are ways to strengthen the rights of women in childbirth.

Some of these are listed.

- Legislation that guarantees human rights.
- Culture and law changes that demonstrate equality for women.
- A mechanism for women to safely complain about breaches of their rights.
- Measurable standards of care so that breaches of human rights can be demonstrated to have occurred
- A strong autonomous regulated midwifery profession that works in partnership with women.
- Ministry of Health requirements that ensure accountability for all health practitioners and enable them to practise to their maximum efficacy while still ensuring protection of the public.
- The establishment of statutory disciplinary bodies where health practitioners are judged equitably and to a reasonable standard by consumers and their own professional peers, and that are able to impose penalties when required.



## References:

- Social Security Act 1938 now Social Security Act 1964http://www.legislation.govt. nz/act/public/1964/0136/latest/resultsin.aspx?search=sw\_096be8ed8106b0bd\_ Social+Security+Act+1938\_25\_se&p=1
- 2. Health Practitioners Competence Assurance Act 2003 at http://www.legislation.govt.nz/act/ public/2003/0048/latest/DLM203312.html?src=qs
- 3. http://www.hpdt.org.nz
- 4. Guidelines for Consultation with Obstetric and Related Medical Services (Referral Guidelines) at https://www.health.govt.nz/system/files/documents/publications/referral-glines-jan12.pdf
- Section 88 Primary Maternity Services Notice 2007 at http://www.health.govt.nz/publication/ section-88-primary-maternity-services-notice-2007
- Maternity Consumer Survey 2011 at http://www.health.govt.nz/publication/maternity-consumersurvey-2011
- 7. Crimes Act 1961 at http://www.legislation.govt.nz/act/public/1961/0043/latest/DLM327382. html?search=ts\_act%40bill%40regulation%40deemedreg\_Crimes+Act+1961\_resel\_25\_a&p=1
- New Zealand Bill of Rights Act 1990 accessed 11/6/15 at http://www.legislation.govt.nz/act/ public/1990/0109/latest/DLM224792.html
- 9. Health and Disability Commissioner Act at 1994 at http://www.legislation.govt.nz/act/ public/1994/0088/latest/DLM333584.html?src=qs
- 10. Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 at http://www.legislation.govt.nz/regulation/public/1996/0078/latest/DLM209080. html?src=qs
- 11. For more information see: Health and Disability Commission at: http://www.hdc.org.nz/
- 12. For more information see: http://www.hdc.org.nz/the-act--code
- 13.Health Practitioners Competence Assurance Act 2003 at http://www.legislation.govt.nz/act/ public/2003/0048/latest/DLM203312.html?src=qs
- 14.For more information see: The Midwifery Council of New Zealand: https://www.midwiferycouncil. health.nz/
- 15.For more information go to: The New Zealand Health Practitioner Disciplinary Tribunal at: http:// www.hpdt.org.nz/
- 16. Guilliland, K., & Pairman, S., Women's Business, The Story of the New Zealand College of Midwives from 1986 – 2000, NZCOM, Christchurch, NZ
- 17. New Zealand College of Midwives at: http://www.midwife.org.nz/
- 18. http://www.nzhistory.net.nz/politics/womens-suffrage



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#### ABOUT JANE STOJANOVIC

Jane Stojanovic is a practicing midwife from New Zealand. She has had many roles in hospital and as a self-employed midwife attending her clients in hospital and at home-birth. After 10 years lecturing in midwifery at Massey University she has returned to clinical midwifery, managing a small rural midwifery led maternity facility. Her main interests include midwifery history, and the birth of the placenta, topics that were the focus of her midwifery profession in New Zealand in 1990 and is an appointed midwife member of the New Zealand Health Practitioner Disciplinary Tribunal. She is passionate about autonomy and human rights in childbirth for women, and also for midwives.





# **HUMAN RIGHTS FACT-FINDING**

## By Adriana Lamačková

Fact-finding and report writing have been used in human rights advocacy, including advocacy related to reproductive health care, in order to make an issue visible by identifying it as a human rights violation, to hold those responsible accountable for the harm, and to seek systemic changes to ensure an effective protection of human rights. Discussing selected examples of human rights fact-finding conducted by the Center for Reproductive Rights and its partners, this presentation explored a potential use of such tools in advocacy related to women's rights in childbirth.

#### ABOUT ADRIANA LAMAČKOVÁ

Adriana Lamačková is the Senior Legal Adviser for Europe at the Center for Reproductive Rights. Her work focuses on the protection of reproductive health and rights in Europe, with a primary focus on Central and Eastern Europe. Prior to joining the Center in 2010, she worked with the Slovak NGO Pro Choice. She also worked as a Legal Consultant at the European Roma Rights Centre and as a Legal Adviser at the Office of the Slovak Government. Adriana received a Master of Laws from the Law Faculty at University of P. J. Šafárik in Slovakia. She also holds an LL.M. from the University of Toronto, and Ph.D. in International Law and Constitutional Law from Charles University in Prague.



# PANEL 5 EUROPEAN COURT OF HUMAN RIGHTS

Overview of decisions at the European Court of Human Rights that pertain to women's rights in childbirth – how has the European Court of Human Rights interpreted women's rights in childbirth? Attorneys will discuss recent decisions including the refusal of the court to acknowledge the right of women in the Czech Republic to have a midwife present at home births and the subsequent referral to the Grand Chamber in the Dubska case.

