NHeLP Principles on Assisted Reproduction

By Elizabeth McCaman Taylor, Jennifer Lav, Abbi Coursolle, and Fabiola Carrión

The National Health Law Program (NHeLP) has developed the following principles to guide its advocacy work on assisted reproduction (AR). Fundamentally we affirm that health coverage programs should cover AR and cost should not be a barrier. NHeLP opposes blanket exclusions of coverage for AR and discriminatory benefit design that excludes groups and individuals from access to AR, including exclusions based on gender, disability, LGBTQ+ identity, or relationship status. Cost-sharing—including copays and deductibles—should be affordable. Utilization controls should be reasonable.

Despite the growing use of AR services in the United States, it remains primarily privately funded. Most health plans and programs, including Medicaid, exclude it from the coverage or provide only very limited coverage, putting AR out of reach for low-income people. Studies demonstrate that insurance coverage of AR is critical for people to access these services. Utilization rates of in vitro fertilization (IVF) services in states with insurance coverage mandates were three times higher than in states with no mandate.[1] Research published in the *Journal of the American Medical Association* also showed that individuals with coverage of IVF were more likely to repeat the intervention if necessary, increasing their likelihood of having a successful pregnancy, compared with individuals who had to pay out of pocket.[2]

Policies regarding AR have a disproportionate impact on LGBTQ+ people, individuals with low incomes, non-partnered people, Black, Indigenous and other Women of Color, and individuals with disabilities.[3] As such, AR must be approached using an intersectional lens and a reproductive justice approach that takes into account histories of injustice, racism, and discrimination and that affirms the right to have a child, not to have a child, and to parent with dignity in healthy and safe environments.

NHeLP's focus is on AR coverage to facilitate access for all potential parents. We believe that AR should be covered by health insurance and programs, including Medicaid, in a manner that is equitable and reduces disparities. At the same time, we acknowledge that AR often

implicates the rights of third parties, including children created by AR and third parties who participate in AR as donors or surrogates. We also believe that the rights of those third parties should be respected and protected, and acknowledge that the role of and risk to third parties can vary significantly.

In recognition of all of the above interests, we affirm the following nine principles that NHeLP believes must underlie all legal and policy decisions regarding coverage of AR, including Medicaid coverage:

1. The right to non-discrimination

Laws, policies, and practices should protect everyone involved in the AR process—whether a potential parent, child born as a result of AR, donor, or surrogate—from discrimination based on race, color, sex, language, ethnicity, gender identity, income, age, national origin, religion, marital or partnership status, sexual orientation, disability, place of residence, socio-economic, genetic information, family history, or immigration status. This right includes the right to be free from discrimination in public or private insurance coverage (*e.g.*, policies may not limit access to AR to couples who have tried and failed to conceive via intercourse) and the right to be free from discrimination in the delivery of services (*e.g.*, policies may not limit people with disabilities to implanting one embryo, when there is no clinical reason for the limit and other individuals are permitted multiple implants).

2. The right to privacy

The right to private and family life includes the right to decide whether or not and when to become a parent. AR implicates intimate and personal decisions, including actions affecting child-rearing, marriage, procreation, and contraceptive use. All individually identifiable information obtained or created in the course of AR treatment is medical information and subject to medical record confidentiality requirements. Testing and counseling must be confidential and provided in a manner consistent with current medical ethics, and confidentiality should be maintained for all parties.

3. The right to autonomous and informed decision-making

All individuals have a right to reproductive autonomy and self-determination during the AR process. In addition, people who are undergoing medical procedures that can impact their future fertility, including certain cancer treatments and gender-affirming treatments, should be informed of that impact and their options regarding fertility preservation services. Everyone,

including potential parents and any third parties, should have access to complete, unbiased, and accurate information about the benefits and risks associated with any treatment, intervention, or procedure in order to make autonomous and informed decisions about AR. Information should be provided in a culturally and linguistically appropriate manner, including use of interpretation and translation services for people with limited English proficiency, and effective communication and auxiliary aids and services for people with disabilities. All participants in the AR process, including potential parents and any third parties, should provide informed consent to medical providers and other vendors involved in the process (e.g., storage facilities).

