

Reproductive Choice: Screening Policy and Access to the Means of Reproduction

*Lucinda Vandervort**

ABSTRACT

The practice of screening potential users of reproductive services is of profound social and political significance. Access screening lacks a defensible rationale, is inconsistent with the principles of equality and self-determination, and violates individual and group human rights. Communities that strive to function in accord with those principles should not permit access screening, even screening that purports to be a benign exercise of professional discretion. Because reproductive choice is controversial, regulation by law may be required in most jurisdictions to provide effective protection for reproductive rights. In Canada, for example, equal access can, and should be, guaranteed by federal regulations imposing strict conditions on the licenses of fertility clinics.

I. INTRODUCTION

Control over access to reproductive technologies is a form of social power with profound moral and political significance. It merits careful scrutiny. Although reproduction is a biological function, it has a central place in the diverse social and cultural patterns developed by human beings over time.

* *Lucinda Vandervort*, Professor, College of Law, University of Saskatchewan, Saskatoon, Saskatchewan, Canada. She received a B.A. in Philosophy (Honors) and English Literature, Bryn Mawr College (1968); M.A (1970) and Ph.D. (1973) in Philosophy, McGill University; LL.B. Queen's University (Ontario) (1977); LL.M. Yale University (1980). She is a member of the Ontario bar, admitted April 1979. She teaches legal theory, jurisprudence, criminal law, evidence, and, on occasion, administrative law and private international law. Her research focuses on the nexus between social knowledge, equality rights, and access to justice, and its significance for the design and operation of laws and legal institutions.

The existence of “others” and social relationships with “others” constitute essential aspects of what it is to be a person in the social sense, as opposed to what it is to be a human being in a bare biological sense. Reproduction is crucial for the creation and maintenance of the interpersonal relationships and communities that transmit languages, cultural practices, and beliefs, and that sustain individuals, materially and spiritually. Infertility is therefore widely experienced as a personal and familial tragedy.¹

Reproductive technologies offer expanded reproductive choices. But when technological knowledge, expertise, and materials are neither widely dispersed in the community of potential users nor easily obtainable, technology is *de facto* a scarce resource. Control over a scarce resource confers power. The exercise of power by some persons over others, whether exercised in a public or private capacity, is often morally and politically problematic. It is especially so when fundamental human interests are affected, as they clearly are when reproduction is at issue.² The human significance, societal implications, and legitimacy of access screening therefore merit careful examination.

-
1. Empirical studies show that in many traditional cultures, childlessness is profoundly stigmatizing and the source of personal suffering and social exclusion. See Abdallah S. Daar & Zara Merali, World Health Organization (WHO), *Infertility and Social Suffering: The Case of ART in Developing Countries*, in CURRENT PRACTICES AND CONTROVERSIES IN ASSISTED REPRODUCTION: REPORT OF A MEETING ON “MEDICAL, ETHICAL AND SOCIAL ASPECTS OF ASSISTED REPRODUCTION” HELD AT WHO HEADQUARTERS IN GENEVA, SWITZERLAND 17–21 SEPTEMBER 2001 (“CURRENT PRACTICES”), at 14 (Effy Vayena et al. eds., 2002); Frank van Balen & Trudie Gerrits, *Quality of Infertility Care in Poor-Resource Areas and the Introduction of New Reproductive Technologies*, 16 HUM. REPROD. 215, 216 (2001); S.J. Dyer et al., *You are a Man Because you Have Children: Experiences, Reproductive Health Knowledge and Treatment-Seeking Behaviour among Men Suffering from Couple Infertility in South Africa*, 19 HUM. REPROD. 960 (2004); S.J. Dyer et al., *Men Leave me as I Cannot Have Children: Women’s Experiences with Involuntary Childlessness*, 17 HUM. REPROD. 1663 (2002); Helma van Zandervoort et al., *Viewpoint: Medical Infertility Care in Low Income Countries: The Case for Concern in Policy and Practice*, 6 TROP. MED. INT. HEALTH. 563 (2001); Arthur L. Greil, *Infertility and Psychological Distress: A Critical Review of the Literature*, 45 SOC. SCI. MED. 1679 (1997); Trudie Gerrits, *Social and Cultural Aspects of Infertility in Mozambique*, 31 PATIENT EDUC. COUNS. 39 (1997). This literature recognizes that the significance of involuntary infertility is socially constructed and that gender roles play a major role in constituting the social meaning of infertility. Gender roles and beliefs also shape the experience of infertility in the “developed” world. See Greil (1997); Gay Becker & Robert D. Nachtigall, *“Born to be a Mother”: The Cultural Construction of Risk in Infertility Treatment in the U.S.*, 39 SOC. SCI. MED. 507 (1994).
 2. Equal rights to procreate and to benefit from medical and technological development are protected, directly and indirectly, by international human rights law. See, e.g., Universal Declaration of Human Rights, *adopted* 10 Dec. 1948, G.A. Res. 217A (III), U.N. GAOR, 3d Sess. (Resolutions, pt. 1), at 71, U.N. Doc. A/810 (1948), *reprinted in* 43 AM. J. INT’L L. 127 (Supp. 1949); Declaration on the Elimination of Discrimination Against Women, G.A. Res. 2263 (XXII), *adopted* 7 Nov. 1967, U.N. GAOR, 22d Sess., 1597th mtg., U.N. Doc. A/6880 (1967); Convention on the Elimination of All Forms of Discrimination against Women, *adopted* 18 Dec. 1979, G.A. Res. 34/180, U.N. GAOR, 34th Sess., Supp. No. 46, U.N. Doc. A/34/46 (1980) (*entered into force* 3 Sept. 1981),

