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Kinga Bączyk-Rozwadowska
Uniwersytet Mikołaja Kopernika, Toruń
kingakarolina@poczta.onet.pl
ORCID: https://orcid.org/0000-0001-6545-2671

Designer disability – is it possible? A case study

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1. Personal freedom and reproductive autonomy

Patient's autonomy is the most important concept in the mutual relation between a patient and a doctor (a health care institution). Contrary to the previous, paternalist approach, the new model of health care assumes that the patient is the subject of medical treatment and as such, he or she may decide about all the matters that concern his (her) psychical and physical integrity.[1] The old principle *voluntas aegroti suprema lex esto*, which each doctor and hospital is obliged to observe, seems to have priority over the rule to respect the welfare of the patient and to preserve, first of all, human health and life (*salus aegroti suprema lex esto*).

The concept of patient's autonomy and his (her) personal freedom of choice is present in all fields of medical activity, including so called reproductive medicine. As the courts and doctrine say,

[1] See K. Bączyk-Rozwadowska, *Prawo pacjenta do informacji w świetle uregulowań polskiego prawa medycznego*, „Studia Iuridica Toruniensia" 2012, nr 1, s. 59 and M. Nesterowicz, *Prawo medyczne*, wyd. XII, Toruń 2019, s. 60 i n.

each individual may decide freely and in un unconstrained way when, with whom and in what manner (including medically assisted reproduction technologies, hereinafter – MAP) conceive and give birth to a child (*right to procreate, reproductive autonomy*).[2] Right to procreate comprises the choice of all available methods of assisted procreation (intrauterine insemination – IUI, *in vitro* fertilization – IVF, etc.) as well as other techniques (necessary procedures) that supplement MAP (cryopreservation of genetic material, preimplantation genetic diagnosis – PGD, etc.).

The essence and meaning of the concept of procreative autonomy is the same in all jurisdictions of the world; the difference concerns its origins. In *common law* countries (like United States, Great Britain) the reproductive freedom is derived from the constitutional right to protect freedom and intimacy. In the precedent judgement *Eisenstadt vs. Baird* of 1972 (405 U.S. 438), the US Supreme Court adjudicated that the right to privacy includes the individual's freedom from undue interference in matters relating to the conception of a child.[3] Subsequently, the Supreme Court of California in *Johnson vs. Calvert* (5 Cal. 4th 84; 1993)[4] and Ohio Court of Appeal in *Cameron vs. Board of Education of Hillsboro* (795 F. Supp. 228, 237; 1991)[5] agreed that woman's right to become pregnant by means of medically assisted procedures results from her constitutional right to private life, which also includes the control of procreation. Instead, in civil law jurisdictions procreative autonomy is an important part (element) of private and family life, protected by Article 8 of the European Convention of Human Rights (ECHR). This is what has expressed the European Court of Human Rights in many of its judgements, for example *Evans vs. United*

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[2] J. Herring, *Medical law and ethics*, wyd. IV, Oxford 2012, s. 353.

[3] https://supreme.justia.com/cases/federal/us/405/438/ (access: 2.12. 2019 r.); see also C. Luckey, *Commercial surrogacy: is regulation necessary to manage the industry*, „Wisconsin Journal of Law, Gender and Society" 2011, No. 2, Vol. 26, s. 216.

[4] https://law.justia.com/cases/california/supreme-court/4th/5/84.html (access: 2.12.2019 r.)

[5] https://law.justia.com/cases/federal/district-courts/FSupp/795/228/ 2596441/ (access: 3.01.2020 r.)

Kingdom of 10 April 2007 (application nr 6339/05)[6] and *S.H. and others vs. Austria* of 3 November 2011 (application nr 57813/00).[7]

However, autonomy of a patient and his personal freedom is not absolute. It may be exercised without constraints within the limits fixed by law and judiciary. The limitations are necessary to protect *bonos mores*, public order and the interests of individuals as well as the society as a whole. In the sphere of assisted reproduction, certain prohibitions (like a ban on sex selection and the outward appearance of the future offspring) are set up by the law – statutes concerning MAP technologies, adopted in most jurisdiction of the world (including Polish Law on Infertility Treatment[8]). Consequently, any medical activity aiming to fulfil the couple's wish to conceive "artificially" is governed by the fundamental principle of the welfare of the child to be born via MAP (IUI, IVF). In other words, economic and non-material interests of the offspring should be given priority to the wishes of future parents, willing to exercise their right to procreate via MAP. In particular, certain acts or omissions of the couple deserving to initiate so called parental project are to be in accordance with the well-being of the future child.[9]

2. Facts of the case

A couple (spouses), suffering both from congenital deafness, want to initiate a parental project to conceive a child. Unfortunately the woman's fallopian tubes are blocked and the only possibility

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[6] https://hudoc.echr.coe.int/eng (access: 31.12.2019 r.)

