

## CASE STUDIES IN HEALTH AND HUMAN RIGHTS

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### CASE STUDY #3

#### WOMEN WHO USE DRUGS AND MATERNAL CARE

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## NARRATIVE

Lena is 20 years old. She works part-time and lives in the city with her boyfriend Peter, with whom she uses intravenous drugs. Lena is pregnant, but her menstrual cycle is irregular so she does not know how far along she is. It is likely too late for a legal abortion. In any case, she is confused about wanting the baby. Lena is terrified that Peter will leave her. “We inject together, he gets the drugs and the needles.” Lena and Peter fight often, sometimes violently. Lena is not close with her parents or other family.

Lena is reluctant to visit a health clinic for prenatal care. “I have heard stories about the way they treat people like me.” Lena chooses to seek care from a government-run drug detoxification and rehabilitation center. Lena was in rehabilitation before, but left because she feared losing Peter. There were strict rules about partners who are active users. This treatment center also has rules. Lena learns it will not accept pregnant women. There is also an eight month waiting period and no child-care services. “We have limited space,” the counselor explains, “We’re nearly always full.” To receive treatment, Lena must also register as a drug-user. She worries about this status. “If my employer finds out, I’ll be fired.” Lena also voices her concerns about seeking prenatal care to the counselor at the treatment center. “I can’t provide a referral. We work in drug treatment not maternal care.”

Late in her pregnancy, Lena visits the public hospital for prenatal care. Nurse Tarasov is warm and attentive until she sees the track marks on Lena’s arms. With her back to Lena, she says: “It makes me sick, women like you. These poor babies ... oh never mind. You never listen. You can’t. You’re high all the time. We should just turn you over to the police now.”

When Dr. Ivanov visits Lena, he is kinder than Nurse Tarasov. He tells her the pregnancy risks of drug use, and that children are rarely born healthy. Holding Lena’s hands, he says: “You don’t want to hurt your child. You’re still young and can change your life. Please get treatment.” Lena explains the limitations of the government center, and asks about drug substitution treatment at the hospital. Dr. Ivanov answers, “I’m an obstetrician not a narcologist. I’m here to make sure you have a healthy baby. That should be enough treatment for you: get clean for your baby.”

Lena’s drug use increases, and feeling shamed, she avoids further prenatal care for the remainder of her pregnancy. “It is too painful to stop. I cannot believe such pain is good for the baby either. I cannot do it on my own.” Lena continues to inject until the week of labour.

In the maternity ward, Lena is surrounded by other women and their families. She is visited by Dr. Ivanov. “I am disappointed you are still using. Consider the well-being of your child. How can you care for a child when you cannot take care of yourself?” Lena sees the disapproval of those around her. Rather than the support and encouragement other mothers-to-be receive during labour, Lena is neglected by the nursing staff. She is terrified. Peter is absent. “Perhaps I will call my parents. But I need more time.”

Lena gives birth to a boy. In recovery, Lena is told she cannot see her son because he is under observation for neonatal abstinence syndrome. Ridden with guilt that she may have harmed her child and in severe pain from drug withdrawal, Lena is desperate to leave the hospital. Nurse Tarasov tells Lena to sign a statement indicating that she cannot care for the child, and giving custody to the state. “Sign it and we can discharge you.” Lena signs. A few months later, Lena reflects on her experience: “What choice did I have? They’re right. I’m no mother.”

*Note: HIV/AIDS issues related to drug use and maternal care are addressed in Case Study 1: Coerced Sterilization of HIV-Positive Women.*

## BACKGROUND

Health-related harms associated with the use of illegal drugs are of public concern worldwide.<sup>1</sup> There are an estimated 3.1 million injecting drug users in Eastern Europe and Central Asia.<sup>2</sup> Drug addiction is recognized in many contexts as a health condition, influenced by a variety of factors including genetics, psychology, and social contexts.<sup>3</sup> Drug use is also associated with other health conditions, such as HIV/AIDS. Injection drug use is the primary route of HIV transmission in Eastern Europe and Central Asia.<sup>4</sup>

In the Soviet era, drug addiction was seen as a social threat and persons labeled as addicts were sent to work-camps for treatment.<sup>5</sup> In the present day, ties between medical and legal authorities in drug policy remain close.<sup>6</sup> Drug policy is often punitive, with strong involvement of criminal law enforcement.<sup>7</sup> Several countries in the former Soviet Union have arrest quotas, and drug-users are targeted as an easy means to fulfill these quotas.<sup>8</sup> Drug-treatment providers are routinely pressured by law enforcement agencies to share the records of registered patients.<sup>9</sup> Mandatory drug user registration laws, for example, require registration of patients who seek treatment in state-run facilities. These laws deter access to treatment not only for fear of arrest

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<sup>1</sup> P.J. Sweeney, R.M. Schwartz, N.G. Mattis & B. Vohr, “The Effect of Integrating Substance Abuse Treatment with Prenatal Care on Birth Outcome” (2000) 4 *Journal of Perinatology*, 219–224 at p. 219.

<sup>2</sup> C. Aceijas, G.V. Stimson, M. Hickman, & T. Rhodes, “Global Overview of Injecting Drug Use and HIV Infection Among Injection Drug Users” (2004) 18 (17) *AIDS*, 2295-2303, at p. 2295.

<sup>3</sup> B. Jupp & A.J. Lawrence, “New horizons for therapeutics in drug and alcohol abuse” (2010), 125 (1) *Pharmacology and Therapeutics* 138-168, at p. 138.

<sup>4</sup> D. Operario *et al.*, *Living with HIV in Eastern Europe and the CIS: The Human Cost of Social Exclusion: Regional Human Development Report on AIDS* (U.N. Development Programme, 2008) at 6; A. Renton, D. Gzirishvili, G. Gotsadze & J. Godinho, “Epidemics of HIV and sexually transmitted infections in Central Asia,” (2006) 17 (6) *International Journal of Drug Policy*, 494-503, at p. 494.

<sup>5</sup> A. Shields. *The effects of Drug User Registration Laws on People’s Rights and Health: Key Findings from Russia, Georgia, Ukraine* (Open Society Institute, 2009). Online: [http://www.soros.org/initiatives/health/focus/ihrd/articles\\_publications/publications/drugreg\\_20091001](http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/drugreg_20091001)

<sup>6</sup> A. Sarang, R. Stuikyte & R. Bykov, “Implementation of harm reduction in Central and Eastern Europe and Central Asia,” (2007) 18 *International Journal of Drug Policy*, 129-135, at pp. 129-130.

<sup>7</sup> Human Rights Watch. *Drug Policy and Human Rights*. (2009). Online: <http://www.hrw.org/en/news/2009/04/10/drug-policy-and-human-rights>

<sup>8</sup> Open Society Institute. *International Drug Policy: The Facts* (2009). Online: [http://www.soros.org/initiatives/drugpolicy/articles\\_publications/listing?type=Publication](http://www.soros.org/initiatives/drugpolicy/articles_publications/listing?type=Publication).

