

# Medical need and medicalisation in funding assisted reproduction: A right to health analysis

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## Abstract

Assisted reproductive technologies (ARTs) promise childbirth to those who are involuntarily childless. Despite an increase in their availability, they remain inaccessible because they are expensive. Some jurisdictions fund or subsidise ARTs. Central to ART funding decisions is the question of whether they are medically needed. This arises first at the stage of whether ARTs are funded at all, and second, in determining who, among those that are involuntarily childless, should access funded ARTs. I compare four representative models to demonstrate that centring medical need at these two stages raises problems of (a) undermining the welfare of ART seekers; (b) discrimination against same-sex couples and single women; (c) prioritising the medical needs of some groups over others; (d) budgetary competition with other medical services; and (e) inconsistent practices across jurisdictions. This has the effect of intensifying the stratified pressure to have children faced by women across the world. Drawing on this, I argue that centring medical need in ART funding is inconsistent with the international human right to health. I further claim that an alternative reproductive health approach to funding has the potential to undo the exclusionary nature of the social pressure to have children.

## Keywords

Fertility funding, assisted reproductive technology, Ontario Fertility Programme, Jiyo Parsi, NHS, NICE

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Assisted reproductive technologies (*ARTs*)<sup>1</sup> have been offering hope to involuntarily childless women and couples,<sup>2</sup> since the increase in in vitro fertilisation's (IVF) availability in the 1980s. While costs associated with administering and procuring assisted reproduction have steadily decreased, they continue to be inaccessible to many across the world. In some jurisdictions, governments contribute to ART costs through public funding schemes and state subsidies.<sup>3</sup> This is especially significant for same-sex couples for whom ARTs might be the only chance at having biologically related children, as well as for women living in environments and societies which view motherhood as a primary aspect of meaningful womanhood.<sup>4</sup>

There is limited legal scholarship on state ART funding. Existing literature primarily comprises policy arguments in favour of, and against, public funding of ARTs.<sup>5</sup> It has been acknowledged that any analysis of ART legislation is incomplete without an examination of who can access them through state funding and other pricing arrangements.<sup>6</sup> Details of funding arrangements have influenced broader questions of whether they

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1. This article considers all funded fertility treatments included in the definition of assisted reproductive technologies (ARTs) within the World Health Organisation's (WHO) Glossary of ART Terminology. This includes 'all treatments or procedures that include the in vitro handling of both human oocytes and sperm or of embryos for the purpose of establishing a pregnancy', including 'in vitro fertilization and embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy, but excluding assisted or artificial insemination'. Artificial insemination is considered to the extent that National Health Service (NHS) funding decisions are based on it. See The International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the WHO's Revised Glossary on ART Terminology, 2009. (subsequently: WHO Glossary)
  2. This usage was recommended in Martha F. Davis and Rajat Khosla, 'Infertility and Human Rights: A Jurisprudential Survey', *Columbia Journal of Gender and Law* 40(1) (2020), pp. 1, 5.
  3. Martin Keane et al., *Assisted Reproductive Technologies: International Approaches to Public Funding Mechanisms and Criteria*. An Evidence Review (Dublin: Health Research Board Ireland, 2017).
  4. Ann V. Bell, 'Beyond (Financial) Accessibility: Inequalities within the Medicalisation of Infertility', *Sociology of Health and Illness* 32(4) (2010), p. 631; Emily McTernan, 'Should Fertility Treatment Be State Funded?' *Journal of Applied Philosophy* 32 (2015), p. 227; J. R. McMillan, 'Allocating Fertility Services by Medical Need', *Human Fertility* 4(1) (2011), pp. 11–13.
  5. Alexa Warnes, 'Exploring Pronatalism and Assisted Reproduction in UK Medicine', *Journal of International Women's Studies* 20(4) (2019), pp. 103–118; Philippa Mladovsky and Corinna Sorenson, 'Public Financing of IVF: A Review of Policy Rationales', *Health Care Analysis*, 18 (2010), pp. 113–115. Also see McMillan, 'Medical Need', p. 11, and Keane et al., *Assisted Reproductive Technologies*.
  6. Isabelle Engeli and Christine Rothmayr Allison, 'Governing New Reproductive Technologies across Western Europe: The Gender Dimension', in Merete Lie and Nina Lykke, eds., *Assisted Reproduction Across Borders: Feminist Perspectives on Normalizations, Disruptions and Transmissions* (New York: Routledge, 2016), p. 87.

should be funded or subsidised. Yet, there remains a gap in the literature, with this analysis having not been extensively undertaken. This article is based on research which analyses jurisdictional funding practices and their treatment of medical need as qualifying criteria for accessing funded ARTs. It shows that this focus on medical need has a medicalising effect.

Medicalisation is the process whereby a social or human problem gets defined as a medical one. While this is not always harmful, it poses significant challenges in the ART context. Sociological research shows that the medicalisation of infertility is based on social and cultural perceptions that some women deserve to be mothers whereas others do not.<sup>7</sup> These results in discriminatory access to ARTs, excluding groups of women on the basis of age, class, race, and sexual orientation.<sup>8</sup> Drawing from the details of ART funding practices in select representative jurisdictions, I show that centring medical need in ART funding regulation has a medicalising effect, raising difficulties. In practice, funding frameworks reinforce problems of stratified medicalisation identified in sociological research.

It is proposed that difficulties arising from medicalisation can and should be addressed by adopting a human rights approach towards ART funding. It is acknowledged that the utilisation of government money to fund ARTs is recommended by the human right to reproductive health under Article 12 of the International Covenant of Economic, Social, and Cultural Rights (the *ICESCR*). Not only do I claim that medical needs-based models are inconsistent with the right to reproductive health, I also argue that a reproductive health approach to funding has the potential to undo the exclusionary nature of the social pressure to have children.

This article is divided into six parts. Section ‘Sociological framework: the social pressure to have children and its medicalisation’ sets down the framework of involuntary childlessness, the social pressure to have children, and stratified medicalisation within which this article is situated. In Section ‘The treatment of medical need in representative ART frameworks’, I survey funding practices in four model jurisdictions (England, Ontario, Maharashtra, and Singapore). In Sections ‘Difficulties from medicalisation at the Whether stage’ and ‘Difficulties arising from medicalisation at the Who stage’, I show that centering medical need in decision-making raises specific problems. These are those of (a) undermining the welfare of ART seekers; (b) discrimination against same-sex couples and single women; (c) prioritising the medical needs of some groups over others; (d) budgetary competition with other medical services; and (e) inconsistent practices across jurisdictions. In Section ‘Evaluating medical need from a right to health perspective’, I claim that the focus on medical need is inconsistent with the human right to reproductive health and that difficulties arising from medicalisation can be resolved by designing policy focused on the right to reproductive health.

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7. Bell, ‘Beyond (Financial) Accessibility’, p. 631. Also see Ann V. Bell, ‘Diagnostic Diversity: The Role of Social Class in Diagnostic Experiences of Infertility’, *Sociology of Health and Illness* 36(4) (2014), p. 516.

8. Op. cit.

## Sociological framework: the social pressure to have children and its medicalisation

### *The paradoxical nature of the pressure to have children*

In most parts of the world, motherhood is viewed as central to meaningful womanhood.<sup>9</sup> Women between the ages of 20 and 40 face varying degrees of social and personal pressures to have children. While the intensity and nature of the pressure varies based on circumstance and age, they continue to affect women everywhere, in some form, manner, or timeline. Not having children at this time has consequences, which could range from raised eyebrows to social exclusion.<sup>10</sup> Women who find it difficult to conceive because of physiological causes, as well as for other reasons such as not having found the right partner or for having different priorities, face these hurdles disproportionately. Increasingly, women in this age group are also made to consider freezing their eggs or embryos so that motherhood remains a continuing option.<sup>11</sup> The emotional, mental, and physical effects of the pressure to have children are substantial and have been well documented in academic writing.<sup>12</sup> The anguish is especially intense for women who want to delay motherhood for reasons relating to mental and other well-being. While it is only in some jurisdictions that these pressures result in pronatalist policies, women in most cultures continue to be subject to social pronatalism.<sup>13</sup>

Although motherhood is seen as central to meaningful womanhood in most communities, most societies and cultures, paradoxically, also perpetuate the view that not all women should be mothers.<sup>14</sup> These opinions are clearly registered in discussions and practices relating to reproductive health management. Sociological research shows that access to fertility care and adoption is designed to exclude women from minority groups, sexual orientations, lower socio-economic status, and those who are too old or too young.<sup>15</sup> The evidence shows that women who face the pressure to have children most intensely are the ones most likely to be excluded from accessing fertility care.<sup>16</sup> In this article, I show that ART access practices often reinforce society's exclusionary perceptions on who should be a mother, despite bearing the potential of having the opposite effect.