Moderator:	Jacqueline Vejlstrup, Midwife, Denmark
Panelists:	Daniela Furtunova, Attorney, Bulgarian Helsinki Committee
	Rita Bence, Attorney, Hungarian Civil Liberties Union
	Felicia Vincze, Independent Midwife, Hungary
	Zuzana Candigliota, Lawyer, League of Human Rights, Czech Republic





# OVERVIEW OF DECISIONS AT THE EUROPEAN COURT OF HUMAN RIGHTS REGARDING WOMEN'S RIGHTS IN CHILDBIRTH

By Daniela Furtunova

Cases concerning rights in childbirth raise issues mainly under Article 8 of the European Convention on Human Rights. Article 8 guarantees the right to private and family life. Still, these cases are just few in number in the practice of the Strasbourg Court. Thus, the current overview has a broader look over cases that might be relevant in a context of childbirth due to the facts of these cases and the consideration of the Court. Some of these cases pertain to the notion of informed consent in its strict meaning in the health law, while others relate to a more general perspective of informed consent understood as one's right to make autonomous decisions about one's own private or family life.

The landmark case of *Ternovszky v. Hungary*<sup>(1)</sup> has set a high standard to be followed by the respondent state Hungary and for the practice of the Court<sup>[2]</sup>. First, the Court stipulated, that "the circumstances of giving birth incontestably form part of one's private life" under Article 8 § 1 of the Convention. This way the Court widened the broad term "private life" which according to the Court's practice encompasses, inter alia, aspects of an individual's physical, psychological and social identity. Second, the Court invoked the positive obligation of the state and held that legislation which dissuades health professionals from assisting *home birth* contradicts patients' right to self-determination. Prospective mothers could not be considered as freely benefiting from such assistance as the lack of legal certainty [meaning the absence of specific and comprehensive legislation on home births] and the threat to health professionals who assist home births have limited the choices of the applicant considering home delivery. For the Court, this situation is incompatible with the notion of "foreseeability" and hence with that of "lawfulness," thus Article 8 was found to be breached.

Previously in its case-law, the Court has noted that since a person's body is the most intimate aspect of private life, medical intervention, even if it is of minor importance, constitutes an interference with this right. The Court has found that there had been a violation of Article 8 of the Convention in cases of lack of **free** and informed consent for medical and related interventions. One of the most



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important cases so far regarding informed consent during childbirth is the recent case of *Konovalova v. Russia*<sup>[3]</sup>. The Court paid special attention to the physical and psychological state of the applicant during labor contractions, and found there has been a serious failing in that her disapproval of the presence of medical students during the delivery of her child was disregarded. The Court noted that the applicant learned of the presence of medical students during the birth the day before, "between two sessions of drug-induced sleep [...] in a state of extreme stress and fatigue on account of her prolonged contractions." The Court considered that "it was unclear whether the applicant was given any choice regarding the participation of students on this occasion and whether, in the circumstances, she was at all capable of making an intelligible informed decision<sup>(4)</sup>. Finally, the Court found that the unwanted presence of medical students during the birth of the applicant's child did not comply with the requirement of lawfulness of Article 8 § 2 of the Convention as the relevant national legislation in force at the time did not contain any safeguards to protect patients' privacy rights, namely to obtain the applicant's consent for this

The lack of informed consent has been at stake also in cases of **sterilization**, which are importantly related to human rights in childbirth not only because they concern reproductive rights but also due to the fact that sterilization has been undertaken during the cesarean sections of the applicants. The first of these cases concerns sterilization of Roma women who had signed the relevant documentation authorizing the sterilization but the Court did not accept that their consent was given freely<sup>[5]</sup>. In these cases the Court found violation of Article 3 of the Convention. The Court held that sterilization as such is not a life-saving medical intervention and carried out without informed consent it was incompatible with the requirement of respect for human freedom and dignity. The Court, furthermore, found breach of Article 8 of the Convention agreeing that there were systemic shortcomings in the procedures for sterilization of Roma women and that the respondent government failed to put in place adequate legislation and exercise appropriate supervision of sterilization practices.

Another group of cases of interest concerns **forceful gynecological examination**<sup>(6)</sup>. In these cases, medical examinations of female detainees were undertaken as a safeguard against false accusations of sexual ill-treatment during custody. The respondent government submitted that it would not have been possible to perform such an examination without the consent of the woman, who could have objected to it when she was taken to the doctor's consulting room. However, the Court considered that, in the circumstances, the woman could not have been expected

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to refuse such an examination in view of her vulnerability at the hands of the authorities who exercised complete control over her throughout her detention. The Court considered that any interference with a person's physical integrity must be prescribed by law and requires the consent of that person. Otherwise, a person in a vulnerable situation, such as a detainee, would be deprived of legal guarantees against arbitrary acts. The Court found that the interference in question was not "in accordance with law" as procedural aspects of the domestic law had not been followed, thus Article 8 was breached.

A few other Article 8 cases relate to the **intervention of the authorities in the** mother-baby relationship. In P., C. and S. v. the United Kingdom<sup>[7]</sup> the applicant P. was a woman with a personality disorder who suffered from a syndrome which manifested itself in exaggerating and fabricating illness in a child. Her husband was the applicant C. and S. - their baby daughter. Prior to the birth of S. the applicant P. was accused of harming one of her elder children by administering laxatives to him inappropriately. This was the reason why a few hours after S. was born the local authority obtained an emergency protection order which placed S. under their care and took S. from the hospital. The Court found violation of Article 8 concluding that the draconian step of removing S. from her mother shortly after birth was not supported by relevant and sufficient reasons and that it could not be regarded as having been necessary in a democratic society for the purpose of safeguarding S.: "[...] the removal of a baby from its mother at birth requires exceptional justification. It is a step which is traumatic for the mother and places her own physical and mental health under a strain, and it deprives the new-born baby of close contact with its natural mother and [...] of the advantages of breastfeeding. The removal also deprived the father, C., of being close to his daughter after the birth (131)." As P. was confined to bed due to the after-effects of blood loss and high blood pressure after her Caesarean section and given the fact that once she had left the hospital, she was permitted to have supervised contact visits with S., the Court concluded that it was not apparent "why it was not at all possible for S. to remain in the hospital and to spend at least some time with her mother under supervision. ... Even on the assumption that P. might be a risk to the baby, her capacity and opportunity for causing harm immediately after the birth must be regarded as limited, considerably more limited than once she was discharged."