[7] https://hudoc.echr.coe.int/eng (access: 2.01.2020 r.); see also B. Oniszkis, *Wolność prokreacyjna – zarys problematyki*, „Prawo i Medycyna" 2013, nr 1–2, s. 161.

[8] Law on 25 June 2015, Dz.U. z 2015 r. poz. 1087.

[9] K. Bączyk-Rozwadowska, *Prokreacja medycznie wspomagana. Studium z dziedziny prawa*, Toruń 2018, s. 55–56 and J. Baudouin, C. Labrusse-Riou, *Produire de l'homme. De quel droit? Étude juridique et éthique des procréations artificielles*, Paris 1987, s. 111. Compare A. Grabinski, J. Haberko, *Dobro dziecka a stosowanie procedur wspomaganej medycznie prokreacji w prawie francuskim i prawie polskim*, „Studia Prawnicze" 2011, z. 1, s. 40 i n.

to achieve pregnancy is to undergo sophisticated procedures of medically assisted procreation – homologous in vitro fertilization (hereinafter – IVF) with the semen of her husband. The method consists in extracting eggs from woman surgically (after treating her with high doses of female hormones to induce hyperovulation), retrieving a sperm sample from a man (*per masturbationem*), and then combining an egg and sperm in a laboratory dish. The embryo, kept for few days *in vitro*, is then transferred to the woman's uterus for implantation. If implanted successfully, the pregnancy starts.[10]

The infertility (MAP) clinic the couple contacts with offers IVF procedure combined with PDG (*preimplantation genetic diagnosis*) – a sophisticated technique performed by embryologist, which enables careful examining of created embryos and choosing the healthy ones for a subsequent transfer. The chances to conceive naturally a child with the same hereditary disease both parents suffer with are indeed relatively high (almost 80%). However, if only defective ("deaf") embryos, chosen by means of PGD are used in IVF procedures, the possibility to have a deaf child is close to certainty. The future parents decide then to undergo homologous IVF combined with PGD, performed to choose defective embryos. The argument they rise to justify their choice is that the offspring, born with the same hereditary defect they suffer themselves, would better assimilate with the family and the society of the deaf people. The question is whether the infertility clinic should proceed with PGD to screen out defective embryos instead of healthy ones (as the ordinary procedure would be) and use them for implantation.

3. Commentary

The problem of creating a child of parents' choice (*designer baby*) by means of IVF combined with PGD is not simple both from moral as well as legal point of view.

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[10] For more information see K. Bączyk-Rozwadowska, *Prokreacja*, s. 167 i n. and J. Badouin, C. Labrusse-Riou, op.cit., s. 66.

Preimplantation genetic diagnosis, used for the first time in the late 90. of the XX century, has been invented to perform screening of embryos created *in vitro* and choose healthy ones for the subsequent transfer to the uterus of a prospective mother.[11] Thanks to this sophisticated method, which requires special knowledge and professional equipment, parents-to-be, who suffer from serious hereditary disease, other severe genetic abnormalities (for example, *Tay-Sachs* syndrome, *cystic fibrosis*, *Duchenne's muscular dystrophy*) or are carriers of defective gens, have the chance to conceive a healthy offspring.[12] What is more, the child may be genetically related to them and there is no need to recourse to heterologous techniques of assisted procreation which require the use of donated gametes or embryos.[13] However, PGD may be also performed in an inappropriate way to select embryos of certain features and quality – sex, phenotype, colour of skin, hair, eyes, etc. Consequently, before the transfer of embryos the parents are allowed to make their choice and decide about the appearance and qualities of their baby, according to their own individual wishes (*designer baby*, *custom designing child*). PGD enables as well, as the facts of the case show, the deliberate creation of a disabled (handicapped) child when parents suffering themselves form certain disability, disease or genetic abnormalities wish so (*designer disability*)[14].

