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Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children

Reply to Recommendation[1]: Recommendation 2156 (2019)
Committee of Ministers

1. The Committee of Ministers has carefully examined Parliamentary Assembly Recommendation 2156 (2019) entitled "Anonymous donation of sperm and oocytes: balancing the rights of parents, donors and children" which it forwarded to the Committee on Bioethics (DH-BIO), the Ad hoc Committee for the Rights of the Child (CAHENF), to the European Committee on Transplantation (CD-P-TO) and to the European Committee on Legal Co-operation (CDCJ), for information and possible comments.

2. In its recommendation, the Parliamentary Assembly "recommends that the Committee of Ministers make recommendations to member States in order to improve the protection of the rights of all the parties concerned, while focusing on the rights of the donor conceived person, who is in the most vulnerable position and for whom the stakes appear to be higher".

3. The Committee of Ministers acknowledges the complexities and interdisciplinary nature of this serious issue. It recognises the value of examining how to best safeguard and promote the rights of donor conceived children, taking into account the evolving legislation and diverse practices in member States. It also agrees with the Assembly that the right of donor-conceived persons to know their origins "is not absolute and must thus be balanced with the interests of the other parties involved in sperm and oocyte donation: principally those of the donor(s) and the legal parent(s), but also those of clinics and service-providers, as well as the interests of society and the obligations of the State".

4. Like the Assembly, the Committee of Ministers notes that there has been movement towards recognition of a right to know one's origins in international human rights law. The United Nations Committee on the Rights of the Child (CRC) and the European Court of Human Rights (ECHR) have both examined the right to access information concerning genetic origins. In several Concluding Observations, the CRC has made specific statements regarding the application of Articles 7 and 8 of the UNCRC to assisted reproduction, highlighting the importance of recognising the right of donor-conceived children to access information about their genetic origins. The Committee has also expressed concern about the fact that children born in the context of a medically assisted fertilisation do not have the right to know the identity of their biological parents. The ECHR's judgments include guidance with respect to the importance of balancing all rights, without giving absolute priority to any of them. However, an additional difficulty is to ascertain the best interest of the child in a given situation, and once this established, how to make sure that this is given primary consideration, while at the same time considering the rights and interests of all other relevant stakeholders.

5. Bearing in mind that the current legislation and practices of Council of Europe member States in the field of medically assisted procreation vary significantly, as observed by the Parliamentary Assembly, the Committee of Ministers considers that any proposal for regulation in this particularly sensitive area should be based on a careful consideration of the implications of anonymous gamete donation from the ethical, legal and societal perspective, give due consideration to the consequences of changing national practices and should not be legally binding. These consequences may include the potential impact on the supply and

1. Adopted at the 1356th meeting of the Ministers' Deputies (9 October 2019).

availability of donated gametes and embryos, the destiny of the cryopreserved gametes and embryos donated before potential legislative changes and the impact this life-altering information might have not only on donors, but also on their families and children.

6. The Committee of Ministers would also draw the attention of the Assembly to the relevant concerns and comments of the committees consulted on this issue, particularly with regard to the principles outlined in paragraph 7 of the Recommendation, as they appear in the appendix to this reply.

7. Finally, given the importance of this issue, and the evolution of legislation and practices of member States in this field, the Committee of Ministers invites the CDCJ, in consultation with the DH-BIO, the CD-P-TO and the CAHENF, to consider, in its future activities, the feasibility and desirability of preparing a draft recommendation or other non-binding instrument to assist member States in protecting the rights of donor-conceived persons to know their origins, whilst ensuring a balance with the interests and rights of other parties involved in sperm and oocyte donation, and of the interests of society and obligations of the State.

Appendix to reply (containing extracts of committees' comments)

Comments by the European Committee (Partial Agreement) on Organ Transplantation (CD-P-TO)

[…]

The CD-P-TO believes that there is a need to foster a broad and informed public debate on the implications of anonymous gamete donation from the medical, societal and ethical perspectives and, most importantly, on the consequences of changing national practices. These consequences include the potential impact on the supply and availability of donated gametes and embryos, the destiny of the cryopreserved gametes and embryos donated before potential legislative changes and the impact this life-altering information might have not only on donors, but also on their families and children.