9. Marcia Inhorn, 'Right to Assisted Reproductive Technology: Overcoming Infertility in Low-Resource Countries', *International Journal of Gynaecology and Obstetrics* 106 (2009), p. 172.
10. Arthur Greil et al., 'The Social Construction of Infertility', *Sociology Compass* 5(8) (2011), p. 736; Gay Becker and Robert D. Nachtigall, 'Eager for Medicalisation: The Social Production of Infertility as a Disease', *Sociology of Health and Illness* 14(4) (1992), p. 456.
11. Vanessa Gruben, 'Freezing as Freedom: A Regulatory Approach to Elective Egg Freezing and Women's Reproductive Autonomy', *Alberta Law Review* 54(3) (2017), p. 753.
12. See Greil et al., 'Social Construction', p. 736 and Becker and Nachtigall, 'Social Production', p. 456.
13. Inhorn, 'Overcoming Infertility', p. 172 and Gilla Shapiro, 'Voluntary Childlessness: A Critical Review of the Literature', *Studies in the Maternal* 6(1) (2014), pp. 1–15.
14. Bell, 'Beyond (Financial) Accessibility', p. 631 and Bell, 'Diagnostic Diversity', p. 516.
15. These biases are also reflected in social practices and policy on access to contraception and pregnancy termination. See Bell, 'Diagnostic Diversity', p. 631.
16. Op. cit.

### *The promise of funded ARTs*

The paradoxes identified above manifest financially. IVF, artificial insemination, gamete intrafallopian transfer, and zygote intrafallopian transfer, and the assistance of donor gametes, are available, but expensive, means to motherhood for women affected by involuntary childlessness. Egg and embryo freezing enable motherhood to be delayed when the choice to not have children within the ‘reproductive age’ is based on social reasons.<sup>17</sup> However, in most parts of the world, women also continue to have lower incomes than their male counterparts, and career pressures often demand that motherhood be deprioritised. In these contexts, state funding has potential to reduce the disproportionate burdens of involuntary childlessness faced by women.

For same-sex couples, ARTs are often the only means to having biologically related children. With natural conception often not being a preferable option,<sup>18</sup> donor gamete-assisted conception and surrogacy are commonly advised routes to parenthood for same-sex couples. While some options like commercial surrogacy are prohibited in many countries, available options are expensive.<sup>19</sup> Same-sex couples who not only face social pressure but also personally desire to become parents are left having to bear the costs of these technologies, which opposite sex fertile couples are not subject to.

The idea that parenthood is a non-negotiable part of a valuable life and should be pursued through high cost and difficulty has been widely criticised for privileging only one view of a valuable life, and for placing disproportionate burdens on women and same-sex couples.<sup>20</sup> Critics of state funding argue that public funding of ARTs validates, and even intensifies, socially pervasive pressures to become parents.<sup>21</sup> According to them, free and easy ART availability would cast involuntary childlessness as an easily solvable problem, thereby intensifying social pressures to give birth. At the same time, reinforcing the message that ARTs are the only viable route to parenthood for couples who can’t conceive naturally, undermines the significance of adoption. It reinforces the idea that genetic links are central to parenthood, thereby invalidating the option as a path to meaningful parenthood. ART funding frameworks should, ideally, be accompanied by a state policy of messaging to prospective parents, the significance of adoption.<sup>22</sup> While there is considerable research indicating that ART availability has amplified the pressure to have children for women from advantaged backgrounds,<sup>23</sup> there is little evidence to support the claim that public funding either amplifies or legitimises it. On the contrary, it is clear that in a world where ARTs are already available to paying customers, easing

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17. Imogen Goold and Julian Savulescu, ‘In Favour of Freezing Eggs for Non-Medical Reasons’, *Bioethics* 23(1) (2009), p. 47.

18. With the exception of surrogacy through natural conception and not ARTs.

19. See Jens M. Scherpe, Claire Fenton-Glynn and Terry Kaan, eds., *Eastern and Western Perspectives on Surrogacy* (Cambridge: Interstentia, 2019).

20. Bell, ‘Beyond (Financial) Accessibility’, p. and McTernan, ‘Fertility Treatment’, p. 227.

21. McTernan, ‘Fertility Treatment’, p. 227.

22. I am thankful to a reviewer for this point.

23. Greil et al., ‘Social Construction’, p. 736 and Becker and Nachtigall, ‘Social Production’, p. 456.

financial access to them ameliorate pressures borne by excluded groups.<sup>24</sup> Warnes further shows that non-discriminatory funding of ARTs enables non-traditional families, thereby further destabilising social pressures to form traditional, heteronormative societies.<sup>25</sup> According to Sandelowski, ARTs have resulted in infertility to ‘mean the potential to have a child of one’s own, rather than merely the incapacity to have a child on one’s own’.<sup>26</sup> Progressive funding policy has the potential to capacitate a wider group of people as well as overcome society’s exclusionary views on who should be a mother.

### *The right to reproductive health and ART funding*

I propose that ART funding practices be developed in accordance with the human right to reproductive health under the ICESCR. The ICESCR recognises a human right to health, which also includes a right to reproductive health.<sup>27</sup> The ICESCR framework adopts a definition of reproductive health to mean ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes’.<sup>28</sup> General Comment 22 defines reproductive health to include not just medical services, but all attempts to safeguard social, mental, and physical conditions of reproductive well-being.<sup>29</sup> This frees ARTs from being viewed as cures to a disease. Instead, the definition’s breadth encourages that ART funding regulation be guided by broader health and welfare-related concerns, within wider socio-cultural realities. Very often, reasons for using ARTs are not linked to clinically diagnosed infertility, but nevertheless further the reproductive health of seekers, as is the case for older women and same-sex couples. As methods of fertility regulation and family planning maximising individuals’ and couples’ chances of reproducing, ARTs are reproductive health services falling within its ambit.<sup>30</sup>

24. This is similar to Gayle Letherby’s approach that he ‘rejects the view that all “infertile” and involuntarily childless’ women need is ‘strong, deep, feminist consciousness raising’ to dissuade them from the ‘technological [. . .] approach is patronising, offensive and simplistic’. As quoted in Gayle Letherby, ‘Challenging Dominant Discourses: Identity and Change and the Experience of ‘Infertility’ and ‘Involuntary Childlessness’, *Journal of Gender Studies* 11(3) (2002), p. 277.

25. McTernan, ‘Fertility Treatment’, p. 227.

26. Margarete Sandelowski, *With Child in Mind: Studies of the Personal Encounter with Infertility* (Philadelphia, PA: University of Pennsylvania Press, 1993) and Ann V. Bell, ‘Trying to Have your Own First; It’s What You Do: The Relationship between Adoption and Medicalized Infertility’, *Qualitative Sociology* 42 (2019), p. 479.

27. International Covenant on Economic, Social, and Cultural Rights (subsequently: ICESCR, Article 12.)

28. International Conference on Population and Development Programme of Action (1994) (subsequently: ICPD, Paragraph 7.2.)

29. The broad definition of reproductive health is not necessarily opposed to the medicalisation of reproduction. As Purdy notes, the adoption of broad and social definitions of health reinforces the medicalisation of reproduction. The merits of this approach will be debated in another part of this thesis. See Laura Purdy, ‘Women’s Reproductive Autonomy: Medicalisation and Beyond’, *British Medical Journal* 32 (2006), p. 287.

30. Davis and Khosla, ‘Infertility’, pp. 1–5.

According to General Comment 22 on the ICESCR,<sup>31</sup> access is an important element of the right to reproductive health.<sup>32</sup> Parties to the ICESCR are responsible for enabling discrimination-free access to reproductive health services for all individuals.<sup>33</sup> This includes aspects of physical access to services,<sup>34</sup> as well as their affordability.<sup>35</sup> States are urged, therefore, to design laws and regulation that foster access at sufficiently affordable prices.<sup>36</sup> Since ARTs maximise prospective parents' chances to reproduce, states' obligations to foster affordability and accessibility extend to ART services as well. While all reproductive health services should be affordable, it is only essential services that must be free at their point of use, according to General Comment 22. While it is evident that ARTs are reproductive health services falling within the ambit of the right under Article 12, there is little guidance on whether they are essential in ways that warrant free universal access. Since ARTs are considered reproductive health services on account of their maximising individuals' chances of reproducing, it can be argued that more efficacious technologies like IVF are more essential than less effective options such as gamete intrafallopian transfer and zygote intrafallopian transfer.<sup>37</sup> In practice, many jurisdictions fund ARTs for their residents, subject to conditions and limitations. IVF, being the most commonly funded ART, may therefore be perceived as more essential than other types of ARTs. Regardless of their degree of essentiality, states have an obligation towards ensuring that if not available for free, ARTs are accessible at affordable prices and without discrimination. One way for states to meet this obligation is through full, conditional, or partial ART funding. Another way for states to achieve this goal is by funding more effective ARTs over less effective ones.