<sup>9</sup> N. Bobrova *et al.*, “Challenges in Providing Drug User Treatment Services in Russia: Providers’ Views,” (2008) 43 *Substance Use & Misuse*, 1770–1784, at p. 1776.

and detention, but for reason of disclosure of their drug use and discrimination in employment, education, and social services.<sup>10</sup>

Women represent an estimated 20% of drug users in Eastern Europe and Central Asia.<sup>11</sup> Their vulnerability to harm differs in important respects from that of men. Many women begin to inject drugs in the context of heterosexual relationships, often leading to increased dependency on their male partners. Women are more likely than men to borrow or share needles.<sup>12</sup> Women who use drugs are also at increased risk of intimate partner violence and abuse in contrast to other social groups.<sup>13</sup> Poverty and decreased employment opportunities among drug-users make commercial or transactional sex a “survival strategy” for some women.<sup>14</sup> The combination of injecting drug use and transactional sex work renders women at a heightened risk of contracting HIV and other communicable diseases such as hepatitis.

Cultural attitudes informed by historical ideas about and the continuing stigma of drug use, addiction and gender shape law, policy and practice, with profound effect on the health and lives of pregnant women who use drugs.<sup>15</sup> Law and policy in turn not only regulate individual behaviour, but individuals themselves: how they are perceived and treated.<sup>16</sup>

While drug use is widely stigmatized, women are doubly impacted because they also transgress cultural norms by engaging in “gender inappropriate” behaviour.<sup>17</sup> Pregnant drug-users are harshly condemned for perceived reckless or indifferent behaviour toward their future children, and broader failure to meet social expectations of motherhood. This perception leads, for example, to challenges in maintaining their parental rights, especially as custodial parents. Drug registration, for example, can be grounds for loss of child custody.<sup>18</sup>

These attitudes and perceptions significantly affect health status. Women who use drugs suffer higher rates of poor nutrition, anemia, and inadequate social support (including partners and family). Stigmatization of pregnant drug-users deters health-seeking behaviour and restricts access to health care,<sup>19</sup> including drug-related and maternal health services. Many women internalize social condemnation of their drug use. This results in feelings of shame and guilt,

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<sup>10</sup> Shields, at p. 19; Bobrova, at p. 1772.

<sup>11</sup> S. Pinkham & K. Malinowska-Sempruch, “Women, Harm Reduction, and HIV,” (2008) 16 (31) *Reproductive Health Matters* 168-181 at p. 168 (“Pinkham & Malinowska-Sempruch RHM”)

<sup>12</sup> Pinkham & Malinowska-Sempruch RHM, at p. 170.

<sup>13</sup> Rates of intimate partner violence are two to three times higher than rates reported among other groups. M.L. Velez *et al.*, “Exposure to violence among substance-dependant pregnant women and their children,” (2006) 30 *Journal of Substance Abuse Treatment*, 31-38 at p. 31; Sweeney *et al.*, at p. 222.

<sup>14</sup> Pinkham & Malinowska-Sempruch RHM, at p. 169.

<sup>15</sup> Pinkham & Malinowska-Sempruch RHM, at p. 169.

<sup>16</sup> N.D. Campbell, “The Construction of Pregnant-Drug-Using Women as Criminal Perpetrators,” (2005-2006) 33 (463) *Fordham Urb. L.J.* 463 at p. 463.

<sup>17</sup> U.N. Office on Drugs and Crime. *Substance abuse treatment and care for women: case studies and lessons learned.* (2004), at p. 20. Online: [http://www.unodc.org/pdf/report\\_2004-08-30\\_1.pdf](http://www.unodc.org/pdf/report_2004-08-30_1.pdf).

<sup>18</sup> S. Pinkham & K. Malinowska-Sempruch. *Women, Harm Reduction, and HIV* (Open Society Institute, 2007), at p. 39. Online: [http://www.soros.org/initiatives/health/focus/ihrd/articles\\_publications/publications/women\\_20070920/women\\_20070920.pdf](http://www.soros.org/initiatives/health/focus/ihrd/articles_publications/publications/women_20070920/women_20070920.pdf) (“Pinkham & Malinowska-Sempruch OSI”).

<sup>19</sup> U.N. Office on Drugs and Crime, at p. v.

manifesting in an unwillingness to admit to substance use or to seek treatment and assistance.<sup>20</sup> Many women also fear the judgment and negative reaction of health providers.

The needs of pregnant women who use drugs are often neglected in health service delivery.<sup>21</sup> Drug treatment, detoxification and rehabilitation services, are available albeit in different forms throughout the region. Most treatment centres are state run, although there are a growing number of private facilities. Some of these facilities are prohibitively expensive, especially those which guarantee full confidentiality or anonymous treatment. Others are free, but religiously-affiliated or labor based. Substitution treatment, with methadone or buprenorphine, is demonstrated to be more effective than alternatives, such as voluntary or enforced drug abstinence.<sup>22</sup> This form of treatment, however, is not legal in all countries,<sup>23</sup> despite the fact that methadone is designated by the World Health Organization as an essential medicine.<sup>24</sup>

Where legal, methadone and other substitution treatment may not be accessible to pregnant women.<sup>25</sup> Methadone maintenance treatment is considered safe for pregnant women, and can assist women to avoid overdose and unsafe injection, harm to the fetus from withdrawal, and provide stabilization in women's lives and in health.<sup>26</sup> Such treatment is prescribed and managed by a narcologist, many of whom are inexperienced with its impact on pregnancy and thus uncomfortable treating pregnant women.<sup>27</sup> Obstetrician-gynecologists, in turn, may oppose substitution treatment on ideological grounds, or be simply uninformed about its availability. Pregnant women who use drugs thus fall victim to failed integration in the health system. Links and referral systems between maternal care and drug treatment are often complicated by the criminal regulation of drug use, which influence both whether and how health providers deliver care.<sup>28</sup> Failed health system integration is particularly unfortunate because pregnancy often presents an opportunity to engage women in positive lifestyle changes respecting drug use.<sup>29</sup>

Other cultural and structural factors limit access to drug treatment programs for women. As the majority of drug-users are male, most drug treatment programs and facilities are designed to meet the needs of men.<sup>30</sup> The complexity of needs relating to primary caregiver roles for children and other family members, intimate partner violence and dependency, and poverty are often

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<sup>20</sup> U.N. Office on Drugs and Crime, at pp. v & 20.

<sup>21</sup> E.L. Wolfe, "Drug Treatment Utilization Before, During and After Pregnancy," (2007) 12 (1) *Journal of Substance Use* 27-38, at p. 28.

<sup>22</sup> See R.P. Mattick, C. Breen, J. Kimber & M. Davoli, "Methadone maintenance therapy versus no opioid replacement therapy for opioid dependence" (2009) 3 *Cochrane Database Syst. Rev.*

<sup>23</sup> See Pinkham & Malinowska-Sempruch OSI; R. Elovich & E. Drucker, "On drug treatment and social control: Russian narcology's great leap backwards," (2008) 5 *Harm Reduction Journal* 23 at p. 23.

<sup>24</sup> World Health Organization. *The Selection and Use of Essential Medicines: Report of the WHO Expert Committee*, 2010. 16th ed. (2010).

<sup>25</sup> K. Burns. *Women, Harm Reduction, and HIV: Key Findings from Azerbaijan, Georgia, Kyrgyzstan, Russia, and Ukraine* (Open Society Institute, 2009), at p. 9.

<sup>26</sup> Pinkham & Malinowska-Sempruch RHM, at p. 176.

<sup>27</sup> U.N. Office on Drugs and Crime, at p. 18-19; Wolfe, at p. 28

<sup>28</sup> Wolfe, at p. 29.