This article undertakes that examination based on a wide-ranging review of access policies and the structural and attitudinal factors that shape those policies. A human rights perspective on access is then articulated and applied to analyze and critique conventional approaches to access screening. The article establishes that access screening is inconsistent with the principles of self-determination and violates international human rights law. Because empirical evidence shows that multiple forms of informal and low visibility access screening are widely practiced, I argue that affirmative steps are required to achieve meaningful implementation of equal access to reproductive services and materials. In Canada, this objective can be secured through the enactment of federal regulations imposing strict conditions on the licenses of fertility clinics. To suggest that law and policy on access to reproductive services would be better resolved through litigation in the courts or complaints before provincial human rights commissions is disingenuous. The problem is clear. The applicable legal principles are well-established. The federal power to enact secondary legislation in the form of regulations should therefore be used forthrightly and promptly to preclude further discrimination in access to these services. No lesser measure can ensure

1249 U.N.T.S. 13, reprinted in 19 I.L.M. 33 (1980); Declaration on the Elimination of All Forms of Intolerance and of Discrimination Based on Religion or Belief, *adopted* 25 Nov. 1981, G.A. Res. 36/55, U.N. GAOR, 36th Sess., Supp. No. 51, U.N. Doc. A/36/51 (1981), *reprinted in* RICHARD B. LILICH, INTERNATIONAL HUMAN RIGHTS INSTRUMENTS 490.1 (1990).

Equal rights to procreate and to benefit from medical and technological development are also protected, directly and indirectly, by regional human rights law. *See, e.g.,* European Convention for the Protection of Human Rights and Fundamental Freedoms, *opened for signature* 4 Nov. 1950, 213 U.N.T.S. 221, Europ. T.S. No. 5 (*entered into force* 3 Sept. 1953); Protocol 3 to the European Convention for the Protection of Human Rights and Fundamental Freedoms, E.T.S. 45 (*entered into force* 21 Sept. 1970); Protocol 5 to the European Convention for the Protection of Human Rights and Fundamental Freedoms, E.T.S. 55 (*entered into force* 20 Dec. 1971); Protocol 8 to the European Convention for the Protection of Human Rights and Fundamental Freedoms, E.T.S. 118 (*entered into force* 1 Jan. 1990); Protocol 11 to the European Convention for the Protection of Human Rights and Fundamental Freedoms, E.T.S. 155 (*entered into force* 1 Nov. 1998).

Parallel provisions are found in many national constitutions and in legislation enacted to provide domestic implementation of international or regional human rights (*see, e.g.,* Human Rights Act 1998, c. 42, 9 Nov. 1998 (UK) (designed to provide a mechanism to secure the human rights guaranteed in the European Convention for persons in the UK, as the government was required to do under Article 1 of the Convention). *See also* Gulam Bahadur, *The Human Rights Act (1998) and its Impact on Reproductive Issues*, 16 HUM. REPROD. 785 (2001) (anticipating changes in the law of the UK as human rights standards are implemented in relation to reproduction); Joseph G. Schenker, *Assisted Reproduction Practice in Europe: Legal and Ethical Aspects*, 3 HUM. REPROD. UPDATE 173 (1997) (reporting wide variation in the laws and practices related to assisted reproductive technologies in effect in 1996 in thirty European countries). It is apparent that as of 1996 the practices followed in many European countries did not adhere to the principle of equal access without discrimination on the basis of legal and social status. Law, professional guidelines, and practitioner discretion were used to legitimate differential access.

equal access to fertility services throughout Canada. Similar constraints on professional discretion appear to be required in order to provide effective legal protection for reproductive rights in many other jurisdictions. Precisely what legal mechanisms will provide effective protection against discrimination in access to fertility services can only be determined with reference to the legal system in operation in each jurisdiction. I leave the specifics of mechanisms to secure equal access in other jurisdictions to the imaginations of those who are in a position to address that matter.