### *Medicalisation of the social pressure to have children and involuntary childlessness*

Medicalisation is the process whereby a social, human, or personal problem gets defined as a medical one, to be managed or treated medically.<sup>38</sup> It has been described as the course through which the medical profession defines the boundaries of a problem and

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31. In 2016, the Committee on Economic, Social, and Cultural Rights of the United Nations Organisations adopted General Comment 22, where it was clarified that reproductive health is an integral part of individuals' right to the highest attainable standard of health under Article 12 of the ICESCR. General Comment 22 is a clarificatory document, which despite not being binding is viewed as 'more or less authoritative', 'highly influential', and having bona fide authority. States are expected to consider them in good faith. In the absence of contrary authority, General Comment 22 is an important and authoritative explanation of states' obligations under Article 12 of the ICESCR.
  32. Paragraphs 15–19, General Comment 22.
  33. Paragraph 15, General Comment 22.
  34. Paragraph 16, General Comment 22.
  35. Paragraph 17, General Comment 22.
  36. Article 2, ICESCR.
  37. I am grateful to a reviewer for this point.
  38. Greil et al., 'Social Construction', p. 736 and Becker and Nachtigall, 'Social Production', p. 456.

decides how it should be solved.<sup>39</sup> The medicalisation of reproduction refers the treatment of non-medical, reproductive, problems as medical, within practice and literature.<sup>40</sup> This is done through diagnosis<sup>41</sup> as well as the standardisation of clinical management or treatment practices. ARTs are shown to have medicalised the social and personal experiences of infertility.<sup>42</sup> Before the proliferation of ARTs, different-sex couples who found themselves in situations where one of them was unable to conceive, would, through a range of social arrangements create children, without involving medical practitioners.<sup>43</sup> However, policies and practices guiding the medical administration of ARTs have casted infertility as a diagnosable ‘disease’. Significant disadvantages arise from this treatment.<sup>44</sup> ART procedures are carried out within clinical settings, by medically trained staff. This serves as a contextual explanation for the equation of ARTs with other medical services.<sup>45</sup> Another justification presupposes that infertility is in fact a ‘disease’ to be cured or managed by ARTs.<sup>46</sup>

The very use of the term ‘infertility’ has been questioned in the literature. Becker and Nachtigall show that infertility is a social problem that has been recast as a disease, through its medicalisation.<sup>47</sup> Diagnostic and clinical treatment practices have resulted in infertility being perceived as a physical disease, warranting treatment.<sup>48</sup> Most healthcare regulatory bodies define infertility as a physiological affliction affecting an individual’s reproductive system.<sup>49</sup> Medicalised definitions of infertility are both over and under inclusive. They characterise those who do not wish to have children as diseased, while excluding others whose inability to have children does not stem from physiological factors. Furthermore, they describe infertility as an absolute state, not adequately recognising that the inability to conceive is often relative, and depends on physiological, social, and environmental factors, many of which can be changed. The term subfertility has been recommended as an alternative to recognise the ‘failure to conceive following a period of regular, unprotected, heterosexual intercourse’.<sup>50</sup> Although subfertility

39. Op. cit.

40. Peter Conrad, *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders* (Baltimore, MD: Johns Hopkins University Press, 2007).

41. Bell, ‘Diagnostic Diversity’, p. 516.

42. Greil et al., ‘Social Construction’, p. 736 and Becker and Nachtigall, ‘Social Production’, p. 456.

43. Marcia C. Inhorn and Frank van Balen, *Infertility around the Globe: New Thinking on Childlessness, Gender, and Reproductive Technologies* (Berkeley, CA: University of California Press, 2002).

44. See Greil et al., ‘Social Construction’, p. 736 and Becker and Nachtigall, ‘Social Production’, p. 456.

45. McMillan, ‘Medical Need’, p. 11, 13 and Warnes, ‘Pronatalism’, pp. 103–118.

46. Warnes, ‘Pronatalism’, pp. 103–118,

47. Becker and Nachtigall, ‘Social Production’, p. 456.

48. Before ART proliferation, the inability to have children was seen as a problem only affecting those who wanted to have children but could not. People affected by it would either reconcile with their situation or choose alternatives such as adoption.

49. For example, see WHO Glossary and NICE Guidelines.

50. Rebecca C. H. Brown, ‘Irresponsible Infertile? Obesity, Efficiency, and Exclusion from Treatment’, *Health Care Analysis* 27 (2019), p. 61.



provides some much-needed breathing room to describe peoples' inability to conceive, it does not capture the experiences of those who cannot conceive for more 'social' reasons, such as being in same-sex relationships or not having access to a partner. The language of involuntary childlessness is now considered an alternative to that of infertility, while describing problems potential parents seek to address using ARTs.<sup>51</sup> It is not merely infertility and subfertility that are medicalised by ARTs, but the overall experience of involuntary childlessness as well as exclusionary pressures to have children.

There is some literature on the mental and physical harms caused by medicalisation in general, and medicalisation through ARTs specifically.<sup>52</sup> There is also writing to suggest that ARTs have been medicalised in ways that reflect values pervasive in society.<sup>53</sup> It draws on cultural and social perceptions that only some women are worthy of being mothers, and therefore should have access to ARTs.<sup>54</sup> I supplement sociological research in this area to show that ART funding regulation contributes to stratified medicalisation in this area, giving rise to additional difficulties.

In funding practice and policy, medicalisation takes the form of a heightened consideration of medical need in ART funding decisions. This implicates questions of whether (a) ARTs are medical procedures at all (the *Whether Stage* of decision-making) and (b) who is entitled to access state ART funding (the *Who Stage of decision-making*). Authors like McMillan claim that ARTs should only be funded if we consider them medically needed treatments and cures for diseases or conditions,<sup>55</sup> such as an appendectomy is for appendicitis. This approach is followed in many jurisdictions, while others consider questions of medical need somewhat differently. I analyse regulatory frameworks and public funding schemes to identify difficulties arising from medicalisation at each of these stages, in Section 'The treatment of medical need in representative ART framework'.

## The treatment of medical need in representative ART frameworks

Many ART funding frameworks factor medical need in some form. However, its treatment varies significantly across jurisdictions.<sup>56</sup> In this article, I consider four regulatory models which represent distinct ways of factoring medical need in ART rationing decisions. These are those of England (United Kingdom), Maharashtra (India), Ontario (Canada), and Singapore. The English framework places high emphasis on medical need and represents highly medicalised models of ART funding. Maharashtra is a 'medical need plus' model, where access is based on medical need as well as social or financial need. Ontario is a demedicalised model, demonstrating the advantages of reduced

51. Letherby, 'Challenging Dominant Discourses', p. 277.

52. Warnes, 'Pronatalism', pp. 103118.

53. Bell, 'Beyond (Financial) Accessibility', p. 631.

54. Bell, 'Beyond (Financial) Accessibility', p. 631.

55. McMillan, 'Medical Need', pp. 11, 13 and Mladovsky and Sorenson, 'Public Financing', p. 113.

56. For an overview, see Keane et al., *Assisted Reproductive Technologies*.

reliance on medical need, and Singapore represents models with relatively low emphasis on medical need. These models, which represent differing degrees of medicalisation in ART funding, form a rich, yet manageable, set of regulatory approaches to draw from. Comparing them sheds light on the effects of medical need at each degree. It is acknowledged that these models exist in very different social, cultural, and economic contexts. However, despite this article's focus on contextually embedded questions, these differences are not relevant to its inquiry. This article studies teleological aspects of regulatory frameworks' treatment of medical need, and lessons drawn from them are transplantable, subject to contextual adaptations.

Usually medical need becomes relevant at two stages of ART funding. First, while deciding whether ARTs should be funded at all (the *Whether Stage*) and second, at the stage of determining whom the funded ARTs should be available to (the *Who Stage*).

The Whether Stage refers to the consideration of medical need, often at the first instance, in formulating broad legal positions on whether specific categories of ARTs (such as IVF or gamete freezing) should be publicly funded at all. Such discussions usually take place during pre-legislative or regulatory consultations and parliamentary debates. Generally, the medical needs of specific individuals are not referred to at this stage. Instead, opinions on whether infertility is a disease, to be cured by the ART, become relevant here.<sup>57</sup>

The second or Who Stage of consideration is when prospective parents' eligibility to access publicly funded ARTs is assessed. Many publicly funded healthcare systems require seekers to meet clinical qualifying criteria, indicating that they are in medical need of the service. In these cases, medical standards and clinical assessments gatekeep access to funded ARTs. Clinical determinations of who among all prospective parents should receive funded ARTs operate to influence medicalisation of the pressure to have children. These can reinforce the stratified nature of the social pressure to have children upon prospective mothers.

In this section, I describe how the model jurisdictions consider medical need at the Whether and Who Stages, respectively. Jurisdictions' treatment of medical need is subject to the architecture of their healthcare systems, and so the latter are also described in this section. While the legal systems and medical cultures of jurisdictions influence how medical need is considered within its framework, common points of comparison and learning emerge. Sections 'Difficulties from medicalisation at the Whether stage' and 'Difficulties arising from medicalisation at the Who stage' draw from this comparison to identify difficulties arising from medicalisation at each stage.