As the Assembly rightly notes, "the current legislation and practices of Council of Europe member States in the field of medically assisted procreation vary significantly". The CD-P-TO highlights the importance of improving practices to ensure the highest standards concerning protection of donors, beneficiaries of medically assisted reproduction treatment and their offspring. In this sense, there is much room for improvement, in particular with regard to compensation of donors, which should not act as an inducement to donation; the protection of donors through long-term medical follow-up; and the establishment of national, or even international, gamete donor registries. These registries should contain information such as at which clinic(s) any given donor has donated and how many children have been conceived by means of their donation(s) and would allow tracing of their offspring through the clinic(s), if and when needed. Thus, such registries would help fulfil the obligation of states, clinics and service providers, including the need for transparency, traceability and an upper limit on the number of possible donations by the same donor. On the other hand, the CD-P-TO calls for caution regarding the recommendation to set up national donor-conceived person registries, where the registered individuals would not have agreed to be included, and which could interfere with their rights to private and family life and data protection. Furthermore, these latter registries would be unnecessary in the presence of the above-mentioned gamete donor registries.

The CD-P-TO expresses concerns about the recommendation that children conceived with the aid of donated reproductive cells should be informed, ideally by the State, about the circumstances of their birth, as this would constitute an undue intromission of the State into their private and family life. Furthermore, it is questionable whether personal data of possible (half-)siblings and the possibility to contact them should be given to donor-conceived persons since a rule requiring the disclosure of their personal data would be an encroachment on their rights to privacy.

The CD-P-TO emphasises that in-depth impact assessments should be carried out on any initiatives expected to have significant economic, social or health-related impacts, in particular, legislative proposals. In this particular case, due to the highly sensitive nature of this topic, such an impact assessment, examining whether there is a need for action and analysing the possible impacts of available solutions, should be carried out before the Committee of Ministers finalises any proposal for a new law. This impact assessment, which should pay particular attention to quality and safety aspects related to the donation and availability of donated gametes and embryos, would provide evidence to adequately inform and support the decision-making process.

The CD-P-TO is committed to continue addressing human rights and medical issues raised by assisted reproductive technologies and recalls in this respect that it regularly updates its "Guide to the Quality and Safety of Tissues and Cells for Human Application". It also monitors practices in Europe, examines questions of interest and contributes to raising public awareness on the donation and use of substances of human origin. As a result, it has recently published the booklet "Donation of oocytes, a guide for women to support informed decisions".

Comments by the Committee on Bioethics (DH-BIO)

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The DH-BIO welcomes the initiative taken by the PACE to analyse problems associated with third party assisted reproduction, which the DH-BIO consider to be very serious. Together with the PACE, it agrees that particular attention should be given to the rights of any child born following the application of third party assisted reproduction techniques, while at the same time considering the rights and interests of all other

relevant stakeholders. In this context, it wishes to draw attention on the replies to its questionnaire on access to medically assisted procreation (MAP) and the right to know about their origin for children born after MAP origin which are regularly updated (doc DH-BIO/INF(2016)4).

Bearing in mind that "(t)he current legislation and practices of Council of Europe member States in the field of medically assisted procreation vary significantly", as observed by the PACE, the DH-BIO considers that any proposal for regulation in this particularly sensitive area should be based on careful consideration of all ethical, legal, societal and practical implications of such a proposal and should not be legally binding.

Having regard to these considerations, the DH-BIO wishes to draw the Committee of Ministers' attention to the following specific points which would warrant additional examination:

With regard to the proposal to waive anonymity "for all future gamete donations in Council of Europe member States" and to prohibit "the use of anonymously donated sperm and oocytes", due account should be taken of the considerations which are guiding the member states in their respective approach to these issues.

The DH-BIO sees need for further clarification on the PACE proposal that the "donor conceived child should be informed" upon his or her 16th or 18th birthday "that there was supplementary information available on the circumstances of his/her birth" and that such information should be given "ideally by the State". The DH-BIO wishes to point out the need to clearly make a distinction between information concerning the conception of the child and information about the identity of the donor which may call for different modalities of access by the donor-conceived child. The DH-BIO agreed that children should be provided as early as possible with information about their conception. Parents are the best placed to provide this information and should be encouraged and, as far as possible, supported to do so. However, as experience shows that this is not always the case, other mechanisms may be considered to ensure this information is accessible when the the child reaches the age of majority.

The DH-BIO agrees with the PACE that a possible waiving of anonymity should have no legal consequences for filiation and that the donor should receive appropriate guidance and counselling before he/she agrees to donate and his/her gametes are used.