Similarly in *Hanzelkovi v. Czech Republic*<sup>(8)</sup> the Court reiterated that Article 8 requires that the decision-making process involved in measures of interference be fair and such as to afford due respect to the interests safeguarded by this provision. Mrs. Hanzelková gave birth to her son and as there had been no complications left



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the hospital that same day despite of the medical team's opposition. Following an interim measure of the domestic court the mother and her child were brought back to the hospital and forced to stay there for two days as a safeguard of the newborn child's health. The Strasbourg Court noted that when the domestic court was considering the interim measure it should have examined whether some less intrusive interference in the applicants' family life at such a critical point in their lives was not possible.

Another group of cases reveal the Court's attitude towards the obligations of the hospital staff towards the parents of a stillborn child. The case of Marić v. Croatia<sup>[9]</sup> concerns the lack of proper burial of the stillborn child born in the ninth month of pregnancy. The parents did not want to take their child's remains, so the hospital took responsibility for the body. As soon as the mother was feeling better, the parents requested information from the hospital about the child's burial to find out that the hospital had given the child's body for cremation with other clinical waste (human tissue, amputated body parts and aborted up to the 22nd week fetuses). According to the legislation in force, unlike a fetus, a stillborn child had to be buried (or cremated) in the same manner as any other deceased person. Thus, the Court found violation of Article 8 as the interference with the applicant's rights guaranteed under this article was not in accordance with the law. Contrary to what the Government suggested, the Court did not accept that, by way of an oral agreement, Mr. Marić had tacitly accepted that the child's body would be disposed of in this way. The Court explicitly considered that it was the hospital's responsibility to carefully inform the parents of the procedure to be followed and required the Government to be able to prove these circumstances: "[b]eing mindful of the fact that the birth of a stillborn child must have been extremely emotionally disturbing for the applicant and his wife, the Court notes that the Government did not submit any records or other documentation to the Court attesting to the information the hospital had provided to the applicant about what would happen to his child's remains."<sup>(10)</sup>

Similarly, in the case *Hadri-Vionnet v. Switzerland*<sup>(11)</sup> the Court found violation of Article 8 as the body of the stillborn child of the applicant had been taken from her and buried without her knowledge in a communal grave in the cemetery and that it had been transported from the hospital to the cemetery in an inappropriate vehicle as though it were common waste and buried in haste, without a ceremony worthy of the name and without the parents having been consulted or even informed.

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Furthermore, of interest for the current selection are cases for access to personal medical records. The Court has reiterated that the concept of "private life" covers also information relating to one's personal identity, including disclosure of personal medical records. The case K.H. and Others v. Slovakia<sup>[12]</sup> concerns the exercise by the applicants of their right of effective access to information concerning their health and reproductive status. The applicants suspected that they had been sterilized during their stay in two hospitals when each one of them delivered via Caesarean section. Domestic courts, following the legislation that was in force at that moment, ordered the hospital to permit the plaintiffs and their representative to only consult their medical records and make handwritten excerpts thereof but not to photocopy their medical records. The Court held that, bearing in mind that the exercise of the right under Article 8 to respect for one's private and family life must be practical and effective, positive obligations should extend so that the applicants are allowed to photocopy their medical records.<sup>[13]</sup> The Court accepted that it is for the file holder to determine the arrangements for copying personal data files and whether the cost thereof should be borne by the data subject. However, the Court did not consider that data subjects should be obliged to specifically justify a request to be provided with a copy of their personal data files. It is rather for the authorities to show that there are compelling reasons for refusing this facility.<sup>[14]</sup>

As regards disclosure of personal information to third parties, the Court has reiterated that the domestic law must afford appropriate safeguards so that disclosure of personal health data be consistent with the guarantees in Article 8 of the Convention. The case *L.H. v. Latvia*<sup>(15)</sup> concerns the indiscriminately request and collection of the applicant's medical data by a public authority with a mandate to convey assessment of the medical treatment provided in hospitals. During the applicant's Cesarean section in a hospital the surgeon performed tubal ligation on her without her consent. Therefor the applicant filed a civil action for damages. At the outset of the civil case the director of the hospital requested by the inspectorate of guality control for medical care an evaluation of the medical treatment the applicant had received during the childbirth in the hospital. The inspectorate requested and received the applicant's medical files from three different medical institutions containing detailed information about the applicant' health over a 7 vear period. The Court observed that the applicable legal norms described the competence of the inspectorate in a very general manner and did not limit the scope of private data that could be collected during its inquiries. The Court found a violation of Article 8 because the interference with the applicant's right to respect for her private life was not in accordance with the law.<sup>[16]</sup>



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In conclusion, we could observe that the practice of the European Court of Human Right, though not firm enough as regards women rights, has recently evolved with some of the most profound and sensitive decisions regarding women giving birth in hospitals.