### *England – highly medicalised model of ART funding*

*Medical need at the Whether Stage in England.* In England, it is possible for residents to avail some ARTs publicly under the National Health Service (The *NHS*), where they compete with other health interventions for funding at various stages.<sup>58</sup> National Institute

57. Mladovsky and Sorenson, 'Public Financing', p. 113.

58. The NHS is England's publicly funded healthcare service, governed by the National Health Act, 2006 and the Health and Social Care Act, 2012. It provides healthcare and medical services to all English residents, with most of them 'being free at the point of use'. GP surgeries are residents' primary point of contact to access NHS services.

for Health and Care Excellence (*NICE*)<sup>59</sup> decides, at the first instance, whether ARTs should be publicly funded.<sup>60</sup> ART referrals are governed by guidelines published by NICE (the *NICE Guidelines*),<sup>61</sup> which have considerable persuasive value.<sup>62</sup> NICE's guidelines are based on a number of factors, chief among which is medical need.

NICE defines infertility as a disease and recommends that women and opposite-sex couples diagnosed with it can access up to three rounds of funded ARTs.<sup>63</sup> NICE bases its recommendations on its evaluation of the cost-efficiency of healthcare interventions by comparing the life years gained by each type of health intervention.<sup>64</sup> IVF is placed on the same pedestal as other medical interventions having the same cost-efficiency, while competing for public money. This, alongside the use of medical terminology 'diagnosis' and 'treatment' in the NICE Guidelines depict infertility as a disease, to be cured, medically, through ART procedures.<sup>65</sup> Same-sex couples or single women who seek IVF for reasons other than medically diagnosed infertility cannot obtain them from the NHS.

The public funding of gamete freezing also depends on whether it is considered medically needed in a specific way. According to NICE's guidelines, it is only when a loss of fertility is feared on account of cancer treatment, or through transition therapy, that individuals are offered an opportunity to freeze gametes of embryos.<sup>66</sup>

The NICE Guidelines are merely recommendatory and enabling in nature. Decisions as to whether these funded services are eventually taken by Clinical Commissioning Groups (*CCG(s)*)<sup>67</sup> CCGs are led by medical practitioners, and they prioritise all medical needs arising in the areas they serve, commissioning only some. ARTs compete with other medical needs for funding at this stage as well. There is recent case law holding that a CCG's refusal to offer NICE recommended egg freezing services was an unlawful breach of public duty, unless there was a special, exceptional factor to justify it.<sup>68</sup> Nevertheless,

59. The National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations, 2013.

60. Op. cit.

61. NICE's Guideline on Fertility: assessment and treatment of people with fertility problems, 2013, as amended in 2016 (subsequently: NICE Guidelines).

62. See, for example, the decision in *Rose v. Thanet Clinical Commissioning Group* [2014] EWHC 1182 (Admin), (England and Wales High Court).

63. NICE Guidelines, pp. 5.13

64. The National Institute for Health and Care Excellence, 'The Principles That Guide the Development of NICE Guidance and Standards', p. 23, available at <https://www.nice.org.uk/about/who-we-are/our-principles#produceguidance> (accessed 16 July 2020).

65. See generally the NICE Guidelines.

66. Section 19, NICE Guidelines. Surrogacy is not ordinarily funded under the NHS, although the retrieval of gametes involved in this process sometimes is. Nevertheless, in *Whittington Hospital NHS Trust v. XX* [2020] UKSC 14 (UK Supreme Court), a negligently late cervical cancer diagnosis had destroyed a woman's embryo and womb, forcing her to opt for commercial surrogacy in California. The Supreme Court, in a judgement delivered by Baroness Hale ordered the NHS to pay for the costs of four overseas surrogacies.

67. Section 25, Health and Social Care Act, 2012.

68. *Rose v. Thanet Clinical Commissioning Group* [2014] EWHC 1182 (Admin), (England and Wales High Court).

many CCGs remain reluctant to fund ARTs, even when they are considered medically needed according to the NICE Guidelines.<sup>69</sup>

*Medical need at the Who Stage in England.* England's centring of medical need extends to the Who Stage as well, where it plays an even heightened role. Only those who are found to be in clinical need of ARTs can access them on the NHS. The process of establishing clinical need is long, uncertain, and exacting. NICE recommends that this process takes opposite-sex couples a 2-year period and includes lifestyle changes, medication, and a complex diagnostic process.<sup>70</sup> Same-sex couples must have undergone six to 12 rounds of self-funded intrauterine insemination (IUI) cycles, before they can access funded IUI or IVF on the NHS.<sup>71</sup> This is to establish that their inability to conceive is related to medical factors, and not merely 'social' or lifestyle related.<sup>72</sup> As was highlighted in the review petition filed by Whitney and Megan Bacon-Evans against the NHS CCG Frimley in 2021, many CCGs in England require same-sex couples to undergo 10–12 self-funded cycles. This can cost up to 75% of the median income of a full-time employee in England.<sup>73</sup> It is only if unexplained infertility is established, that they are eligible for funded IVF.<sup>74</sup> Similarly, individuals can only access publicly funded gamete cryopreservation if it is foreseen that their fertility will be compromised for cancer treatment or during transitioning.<sup>75</sup>

### *Maharashtra – 'medical need plus' model of ART funding*

*Medical need at the Whether Stage in Maharashtra.* In the Indian state of Maharashtra, ARTs are not usually considered medically essential in the same way as other clinical interventions.<sup>76</sup> The state's public healthcare scheme funds medical services on need-based criteria.<sup>77</sup> Individuals falling below Maharashtra's poverty line, and those who are

69. See, for example, Human Fertilisation and Embryology Authority (HFEA), *HFEA Fertility Treatment 2017: Trends and Figures* (London: HFEA, 2019), p. 32.

70. See generally the NICE Guidelines.

71. Section 12.2, NICE Guidelines.

72. HFEA, *HFEA Fertility Treatment 2017*, p. 32.

73. 'BPAS Investigation into the IVF Postcode Lottery: An Examination of CCG Policy for the Provision of Fertility Services', 2021, available at <https://www.bpas.org/media/3369/bpas-fertility-ivf-postcode-lottery-report.pdf> (accessed 20 June 2021) (subsequently: BPAS Report).

74. At this stage, if the woman is aged under 40 years, then she can be offered up to three full cycles of IVF. If she is aged between 40 and 42 years, then she can be offered one IVF cycle. Older women are not offered funded IVF on the NHS.

75. Section 19, NICE Guidelines.

76. Santosh Andhale, 'Wadia Gives IVF Hope to Poor Childless Couple', *DNA*, 15 January 2016, available at <https://www.dnaindia.com/india/report-wadia-gives-ivf-hope-to-poor-childless-couple-2165899> (accessed 1 July 2022).

77. This is the Mahatma Jyotiba Phule Jan Arogya Yojana (Scheme) run by the Government of Maharashtra, available at <https://www.jeevandayee.gov.in/MJPJAY/FrontServlet?requestType=CommonRH&actionVal=RightFrame&page=undefined%3E%3E%3Cb%3EMJPJAY%3C/b%3E&pageName=MJPJAY&mainMenu=About&subMenu=MJPJAY> (accessed 15 July 2020).

just slightly above it, have free access to essential medical services at government-run hospitals.<sup>78</sup> ARTs are not funded under this scheme. According to the State's Minister for Health, 'government schemes [. . .] cover only life-threatening diseases'.<sup>79</sup> Indian insurance regulators (whose guidelines apply within Maharashtra) also clarify that medical insurance should not typically cover ARTs, as they are not medical requirements in the way other treatments are.<sup>80</sup> So, while the question of whether ARTs are medically needed is significant to this stage, Maharashtra's answer to it differs from NICE's in England, where they are considered essential in many circumstances.

*Medical need at the Who Stage in Maharashtra.* While ARTs are not ordinarily funded in Maharashtra, clinical diagnosis of infertility becomes relevant when they affect opposite-sex couples belonging to some groups and communities.<sup>81</sup> This could include couples where one partner is a central government employee or where they belong to a protected schedule tribe. Even in these cases, medical need must be established through either a gynaecologist's recommendation or by the exhaustion of all other relevant fertility treatment options.<sup>82</sup> While this is a rigorous process, it is not as exhaustive as the one course recommended by NICE in England. Thus, while medical need is relevant, it is not the only or most-vital criteria for obtained ART funding in Maharashtra. Group membership is more important.

I examine the specific example of infertile, married couples belonging to the Parsi community as a representative example of group-based access in Maharashtra. This is an interesting example, because the Parsis are not a traditionally disadvantaged community, such as scheduled tribes.<sup>83</sup> They are a historically wealthy community, who continue to lead business, law, and finance. Their dwindling numbers, however, have caused members of the community concern.<sup>84</sup> Interestingly, it is not the wealthy Parsi community that

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78. Op. cit.

79. Andhale.

80. Indian Insurance Regulatory and Development Authority, Guidelines on Standardization of Exclusions in Health Insurance Contracts vide Ref No. IRDAI/HLT/REG/CIR/177/09/2019 and Modification Guidelines on Standardization in Health Insurance vide Ref No. IRDAI/HLT/REG/CIR/176/09/2019 dated 27 September 2019.