II. STRUCTURAL AND ATTITUDINAL CONSTRAINTS ON ACCESS

Medical treatment for infertility may be unavailable for a number of reasons. Poverty, lack of information, and an insufficient supply of healthcare workers and essential materials are obvious impediments to the use of medical knowledge and skill to maintain and improve reproductive health. In addition, cultural and religious beliefs may influence the exercise of professional discretion and the formulation of governmental healthcare policies in ways that facilitate informal and low visibility access screening and result in the denial of services on non-medical grounds. Many of the factors that curtail access to fertility services are easy to identify.

A. Information

Developments in reproductive technology continue to be rapid and many techniques are subject to ongoing evaluation. In these circumstances, patients may find it difficult to obtain current and comprehensive information about technological improvements or empirical studies evaluating benefits, risks, and relative outcomes. Service providers and clinics whose tasks include the conduct of clinical trials as well as the provision of services are not in a position to provide impartial information. Governments may create user advisory branches or bureaus and grant them independence from conflicting regulatory roles, but such initiatives require political recognition of the potential for conflicts of interest and a commitment to respond to patient needs. Non-profit organizations with a patient advocacy mandate are often in a better position to disseminate the information that potential users of these technologies require to make informed choices. Such organizations may also have the capacity to lobby government on public and healthcare policy issues that affect the reproductive interests of the general public. User-funded information and referral networks can be highly cost-effective

when they operate on a scale that permits response to the concerns of a variety of sub-groups of users and potential users.³

B. Healthcare Service and Funding Policy

The history of reproductive medicine shows that standards of service and treatment often correspond to social and economic status and geographic location. Few would advocate that membership in specific social groups “should” automatically determine the range of available treatment options or the standard of care. Yet such questions are often patently at stake when questions of public health and healthcare funding policy are debated. A common effect of rejecting the principle of public funding for healthcare, or, where a public health insurance plan exists, failing to fund a full range of reproductive services, is to curtail access along cultural and social as well as economic lines, especially in jurisdictions where socioeconomic status mirrors racial and ethnic divisions.

Individuals are able to avoid some of the effects of domestic regulations and funding decisions, as well as any discretionary restrictions imposed by local practitioners, if they can afford to purchase the medical services they wish to use and have the time and means to travel or relocate to obtain those services. All others are captives of local public and professional, formal and informal, regulatory regimes. Some women may choose to use locally available but unregulated and unlicensed alternate services, as has often been the case in the past in response to the denial of access to services for alternate insemination, termination of pregnancy, and midwife assisted home births. Whether unregulated services pose a greater or lesser risk to the

-
3. Ruth Deech, *Guide to Donor Insemination and IVF Clinics*, 11 HUM. REPROD. 1363, 1363–64 (1996), reports some resistance in the UK in 1996 to the collection and publication of empirical data on IVF clinic performance. However, international opinion now clearly supports the collection and release of such information, preferably linked to national health registries. See Karl Nygren, *International Registries of Assisted Reproductive Technologies*, in CURRENT PRACTICES, *supra* note 1, at 377–80. In the United States data collection is mandated under Fertility Clinic Success Rate and Certification Act of 1992, Pub. L. 102–493, 106 Stat. 3156 (1992). The Center for Disease Control contracts with a professional society, the Society for Assisted Reproductive Technology (SART), to collect the data from fertility centers in the US. The surveillance system was developed and initiated in 1996 in conjunction with RESOLVE, a national infertility association. Annual Assisted Reproductive Technology Surveillance summaries for the United States are available at <http://www.cdc.gov>. Since 2001 the Canadian Fertility and Andrology Society has collected clinic data on a voluntary basis and a national registry (CARTR) has been established. Nygren advocates the development and international adoption of uniform definitions and methodologies. Working within a broad public health mandate, such registries could, I suggest, develop regional profiles of the incidence and causes of infertility useful for delivery of programs designed to protect reproductive health and prevent infertility.

overall health and well-being of women is a question of fact in each case; it should not be simply assumed that state regulation invariably guarantees safer and more “appropriate” standards and options in all services. Reproductive interventions that require complex technological support, however, are less likely to become generally available outside the regulated medical sector. In any event, healthcare policies and funding schemes have their greatest impact on the options actually available to persons who are not members of socially and economically advantaged groups. Anxiety and hardship can result for these individuals and their families if treatment is not available.⁴ Here, as is the case whenever the state fails to recognize, or recognizes but refuses to take positive steps to meet the fundamental needs of its citizens, human rights may be violated.