4. The right to equitable access to health care

Health care is a human right and a moral imperative. Individuals participating in AR, including potential parents and any third parties, should have access to affordable, high-quality, safe, respectful, dignified, and effective interventions, procedures, and treatments related to AR. Individuals should also have access to the health care providers of their choice. Should they need and request it, they should also have access to mental and psychological care, education, and support/counseling.

5. The right to quality care

Adequate safeguards and continuous research are vital to ensuring that AR procedures are safe and effective and that all parties involved know about potential side effects and are able to provide informed consent. Everyone should benefit from the same high ethical standards in medicine and life science research and have access to high quality care.

6. The rights of involved third parties

Any AR-related process should protect the rights of all parties involved. It should also permit people who are willing and able to serve as a third party—such as oocyte, embryo, or sperm donors, as well as surrogates—to do so or refuse to do so without discrimination. All parties, including third parties, must give informed consent based on complete, unbiased, and accurate information about the risks associated with the procedures they intend to undergo for any AR activity. The informed consent process must account for the different burdens and roles played by oocyte, embryo, and sperm donors, as well as surrogates, and the different risks they face by participating in AR. Third parties should also be fully empowered to make choices about whether and how they will participate in the AR process (e.g., surrogates should have the option to choose to transfer one embryo or multiple).The AR process should acknowledge the

financial incentives involved and the possibility of financial coercion on third parties. Information should be provided in a culturally and linguistically appropriate manner, including use of interpretation and translation services for people with limited English proficiency, and effective communication and auxiliary aids and services for people with disabilities.

7. Embracing diversity and rejecting ableism, racism, homophobia, transphobia, and sexism

We denounce policies or practices that promote selection based on racism, ableism, homophobia, transphobia, and sexism. Decisions made about genetic testing in conjunction with AR cannot exist separate and apart from social, political, and economic constructs.

Potential parents and third parties should have the right to make informed, personal decisions including the use of genetic testing or other screening in conjunction with reproductive technologies. We also affirm the right of potential parents and third parties to decline such testing or screening. We recognize that genetic screening and testing can have consequences not just for the individual patient, but also for other individuals to whom the patient is biologically related. Potential parents and third parties must receive accurate, unbiased information and counseling that does not reinforce or perpetuate ableism, racism, homophobia, transphobia, and sexism.

8. Data collection and research

Using systematic, segregated, nationwide data collection that protects individual privacy to ensure that AR treatments are safe, effective, accessible, and non-coercive is essential to understanding short- and long-term risks.[4] This is particularly true with regard to oocyte providers and others undergoing egg-retrieval since there is currently no systematic data collection on people providing oocytes for AR. More data and research to examine birth outcomes, postpartum health, and the longer-term health of children born following AR are critical for all parties to provide truly informed consent.

To improve data collection, we recommend that the Centers for Disease Control and Prevention (CDC) expand monitoring systems beyond the current cycle-based system to include a person-based reporting system to determine immediate and long-term outcomes.[5] Such measures must account for factors including how many eggs are retrieved, whether AR procedures use fresh or frozen eggs or embryos, whether AR interventions use the person's own eggs or purchased or donor eggs, and how many embryos are transferred. We also recommend CDC make efforts to expand the number of states that link vital records data with

the National Agricultural Statistics Service (NASS).[6] Finally, we support the expansion of uniform federal data collection to include patient-centered quality measures.[7] Data collection should include all demographic characteristics—including race, sex, language, ethnicity, gender identity, age, income, national origin, marital or partnership status, sexual orientation, disability, place of residence, and national origin—disaggregated whenever possible. This data should be reported annually.

Conclusion

The National Health Law Program believes that health care is a fundamental right and that every human being should have access to quality health care, including sexual and reproductive health care that includes access to assisted reproduction and fertility care. The above principles affirm our belief that AR policies and practices must address the unique needs of low-income and underserved individuals and families.