## **References:**

- 1. Application no. 67545/09, Judgment of 14 December 2010.
- Hopefully, the Grand Chamber would revoke the Chamber decision of Dubská and Krejzová v. the Czech Republic that came four years after Ternovszky judgment (applications nos. 28859/11 and 28473/12, Judgment of 11 December 2014) and deals with the same matters as Ternovszky. Referral to the Grand Chamber was made on 01 June 2015.
- 3. Application no. 37873/04, Judgement of 9 October 2014.
- 4. See § 47.
- See V.C. v. Slovakia (application no. 18968/07, judgment of 8 November 2011), N.B. v. Slovakia (application no. 29518/10, judgment of 12 June 2012), I.G. and others v. Slovakia (application no. 15966/04, judgement of 13 November 2012).
- 6. Juhnke v. Turkey (application no. 52515/99, judgment of 13 May 2008) and Y.F. v. Turkey (application no. 24209/94, judgment of 22 July 2003).
- 7. Application no. 56547/00, judgement of 16 July 2002.
- 8. Application no. 43643/10, judgement of 11 December 2014.
- 9. Application no. 50132/12, judgement of 12 June 2014.
- 10. See § 63.
- 11. Application no. 55525/00, judgement of 14 February 2008.
- 12. Application no. 32881/04, judgement of 28 April 2009.
- 13. The Court also found a violation of Article 6 the right of access to a court in this regard.
- 14. See § 48.
- 15. Application no. 52019/07, Judgment of 29.4.2014.
- 16. See also Case of M.S. v. Sweden (application no 20837/92) regarding the transmission to a social-security body of medical records regarding inter alia an abortion performed by the applicant in the hospital which was found by the Court to be in line with Article 8 as the body in question had been responsible for examining her claim for compensation for alleged back injury from the public funds and needed such information to cross check the statement of the applicant for the reasons for the injury.

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#### **ABOUT DANIELA FURTUNOVA**

Daniela Furtunova is an attorney with the Sofia bar association since 2007. In 2005 she joined the Bulgarian Helsinki Committee, a major independent non-governmental organization for the protection of human rights in Bulgaria. In 2006 she received her LLM from Sofia University. Currently, Daniela practices as a lawyer in BHC's Monitoring and Research Program working on monitoring and reporting as well as strategic human rights litigation before the Bulgarian courts, Equality body and the European Court of Human Rights. Throughout the years, Daniela has also participated in monitoring missions in closed institutions (prisons and detention facilities, institutions for children and adults with disabilities). Daniela is the Bulgarian national expert in the network European Commission on Sexual Orientation Law. Since 2011 she is a member of Association Estestveno advocating for the rights of pregnant women as well as current and future parents to give birth and raise their children in natural, thoughtful and non-violent manner.





# **AFTER TERNOVSZKY – HOMEBIRTH IN HUNGARY**

By Rita Bence

## Discrimination

As many of us have mentioned before - homebirth has been regulated since 2011 in Hungary after the decision in the Ternovszky case. The European Court of Human Rights emphasized that homebirth has to be a real choice for every woman as part of the right to respect private life. Now, in April 2015, we have the fourth anniversary of the decree on homebirth but the real choice has not been given yet.

## The core statements of the Ternovszky decision were the following:

Firstly, in the Hungarian case the Court held that the right to respect for private life includes the right to choose the circumstances of birth. Secondly, a regulation which imposes fines on midwives assisting at home births constitutes an interference in the exercise of the rights of women and of similarly situated pregnant mothers.

Thirdly, according to the Court's opinion, the threat of sanctions – along with the absence of a specialized, comprehensive regulation in this area – are detrimental to the complainant's ability to choose home birth. This in turn constitutes a violation of the legal security for the exercise of privacy rights, and in particular, violates the principle of legal certainty.

We found this judgment to be very important, and we were hoping that women can really choose the circumstances of birth. Unfortunately, this is not the case, and not only in regard of homebirth or giving birth in hospital. In hospital birth there is a lack of informed consent, mothers usually do not get the necessary information and they cannot even decide in which position they wish to give birth.

Sections 15 and 20 of the Health Care Act 1997 recognize patients' right to selfdetermination in the context of medical treatment, including the right to reject certain interventions. But under section 20(1), it is also written, that a competent patient may reject medical treatment unless this endangers the life of another person. This causes many problems in practice: doctors often refer to this law in order to supress women's real choice. This is an emotional stress for women as mothers obviously do not want to endanger their babies' lives.



#### AFTER TERNOVSZKY – HOMEBIRTH IN HUNGARY By Rita Bence

Homebirth is still not financed by the national health insurance compared to giving birth in state hospitals. That results in denying the choice of homebirth because of financial circumstances. This situation has also been criticized by CEDAW. The Committee expressed its concerns not only about the fact that homebirth regulations implemented in April 2011 have not provided Hungarian women with a real option for homebirth, but CEDAW also emphasized that the costs of out-ofhospital births are not covered by the National Health Insurance Scheme, which results in the fact that home birth is available only for wealthy families. The second problem is that midwifery as an independent medical profession has not been legally recognized so far.

I will explain the second concern later, let's concentrate now on the issue of financing. I would just like to give you a comprehensive picture about the Hungarian health insurance. Everybody has to pay some health insurance according to their income. It is mandatory even if you choose private services. There is only one big state insurance company, which is responsible for financing the whole state health care. And there is a Hungarian custom: patients pay so called gratitude money to the doctors directly after or even before the service. So health care is far from being free, but if somebody wishes to give birth at home, she has to pay an extra fee for the midwives.

In 2010, together with other organizations like Alternatal Foundation, Doctors for Free and Secure Birth, Birth House Association - we formed an opinion on homebirth should be regulated. We pointed out that the regulation should be reconsidered every two years. Unfortunately, there was not a wide range of debate or discussion between the health care government and the professionals after creating the decree, but it would not only be useful but necessary to consider the every-day life experience of midwives, and adjust the law accordingly.

There have not been real changes since then, only a few less important modifications. There is a long list in the decree which contains the causes of exclusion. It has not been changed. We are aware that this is a medical question but in our view the regulation should be more flexible: it would be desirable to decide in every single situation individually and not to decide prior to the case.

We also emphasized that a professional protocol has to be created. It is crucial to involve midwives so that they could create an appropriate protocol according to their every-day life experience. This protocol has been worked out, Felicia Vincze was one of the developers. It only misses the opinion and the approval of the health care government so we can be happy about it.