81. Such as the Jijo Parsi Scheme or the Central Services (Medical Attendance) Rules, 1944.

82. See generally Guidelines/Criteria for Reimbursement of Expenses of In-Vitro Fertilisation Treatment to CGHS beneficiaries and beneficiaries under Central Services (Medical Attendance) Rules, 1944.

83. Historically deprived tribal groups in India are classified as Scheduled Tribes under the Constitution of India. The government is entrusted with enacting policy to protect these groups and their interests.

84. Parsis are ethnically Persian and are Zoroastrian by religion. Narrowly defined family laws and rules of identification and succession mean that very few descendants of mixed marriages are considered Parsi. As a result, the community is threatened with extinction, and young Parsis face an intense degree of pressure to have children. Children of Parsi mothers and non-Parsi fathers are not considered Parsi – a practice that has been the source of significant debate within the community. Despite this, on an individual level, Parsi women face less pressure to have children than women from other communities. With an average

subsidises ARTs for those of its members who cannot afford it. This funding comes from the government under the *Jiyo Parsi* (Live Parsi) Scheme.

### Ontario – demedicalised model of ART funding

*Medical need at the Whether Stage in Ontario.* In Ontario, the decision to fund ARTs is less reliant on their perception as medically needed that it is in England and Maharashtra. The province's ART funding programme, the Ontario Fertility Programme (*OFP*) is structured to avoid questions of medical need. It was created in 2015, alongside de-insurance of IVF and gamete storage from Ontario's general healthcare insurance programme called the Ontario Health Insurance Programme (*OHIP*).<sup>85</sup> Although the OHIP receives federal Canadian funds, Ontario's government has moved towards making a separate budgetary allocation for the funding of a finite number of ART cycles in the province.<sup>86</sup> As a result, ARTs no longer compete with other medical services to obtain public funds.

According to Conrad, the inclusion of new services in health insurance programmes is a matter of their medicalisation.<sup>87</sup> It follows from this that the delisting of services from a health insurance programme should reverse this medicalisation. While medical eligibility criteria govern access to funded gamete freezing, they are not qualifying criteria. This shows that the state funding of ARTs in Ontario is not significantly influenced by considerations of medical need.

Alana Cattapan argues that the OFPs origins lie in the deep medicalisation of ARTs. She draws on policy documents leading up to the OFP's adoption to show that the expenditure of tax-payer money on ARTs was justified by involving the language of medical need and necessity.<sup>88</sup> The Expert Panel on Infertility and Adoption which preceded the establishment of the OFP saw infertility as a medical condition, requiring 'medical treatment'.<sup>89</sup> By asserting that same-sex couples and single individuals require ARTs as medical treatment, it even went on to posit that 'social infertility' is a medical condition.<sup>90</sup> According to her, such medicalisation, along with considerations of efficiency and immediacy, led to

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age of marriage that is higher than the rest of India, the social pressure to have children, within families, appears to be low. However, concerns over the community's decline in numbers have led to demands for subsidised and government-funding ARTs. Zubin Shroff and Marcia C. Castro, 'The Potential Impact of Inter-marriage on the Population Decline of the Parsis of Mumbai, India', *Demographic Research* 25(7) (2011), p. 545.

85. Bulletin 4662, Fertility Services: Changes to the Schedule of Benefits for Physician Services and Regulation 552 of the Health Insurance Act Effective 21 December 2015 (subsequently: Bulletin 4662).

86. This includes 12,000 rounds of funded IVF, AI, or IUI cycles.

87. Conrad, *The Medicalization of Society*.

88. Alana Cattapan, 'Medical Necessity and the Public Funding of In Vitro Fertilization in Ontario', *Canadian Journal of Political Science* 53 (2010), p. 61.

89. Expert Panel on Infertility and Adoption, 'Raising Expectations: Recommendations of the Expert Panel on Infertility and Adoption' (2009).

90. Cattapan, 'Medical Necessity', p. 73.

the establishment of the OFP. She further argues that the OFP's establishment is akin to a re-listing of ARTs as insured services. While Cattapan's depiction is accurate, it only describes the policy background to the OFP. The OFP, itself, is constituted by regulatory material, government contracts, and budgetary allocations. Each of these is relevant while assessing whether ART funding is medicalised in Ontario. Changes like the separation of the OFPs budget from the OHIP, the removal of medical eligibility criteria for accessing services, and steering away from the language of infertility in the OFPs public documents show diminished levels of medicalisation. As it stands today, medical considerations only exert a weak influence on the public funding of ARTs in Ontario.

*Medical need at the Who Stage in Ontario.* Ontario's approach to the Who question was very strongly based on medical need till 2015. IVF and IUI were categorised as insured services before 2016. As a result, only those couples who met limited medical eligibility criteria (fallopian tube blockage or severe male factor infertility) could access IVF and IUI in Ontario up until then.<sup>91</sup> As explained in Section 'The treatment of medical need in representative ART frameworks', in 2016, the OHIP Act was amended to remove IVF and IUI from its list of insured services.<sup>92</sup> Simultaneously, Ontario's Ministry of Health and Social Care created the OFP to fund fertility services in the province.<sup>93</sup> The OFP's budget disbursed among fertility clinics in the province, in accordance with individually customised Transfer Payment Agreements. These are governed by principles of administrative law. The OFP intended to expand access to fertility services to individuals suffering from both medical and non-medical infertility, and therefore, barring an upper age limit,<sup>94</sup> no other eligibility criteria is set out.<sup>95</sup> Services are available to all Ontarians, irrespective of 'sex, gender, sexual orientation, or family status'.<sup>96</sup>

Since only a limited number of cycles are funded, waitlists often occur.<sup>97</sup> In the absence of established eligibility criteria, Ontario's Ministry of Health mandates that clinics develop their own prioritisation mechanisms to manage the waitlists.<sup>98</sup> As a result, patients often need to wait for long periods before they can access ARTs.

### *Singapore – minimally medicalised model of ART funding*

*Medical need at the Whether Stage in Singapore.* Singapore's Ministry of Health subsidises the costs of IVF availed by Singaporean citizens at public fertility hospitals,

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91. Erstwhile Schedule of Benefits for Physician Services (Schedule) and Regulation 552 under the Health Insurance Act, 1990 (Ontario). Governed by the Ontario Health Insurance Act, 1990 (subsequently: the OHIP Act) and the Canada Health Act, 1984 the OHIP funds health services and medical care for Ontario's residents. Services insured under the OHIP Act cannot be availed privately in the province.

92. Bulletin 4662.

93. Bulletin 4663, Changes to publicly funded fertility services (2015).

94. Op. cit.

95. Op. cit.

96. *Id.* Op. cit.

97. Email Correspondence with the Ontario Fertility Program Team dated 23 June 2020.

98. Op. cit.

without establishing medical need.<sup>99</sup> Under the Ministry of Health's co-funding scheme (*Singapore's co-funding scheme*), opposite-sex married couples can avail subsidised IVF, if either one or both of them are Singaporean citizens. Medical need does not play a decisive role here. Instead, Singapore's co-funding scheme was set up in 2019, as a follow-up to the Prime Minister's announcement that his government would provide more support to marriage and parenthood for Singaporeans,<sup>100</sup> broadly following the country's population policy objectives outlined in other parts of this article.<sup>101</sup> The article indicates that the scheme intends to enable working couples to have healthy family lives, while also encouraging them to start their families young.<sup>102</sup> A key component of Singapore's domestic policy has been that of encouraging family life and grappling with low fertility rates.<sup>103</sup> The co-funding scheme is in furtherance of the same objective. Same-sex couples and single women are not eligible for these funds.