The DH-BIO agrees that in countries which decide to waive the anonymity of donors, special attention should be given to set up a support system to accompany and counsel all persons throughout this process, including the offer of mediation by qualified personnel for possible contacts between the persons concerned.

With regard to the proposal to member States to "set up and run a national donor and donor-conceived person register" the DH-BIO wishes to draw the Committee of Ministers' attention to the particular sensitivity of the personal data relating to a person's conception and genetic origin, which are relevant to the person born following the application of third party assisted reproduction techniques, to the respective donor(s), to biological relatives and to the social family. Among the issues which would warrant further consideration is the safety of this information, including in case of transborder flow, and advisability of including, in a registry, donor-conceived children, given that they have not consented to this. These considerations should be extended to registers run by private establishments.

The DH-BIO fully agrees with the PACE that any regulation in this field must be "without prejudice to the overriding consideration that gamete donation must remain a voluntary and altruistic gesture with the sole aim of helping others, and thus without any financial gain or comparable advantage for the donor". It wishes to recall that this is a requirement laid down in Article 21 of the Convention on Human Rights and Biomedicine (ETS No. 164, Oviedo Convention) which states that "the human body and its parts shall not, as such, give rise to financial gain". In this context, it wishes to draw attention on its Guide on prohibition of financial gain also adopted by the European Committee on Organ Transplantation (CD-P-TO), which aims at facilitating the implementation of this Article of the Oviedo Convention.

Comments by the European Committee on Legal Co-operation (CDCJ)

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Bearing in mind that the current legislation and practices of Council of Europe member States in the field of medically assisted procreation vary significantly, as observed by the Parliamentary Assembly, the CDCJ considers that any proposal for regulation in this particularly sensitive area should be based on a careful consideration of all ethical, legal, societal and practical implications of such proposal and should not be legally binding.

More generally, the CDCJ notes that its draft Recommendation CM/Rec(2012)… of the Committee of Ministers to member States on the rights and legal status of children and parental responsibilities (document CM(2011)158-add1prov) includes various provisions relating to situations where States permit medically-assisted procreation, in particular access of children to recorded information concerning their origins (principle 4) and rules for establishing and contesting parental affiliation (principles 17 and 18).

CDCJ recalls that at their 1156th meeting (28 November 2012), the Committee of Ministers' Deputies decided to postpone consideration of the draft recommendation because of a lack of consensus within the Committee of Ministers, principally in relation to the inclusion of the above-mentioned provisions on medically-assisted procreation in the draft recommendation.

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Comments by the Ad hoc Committee for the Rights of the Child (CAHENF)

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With regard to the principle of waiving anonymity for all future gamete donations in Council of Europe member states, and of informing the child (upon his 16th or 18th birthday), and any other rights and support services in this context (filiation, right to contact the donor and possible half-siblings), some CAHENF members underlined the vast differing legal approaches that are currently being implemented, and that any further discussions should involve all relevant stakeholders.

It was raised in this context that, while legislative changes waiving donor anonymity may play a part in facilitating parental disclosure, a parental decision to reveal or not the truth to a donor-conceived child would be difficult to regulate and enforce. Such disclosures may relate to information that the child has been conceived by gamete donation, to genetic and medical information and/or information about the identity of the donor. In any case, the proposal by the Assembly for the modalities of information to be provided (ideally by the State) to the donor-conceived child, should be further clarified, including any proposals with respect to relevant age thresholds. It was also stressed that in the best interest of the child; any information given to the child should take into account the child's evolving capacities and level of maturity.

Other members underlined the importance for the child to have access to genetic and medical information, notably considering any health-related implications, and indicated numerous challenges in practice with respect to genetic screening and medical record keeping. The risk of abuse of donor, parental and child-generated data in the context of assisted reproduction methods was also raised, which requires careful consideration from a data protection perspective and in particular considering donor-conceived children's data.

CAHENF members agreed about "the importance of gamete donation to remain a voluntary and altruistic gesture" and the need to limit the number of possible donations by the same donor.

The CAHENF considered that any proposals for future work or recommendations on this topic should involve a careful evaluation of all relevant issues, while taking into account the need to safeguard all children's rights (including the child's emotional well-being), to ascertain the child's best interest and to promote it as a primary consideration, while giving adequate weight to the rights of all the other parties involved. Considering the interdisciplinary implications and the complexity of this issue, the CAHENF expressed its readiness, if necessary and if requested to do so, to contribute to future activities on this topic by making available its expertise in the area of the rights of the child.