I would also like to describe briefly the situation of ambulant births.

Although no law does prohibit it, what is more, the right to leave the institution is a named patients' right, it is not a practice. Health care professionals at hospitals also use the same rhetoric as pressing the cesarean section and other interventions: the baby is in danger, so they cannot leave the hospital. It is not just because of the medicalized approach, but hospitals get money from the state insurance, if the mother spends at least 72 hours at the institution.

Just to put you a bit in the picture of Hungarian legislation and practice I would like to highlight that generally we have quite good laws in terms of patients' rights which include informed consent, the right to human dignity, the right to refuse treatment etc., but in practice it does not always prevail. What is more, it does not prevail in most cases. There is still a patriarchal approach not only during giving birth but in the whole system.

Another core issue is the right to contact during hospital care. It is declared by law that delivering women have the right to have a person to stay with them. The law does not say that it should only be one, but doctors interpret it this way. So that is why women have to choose whether they want their husband or their midwife to stay with them during giving birth. We took actions in this field as well, and now there is a reconciliation between midwives and doctors, with the support of the National Patients' Rights and Documentary Center.

We are also carrying out a campaign which helps the enforcement of the right to contact. It refers not only to the mothers' togetherness with their newborn babies and fathers' presence, but sick children, who have to spend time in hospital.

Let's turn back to the other concern of the CEDAW regarding the recognition of midwives independence.

# Petition

A petition was sent by three NGO-s to the Committee on Petitions of the European Parliament (I will henceforth call it just Committee) concerning the fact that Hungary has not implemented the provisions of Directive 2005/36/EC<sup>1</sup> into the national legislation and therefore the recognition of professional qualifications with regard to the competence of midwives has failed.

<sup>1</sup> DIRECTIVE 2005/36/EC OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL, of 7 September 2005, on the recognition of professional qualifications, at http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=0J:L:2005:255:00 22:0142:en:PDF



The Committee placed the issue on its agenda and held a hearing on 25th November 2013. We were assured of the support of the Committee and they decided to keep the question open and get in contact with the Hungarian government in order to transpose the directive properly.

## Our main concerns were:

Firstly, the Directive refers to the professional competence of midwives and in a broader sense to their professional autonomy and independence. Secondly, it has relevance to those women who, based on exhaustive and objective information, would like to decide autonomously on where, how and with whom they want to give birth. This is absolutely important so that self-autonomy and the right to respect private life can prevail.

Recently we have received the reply from the PETI. The Committee has declared that Hungarian legislation does not violate the Directive. In their interpretation the directive does not say that midwives have the right to practice independently from doctors. The PETI says that it is a Member States' competency how to share the tasks and responsibilities between midwives, doctors and other health care professionals. In our opinion, this is a misinterpretation of the directive, so we are thinking about taking further steps.

# Public opinion

It has not really changed yet. Women and midwives have to face stigma. Information about fatal homebirths is published in the media but nobody speaks about the unfortunate stories at hospitals. This practice is very harmful because it suggests that homebirth is more dangerous compared to giving birth in an institutional environment.

I would like to stress the ECHR's statement here, that such regulation which imposes fines on midwives assisting at home births constitutes an interference in the exercise of the rights of women and of similarly situated pregnant mothers. We have to be aware of the fact, that if this practice sustains, we are systematically breaking the law if only midwives are facing criminal procedures for assisting fatal homebirths.

#### AFTER TERNOVSZKY – HOMEBIRTH IN HUNGARY





#### **ABOUT RITA BENCE**

Rita Bence is a lawyer at the Hungarian Civil Liberties Union. She has been engaged in the protection of patients' rights and is very interested in health care and public health systems. She is also deeply concerned about the issue of giving birth and home birth as this is a core issue of self-determination in health care. She is engaged in reducing the inequalities in health care within all legal and non-legal measures. Her interest in health care formed in the very early years of her university studies. She has also worked in the state sector on patients' rights, patients' safety and public health. She has been with HCLU since September 2012 as the Director of Patients' Rights and Self-determination Rights Program.

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# **HOMEBIRTH IN PRACTICE IN HUNGARY**

# By Felicia Vincze

Until 2011, homebirth in Hungary was not regulated, which was good from one point of view and risky from another. It was good, because it meant less administration and cheaper practicing, but it was also bad because the issue was put on the periphery, which made it difficult for both midwives and families. As with almost everything in life, the need for change came from tragedy. Nobody cares if everything is going fine, but a bad outcome is always interesting. Due to the events around Agnes Gereb and pressure from the European Union the government finally issued the regulation of out-of-hospital birth in 2011. It was a dramatic change that meant a lot of hardship for midwives. The regulation included such requirements that were not possible to fulfill. More meetings and coordination followed with the government and a new change in the regulation in January of 2012 resulted in the situation that we have today, where you can get licensure for homebirth. I feel that the regulation is correct and stands in line with other countries' regulations. The difficulties we had in the beginning were finding an insurance company willing to make a liability contract with us and finding a collaborating pediatrician. Since there was only one insurance company that offered a contract, it could give as high a price as it wanted to. However, it was still doable. Finding a pediatrician in southeast Hungary who is willing to perform an exam on a newborn within 24 hours after birth seemed impossible. I got many rejection and criticism from doctors. First, I had to beg a doctor to come and examine the baby, but then I found a neonatologist who is very supportive and I am very grateful for this.