A degree of medicalisation is discernible in Singapore's MediSave arrangements that facilitate payment for ART costs borne privately. Singaporean residents have the option of covering the remaining amount from withdrawals made from their MediSave accounts, which is Singapore's mandatory medical savings scheme. Residents are allowed to withdraw a capped sum for "medical treatment for conception" as "assisted conception procedures, for example, In vitro Fertilisation (IVF), Gamete Intra-fallopian Transfer (GIFT), etc".<sup>104</sup> MediSave funds cannot be used to pay for medical investigations to establish the cause of infertility, further showing that the focus is not on establishing clinical need through diagnosis.<sup>105</sup>

*Medical need at the Who Stage in Singapore.* Access to ART subsidies in Singapore is not based on medical need at all. Instead, eligibility depends on whether the prospective parents are heterosexual, married, and citizens or residents of Singapore. Up to 75% of IVF costs can be claimed if they are both Singaporean citizens. If the couple is formed of one Singaporean citizen and one permanent Singaporean resident, then up to 55% of

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99. Ministry of Health, Marriage and Parenthood Schemes, available at <https://www.moh.gov.sg/cost-financing/healthcare-schemes-subsidies/marriage-and-parenthood-schemes> (accessed 15 July 2020) (subsequently: Singapore Marriage and Parenthood Schemes).
  100. Ministry of Health's Press Release on More Support for Childhood Preventive Healthcare and Fertility Treatments (2019), available at <https://www.moh.gov.sg/news-highlights/details/more-support-for-childhood-preventive-healthcare-and-fertility-treatments> (accessed 15 July 2020).
  101. Danicar Marino, Brenda S.A. Yeoh et al., 'Crossing Boundaries of State and Religious Power: Reproductive Mobilities in Singapore', *Asia Pacific Viewpoint* 58(2) (2017), p. 203.
  102. PAP Women's Wing, 'Position Paper on Supporting Young Families' (2019), available at <https://www.pap.org.sg/womens-wing/enhanced-support-for-parenthood-and-young-families-pap-womens-wing/> (accessed 1 July 2022).
  103. Poh Lin Tan, 'Reversing Demographic Decline', Finance and Development Article, International Monetary Fund (2020).
  104. Regulation 18, read with Regulation 2(1), Central Provident Fund (Medisave Account Withdrawal) Regulations. It has recently been proposed that 'social' egg freezing also be included within the services for which MediSave can be used.
  105. Regulation 18(3), Central Provident Fund (Medisave Account Withdrawal) Regulations.



the IVF costs are covered. Singaporean citizens married to ‘foreigners’ are entitled to a 35% subsidy.<sup>106</sup> It is citizenship, and not medical need which gatekeeps ART funding. This too reflects social and cultural perceptions of who deserves to be a parent. This discussion narrowly falls out of the scope of this article’s analysis of medical need.

This is not to say that Singapore does not view ARTs to be medical, but that medical considerations do not influence their public funding decisively. To this extent, ARTs compete with other medical procedures to feature in individuals’ medical spending decisions.<sup>107</sup>

## Difficulties from medicalisation at the Whether Stage

### *Budgetary competition with other healthcare services*

On a budgetary level, the medicalisation of ARTs means that they compete with other medical services to be funded. While on the one hand, this means that they do feature in the competition for public health money, it also poses some disadvantages.

In England, for instance, where CCGs make decisions on what medical services are funded, ARTs end up in tight competition with other services, and often lose out. Since each CCG is allocated a corpus of NHS funds,<sup>108</sup> they attempt to put this money to its best possible use. As a result, NICE recommended services compete with one another to be commissioned. For instance, an infertile couple’s need for IVF would compete with other medical requirements like that of a teenager’s need to have her appendix removed. In practice, most CCGs appear to be funding ARTs at inadequate levels.<sup>109</sup> One reason for this is that CCGs are allocated funds based on where they operate. In general, CCGs in areas with mature or vulnerable populations are left with higher amounts per person, while those with younger populations are funded less. Therefore, areas where more people fall within the reproductive age get lower per capita funding. As a result, in these areas, ARTs have to compete more intensely with other medical expenditures to be funded. This has resulted in some CCGs halting ART funding entirely for long durations.<sup>110</sup> In Maharashtra also, medical regulators conclude that ARTs are not medically necessary in the same way as other essential services are, thereby denying them state funds.

Ontario presents a contrasting picture, where ARTs not having to compete with other services means that a certain number of cycles are definitely funded each year. It is

106. More Support for Childhood Preventative Healthcare and Fertility Treatments, available at <https://www.moh.gov.sg/news-highlights/details/more-support-for-childhood-preventive-healthcare-and-fertility-treatments/> (accessed 2 March 2022).

107. Regulation 18, read with Regulation 2(1), Central Provident Fund (Medisave Account Withdrawal) Regulations.

108. Section 27, Health and Social Care Act, 2012, and Rachel Harker, House of Commons Briefing Paper on NHS Funding Allocations: Clinical Commissioning Groups’ (2019).

109. See HFEA, *HFEA Fertility Treatment 2017*, p. 32.

110. For instance, Denis Campbell, ‘Hopes Rise for an End to ‘Heartless’ Rationing of IVF’, *The Guardian*, 29 June 2009, available at <https://www.theguardian.com/society/2019/jun/29/ivf-rationing-policy-nhs-childless-women-uk> (accessed 1 July 2022).

beyond this article's methodological scope to comment on whether this results in higher coverage in absolute terms. Nevertheless, it is clear that the scope of coverage in Ontario is wider than in England and India. This effect is not achieved in Singapore, but for reasons unrelated to medical need. However, government funding is not contingent on conversations about medical need, thereby making the Co-Funding Scheme more reliable and better for opposite-sex married couples. However, on the individual level, ARTs compete with other services insofar as this relates to Singaporean residents' decisions to dip into their MediSave accounts. I discuss the reproductive health implications of budgetary competition between ARTs and other medical services in Section 'Budgetary competition with other services'.

### *Inconsistent practices across jurisdictions*

Medical gatekeeping also generates a range of inconsistent and unreliable results described in previous sections. In England and Ontario, medical regulators are of the opinion that there are at least some circumstances where fertility freezing is medically necessary and should be state funded. However, perceptions of medical necessity vary in other jurisdictions. Regulators in Ontario and Maharashtra have come to different conclusions. The analysis in Section 'Ontario – demedicalised model of ART funding' shows that while viewing ARTs as medically needed led to the OFP's establishment, the idea does not exclusively influence the Whether Stage. It is my argument that the OFP is currently regulated in ways that places diminished importance to the question of medical need in funding. While NICE clearly defines infertility in medical language as a disease requiring medical treatment through ARTs, Maharashtra's regulators are clear that it is not medically necessary in ways that warrant state funding like other essential services do. Despite this, they are found to be medically necessary enough to be funded by the state, when needed by some communities.

These inconsistencies are especially significant in a global context where medical terminology, standards, and responses are largely viewed as universal. Universality is also central to the human rights approach; and argument that I develop more in Section 'Inconsistent practices across jurisdictions'. Despite this aspiration for universality, regulatory conversations between regulators and healthcare professionals have resulted in divergent outcomes on medical need. A useful clinical concept, medical need does not sit coherently with a right to health approach towards ART funding, and is therefore not a useful metric for designing policy in this area.

## **Difficulties arising from medicalisation at the Who Stage**

### *Discriminatory effects of medicalisation at the Who Stage*

The focus on medical need in determining eligibility to funded ARTs means that same-sex couples and single women cannot access ARTs in the same ways as opposite-sex couples diagnosed with infertility. As discussed in the previous section, under the NICE Guidelines, fertility treatment is only recommended to couples who clinically diagnose

as infertile,<sup>111</sup> and same-sex couples and single individuals have to self-fund initial rounds.<sup>112</sup> Consequently, it is only where a diagnosed clinical need is identified that public funds pay for ART for same-sex couples.<sup>113</sup> Contrastingly, the NHS pays for the diagnostic process undergone by opposite-sex couples seeking IVF, and where AI or IUI is necessary, all rounds are funded by the NHS.<sup>114</sup> This further exacerbates the already disproportionate anguish same-sex couples, and single women, face on account of involuntary childlessness and the pressure to have children.<sup>115</sup> It also violates public duties towards equality, as was highlighted in the recent review petition against the NHS CCG Frimley's policy, filed by social media influencers Whitney and Megan Bacon-Evans in November, 2021. Flowing from the NICE recommendation, the CCG's policy needed same-sex couples to undergo up to 12 rounds of self-funded artificial insemination treatment before being offered IVF. *These rounds, often costing as much as £30,000, impose a financial burden on lesbian women (and sometimes single women) seeking IVF, that is not incurred by opposite-sex couples trying to conceive through unprotected sexual intercourse. The review petition claims that the CCG's policy is discriminatory and violates the public sector equality duty to which the NHS is subject.*<sup>116</sup>

In jurisdictions like Ontario, where access is not determined through medical diagnoses of infertility, same-sex couples can access funded ARTs in non-discriminatory ways. A decreased focus on medical need can, therefore, open access to individuals who are not placed in opposite-sex relationships. Medical need, however, is not the only factor limiting access to same-sex couples and single women. In Maharashtra and Singapore, it is other social factors and not medical need that produces the same discriminatory effects against same-sex couples and single women.

Maharashtra's practice of appending medicalisation to group membership has the effect of demonstrating that the medical needs of a specific group are more important than others, even where they occupy positions of privilege as the Parsi community does. Structurally, this is similar to privileging heterosexual couples' medical needs over those of same-sex couples. Casting infertility as a disease restricts ARTs to couples suffering from some types of clinical infertility, thereby indicating that the needs of same-sex couples are less important than those of opposite-sex infertile couples. This additionally exacerbates restrictive perceptions of parenthood and families by suggesting that not living within heteronormative family structures prevents people from living valuable lives as parents, in the same way as it indicates that Parsi couples are more deserving of ART subsidies from the government than those of other minority communities. This is dissimilar to Singapore's system where eligibility is not based on medical need, but on citizenship. In Section 'Difficulties from medicalisation at the Whether stage', I consider whether declining community numbers are justified under a reproductive health approach.