There are only few arguments to support the view that parents' desire should be accepted by a MAP clinic. Proponents of the con-

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[11] More about the history of PGD E. Jackson, *Medical law. Text, cases, materials*, Oxford 2006, s. 840. See also O. Nawrot, *Diagnostyka preimplantacyjna w prawodawstwie Rady Europy*, „Zeszyty Prawnicze Biura Analiz Sejmowych" 2009, nr 2, s. 43 and J. Kapelańska-Pręgowska, *Preimplantacyjna diagnoza molekularna w międzynarodowych standardach wiążących i zalecanych*, „Prawo i Medycyna" 2009, nr 2, s. 86.

[12] See J. Bal, W. Wiszniewski, J. Wiszniewska, *Diagnostyka molekularna*, w: *Biologia molekularna w medycynie. Elementy genetyki klinicznej*, red. J. Bal, Warszawa 2006.

[13] Compare M. Brazier, E. Cave, *Medicine, patients and the law*, wyd. V, London 2011, s. 367 and E. Jackson, op.cit., s. 840.

[14] For more information see K. Bączyk-Rozwadowska, *Aktualne problemy diagnostyki preimplantacyjnej w kontekście dążeń rodziców do realizacji projektu rodzicielskiego*, „Białostockie Studia Prawnicze" 2017, nr 2, s. 11 i n.

cept of designer disability argue that all individuals are entitled to procreative autonomy and have the fundamental human right to procreate in any manner they want. The essence of this right is, as it was already mentioned, that each person may freely decide when, in what manner (naturally or by means of assisted reproduction) and how many times conceive and give birth to a child or children. Furthermore, there is no difference between fulfilling procreative plans via IVF combined with PGD and realizing so called natural parental eugenics. As the proponents of designer disability practice explain, a woman may choose a sexual partner (a future father in natural conception) with particular qualities, including certain defect, like deafness, dwarfism, congenital blindness, etc. The other argument is that planning conception of a disabled child with the use of IVF/PGD procedures may be seen as an objection against discrimination of handicapped people and individuals with certain forms of disability (e.g. *Down's syndrome*). The infertility clinic that "rejects" defective embryos due to their improper condition or unsuitability for implantation "sends a message" to the society that a particular forms of disability are not accepted and should be eliminated at a pre-conception stage.[15]

More arguments may be found against deliberate creation of a disabled child. Firstly, such practice constitutes a new kind of positive eugenics, since it is (as embryo selection in general) an excessive and unjustified interference in the sphere of reproduction (*playing God*) and constitutes a practice of positive eugenics.[16] MAP techniques should be as close as possible to natural procreation (*procreatio artificialis naturam imitatur*), where no one can decide on the child's sex and characteristics. Secondly, designer baby practice seems to be a highly undesirable step towards "commodification" of assisted reproduction technologies. The future parents who decide to give birth to a child of a certain health condition behave – as

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[15] M. Brazier, E. Cave, op.cit., s. 369–370. See also J. Savulescu, *Deaf lesbians, "designer disability" and the future of medicine*, "British Medical Journal" 2002, Vol. 325, s. 771.

[16] R. Deech, *Playing God: who should regulate embryo research?*, „Brooklyn Journal of International Law" 2006–2007, No. 2, Vol. 32, s. 321.

it is emphasized – more like consumers who choose a product on the market.[17] Thirdly, the practice of PGD combined with the selection of defective (deaf but also blind or dwarf) embryos seems to be contrary to the fundamental obligation of the State to protect a child and his (her) well-being as far as material and non-pecuniary interests (like health and life) are concerned. As it was previously mentioned, the guiding principle of a child's welfare should be taken into consideration each time when assisted conception technologies (including PGD) are to be performed. The intentional creation of a deaf, blind or dwarf child as well as an offspring affected with any other more or less severe disability never serves his best. On the contrary, such a parental choice always violates the fundamental principle of child's welfare and deserves criticism. As doctrine say, designer disability practice may (and should) be perceived rather like as manifestation of an egoistic parental choice and cannot be justified on any grounds, let alone the assimilation in a family of the disabled.[18] Fourthly, an illness is always (and without any exception) an undesired and unwelcomed condition, especially if it affects a child. The aforementioned argument (risen by the couple) that the child will be better assimilated within his family, while he or she is deaf like them, may be overthrown very easily. The deliberate implantation of defective embryos does not take into account the interests of a future child, who later in his life, after reaching the age of majority, will probably leave the family to live on his own, start education and subsequently – work. His or her perspectives are *a priori* limited in both the professional sphere (studies, occupation) and personal one as well (risk of transmission the "planned" defects to his or her offspring).