<sup>29</sup> Wolfe, at p. 35.

<sup>30</sup> U.N. Office on Drugs and Crime, at p. 18.

neglected. Drug treatment programs seldom have the services and flexibility to enable women to utilize them effectively.<sup>31</sup>

Access to reproductive health care, prenatal and maternal care, is important to women's health status. Poor nutrition and other stressors associated with substance use can cause amenorrhoea, the cessation of, or irregular menstrual cycles. This in turn means that women who use drugs may not realize they are pregnant until several months into pregnancy. Abortion is lawful on broad grounds in much of the region, but gestational limitations disproportionately restrict access for drug users because of late diagnosis of pregnancy.<sup>32</sup> Access to prenatal care for women who use drugs is conclusively linked to birth outcomes. Studies report increased rates of pregnancy-related risk and complications for pregnant drug users compared to women who do not engage in drug use. Drug use during pregnancy increases risks of lower birth weight and shorter gestational periods.<sup>33</sup> The use of heroin and other opioids, more specifically, can result in miscarriage or premature delivery. HIV screening in antenatal care is important for ARV treatment and prevention of mother-to-child transmission.<sup>34</sup> Neglect or failure to address drug use in maternal care undermines successful health outcomes for women and their children. Where pregnant women are denied access to drug treatment, for example, their children may experience withdrawal symptoms and women may be forced to leave hospitals immediately after giving birth to obtain drugs and relieve their own withdrawal symptoms.<sup>35</sup> Many infant health outcomes associated with maternal drug use are linked to inadequate pre- and post-natal care, including inadequate provision for mother-child bonding.<sup>36</sup>

## HUMAN RIGHTS STANDARDS

### *The European Convention for the Protection of Human Rights and Fundamental Freedoms*<sup>37</sup>

#### Prohibition of Torture

Art 3. No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

#### Right to Respect for Private and Family Life

Art 8.1. Everyone has the right to respect for his private and family life ...

Art 8.2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of

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<sup>31</sup> Pinkham & Malinowska-Sempruch RHM, at p. 173; WHO, UNODC, UNAIDS. *Technical Guide for Countries to Set Targets for Universal Access to HIV Prevention, Treatment and Care for Injecting Drug Users* (WHO, 2009), at p. v. Online: [http://data.unaids.org/pub/Manual/2010/idu\\_target\\_setting\\_guide\\_en.pdf](http://data.unaids.org/pub/Manual/2010/idu_target_setting_guide_en.pdf) ("WHO Technical Guide").

<sup>32</sup> See e.g. F. Perlman & M. McKee, "Trends in Family Planning in Russia: 1994-2003" (2009) 41(1) *Perspectives on Sexual and Reproductive Health* 40-50, at p. 41.

<sup>33</sup> *WHO Technical Guide*, at pp. 219-222.

<sup>34</sup> Pinkham & Malinowska-Sempruch RHM, at p. 171.

<sup>35</sup> Pinkham & Malinowska-Sempruch RHM, at p. 171.

<sup>36</sup> Pinkham & Malinowska-Sempruch RHM, at p. 172.

<sup>37</sup> *European Convention for the Protection of Human Rights and Fundamental Freedoms*, 4 November 1950, 213 U.N.T.S. 222 (entered into force 3 September 1953).

national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

### ***International Covenant on Civil and Political Rights***<sup>38</sup>

#### *Freedom from Torture or Cruel, Inhuman or Degrading Treatment*

Art 7. No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

### ***International Covenant on Economic, Social and Cultural Rights***<sup>39</sup>

#### *Rights to Non-Discrimination*

Art 2.2. The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to ... sex ... or other status.

Art 3. The States Parties to the present Covenant undertake to ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.

#### *Right to Health*

Art 12.1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

Art 12.2(a). The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

### ***International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities***<sup>40</sup>

Art 25. States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive ...

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<sup>38</sup> *International Covenant on Civil and Political Rights*, 19 December 1966, U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (entered into force 23 March 1976).

<sup>39</sup> *International Covenant on Economic, Social and Cultural Rights*, 16 December 1966, U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3 (entered into force 3 January 1976)

<sup>40</sup> *International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 30 March 2007, U.N. Doc. A/61/49, 993 U.N.T.S. 3 (entered into force 3 March 2008).

***Convention on the Elimination of All Forms of Discrimination against Women***<sup>41</sup>

Art 5(a). States Parties shall take all appropriate measures: (a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of ... all other practices which are based ... on stereotyped roles for men and women;

Art 12.1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services ...

Art 12.2. Notwithstanding the provisions of paragraph I of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period ...

Art. 16.1(e). States Parties shall take all appropriate measures to eliminate discrimination against women in all matters relating to marriage and family relations and in particular shall ensure, on a basis of equality of men and women: (e) The same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.

***Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment***<sup>42</sup>

Art 16. Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment

***Convention on the Rights of the Child***<sup>43</sup>

Art 8.1. 1. States Parties undertake to respect the right of the child to preserve his or her identity, including ... family relations as recognized by law without unlawful interference.

Art 24.1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Art 24.2(d). States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures: (d) To ensure appropriate pre-natal and post-natal health care for mothers.

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<sup>41</sup> *Convention on the Elimination of All Forms of Discrimination against Women*, 18 December 1979, U.N. Doc. A/34/46, 1249 U.N.T.S. 13 (entered into force 3 September 1981)

<sup>42</sup> *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, 10 December 1984, U.N. Doc. A/39/51 (entered into force 26 June 1987).

<sup>43</sup> *Convention on the Rights of the Child*, 20 November 1989, U.N. Doc. A/44/49, 1577 U.N.T.S. 3 (entered into force 2 September 1990).

## I. ACCESS BARRIERS TO HEALTH CARE SERVICES

*Discussion Questions: What barriers did Lena experience in accessing: Drug Treatment and Reproductive Health Services (Abortion, Prenatal and Maternal Care)? What human rights are implicated by these barriers?*

Accessibility is an essential feature of the right to health under international human rights law. Although the European Convention does not guarantee a right to health per se, the right to respect for private life encompasses physical and psychological integrity, which states are under a positive obligation to secure.<sup>44</sup> Health facilities goods are services must be accessible to all, especially the most vulnerable and marginalized sections of the population, without discrimination.<sup>45</sup> This includes discrimination on grounds of sex/ gender, as well as health status, such as drug addiction.<sup>46</sup> In an addition to non-discrimination, accessibility depends on the acceptability of services, namely that services are “sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.”<sup>47</sup> The right to health is related to and dependent on the right to privacy.<sup>48</sup>

### A. Access Barriers to Drug Treatment

Lena experienced several access barriers to drug treatment, including: structural neglect of gender/sex specific needs of women in drug treatment services, and failure to protect privacy.

#### Neglect of Gender/Sex Needs of Women

The right to non-discrimination in access to health care requires that drug treatment services be delivered in a manner sensitive to gender and lifestyle requirements. Lena describes leaving drug rehabilitation in the past because of strict rules about partners who are active users. Lena feared losing Peter if she stayed in treatment. Treatment programs often refuse to acknowledge and engage with the role of intimate relationships and partner dependency in women’s drug use. Many women, however, inject drugs with their partners, leading to increased dependency. When programs fail to address partner relationships, many women start using again following treatment when reunited with their partners. The government-run treatment center Lena visits will not accept pregnant women. When space is available, in eight months time, Lena would have to be separated from her child. No child-care services are available, thus neglecting the needs of many women who are primary caregivers for children and other family members. Neglect of women’s

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<sup>44</sup> *Tysiac v. Poland*, App. No. 5410/03 (2007) (European Court H.R.) at para. 107.