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111. Section 5.13, NICE Guidelines.

112. With some CCGs requiring them to undergo up to 12 rounds.

113. BPAS Report.

114. NICE Guidelines.

115. As quoted in Letherby, 'Challenging Dominant Discourses', p. 277.

116. Alice Hutton, 'Married Lesbian Couple Launch Discrimination Action against NHS', *The Guardian*, 7 November 2021, available at <https://www.theguardian.com/world/2021/nov/07/married-lesbian-couple-launch-discrimination-action-against-nhs> (accessed 1 July 2022).

Earlier, I referred to sociological literature which shows that medicalisation reflects socially prevalent attitudes and prejudices about specific groups of women's worthiness to be mothers. The practice of medicalisation is such that lesbian women and women from disadvantaged backgrounds are discouraged from seeking ARTs while advantaged women are unduly pressurised to do so.<sup>117</sup> Here I have shown that centring medical need in funding regulation has a similar effect. On the contrary, universal funding can reverse the effects of stratified medicalisation.

### *Obstructions to welfare on account of medicalisation at the Who Stage*

Discriminatory practices, as highlighted in the above section, usually have implications for the welfare and mental health for those who are discriminated against. In addition, the focus of medical need gives rise to welfare challenges even if it is not discriminatory on prohibited grounds.

In jurisdictions like England and Maharashtra, where medical need plays a heightened role in access, diagnostic processes are emotionally and psychologically harmful. The diagnostic process followed in England spreads over 2 years, involves intrusive personal questions, lifestyle change suggestions, body shaming,<sup>118</sup> as well as painful tests and treatment.<sup>119</sup> This time is often crucial and often corresponds with a natural decline in ART-seeking women's fertility levels. In Maharashtra, the diagnostic process is less exacting, but is very dependent on the medical professional assessing infertility. This can lead to inconsistent practices and results. In Singapore and Ontario, funding decisions are not as medicalised, exacting diagnostic processes are avoided. Crucial time and resources are also saved by circumventing arduous diagnostic periods.

Similarly, the focus on medical need while determining access to fertility preserving gamete freezing in Ontario and England disqualifies women who wish to delay motherhood for reasons that are not appropriately clinical. They must pay for expensive gamete extraction and storage services if they are to focus on other priorities, or even their own mental health and well-being, during their reproductive age. The focus on a clinical need, therefore, avoids other aspects of seekers' health. Differences between medical need and overall well-being in health are discussed in further detail in the next section.

### **Evaluating medical need from a right to health perspective**

In previous sections, I showed how the emphasis on medical need at various stages of ART decision-making medicalises involuntary childlessness and the pressure to give birth, raising some difficulties. These are (a) discrimination against same-sex couples and single women; (b) prioritising of the medical needs of some groups over others; (c) welfare concerns; (d) budgetary competition with other medical services; and (e) inconsistent practices across jurisdictions. In this section, I show that centring medical need in funding practice is inconsistent with the right to reproductive health. I also propose an alternative approach based on the right to address these problems.

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117. Bell, 'Beyond (Financial) Accessibility', p. 631 and Bell, 'Diagnostic Diversity', p. 516.

118. Brown, 'Irresponsible Infertile', p. 61.

119. Drawing from the discussion in Chapters 5–10, NICE Guidelines.

### *Medical need and the welfare of prospective parents*

In Section ‘Obstructions to welfare on account of medicalisation at the Who stage’, I showed that the heightened focus on medical need is harmful to the welfare of prospective parents. Complex diagnostic procedures and restrictive clinical eligibility criteria for accessing ARTs in England and Maharashtra are physically and emotionally exacting, with seekers dropping out midway through the process.<sup>120</sup> Similarly, medical need-based criteria in gamete freezing exclude individuals and couples wishing to preserve their fertility for reasons ranging from mental health to other priorities. Medical definitions of infertility also exclude individuals and same-sex couples from meeting their reproductive objectives, thereby compromising welfare.<sup>121</sup>

This article is premised on the definition of reproduction health, which includes healthcare interventions that go beyond just curing diseases and ailments.<sup>122</sup> For something to classify as a healthcare service, it does not have to cure a diagnosed ailment or disease, and instead it could be in furtherance of the overall health and well-being of a person.<sup>123</sup> ARTs are often sought for reasons that do not stem from diagnosed infertility, but nevertheless further the reproductive health of seekers. Drawing from this, the right to reproductive health is inhibited by regulatory arrangements which require seekers to be diagnosed as medically infertile to access ARTs.

From among the considered funding models, Ontario’s treatment of medical need comes closest to the definition’s guidance. While the language of medical necessity led to the OFP’s institution, medical need-based requirements do not guide its operation. It is recognised that access falls within the scope of individuals’ healthcare entitlements, regardless of medical need. Singapore’s model is similar to Ontario’s, to the extent that seekers are not required to meet clinical eligibility criteria to access Singapore’s co-funding scheme. ARTs are primarily seen as means to encourage marriage and parenthood, and not as mere cures for infertility.<sup>124</sup> Singapore’s co-funding scheme is not closely related to the country’s healthcare objectives, but with its population policy. Despite this, the scheme better safeguards overall reproductive welfare of eligible citizens, that is, opposite-sex married couples.

Under the reproductive health approach recommended by this article, patients would not have to undergo elaborate tests to be diagnosed as physiologically infertile to access funded ARTs. Not basing the Who question on medical need would improve the overall reproductive health of ART seekers. Any criteria used to determine eligibility should be

120. HFEA, *HFEA Fertility Treatment 2017*, p. 32 and Fertility Network UK and Middlesex University London, ‘Fertility Network UK Survey on the Impact of Fertility Problems’ (2016), available at [https://www.google.com/url?sa=i&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=0CAMQw7AJahcKEwiYg6j3z9f4AhUAAAAAHQAAAAQAg&url=https%3A%2F%2Ffertilitynetworkuk.org%2Fwp-content%2Fuploads%2F2016%2F10%2FSURVEY-RESULTS-Impact-of-Fertility-Problems.pdf&psig=AOvVaw3ornBgiUJaS\\_0MhQ9Ak-T4&ust=1656762635844856](https://www.google.com/url?sa=i&rct=j&q=&esrc=s&source=web&cd=&cad=rja&uact=8&ved=0CAMQw7AJahcKEwiYg6j3z9f4AhUAAAAAHQAAAAQAg&url=https%3A%2F%2Ffertilitynetworkuk.org%2Fwp-content%2Fuploads%2F2016%2F10%2FSURVEY-RESULTS-Impact-of-Fertility-Problems.pdf&psig=AOvVaw3ornBgiUJaS_0MhQ9Ak-T4&ust=1656762635844856) (accessed 1 July 2022).

121. HFEA, *HFEA Fertility Treatment 2017*, p. 32.

122. Paragraph 7.2, ICPD.

123. WHO Glossary and NICE Guidelines.

124. See Singapore Marriage and Parenthood Schemes

consistent with the right to reproductive health. This could include means testing, distributive justice, or cost-effectiveness.

### *Discrimination against same-sex couples and single women*

Non-discrimination in access is an important element of the right to reproductive health. It is a core obligations of the right to health, and equality in access to healthcare services has been emphasised in human rights jurisprudence.<sup>125</sup> Applying General Comment 22, access to ARTs should not be denied to individuals merely because of group membership. Since the right to reproductive health is part of an interconnected network of human rights, broader principles of non-discrimination govern it as well.<sup>126</sup> Same-sex couples should especially not be discriminated against while determining access.<sup>127</sup> In the previous sections, I showed how medical eligibility criteria exclude same-sex couples and single women from accessing ART funding at the first instance. NICE's requirement that individuals/couples not having regular unprotected peno-vaginal penetrative intercourse undergo six cycles of self-funded IUI before being considered infertile places an unequal financial burden on same-sex couples, as many NHS clinics do not consider free, at-home attempts at IUI to be fulfilling the requirement under the NICE Guidelines<sup>128</sup> On the contrary, the diagnostic process for opposite sex infertile couples is offered and funded by NHS. Ontario's model, which does not focus on medical need, effectively does not discriminate against single women and same-sex couples. It is closer to the reproductive health model that favours state funding of ARTs.

It is, however, significant that medical need is not the only funding criterion that leads to discrimination, and overall legal arrangements should be consistent with the right to reproductive health. In Singapore and India, broader family law frameworks as well as the requirement that seekers be heterosexual, married couples has the same effect. These provisions are also inconsistent with the right to reproductive health in prohibited ways, and also do not fit into the right to reproductive health approach recommended in this article.

### *Prioritising medical needs of some groups over others*

The discussion above reveals that in some jurisdictions, ART funding policies give better access to specific groups over others. In Singapore, this is based on seekers' citizenship status, and in Maharashtra it is on account of a variety of factors such as group membership, historical disadvantage, population concerns, or employment status. In all three jurisdictions, it is broadly the group of heterosexual couples who enjoy an advantage

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125. See, for example, *Evans v. United Kingdom*, 43 E.H.R.R. 21.