As far as regulations are concerned, the majority of world's domestic laws on medically assisted procreation do not deal directly

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[17] D. King, *Preimplantation genetic diagnosis and the "new" eugenics*, "Journal of Medical Ethics" 1999, Vol. 25, s. 176. Compare J. Lipski, *Opinia prawna na temat projektu ustawy o zmianie ustawy o pobieraniu, przechowywaniu i przeszczepianiu komórek, tkanek i narządów*, "Zeszyty Prawnicze Biura Analiz Sejmowych" 2011, nr 4, vol. 32, s. 145 (about embryo selection in general).

[18] Compare K. Bączyk-Rozwadowska *Prokreacja*, s. 357.

with the controversial designer baby practice. Neither does the main international documents concerning bioethics: *The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine* of 1997 (hereinafter – *Oviedo Convention*) and *The Principles of Medically Assisted Procreation of the Ad Hoc Committee of Experts on Progress in the Biomedical Sciences* of 1989 (hereinafter – *CAHBI Recommendation*).

However, the prohibition of creating a child according to parents' wishes may be derived from the reading of PGD conditions set by statutes. According to most countries' laws, preimplantation genetic diagnosis may be legally performed only to avoid transmission to a child a severe genetic disease or other serious disability that one or both spouses or partners are affected by or are carriers thereof.[19]

Furthermore, international documents (e.g. *Oviedo Convention*, Article 14) as well as MAP statues of most countries *expressis verbis* prohibit the selection of sex and other features of the future child (Article 26 sec. 2 of Polish Law on Infertility Treatment, Article 1455 of the Greek Civil Code, etc.). However, one important exception to this prohibition exists. Namely, it is possible to choose, by means of PGD, embryos of a certain sex when the future child is at risk of inheriting a sex-linked disease (like *Turner's syndrome*, characteristic for females and haemophilia, suffered only by males). So if a child health or life is in danger, the doctor (clinic) may use the IVF/PGD procedure and to transfer to the mother's uterus only embryos of a sex which does not inherit a certain type of disease.[20]

In view of such strict regulation of PGD, which limits performing the preimplantation diagnosis only to truly exceptional situations,

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[19] See for example Article 2–4 the Swedish Genetic Integrity Act of 18 May 2006, Article 1455 of the Greek Civil Code, amended by the Act on Assisted Reproduction Technologies of 27 January 2005 and § 2–14 of the Norwegian Law on the Application of Biotechnology in Medicine of 5 December 2003. The alike conditions of PGD have been set up in Article 26 of the Polish Law on Infertility Treatment. More on this topic J. Haberko, *Ustawa o leczeniu niepłodności. Komentarz*, Warszawa 2016, s. 164–169. Compare K. Bączyk-Rozwadowska, *Prokreacja*, s. 345–346.

[20] Ibidem.

the practices of custom designing child are indirectly banned and cannot be legally exercised by any infertility clinic.

However, in practice the rules governing the transfer of *in vitro* embryos may sometimes raise serious doubts and encourage parents to conceive a defective child. In particular, the English *Human Fertilization and Embriology Act of 1990*, amended in 2008 (hereinafter: *HFEA 2008*) does not explicitly ban the transfer of defective embryos to woman's uterus. According to the Article 13 section 10 of *HFEA 2008*, healthy embryos are given priority (over the defective ones – K.B.R.) while implantation is to be completed. Therefore, in case only healthy embryos have been successfully created in IVF procedures, the couple may refuse the transfer, continue with another *in vitro* cycle and wait until only embryos with certain disability are available for implantation. However, in such a situation a question arises whether a doctor may (or even should) refuse performing transfer on the grounds that it is contrary to the principle of the child's welfare. According to the provisions of *HFEA 2008*, before performing any procedure of infertility treatment, each MAP clinic is obliged to assess whether a child's interests are not to be infringed in case of exercising UIU or IFV (Article 13 sec. 5). In particular, thorough and careful analysis of the circumstances of the case is necessary to verify, on one hand, whether certain disability is so serious that it justifies a refusal of transfer and, on the other, what the probable consequences of being born with a certain defect are.