<sup>45</sup> Committee on Economic, Social and Cultural Rights, General Comment 14: The Right to the Highest Attainable Standard of Health (Article 12), UN ESCOR, 2000, UN Doc. E/C.12/2000/4, at para. 12(b) (“CESCR General Comment No. 14”).

<sup>46</sup> *Convention on the Elimination of All Forms of Discrimination against Women*, at art. 12; *Convention on the Rights of Persons with Disabilities*, at art. 25.

<sup>47</sup> *CESCR General Comment No. 14*, at para. 12(c).

<sup>48</sup> U.N. Comm. on the Elimination of all Forms of Discrimination against Women, *General Recommendation No. 24: Women and Health*, U.N. Doc. A/54/38/Rev.1 (1999) at para. 31(e) (“CEDAW General Recommendation No. 24”).

needs in the design of drug treatment programs may be premised on gender role stereotyping, that women do not or should not engage in drug use, gender inappropriate behaviour.<sup>49</sup>

Health system resource constraints may be offered in justification for lack of acceptable drug treatment services for women: the vast majority of drug users are men. The drug treatment counselor explains that there is limited space, the centre is always full.<sup>50</sup> Resource constraints are acknowledged under the right to health.<sup>51</sup> The “critical measure of the performance of health systems in a country is its achievement relative to resources.”<sup>52</sup> However, the burden of this constraint cannot fall on the shoulders of vulnerable groups.<sup>53</sup> The right to non-discrimination requires equitable resource allocation between general populations and vulnerable groups, which may require provision of targeted healthcare services for women who use drugs.<sup>54</sup>

The right to non-discrimination thus does only require equal treatment between women and men, but also treatment that recognizes and accommodates relevant differences. Relevant differences relate not only to gender but also biological sex, such as reproductive function.<sup>55</sup> A restriction on access to drug treatment based on pregnancy status constitutes discrimination on the ground of sex.

Lena asks Dr. Ivanov about drug substitution treatment at the hospital. He explains to Lena that he is an obstetrician not a narcologist, and that his primary concern is the health of her pregnancy and child. The division drawn between obstetric care and drug treatment is a false division from the perspective of the health needs of pregnant women who use drugs. Women in maternal care are too often reduced to their physical state of pregnancy, and their health care needs confined to their gestating function. This singular focus is then reflected in health care organization and practice: the isolation of reproductive health services from other health services, such as drug treatment, and weakening of multi-disciplinary practice. Dr. Ivanov declines responsibility for treating a medical condition outside of his immediate expertise, and to the extent that he does address drug treatment, demonstrates a lack of knowledge and experience. Withdrawal without treatment is painful for the woman, and moreover, can cause premature labour or fetal death. Collaboration among obstetricians and other specialists is the standard of care in maternal health.<sup>56</sup> The World Health Organization recommends that where multiple health services cannot be provided at one site, models for collaboration and partnership be developed.<sup>57</sup>

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<sup>49</sup> Convention on the Elimination of All Forms of Discrimination against Women, at art. 5(a); U.N. Comm. on Econ., Soc. and Cultural Rights. *General Comment No. 20. Non-discrimination in economic, social and cultural rights* (art. 2.2), U.N. Doc. E/C.12/GC/20 (2009) [“CESCR General Comment No. 20”] at para. 12; R. Cook, B. Dickens & M. Fathalla. *Reproductive Health and Human Rights*. (2003), at p. 199.

<sup>50</sup> Illustrative is an example from Russia: In 2005, there were only fifty-nine government run rehabilitation centres for four million drug users. G. Babakian et al., *Positively Abandoned: Stigma and Discrimination against HIV-Positive Mothers and their Children in Russia* (Human Rights Watch: 2005), at p. 15; *Health and Human Rights*, eds. R.J. Cook and C.G. Ngwena (2007), at *xiv*.

<sup>51</sup> *CESCR General Comment No. 20*, at para. 47.

<sup>52</sup> Cook, Dickens & Fathalla, at p. 56.

<sup>53</sup> *CESCR General Comment No. 20*, at para. 43(a).

<sup>54</sup> *Health and Human Rights*, eds. R.J. Cook and C.G. Ngwena (2007), at *xiv*.

<sup>55</sup> CEDAW General Recommendation No. 24, at para. 12(a).

<sup>56</sup> E. Keely & K. Rosene-Montella. “An Approach to Medical Disorders in Pregnancy” *Medical Care of the Pregnant Patient*. (2008), at p. 7.

<sup>57</sup> *WHO Technical Guide*, at p. 18.

## Failure to Protect Privacy

Acceptable health services are defined as those “designed to respect confidentiality and improve the health status of those concerned.”<sup>58</sup> In order to receive treatment, Lena must register as a drug-user. This status carries risk of adverse consequences not only with respect to arrest and detention but also employment and other private sector discrimination. Lena worries that she will be fired from her job if her employer discovers she is a registered drug user. Failure to protect privacy is a significant deterrent to Lena enrolling in drug treatment, a limitation of her right to health.

The right to privacy is not an absolute right, but any limitation on that right must be justified by a sufficiently important public interest.<sup>59</sup> In the case of drug-registration programs, justification is a heavy burden to meet, especially where the scope of the violation extends not to an individual, but to an entire marginalized population.<sup>60</sup> Moreover, given that registration deters enrolment in treatment programs, any legitimate public objective in surveillance is effectively undermined. No public benefit can thus offset the deleterious effects of registration.

## **B. Access Barriers to Reproductive Health Services (Abortion and Prenatal Care)**

Lena faced access barriers to reproductive health services including abortion and prenatal care on the basis of her health status as a drug user, a prohibited ground of discrimination. For example, failure in multidisciplinary collaboration also creates an access barrier to maternal care. The drug treatment counselor would not provide Lena with a referral for prenatal care, citing her work in drug treatment not maternal care. Access to reproductive health care is an essential component of women’s right to health.<sup>61</sup> The right to non-discrimination includes the right of women “to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.”<sup>62</sup> Access to reproductive health services is essential to the right of reproductive self-determination.<sup>63</sup>

## Abortion Services

Women who use drugs may experience irregular menstrual cycles, leading to later pregnancy diagnosis. When Lena learns that she is pregnant, she considers that it is likely too late for a legal abortion. Many countries limit access to abortion based on length of pregnancy or gestation. These limitations disproportionately restrict access for women who use drugs because of later diagnosis of pregnancy. Denied access to lawful abortion may lead many women with unwanted pregnancies to seek unsafe abortion, a recognized violation of the rights to life and health.

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<sup>58</sup> *CESCR General Comment No. 14*, at para. 12 (c).

<sup>59</sup> L. Gostin & J. Mann, “Toward the Development of a Human Rights Impact Assessment,” in *Health and Human Rights: A Reader* (1999), at p. 63.

<sup>60</sup> Gostin & Mann, at p. 64.

<sup>61</sup> *CESCR General Comment No. 14*, at paras. 14 & 21; *CEDAW General Recommendation No. 24*, at paras. 1, 23, 29 and 31(b).