Despite regulation, we still have to face many problems on a daily basis. First of all, if a doctor, health visitor, pediatrician, physician or even the cleaning lady in a hospital or clinic hears that a woman wishes to give birth to her own child outof-hospital, they will tell her she is irresponsible, she wants to put the life of her baby at risk for her own comfort, she is selfish, stupid and this whole craziness should be stopped by force, and the government made a huge mistake when they regulated homebirth because it legalized something that actually should vanish from the face of the Earth. I had clients who didn't dare choose homebirth after an insult like this and I think this is unfair and that this kind of behavior should vanish because what we do is legal, we are trained to attend homebirth, we care more for the mothers, babies and families than most of the care providers in hospitals. And



on top of everything else, they don't even know what homebirth is, the requirements we have to fulfill, the instruments we carry, and of course, they have never even seen a homebirth or talked to someone who did. This is extremely unfair.

Another difficulty is the price. Homebirth families have to pay a lot of money for this service; it is around 200.000 forints, which is about a month's salary for a middle class family where both parents work. The amount that the hospital gets after a vaginal birth is about half of this. It clearly means that there is a problem with the financing of hospital births that should be solved, because it is underfinanced. And of course homebirth should be financed by the government, because the health insurance system is socialized in Hungary, we pay every month for healthcare that includes birth care too.

Another great step by the Health Ministry was establishing the possibility for midwives to give prenatal care to low-risk mothers. It was a great step because it made providing holistic care possible, allowing us to provide care for the mother and baby from the beginning of her pregnancy through childbirth, and till the end of the postpartum period. Naturally, this is not going smoothly either. The first step is the risk assessment of the mother that has to be performed by an Obstetrician. As you can imagine if an obstetrician finds out that the mother wants to choose a midwife as her care provider, he will do everything he can to stop this and will categorize the mother as high risk. I have a client who is young and healthy, so the doctor couldn't find any reason to say she is high risk. Yet he still put her in the high risk category saying that she is emotionally unstable.

After the regulation of homebirth, my practice was established in December 2011 and got licensed on March 12th, 2012. The first legal homebirth of my practice and also in Hungary happened in Szeged, in south-eastern Hungary on March 19th, 2012. We have had about 150 homebirths since then, with about 15% resulting in a hospital transport. Most of the time, transfer of care went smoothly, however in some cases it was problematic. Either the parents got criticism for their choice or we, the midwives were rebuked.

A year and a half ago I opened my birth center, which became very popular, not just because most people still feel that someone having a baby should go away from home, but also because it fulfills the requirement that there is a hospital with OB ward where the mother or baby can be transported within 20 minutes of the place of birth. Since we live in the country, there are villages and farms from where there is no hospital within 20 minutes.

#### HOMEBIRTH IN PRACTICE IN HUNGARY

By Felicia Vincze



When I was preparing for this conference, I read your posts. I started to feel that we as providers are also affected by this issue. In hospitals, mothers sometimes get abused and their options are extremely limited in Hungary. But we, midwives are here too. We get abused verbally and sometimes even physically by doctors. I had an unexpected stillbirth 2 months ago that was very traumatic for all of us and we couldn't imagine standing up again. Next day, it was all over the news. They knew my name, my phone number, the place I live, everything. What rights do I have as a midwife? Why don't I have the right that a bad outcome stays within the walls of my practice? Why don't I have the right to protect myself, the right for fair treatment? Homebirth midwives are also human beings with human feelings. Attending births and helping families is our calling and we do it with enthusiasm. This is something that deserves respect.

#### **ABOUT FELICIA VINCZE**

Felicia Vincze has an MSc in Physics (University of Szeged, Hungary, 1996) and an MSc in Midwifery (Midwives College of Utah, USA, 2009). After giving birth to five children in Hungary, she had her sixth child with the help of independent midwives in Canada. The experience changed her life, she enrolled in a midwifery program at MCU and moved to the USA. She worked with out-of-hospital midwives in Indiana and in a birth center in Texas. She had her seventh child at home and moved back to Hungary in 2009. She joined the local midwives associations and started working with the Ministry on the legislation of homebirth. In 2012 she became the first legally licensed midwife in Hungary. She attends homebirths, opened a birth center and occasionally works in hospital as a midwife or doula. She teaches at Semmelweis University, Hungary and at MCU, USA.





# DUBSKA DECISION AND APPEAL AND HANZELKOVI DECISION

# By Zuzana Candigliota

The European Court of Human Rights (ECtHR) ruled on human rights in childbirth in the case Dubská and Krejzová v. Czech Republic and Hanzelkovi v. Czech Republic in December 2014. The case Dubská and Krejzová concerns women's right to assisted home birth. The previous decision Ternovszky v Hungary was overruled and the right of the applicants was denied. A referral request to the Grand Chamber was submitted in March 2015. The case Hanzelkovi is about women's right to leave the hospital after childbirth. In this case, the applicants succeeded. Both cases have an impact on the domestic situation regarding birthrights, even though the decisions are not final yet.

#### ABOUT ZUZANA CANDIGLIOTA

Zuzana Candigliota is an attorney at law and a lawyer at the League of Human Rights (www. llp.cz). She is engaged in medical law, the rights of women and children related to childbirth, and parents' right to freely decide about vaccination. As a member of the legal team, she is involved in the application of Mrs. Dubská against the Czech Republic. She has a blog on topics of her interest (in Czech) –http://candigliota.blog.respekt.ihned.cz.



# PANEL 6 CONVENTION ON THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN

How does the Convention on Elimination of all forms of Discrimination protect the rights of women in childbirth? How can advocates utilize CEDAW's review mechanism to bring international attention to local violations against women in childbirth? Advocates will discuss recent examples of successful advocacy in Greece and the Czech Republic. How can individuals and groups of individuals bring individual complaints to the CEDAW Committee?

- Moderator: Karolina Więckiewicz
  - Panelists: Leah Hoctor, Regional Director for Europe, Center for Reproductive Rights Electra Koutra, Attorney, Hellenic Action for Human Rights, Greece
    - Kateřina Červená, Lawyer, League of Human Rights, Czech Republic





# **IMAGINE WHAT YOU CAN DO**

# By Karolina Więckiewicz

There are certain facts that I need to share about myself at the beginning. First of all – I have never given birth.