Federal and state laws should regulate the provision of AR in accordance with these principles and consistent with evolving research. Laws, regulations, and policies should protect the rights of individuals involved and account for technological developments. These laws, regulations, and policies must be based on sound scientific evidence and recognized human rights standards. As state and federal advocacy around infertility treatment grows, we will evaluate coverage proposals based on whether they advance or impede our core values and the eight principles set forth above.

Resources for Further Reading

Sister Song – **What is Reproductive Justice**?

Center for American Progress – **Future Choices II: An Update on the Legal, Statutory, and Policy Landscape of Assisted Reproductive Technologies**

UNESCO – **Universal Declaration on Bioethics and Human Rights**
American Medical Association – **Code of Medical Ethics Opinion 4.1.1**

World Health Organization – **International Committee for Monitoring Assisted Reproductive Technology (ICMAR) and the World Health Organization (WHO) revised glossary of AR terminology, 2009**

The Nairobi Principles on Abortion, Prenatal Testing, and Disability

Surrogacy360

Center for Reproductive Rights – **Baseline Guiding Human Rights-Based Principles on Compensated Gestational Surrogacy in the United States**

We Are Egg Donors

Center for Reproductive Rights – **Ensuring Equitable Access to Infertility Care in the United States**

National Partnership for Women and Families – **Access, Autonomy, and Dignity: A Series on Reproductive Rights and Disability Justice**

ENDNOTES

[1] *See* Tarun Jain & Mark D. Hornstein, *Disparities in Access to Infertility Services in a State with Mandated Insurance Coverage*, 84 FERTILITY & STERILITY 1 (2005), https://www.fertstert.org/article/S0015-0282(05)00601-1/pdf. *See also* Gabriela Weigel et al., *Coverage and Use of Fertility Services in the U.S.* (2020) (collecting studies and concluding that IVF utilization appears to be higher in states with mandated IVF coverage), https://www.kff.org/womens-health-policy/issue-brief/coverage-and-use-of-fertility-services-in-the-u-s.

[2] *See* Emily Jungheim et.al, *In Vitro Fertilization Insurance Coverage and Chances of a Live Birth*, 317 JOURNAL OF THE AM. MED. ASS'N 1273–1275, https://jamanetwork.com/journals/jama/fullarticle/2613146. *See also*, Leah H. Keller & Adam Sonfield, *More to Be Done: Individuals' Needs for Sexual and Reproductive Health Coverage and Care*, 22 Guttmacher Policy Review (2019), https://www.guttmacher.org/gpr/2019/02/more-be-done-individuals-needs-sexual-and-reproductive-health-coverage-and-care.

[3] *See* Ashley Wiltshire et. al, Infertility Knowledge and Treatment Beliefs among African American Women in an Urban Community, 4 CONTRACEPT. REPROD. MED 16 (2019), https://pubmed.ncbi.nlm.nih.gov/31572616 (concluding that Black women between the ages of 33-44 are twice as likely to experience infertility as white women in the same age demographic). *See also* Jain & Hornstein, *supra* note 3 (finding that even in a state that mandates IVF coverage, disparities in access to infertility services exist, with the majority of individuals accessing those services being Caucasian, highly educated, and wealthy).

[4] In 1995, CDC began collecting data on AR procedures performed in fertility clinics in the US as mandated by the Fertility Clinic Success Rate and Certification Act of 1992. Data are collected through the National AR Surveillance System (NASS), a web-based data collection system, and include 52 reporting areas (50 states, DC, and Puerto Rico).

[5] The NASS data file currently contains one record per AR procedure (or cycle of treatment) performed.

[6] As of January 2016, all states had adopted the 2003 revision of the birth certificate that includes information on whether the pregnancy resulted from the use of infertility treatment, but only four states (CT, FL, MA, MI) link data from their vital records with NASS.

[7] Current NASS data include patient demographics, medical history, and infertility diagnoses; clinical information pertaining to the AR procedure type; and information regarding resultant pregnancies and births.