<sup>62</sup> *Convention on the Elimination of All Forms of Discrimination against Women*, at art. 16(e).

<sup>63</sup> Cook, Dickens & Fathalla, at 176.

Free decision-making of whether to continue pregnancies to term is equally important to the right to reproductive self-determination. Lena is confused about wanting the baby, and terrified that Peter will leave her. There is a history of intimate partner dependence and violence. Protection against coercion of third parties is essential to free decision-making in reproductive health. Internalized stigma against women who use drugs and motherhood may also influence a woman's decision to terminate her pregnancy. Counselling and support services are thus an important means by which to ensure that Lena can effectively exercise her right to reproductive decision-making (For further discussion of *free* decision-making see below).

### Prenatal Care

Stigma related to drug use and pregnancy is a significant barrier to health care. Some women may accept the stigmatized view of pregnant drug users, experiencing shame and guilt about their behaviour. This can lead to a form of self-discrimination.<sup>64</sup> When Lena's drug use increases after her first visit to the hospital, she avoids returning for further prenatal care because she feels ashamed. Because prenatal care can be an important opportunity for drug treatment, the impact on health outcomes is compounded. Lena's drug use increased and continued until the week of delivery. Stigma is also manifested in mistreatment by others, including health providers. Fear of judgment and negative reaction deters women from seeking prenatal care. Lena is reluctant to initially seek prenatal care based on reports of mistreatment.

Pre-natal care is conclusively linked to birth outcomes, including lower birth weight and premature delivery. Access barriers to pre-natal care as well as drug treatment thus violate the right to health of both women and their children. Denied access to drug treatment for pregnant women can also result in neonatal withdrawal. Lena's son is under observation for neonatal abstinence syndrome. It is widely accepted that substitution treatment for pregnant drug-users is appropriate and beneficial to promoting the physical and psychological well-being of both mother and child. Women may be forced to leave the hospital immediately after giving birth to relieve their own withdrawal symptoms, resulting in inadequate mother-child bonding. Lena suffers from drug withdrawal, experiencing significant pain. She is denied the opportunity to bond with her son, departing the hospital soon after giving birth. The right to health requires that no child be deprived of access to health care services, expressly defined to include "appropriate pre-natal and post-natal health care for mothers."<sup>65</sup>

## **II. MISTREATMENT IN THE CLINICAL CONTEXT**

*Discussion Questions: How is stigma of pregnant women who use drugs enacted against Lena in the clinical context? Does the behaviour of Nurse Tarasov and Dr. Ivanov constitute cruel, inhuman and degrading treatment? If so, why?*

Access to health care depends not only on the availability of services, but the manner in which they are delivered and treatment in the clinical context. Stigma against pregnant women who use drugs is enacted through devaluing and degrading treatment, a failure to respect their human

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<sup>64</sup> See e.g. S. Burris. "Stigma and the law" (2006) 367 *The Lancet* 529-531.

<sup>65</sup> *Convention on the Rights of the Child*, at art. 24.1 and art. 24.2 (d).

dignity and equal worth.<sup>66</sup> Gender-specific stigma of pregnant drug users – their engagement in illicit activity and transgression of maternal norms – function as rationales for mistreatment by health providers in the clinical context. Women are treated on the basis of what Erving Goffman labeled their “spoiled identity.”<sup>67</sup> Both Nurse Tarasov and Dr. Ivanov act on the belief that Lena uses drugs with reckless disregard for the health and well-being of her future child, and thus cannot be a “good mother.” The most insidious harm resulting from mistreatment in the clinical context is that women themselves come to believe in their limited worth. Stigma is manifested in the affective responses of stigmatized individuals.<sup>68</sup> When Lena reflects on her experience, she states: “They’re right. I’m no mother.”

The right to be free from cruel, inhuman and degrading treatment protects against acts which cause severe physical pain and mental suffering.<sup>69</sup> ‘Degrading’ treatment includes that which arouses feelings of fear, anguish, and inferiority capable of humiliating and debasing an individual.<sup>70</sup> The use of mental or physical abuse against a marginalized group is an important factor when interpreting the nature of treatment.<sup>71</sup> Gender is a key and intersecting factor which renders women at risk of ill-treatment, particularly in the context of medical treatment involving reproductive decisions.<sup>72</sup>

### **A. Neglect, Humiliation and Shaming**

Nurse Tarasov is warm and attentive until she identifies Lena as a drug user. She then treats Lena on the basis of this status, “women like you,” rather than as an individual. Nurse Tarasov judges Lena, communicating her personal disgust: “It makes me sick.” Lena’s use of drugs becomes the sole focus of their interaction, informing Nurse Tarasov’s punitive attitude. Rather than treating Lena as an individual with health care needs, Nurse Tarasov threatens to turn Lena over to law enforcement. Lena’s status as a drug user becomes reason to disentitle her from equal care and compassion. Nurse Tarasov decides without evidence that Lena is uninterested and incapable of following health care advice. Neither Nurse Tarasov nor Dr. Ivanov offer health care options to meet Lena’s current needs, which would include much of the same advice given to pregnant women generally. In the maternity ward, rather than the support and encouragement other mothers-to-be receive during labour, Lena is neglected by the nursing staff. This neglect is intended to communicate judgment and disapproval much the same as Nurse Tarasov’s treatment in prenatal care; and its effect similarly shames and isolates Lena. Following her initial treatment at the hospital, Lena avoids prenatal care for the remainder of her pregnancy. Her treatment in the clinical context compounds Lena’s already marginalized status. Health care practice that

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<sup>66</sup> UN Economic and Social Council, Commission on Human Rights, Fifty-ninth session, Item ten of the provisional agenda, *Economic, Social and Cultural Rights: The right of everyone to the highest attainable standard of physical and mental health*, Report of the Special Rapporteur, Paul Hunt, submitted in accordance with Commission resolution 2002/31, at para. 62.

<sup>67</sup> See: E. Goffman, *Stigma: Notes on the Management of Spoiled Identity*. (1963).

<sup>68</sup> S. Burris, “Disease Stigma in U.S. Public Health Law” (2002) 30(2) *Journal of Law & Medical Ethics* 179-90.

<sup>69</sup> Human Rights Committee, General Comment 20: Replaces general comment 7 concerning prohibition of torture and cruel treatment or punishment (Art. 7), U.N. Doc. HRI/GEN/1/Rev.1 at 30 (1994), at para. 5.

<sup>70</sup> *Jalloh v. Germany*, (2006) E.C.H.R. Application No. 54810/00 (European Ct. HR).

<sup>71</sup> Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, *General Comment No. 2: Implementation of article 2 by States parties*. U.N. Doc. CAT/C/GC/2/CRP. 1/Rev.4 (2007), at paras. 20-22 (“CAT General Comment No. 2”).