126. Rebecca J. Cook, Bernard M. Dickens and Mahmoud F. Fathalla, *Reproductive Health and Human Rights* (Oxford: Oxford University Press, 2003), pp. 149–219.

127. Paragraph 22, General Comment 22.

128. Stonewall, 'Donor Inception and Fertility Treatment', available at <https://www.stonewall.org.uk/help-advice/parenting-rights/donor-insemination-and-fertility-treatment-0> (accessed 20 January 2022).

over same-sex couples and single women in accessing ART funds. In each case, we see ART funding policies prioritising the needs of one group over another; and in Maharashtra and England, where medical need is decisive in determining access, it is the medical needs of some groups that are prioritised over those of others.

Through this article, I have invoked sociological frameworks on medicalisation to show that funding regulation reinforces society's attitudes about who should be a parent. Human rights, on the contrary, are entitlements available to all, regardless of society's perceptions of their worthiness. Prioritising the medical needs of some groups over others appears, on the face of it, inconsistent with principles of equality law and non-discrimination. The principles are included within the core minimum obligations of the right to reproductive health as well. However, there is scope for positive discrimination in access, and special provisions allowing disadvantaged groups to avail reproductive health services are justified. Therefore, it becomes relevant whether prioritised groups can be considered disadvantaged in relevant ways. Heterosexuality and being in heterosexual relationships is not a relevant disadvantage. On the contrary, same-sex couples and single women face both structural disadvantages as well as social pressures to have children in contexts of involuntary childlessness. Deprioritising their medical needs over those of heterosexual couples is not incompatible with principles of equality law.

When it comes to selective ART funding for some communities in Maharashtra, identifying disadvantage is more complex. The Jiyo Parsi scheme has been justified on grounds of dwindling numbers of a community on the verge of dying out. The Parsi community also enjoys traditional prominence and wealth, and most of its members are significantly advantaged or privileged. Other indigenous ethnic subgroups, categorised as scheduled tribes under its constitution, are often not extended similar ART funding, despite similarly dwindling numbers.<sup>129</sup> Maharashtra's scheduled tribes do not occupy the same position of social and financial privilege that the Parsis have. Despite this, there are no ART funding arrangements for them. The central Ministry of Minority Affairs which administers the Jiyo Parsi Scheme is also responsible for the welfare of Scheduled Tribes and other minorities. Other than social and financial advantage, the other relevant difference between Parsis and Scheduled Tribes, with specific regard to ART funding, appears to be that Scheduled Tribes are not in immediate fear of extinction on account of dwindling numbers in the same way as the Parsi community is. Where fertility care for scheduled tribes is funded, it is only done at a state level, and not as a national priority. Therefore, the Jiyo Parsi scheme can be thought of as a governmental attempt to achieve population goals by prioritising the needs of a wealthy community over another. It also registers a policy tendency to consider women of the community who marry within the community to be more worthy of motherhood than others.<sup>130</sup> This settles uncomfortably

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129. Planning Commission, Government of India, Report of the Steering Committee on Empowering the Scheduled Tribes (2002–2007) available at [https://niti.gov.in/planningcommission.gov.in/docs/aboutus/committee/strgrp/stg\\_sts.pdf](https://niti.gov.in/planningcommission.gov.in/docs/aboutus/committee/strgrp/stg_sts.pdf) (accessed 16 August 2021) and Soudarssanane M. Bala and D. Thiruselvakumar, 'Overcoming Problems in the Practice of Public Health among Tribals of India', *Indian Journal of Community* 34(4) (2009), p. 283.

130. The Jiyo Parsi scheme is only applicable to Parsi women married to Parsi men.

with the structure and origins of reproductive rights. Reproductive rights, including that to reproductive health, arose from a need to break health and reproductive issues from governments' population policy agendas.<sup>131</sup> Human rights entitlements apply to everyone equally, with some additional help to disadvantaged groups. In this context, disadvantage should be seen as means-based or other access barriers to realise their healthcare rights.

Alternative need-based models that are not only consistent with the right to reproductive health are also encouraged. Examples of these would include Indian state government schemes for indigenous Scheduled Tribes, as well as other models where all individuals who face financial or other hardship. Nevertheless, it is accepted that there are often compelling reasons for prioritising other values and principle over the reproductive health approach; and India's approach towards the Parsi community is an example of this.

### *Budgetary competition with other services*

In Section 'Budgetary competition with other healthcare services', I showed that basing decisions on basing ART funding on medical need results in them having to compete with other health services and processes. Considering limitations, ARTs run the risk of being deprioritised over other services perceived as more important. General Comment 22 recognises reproductive health as a distinct aspect of the right to health, requiring specific fulfilment even when not used to cure diseases or illnesses. If ARTs are not considered medical services but as healthcare entitlements, they would be freed from budgetary competition with other healthcare services.

Ontario's OFP allocates specific sums for funding ARTs in the province. These funds are not rationed among different medical services, but instead, are used exclusively to pay for ARTs. It is not essential, therefore, to establish a compelling medical need for ARTs at each instance of allocation. Contrastingly, in England, ARTs compete with other medical interventions for funding at the CCG level. Since CCGs are finitely endowed, they are prone to deny access to funded ARTs when the same amounts can be dedicated to other medical interventions.<sup>132</sup> This problem might be mitigated if England, borrowing from Ontario's model, were to ring-fence amounts to be used exclusively to fund ARTs. In the past, the NHS has ring-fenced its budget for cancer treatment, setting aside money for treatments that are not cost-effective.<sup>133</sup> A similarly ring-fenced budget for ARTs would free them from competing with other medical interventions, thereby boosting the chances of theirs being funded. A comparable dedication of amounts in India's

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131. Willem Ombelet, 'Global Access to Infertility are in Developing Countries: A Case of Human Rights, Equity, and Social Justice', *Facts, Views and Vision in Obgyn* 3 (2011), p. 257.

132. Ian Sample, 'England lagging behind rest of UK in IVF cycles funded by the NHS', *The Guardian*, 9 May 2019, available at <https://www.theguardian.com/society/2019/may/09/england-lagging-behind-rest-of-uk-in-ivf-cycles-funded-by-the-nhs> (accessed 1 July 2022).

133. This was done by setting up England's Cancer Drugs Fund in 2016.



healthcare budget would support measures to publicly fund ARTs in the state. It is unclear whether Singapore apportions a part of its healthcare budget to the Singapore' co-funding scheme. However, this is not a limitation in practice. Specific budgetary allotment might, on the contrary, place an upper limit on ART funding expenditure. This would negatively affect the right to reproductive health. Drawing from these suggestions, other jurisdictions should consider dedicating part of their healthcare budgets to the funding of ARTs. The allocations should be large enough to not unreasonably limit the number of cycles funded.

### *Inconsistent practices across jurisdictions*

Another drawback of centring ART funding around medical need is that procedures to establish medical need are inconsistent. While NICE concludes that ARTs are medically needed in some narrowly defined circumstances, Maharashtra's regulators do not. This is because Maharashtra's regulators view only essential life-saving interventions as medical.<sup>134</sup> The definition of what is medically needed varies according to legal context. Within clinics, it varies from practitioner to practitioner. Gatekeeping by the medical profession, at both Who and Whether stages of decision-making, results in inconsistencies, often excluding seekers from accessing services. This is inconsistent with the right to reproductive health, which encourages ART access for all individuals, irrespective of their meeting medical criteria.

## **Conclusion**

ART funding policies medicalise the problems that technologies have the potential to solve. Most jurisdictions centre ART funding decisions on whether they are medically considered needed. This medical gatekeeping results in some difficulties. Drawing on examples from representative jurisdictions, I showed that the problems arising from such medicalisation include (a) discrimination against same-sex couples and single women; (b) prioritising of the medical needs of some groups over others; (c) welfare concerns; (d) budgetary competition with other medical services; and (e) inconsistent practices across jurisdictions.

To address these problems, this article proposes an alternative approach to ART funding, based on the human right to reproductive health. The right to reproductive health approach, recommended by this article, is one of many arguments in favour of publicly funding ARTs for all those who are involuntarily childless, including single women and same-sex couples. It forms a convincing human rights argument for states to ameliorate these problems associated with high ART costs, through public funding and other means. Drawing from representative funding models, I show that centring medical need in ART funding decisions is inconsistent with the right to reproductive health. Furthermore, the alternative approach suggested in this article has the potential to resolve the social problems of medicalisation and exclusionary pressure to have children.

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134. Andhale, 'Wadia Gives IVF Hope to Poor Childless Couple'.

This article also provides guidance on the types of funding practices and policies that should be in place, in practice, for furtherance of the right to reproductive health. It is acknowledged that public healthcare systems routinely face resource crunches, necessitating the evolution of principles for the rationing of healthcare funds. My claim is that such principles should be consistent with the right to reproductive health, and not contrary to it. Examples of consistent rationing principles include means testing, distributional justice, or carefully considered cost-effectiveness models.

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