What is more, in few countries (China and USA since 1995), in spite of prohibitions set by law or judiciary, some MAP clinics offer couples, for a relatively high fee, the possibility to select exclusively the sex of the future child. In the USA for example, sex selection is carried out by inseminating a woman with selected sperm (male – X or female – Y). Approximately 2.000 women or couples use this option each year, mostly for social reasons, like family balancing.[21]

[21] http://www.givf.com/familybalancing/ (access: 2.01.2020 r.)

4. Conclusions

Deliberate creation of a child with certain defects, possible by means of PGD, raises so many moral, ethical and legal objections that it shouldn't be performed at all, even if it is not explicitly forbidden by law. This practice is even more controversial than the concept of designer baby, consisting of the choice of sex and phenotypical virtues of the future offspring.

The disabled parents, who intentionally "design" their offspring to be born with the same defects they suffer themselves, seem to fulfill mere egoistic needs and wishes. Therefore, their desire to be parents is not worth protection; the concept of reproductive autonomy may not justify any parental project which interferes with the fundamental principle of the child's welfare. In other words, the well being of a child serves as a limit of personal choices including autonomy of procreation. What is more, intentional creation of a defective child interferes the other binding rules of family law and international standards of child protection, including the United Nations Convention on the Rights of the Child of 20 November 1989.[22] Article 3 sec. 2 of the Convention warrants the State to take steps adequate steps to ensure the child's well-being to the extent that it is necessary for his or her good.

SUMMARY

Designer disability – is it possible? A case study

Preimplantation genetic diagnosis (PGD) precedes the performance of assisted reproductive technologies when a couple is affected by a serious hereditary (genetic) disease and it is necessary to screen out embryos that carry certain abnormalities. However, the procedure may be applied in an unauthorized manner if parents-to-be intentionally create a child with the same particular defect (deafness, blindness, dwarfism, etc.) they

[22] Dz.U. z 1991 r. Nr 120, poz. 526.

suffer themselves. This practice is even more controversial than the concept of designer baby, consisting of the choice of sex and the phenotypical virtues of the future offspring. Procreative autonomy, including free and unconstrained decision to conceive and give birth to a child, doesn't seem to justify such activities.

Key words: medically assisted procreation; in vitro fertilization; parental project; designer baby; disability; embryo screening, congenital disease; embryo transfer; preimplantation genetic diagnosis; sex selection; welfare of the child.

STRESZCZENIE

Czy możliwe jest zamierzone powołanie do życia dziecka z wadą? Studium przypadku

Procedury preimplantacyjnej diagnostyki genetycznej (PGD) znajdują zastosowanie podczas przeprowadzania zabiegów medycznie wspomaganej prokreacji w sytuacjach, w których przyszli rodzice bądź jedno z nich cierpi na poważną chorobę genetyczną lub jest jej nosicielem i istnieje ryzyko transmisji wad na przyszłe potomstwo. Będący istotą PGD wybór embrionów niewadliwych, wolnych od obciążeń, umożliwia parze poczęcie „genetycznie" własnego, zdrowego dziecka. Procedura ta może być jednak zastosowana w sposób nieuprawniony, jeśli przyszli rodzice dążą do powołania do życia potomstwa dotkniętego wadą (np. wrodzoną głuchotą, ślepotą czy karłowatością). Działanie to wzbudza dalej idące kontrowersje niż praktyka polegająca na wyborze płci i innych cech fenotypowych przyszłego dziecka. Nie uzasadnia go w szczególności zasada autonomii prokreacyjnej wyrażająca się w swobodzie podejmowania decyzji o tym, czy, kiedy i w jaki sposób (naturalny czy medycznie wspomagany) wydać na świat potomstwo.

Słowa kluczowe: prokreacja medycznie wspomagana; zapłodnienie pozaustrojowe – *in vitro*; projekt rodzicielski; dziecko o „zaprojektowanych" cechach; niepełnosprawność; selekcja embrionów; choroba dziedziczna; transfer zarodka; genetyczna diagnostyka preimplantacyjna; wybór płci; zasada dobra dziecka

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