But this is not the worst thing.

I have a more serious confession to make. No matter how strange it may sound to speak aloud about this at the Human Rights in Childbirth conference, I need to be fair. For a long time in my life I was sure that if I ever get pregnant, I would deliver a baby by caesarian section. I was so sure it was the only option for me as I am so afraid of pain and cannot even imagine anything else.

It gets worse.

I remember exactly that in early 2012 I spoke to a doctor and a psychologist my organization cooperates with and I told them openly and with no shame whatsoever that this is what I wanted. You can imagine the look on their faces and the concern it must have caused. Clearly, they understood that it was not a conscious decision that I made knowing all the facts and having thought it through. We started talking, they were very sincere with me because they knew me as the pro-choice, women's rights, reproductive health activists and expert and they were very surprised such statements can come out of my mouth.

Yes – to give you the whole picture – I need to explain also that I work at a women's organization aimed at advancing women's reproductive rights. Inn a way, I have dedicated my life to raise awareness among women so that they can make informed decisions about their pregnancies, be respected in such a way that they are provided with comprehensive information based on which they can choose the best options. It seemed though that I was lacking awareness in this field to a very high extent.

But as I am a person who is very humble, who listens to wiser people and learns from them, I started to think about it. I listened very carefully and I knew exactly that my "choice" came out of misconceptions and was not based on anything it should be based on. I very quickly knew that it is not my final decision. In fact I was quite sure that deciding about a caesarian on demand way in advance before even deciding about pregnancy is probably not the best way to go. It didn't take me long



to know that I will find a better way. Still, at the time I did not think about natural birth or – that was a really remote concept – a home one. No, not then.

I had no idea, though, that the big change was approaching very soon.

In fact, 2 months later I went to The Hague (I should rather be saying THE Hague actually – you will see why shortly). It was, of course, on the occasion of the first Human Rights in Childbirth conference in 2012. All I knew before coming, was that it was supposed to be connected with the Ternovszky case and since the European Court is a big part of what we do at my organization, I went there.

It was a life changing experience for me.

I am not kidding you. I do not recall any – literally ANY – conference or training in my life that would have had such an impact on me. And really – as you know – I was this "2 months ago I thought I wanted a caesarian on demand" person at the time!

Three years have passed by and I still have vivid memories of this event, I love to talk about it and share that with other people.

I remember the first moment when I walked into the room, when I saw all the midwives, doulas and activists and I felt such a strong energy that made me so excited about what was going to happen. Actually – and I remember that very well too – it was the moment when I met my very first doula. I talked to her for five minutes, she spoke about her work, the idea that I only had a slight imagination of before – and all I knew was that there was something absolutely amazing about that woman – the warmth, kindness and wonderful spirit of her mission, that all I could have done at the moment was to ask her: "If I get pregnant, you will come to Poland and support me in my labor, ok?". And I meant it! She laughed, she knew that I would find good doulas in Poland too and she was right. But, Farola Dumont, if you read this – I want you to know that I keep you in my heart as the very first one I met and will remember that always. Now, I know amazing Polish doulas and I know that my first impression was a right one – isn't there something undefinably amazing about doulas?

I remember all the pictures, movies and testimonies of women who went through home births and I was speechless.

You must also know that a great part of my work is dealing with women whose pregnancies went wrong, who either do not accept them at all and in my country need to find the ways to terminate outside the legal provisions or who discover at a later stage that it causes a threat to them, who have to face the fact that the fetus



is seriously damaged and things like this. Women I am helping everyday are lied to by doctors about their right to prenatal examinations, denied legal termination, disrespected in so many ways. I deal with cases of non-sufficient help at labor, complications, delayed caesarians and the real tragedies that it causes. We even have obstetric care standards that apply to physiological pregnancy and birth and – no matter how badly they are sometimes implemented – I have always had a problem with the non-physiological pregnancies and births that these standards might not apply to. I had always defended and worried about women who face complications. I had helped them on their way to execute their human rights and hold those who breach them responsible.

And I still do that. I am a women's rights lawyer.

But after THE Hague I discovered another perspective. Not that the one I described above is not accurate. But I suddenly realized that – oh wow – there is a whole other side of it. Actually everything can go naturally well and you know what – in these cases... you just have to leave this woman alone and let her do it her way, the way she wants, she chooses. And that it is extremely important that you don't interfere with all these unnecessary medical interventions that are needed at times but not always, not even to mention the harmful ones. That you don't have to impose the idea of a hospital birth on her, that you must not threaten her with the danger of a home one and lie to her about it. That you just have to know when to back off and let her do it by herself and support her and her choice.

I realized that there is a strength in women that makes them make choices regarding their births. And it empowered me. I understood that I have been following a pattern – a scheme so present in my country. You discover you are pregnant, you go see a doctor who is there with you through the whole pregnancy, you establish a term and you refer yourself to the hospital when it comes. You give birth in a horizontal position and if you are lucky enough you are given anesthesia. Then your baby is taken away from you to be weighed and cleaned. That is how it is. Simple.

After THE Hague I knew it was not the way to go. I understood that it really is not about the pain itself. About feeling it or not feeling it. It is about the "management of pain" (yes, I came up with that). It can either bring you down, humiliate you, and because serious trauma or... it can set you free, empower you and make you feel like the strongest person in the world. And I knew I wanted that.



This conference empowered me both as a women's rights lawyer and activist but also – and maybe more importantly – as a woman. Two days with all these amazing women, their stories and all the scientific facts, studies and legal arguments, had changed me completely. I went back home and told my partner – "You know what, when I get pregnant, I am going to deliver here, at home. I will have doula and a midwife, we will have a tub with water and you will be with me!"