<sup>72</sup> CAT General Comment No. 2, at para. 22.

humiliates and degrades the individual serves no public interest, and thus cannot be justified. Such practices are inherently inconsistent with human rights.<sup>73</sup>

## **B. Stereotyping, Paternalism and Withholding of Treatment**

Dr. Ivanov addresses all of Lena's health care needs solely from the perspective of her pregnancy and future child. Lena is treated as means to an end, the delivery of a healthy child.<sup>74</sup> Although Lena too desires this end, she remains an individual with needs and interests, entitled to be treated with dignity and worth on this basis. Dr. Ivanov, however, assesses Lena's behaviour and needs solely with respect to her pregnancy status. Medical paternalism is defined by subordination of the individual's expressed needs to the health provider's idea of what is in the individual's "best interest."<sup>75</sup> Best interests in maternal care are often informed by gender stereotyped roles. Motherhood is prescribed as a primary role, confining the medical needs of pregnant women to their gestating function with care delivered from this perspective. It is assumed that pregnant women will and should act only in service of their pregnancy. Thus rather than understanding drug addiction as an important health need of the woman as an individual, drug use is characterized as irresponsible maternal behavior that women as mothers would change if willing. The fact of wanting to have a healthy child, Dr. Ivanov states, should be reason enough for Lena to stop using drugs. He does not inquire into the many factors that influence Lena's use of drugs, nor despite her inquiries, into treatment and counselling beyond her maternal resolve. He interprets her drug use as disregard from the well-being of her child, a transgression of maternal norms. Drug use thus becomes a reflection of character and worth. Women who use drugs are judged as selfish and uncaring, incapable of being a good mother.

Neglect of Lena as an individual with health care needs apart from her pregnancy is reflected in the failure to care for her drug withdrawal and related pain post-delivery. Denied access to health care implicates the prohibition against cruel, inhuman and degrading treatment when it is withheld contrary to medical indication and despite a known risk to life and health.<sup>76</sup>

## **C. Patient-Centered Care**

As an alternative approach, patient-centered care reflects a commitment to individual's dignity and worth in the clinical context. Patient-centered care recognizes that caring *for* means caring *about*. Health care services are delivered in a manner that respect and responds to individual needs and values.<sup>77</sup> This approach accepts each individual as they are, without judgment, and with the goal of promoting best possible health outcomes. Harm reduction programs in the drug treatment context exhibit many of these features, reflecting two main objectives: first, to accept

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<sup>73</sup> Burris 2006, at p. 531.

<sup>74</sup> Cook, Dickens & Fathalla, at p. 45.

<sup>75</sup> E. Nelson, "Reconceiving Pregnancy: Expressive Choice and Legal Reasoning" (2004) 49 *McGill Law Journal* 593-634, at p. 609.

<sup>76</sup> See e.g. *K.L. v. Peru*, Comm. (2005) CCPR/C/85/D/1153/2003 (Human Rights Committee); Cook, Dickens & Fathalla, at p. 173.

<sup>77</sup> See: M. Krumholz, "Informed Consent to Promote Patient-Centered Care" (2010) 303 (12) *Journal of the American Medical Association* 1190-1191.

the drug user as she is (comprehension), and second, to take responsibility to promote the welfare of the drug user (action).<sup>78</sup>

Rather than condemn women for their drug use, comprehension would require health providers to take an open-minded stance toward the complicated lives of women who use drugs, the vulnerabilities and other factors that influence use, and the best available means to assist those seeking treatment. Comprehension recognizes the importance of respecting and encouraging participation of the individual – learning of her needs and wishes – in health service delivery.<sup>79</sup> Neither Nurse Tarasov nor Dr. Ivanov made an effort to understand Lena and the complexity of her life. Rather, their mistreatment borne in ignorance undermined positive outcomes for both mother and child, deterred Lena from seeking care and reaffirmed rather than challenged her social marginalization and diminished self-worth.

### **III. FREE AND INFORMED DECISION-MAKING**

*Discussion Questions: Was Lena fully and appropriately informed by Dr. Ivanov about her options for drug treatment? If not why? What were Dr. Ivanov's human rights obligations in this respect? Was Lena's decision to relinquish custody of her child undertaken freely, without coercion or inducement? If not why? What do human rights require to ensure that decision-making is undertaken without undue influence?*

Free and informed decision-making rests on the right to self-determination, reflecting respect for individuals to make decisions about their lives including medical treatment grounded in rights among others to autonomy, health, and privacy.

#### **A. Right to Informed Decision-Making: Drug Treatment**

The right to non-discrimination in health care entitles women “to be fully informed, by properly trained personnel, of their options in agreeing to treatment ... including likely benefits and potential adverse effects of proposed procedures and available alternatives.”<sup>80</sup> These include all reasonably accessible medical, social and other means to address a patient's health status.<sup>81</sup>

Dr. Ivanov responds to Lena's inquiry about drug substitution therapy by directing her to abstain from drug use. Simple withdrawal, however, is painful and moreover, can cause premature labour or fetal death. His misinformation can be explained either by his inexperience in drug treatment, or an ideological opposition to it. Regardless, the right to informed decision-making entitles Lena to accurate information. The right imposes an obligation on Dr. Ivanov to become informed and to communicate accurate information about the efficacy of substitution treatment and risk of withdrawal, or to refer Lena to a knowledgeable provider. His direction for her to abstain for further drug use, without knowledge of the risks and health effects of withdrawal, recklessly endangers both Lena and her child's health. Selective disclosure of information is a

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<sup>78</sup> S. Burris, “Harm reduction's first principle: ‘the opposite of hatred,’” (2004) 15 *Int'l J. of Drug Policy* 243-244, at 243.

<sup>79</sup> Cook, Dickens & Fathalla, at p. 44.

<sup>80</sup> *CEDAW General Recommendation No. 24*, at para. 20.

<sup>81</sup> Cook, Dickens & Fathalla, at p. 110.

form of paternalistic care. Doctor Ivanov instructs Lena on a course of treatment based not on her health needs and interests, but his own expectations of how a pregnant woman should behave. Dr. Ivanov seeks to exercise control over Lena, rather than to inform her decision-making.<sup>82</sup>

The right to informed decision-making places a duty on health providers to *inform* individuals rather than *obtain* consent.<sup>83</sup> Decision-making in this respect is a process of communication: information flowing both *to* and *from* health care providers. Health providers are to elicit and take seriously information shared by the patient.<sup>84</sup> This conception of decision-making acknowledges that “medical decisions” are “personal decisions.”<sup>85</sup> Health providers should thus consider what information “a reasonable person in the general circumstances of the patient would consider material for the exercise of choice.”<sup>86</sup> Material information should be adjusted to the individual perspectives of patients, and without application of stereotyped assumptions.

Contrary to a patient-centered approach, none of the health providers Lena came into contact adjusted the information they provided to Lena’s life circumstances, recognizing and taking into account, for example, the nature of her relationship with Peter and her isolation from family, which may have affected her decision-making about treatment. Rather health providers acted on the basis of stereotyped assumptions about pregnant drug users, and allowed these assumptions to guide their actions, including their provision and withholding of information.

## **B. Right to Free Decision-Making: Child Custody Post-Partum**

The right to free decision-making is concerned with freedom from coercion or inducement.<sup>87</sup> Adoption and by extension any decision of a parent to relinquish custody of their child to the state requires free and informed decision-making, in recognition of the family as fundamental to the well-being of children, and respect for the responsibilities, rights and duties of parents.<sup>88</sup> This requires among other conditions that parents are properly counselled and duly informed of the effect of their consent. Public authorities are obligated to respect the right of children to preserve their identity, including family relations without unlawful interference.<sup>89</sup>

Lena’s surrender of her child to the state cannot be described as free of coercion or inducement. Dr. Ivanov pleads with Lena to give up custody of her child in the maternity ward, surrounded by other women and their families. She is alone in contrast, without partner or family. Her drug use is given as reason for this decision: that she cannot care for a child, if she cannot care for herself, a failure to acknowledge the structural barriers which effectively deny pregnant women and women with children access to drug treatment. Dr. Ivanov again relies on maternal stereotypes and drug-related stigma to influence Lena’s decision-making. Lena is further provided with no

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<sup>82</sup> L.P. Freedman, “Censorship and the Manipulation of Family Planning Information,” in *Health and Human Rights: A Reader* 145-178 (1999) at p. 169.