Oh, he knew I was not kidding.

I have not changed my mind ever since. I am sure that if I ever get pregnant I will do anything possible to deliver my baby in such a way. And I will be telling all women about this to make them at least consider it, to give them a wider picture.

You – the whole Human Rights in Childbirth community – have done this for me. You changed me into a person who knows that labor can and should be beautiful. I realized how strong and wise and self-aware those women who choose to give birth in accordance with themselves are. That it is hard not to follow the wellknown pattern but to know more and do it in a way that makes us happy. That it is extremely important to know our bodies and to know what can and cannot be done to us, to be aware that the commonly used practices can be harmful and are not necessary in most cases. That we can and should play the main role in this because the way we give birth stays with us and our children forever.

It is hard work to do at times, I know that very well. But if you – no matter if you are doulas, midwives, activists or lawyers – ever have a weaker moment, doubting that it makes sense, please recall this story. Because you have changed me in two days without an intention to do so. When I try to imagine what you can do in a year and with a good strategy, I feel excitement because I know that this world will be a different place soon.

You do bring about change and I am one of the examples of that. And I will keep that in my heart forever.





# CEDAW SHADOW REPORTING AND INDIVIDUAL COMMUNICATIONS

# By Leah Hoctor

International human rights treaties, including the Convention on Elimination of all forms of Discrimination against Women, protect the rights of women in childbirth and place legal obligations on states to respect and guarantee their rights. There are a number of ways in which advocates can engage with the treatymonitoring bodies (the international authorities who are tasked with reviewing and assessing compliance with those treaties) to call for accountability for violations of women's rights in childbirth and to seek recommendations for change in laws and practice. At times engagement with these mechanisms can have powerful results. However, awareness of the challenges and practical and strategic considerations is also vital.

This presentation provided participants with a practical overview of the ways in which these mechanisms can be used to advocate for change. It focused particularly on the Committee on the Elimination of Discrimination against Women (CEDAW Committee), which monitors implementation of the Convention on the Elimination of All Forms of Discrimination against Women. It outlined how advocates can participate in CEDAW's periodic review mechanism and how individual complaints of violations can be filed with the CEDAW Committee. It provided insight into the formal and informal avenues of engagement and advice on challenges and strategy.

#### **ABOUT LEAH HOCTOR**

Leah Hoctor joined the Center for Reproductive Rights in November 2014 and leads the Center's Europe Programme, directing the Center's litigation, advocacy and policy work in Europe. Before joining the Center Leah was a Senior Legal Advisor with the International Commission of Jurists (ICJ), where she established and led the ICJ's inaugural Women's Human Rights Programme. In that role she managed in-country and cross-regional projects in Africa, Asia and Europe on women's access to justice and women in the judiciary, provided third-party support for litigation and directed ICJ's legal and policy advocacy on a wide range of women's human rights issues. Leah received her law degree from University College Dublin, Ireland and Masters Degree (LL.M.) in International Human Rights Law from the University of Lund, Sweden (Raoul Wallenberg Institute).





# ADVOCATING FOR LOWERING THE C-SECTION RATE IN GREECE

## By Electra Leda Koutra

In February 2013, after submissions by the NGOs Greek Helsinki Monitor (GHM) and Hellenic Action for Human Rights – "Pleiades," Greece was examined for generalized violence and discrimination against women in front of the CEDAW Committee and as a result, since March 1st, 2013, suggestions have been made by the UN body and Greece is being monitored on the issue of its extremely high rate of caesarean sections (60% and coming up to 80% in some areas), the highest globally. The speaker is connected to both NGOs who managed to bring Greece in CEDAW's monitoring (2013-2017), being the head of "Pleiades" since 2009 and cooperating for years with GHM as a litigator in strategic cases. She presented on how bringing such complaints in procedures before the CEDAW Committee can prove to be a powerful tool for civil societies' efforts to provoke social reform and/ or advances on birthrights, using the example of Greece in the matter of cesarean sections.

#### ABOUT ELECTRA LEDA KOUTRA

Electra Leda Koutra is an Athens based lawyer specializing in human rights and criminal law. Since 2009, she has led the "Hellenic Action for Human Rights" – "Pleiades" (NGO) and is involved in activism and strategic litigation, currently representing hundreds of applicants in front of the ECtHR. Besides law, she has studied psychology, system dynamics and theatre. She is also a published poet, has had several exhibitions of her paintings and has been involved in acting. Being herself a mom who gave birth naturally, in the country with the highest caesarean rates globally, she has attempted, among other human rights quests, to sensitize the public on human rights in childbirth, and to initiate proceedings related to homebirth in front of supra-national bodies.





# CZECH REPUBLIC - HOW WE SUCCEEDED AT THE CEDAW COMMITTEE AND HOW WE USED IT FOR ADVOCACY

By Kateřina Červená

The author described her experience with advocacy at CEDAW and explained what was behind its success which resulted in the Committee's recommendation to the Czech Government to solve the situation in Czech maternity hospitals. The author shared several practical tips for advocacy at the UN level - mainly on writing of shadow reports and on face to face communication with committee members. The author then focused on advocacy at the national level. She emphasized how Czech NGOs used the CEDAW recommendation for lobbying and strategic litigation and how the recommendations were perceived by Czech authorities.

#### ABOUT KATEŘINA ČERVENÁ

Kateřina Červená is lawyer at the League of Human Rights, an NGO in the Czech Republic which works on patients ´ rights. She used to lead a free legal counseling office called Fair Hospital. Now she specializes in the topic of unlawful sterilization of Romany women. She defended her Ph.D. thesis on complaint mechanisms for patients.





Ljudska prava u porodu u Istočnoj Europi