<sup>83</sup> Cook, Dickens & Fathalla, at p. 109.

<sup>84</sup> Freedman, at p. 171.

<sup>85</sup> Cook, Dickens & Fathalla, at p. 110.

<sup>86</sup> Cook, Dickens & Fathalla, at p. 113.

<sup>87</sup> Cook, Dickens & Fathalla, at p. 114.

<sup>88</sup> *Convention on the Rights of the Child*, at Preamble, art. 5.

<sup>89</sup> *Convention on the Rights of the Child*, at art. 8.

counseling of her parental rights or offer of support services, such as parenting assistance or temporary childcare placement. Nor did Nurse Tarasov provide counseling or information in recovery. Lena is told to sign a statement indicating that she cannot care for the child and giving custody to the state. She is not provided with any information about the consequences of signing, its effect, for example, on the legal relationship between parent and child.

Nurse Tarasov only informs Lena that once she signs the statement, she can be discharged. Lena is desperate to leave the hospital. She is in severe pain, suffering from drug withdrawal and denied access to drug treatment. Without an opportunity to see or bond with her son, Lena is ridden with guilt that she may have harmed her child. Regardless of whether Lena's decision was properly informed, the timing of the request for her consent was inappropriate. Her state of distress, both physically and psychologically, gives reason to question whether her decision respecting child custody was a free decision, voluntarily made.<sup>90</sup> The circumstances in which Lena relinquished custody of her child violated both her and her child's right to respect for family life. The manipulation of an individual in distress to acquire consent is a profound violation of respect for human dignity.

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<sup>90</sup> See e.g. *A.S. v. Hungary*, CEDAW/C/36/D/4/2004, at par.11.2 and 11.3.

## Access to Medical Care for Pregnant Drug Users: Case Study of Ethics Issues

Karen Maschke, The Hastings Center

### **First part of case:**

*Late in her pregnancy, Lena visits the public hospital for prenatal care. Nurse Tarasov is warm and attentive until she sees the track marks on Lena's arms. With her back to Lena, she says: "It makes me sick, women like you. These poor babies . . . oh never mind. You never listen. You can't. You're high all the time. We should just turn you over to the police."*

### **Discussion questions on first part of case:**

1. How can health care providers meet their obligations to patients, and even express compassion for them, when they disapprove of patients' behaviors or may have had difficult experiences with marginalized and stigmatized populations like injection drug users (IDUs)?
2. Should Nurse Tarasov tell the police that she is treating a pregnant IDU?

### **Ethics commentary on first part of case:**

Compassion and respect for patients are among the core values of medicine. When people seek help from health care providers, they are vulnerable in the face of illness and possible death. As the World Medical Association (WMA) notes:

"People come to physicians for help with their most pressing needs – relief from pain and suffering and restoration of health and well-being. They allow physicians to see, touch, and manipulate every part of their bodies, even the most intimate. They do this because they trust their physicians to act in their best interests"<sup>i</sup>

Because people entrust their health and wellbeing to skilled professionals – who more often than not are strangers – it is not unreasonable to expect health care providers to treat all patients with compassion and respect. Yet it is not unusual for health care providers to have contact with patients they do not like, who are difficult to deal with, or who might remind them of their own difficult experiences. In the case of drug users, the negative attitudes of health care providers could be the result of mistaken beliefs that people can easily control their craving for drugs or that they have access to drug treatment but refuse to seek help (see below). Or maybe Nurse Tarasov has difficulty being compassionate because she has struggled in her personal life with a friend's or a relative's drug addiction. Moreover, health care providers may be more likely than others to be critical of women's behaviors during pregnancy because they have seen first hand the impact this behavior can have on fetuses and babies.<sup>ii</sup>

Nonetheless, health care providers are expected to respond professionally to people whose behavior they disapprove of and to align health care delivery with patients' needs. Although it may be especially difficult for health care providers to modify their negative attitudes about

pregnant drug users, medical ethics and medical professionalism require health care providers to treat patients with compassion and not to discriminate against them on the basis of personal attitudes, beliefs, or prejudices.

Another core principle of medical ethics is the duty to keep a patient's health information confidential. Reporting drug users to law enforcement officials would be a breach of confidentiality. However, in some jurisdictions health care providers are required by law to report drug users to law enforcement officials, particularly if the drug users are pregnant women. When reporting laws are in place, they raise the problem of "dual loyalty", i.e., a conflict between the ethical obligation to act as advocates for patients and the obligation to comply with legal mandates, even when such mandates conflict with the norms of medical ethics and contribute to human rights abuses. These mandates are especially problematic when legal officials try to criminalize prenatal drug use, since many health professionals contend that drug use during pregnancy should be treated as a public health matter rather than an issue handled by the criminal justice system.<sup>iii</sup>

Even though medical ethics requires health care providers to "put the patient first," it may be difficult for individual health care providers to manage dual loyalty conflicts, especially if they do not have support from colleagues, from the institution where they work, or from relevant professional organizations.<sup>iv</sup> And there may be situations in which acting in the best interests of patients puts health care providers – and their family – at risk of harm if they do not comply with institutional, governmental, or legal mandates.<sup>v</sup> Thus, there may be instances when it is unfair to criticize health professionals for violating ethical norms when they choose their own safety or the safety of their family over the interests of their patients.

### **Second part of case:**

*When Dr. Ivanov visits Lena, he is kinder than Nurse Tarasov. He tells her the pregnancy risks of drug use, and that children are rarely born healthy. Holding Lena's hands, he says: "You don't want to hurt your child. You're still young and can change your life. Please get treatment." Lena explains the limitations of the government center, and asks about treatment at the hospital. Dr. Ivanov answers, "Some of my colleagues may use substitution treatment with methadone, but I don't. Get clean for your baby. It is not enough to switch from one drug to another."*

### **Discussion questions on second part of case:**

1. Are there some situations in which health care providers might think that giving patients misleading information is in the patients' best interests?
2. If Dr. Ivanov does not believe in using methadone as "substitution treatment," should he have given Lena the opportunity to talk to his colleagues who do use methadone maintenance therapy?

### **Ethics commentary on second part of case:**

Health care providers are expected to maintain the highest standards of professional conduct and to provide competent medical services to their patients.<sup>vi</sup> This means they must continue to

enhance their knowledge base and skill sets throughout their career as health professionals. Making treatment decisions based on inaccurate or misleading information about patients' medical conditions or about their activities like drug use that have health implications, might result in "doing harm" rather than "doing good." For instance, Dr. Ivanov's claim that children born to women who used drugs during their pregnancy "are rarely born healthy" may be exaggerated. Only some children who were exposed to drugs in utero experience physical and mental health implications at birth and over time, and even then the nature and extent of those implications varies. The health of children who were exposed to drugs in utero is mediated by many factors, including but not limited to the frequency, amount, and time of the pregnant woman's drug use; whether the drugs were used in combination with other substances that may affect the fetus's health (e.g., tobacco and alcohol); and the pregnant woman's overall health status during her pregnancy.<sup>vii</sup>

It is possible that Dr. Ivanov intentionally exaggerated the harms of drug use during pregnancy as a scare tactic to get Lena to stop using drugs. While this approach may have intuitive appeal, it is not evident that giving patients misleading information with the goal of getting them to alter their behavior is appropriate or helps modify behavior. Indeed, the ethical principle of respect for persons—and the respect for autonomy that flows from it—require physicians and other health professionals to be honest with all their patients all of the time, even if they think that a little "white lie" might motivate the patient to change her unhealthy behavior. Moreover, drug addiction is very difficult to overcome even when people receive adequate, sustained drug treatment services. Thus, trying to scare Lena into giving up her drug habit is likely to be ineffective; referring her to a drug treatment program – or at least to a mental health counselor – would have been a more appropriate medical treatment response.

Dr. Ivanov may also be misinformed about the safety and effectiveness of methadone as substitution treatment, including during pregnancy. Studies about methadone as substitution treatment for heroin addiction show that it is effective in managing heroin dependence, it retains patients in treatment, and it reduces heroin use.<sup>viii</sup> For instance, methadone maintenance treatment is the standard of care in the U.S. for opioid dependence in pregnant women. Such treatment has been found to result "in improved prenatal care, increased fetal growth, reduced fetal mortality, reduced foster care placement, and decreased risk of HIV infection, preeclampsia, and neonatal withdrawal."<sup>ix</sup>

Dr. Ivanov was honest with Lena about his views regarding the use of methadone as substitution treatment. However, while physicians often disagree about what treatments to use, their treatment decisions should be based on the best available medical evidence, not personal biases. If Dr Ivanov's knowledge is out of date, he is obliged, as discussed above, to seek out the latest research or treatment guidelines on a particular question. If his reluctance to use methadone reflects his personal view of its safety and effectiveness, he should inform his patients about treatment options and give them the opportunity to talk to physicians whose treatment approaches differ from his own.

### **Third part of case:**

*Fearful of being reported to the police, Lena avoids the hospital for the remainder of her pregnancy. Her drug use increases. “Using keeps my stress down. It’s a way to escape, to avoid thinking about what I will do with a child.” She continues to inject until the week of labour. In the maternity ward, Lena is surrounded by other women and their families. She is visited by Dr. Ivanov. “I am disappointed you are still using. Consider the well-being of your child. Give it to a good family. How can you care for a child when you cannot take care of yourself?” Lena sees the disapproval of those around her. Rather than the support and encouragement other mothers-to-be receive during labour, Lena is neglected by the nursing staff. She is terrified. Peter is absent. “Perhaps I will call my parents. But I need more time.”*

### **Discussion questions on third part of case:**

1. How can health care providers meet their obligations to patients, and even express compassion for them, when they disapprove of patients’ behaviors, especially if their behaviors may have harmful effects on the developing fetus?
2. Is it appropriate for health care providers to ignore patients because they disapprove of the patients’ behaviors?
3. Is it appropriate for health care providers to tell patients what they should do about reproductive and family matters?

### **Ethics commentary on third part of case:**

Lena had limited treatment options to deal with her drug addiction, and there is no evidence that Dr. Ivanov made any attempt to help her get treatment or counseling. His disapproval of her continued drug use is uncompassionate and harsh and fails to prioritize her health needs over his personal views. Moreover, he seems to care only about the wellbeing of the fetus, rather than the wellbeing of the fetus *and* Lena. The tendency to view the fetus as a “patient” that is physiologically enmeshed in the “environment” of the body of an autonomous agent may obscure the fact that the pregnant woman is a patient in her own right, not just an environment in which the fetus develops.<sup>x</sup> Advances over the past 40 years in neonatal, obstetrical, and pediatric medicine – along with legal mandates to protect the fetus – have resulted in increased tension between “maternal interests, fetal interests, and the interests of the child-to-be.”<sup>xi</sup> This tension is exacerbated when pregnant women use drugs. Yet as Oberman and others have argued, what is often referred to as “maternal-fetal” conflicts may actually reflect maternal-doctor conflicts, i.e., conflicts that arise when doctors invest the fetus with interests and rights that directly coincide with their own personal preferences.<sup>xii</sup>

Nonetheless, health care providers cannot ignore the health needs of the fetus. Ignoring pregnant drug users while they are in labour means that the fetus may not be receiving optimal monitoring. Moreover, it is possible that Lena has medical problems resulting from her drug use, yet there is no evidence that either Dr. Ivanov or Nurse Tarasov are interested in identifying or attending to her medical needs that are separate from those related to her pregnancy.<sup>xiii</sup>

The principle of autonomy, and the related notion of self-determination, requires that individuals be given the opportunity to make decisions about reproductive and family matters without pressure or coercion from others. Thus, when health care providers tell a woman that she should

give her baby up for adoption without giving her the opportunity to discuss and consider her options, they are not promoting and facilitating a patient's autonomous decision-making. Health care providers should give patients all the information they need, or refer them to other appropriate professionals, so the patients can make informed, autonomous decisions about their health and matters like adoption that will have a significant impact on their lives.<sup>xiv</sup>

#### **Fourth part of case:**

*Lena gives birth to a boy. In recovery, she suffers from drug withdrawal, experiencing significant pain. Lena does not ask to see her baby. She cannot focus beyond her own physical needs. She is desperate to leave the hospital. Nurse Tarasov asks Lena to sign a document: "This is for the adoption. Sign it and we can discharge you." She signs. A few months later, Lena reflects on the experience: "What choice did I have? Give him up or lose him anyway. They're right. I'm no mother."*

#### **Discussion questions on fourth part of case:**

1. How can health care providers respond to the emotional and medical needs of patients like Lena, who appears to be uninterested in her newborn, without being judgmental or coercive?
2. Should the hospital have tried to help Lena obtain post-partum counseling and treatment for her drug withdrawal?
3. Is it in the best interests of children of drug addicts to be placed for adoption?

#### **Ethics commentary on fourth part of case:**

There is no evidence that Dr. Ivanov or Nurse Tarasov considered the possibility that Lena's lack of desire to see her newborn may be due to her physical and mental state resulting from drug withdrawal, including post-partum depression. Further, it is possible that Lena's decision-making is impaired as she goes through drug-withdrawal, particularly since she is not receiving any medical treatment for the symptoms and effects of withdrawal. Drug addiction is a dependence disorder, and drug withdrawal can involve physical and emotional symptoms. Although drug withdrawal symptoms are typically not life-threatening, they can be painful and lead to serious consequences such as drug relapse and thoughts of suicide. It appears that no attempt was made to investigate whether Lena needed medical care for the symptoms of drug withdrawal or post-partum psychological and drug counseling. Yet there is evidence that substance use disorders may include the "co-occurrence of a plethora of psychiatric conditions which may be exacerbated by the psychological and physiological stresses of pregnancy, a period widely considered a time of increased sensitivity to psychiatric disorders."<sup>xv</sup>

Since it is likely that health care providers will at times be treating pregnant drug users, hospitals and clinics should have education programs as well as policies and procedures in place that support ethical practices regarding drug addiction and pregnancy, including providing access to referral services for drug treatment, mental health services, and family support.<sup>xvi</sup>

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