C. Control Over Treatment Decisions

Like many other areas of medicine, reproductive medicine encompasses a range of treatment options. Patients make choices among the treatments available to them on the basis of complex information in a context of uncertainty. It is common for patients to be offered a limited selection of treatment options as a pragmatic response to the realities of practice within a particular funding and policy structure. Practitioners, however, are seldom required to defend their practices in this regard. The lay patient is often not in a position to challenge a physician who fails to disclose that “x” or “y” is widely regarded as a standard treatment or test. Many patients never become aware of options other than those disclosed by the physician. This phenomenon can have serious effects. The result is the same when physicians lack the knowledge and expertise required to recognize when it is appropriate to refer a patient to a specialist. In either case, the patient may not realize that further investigation and possible intervention is indicated. Much *de facto* access screening likely occurs through such “low-visibility” mechanisms. Such experiences make the case for independent patient information and referral services.

Few practitioners would claim that non-disclosure and the selective provision of treatment options to shape patient choice is justified in an ab-

4. Florencia Luna reports that many Latin American countries have a strong tradition of publicly funded healthcare; lack of access to publicly funded ART services is therefore deeply resented and experienced as an “injustice” by the general population, see Florencia Luna, *Assisted Reproductive Technology in Latin America: Some Ethical and Sociocultural Issues*, in *CURRENT PRACTICES*, *supra* note 1, at 32. See Balen & Gerrits, *supra* note 1, at 217–18, who observe that ART is not publicly funded in Egypt, the typical IVF fee is twice the annual income of the average Egyptian, and “IVF treatments can ruin one’s middle class status.”

solute sense, but only that it is inevitable because there is insufficient time, personnel, and funding to provide all patients with a full range of treatment options and to counsel and educate them to make informed decisions. Many practitioners would also suggest that in most cases non-disclosure is benign because most patients would make identical treatment choices in any event. A few practitioners might suggest that those who would not *should*. The use of professional non-disclosure to pre-empt patient decisions related to fertility treatment no longer appears benign, however, once the individual and social significance of the issues at stake in the debate over the legitimacy of access screening is recognized.

D. Ideological Climate

Universal healthcare is widely espoused as a desirable social goal in principle. In jurisdictions without publicly funded healthcare services, debates about universal access generally focus on issues related to implementation—feasibility, efficiency, conflicts over costs and profits, and competing social goods. Yet it is not possible to say that there is universal agreement that all potential users—for whom funding is not a barrier—*should have* access to reproductive technologies and materials.⁵ In some jurisdictions there is differential access to reproductive materials and technologies *other than* as a consequence of economic barriers.⁶ Access to reproductive technologies and materials by the members of certain groups has been the subject of overt and often strident controversy in North America and Western Europe. Authors have criticized and defended professional practices and protocols and debated the merits of proposed legal standards and provisions designed to protect or curtail access by disabled persons, homosexuals, unmarried women, cohabiting but unmarried couples, and members of other identifi-

-
5. Views on this issue continue to evolve. Sheila McLean, *The Right to Reproduce* in HUMAN RIGHTS: FROM RHETORIC TO REALITY 99–122 (Tom Campbell et al. eds., 1986), examining the legal context of the right to make affirmative reproductive choices from a historical perspective but left resolution of the access question open. Bartha M. Knoppers & Sonia LeBris, *Recent Advances in Medically Assisted Conception: Legal, Ethical and Social Issues*, XVII(4) AM. J.L. & MED. 329, 332–33 (1991), reporting the emergence of a consensus in Europe that “access to fertilization techniques should be limited to heterosexual married couples or to those living in stable unions.” But see Schenker, *supra* note 2; Bahadur, *supra* note 2, on the recent impact of human rights law on reproductive law and practice in Europe and the UK.
 6. Commissions established more than two decades ago to propose regulations for reproductive technologies often presumed, for example, that there would not and should not be equal access by unmarried women. See MARY WARNOCK, A QUESTION OF LIFE: THE WARNOCK REPORT ON HUMAN FERTILISATION AND EMBRYOLOGY (Basil Blackwell, 1985) (originally a report delivered to the British Committee of Inquiry into Human Fertilisation and Embryology).

able groups.⁷ Concerns typically focus on family structure and behaviors and medical conditions believed to pose potential risks for the welfare of patients or children conceived and carried to term.⁸

In those discussions the distinction between access to reproductive services and technology and access to reproductive materials is not always clearly drawn. Conclusions based on considerations deemed pertinent to access to reproductive materials are sometimes used, without further analysis, to provide a rationale for the regulation of access to reproductive services and technology or *vice-versa*. In the confusion, social and political issues are often “medicalized” as healthcare providers exercise “professional

-
7. Bartha Knoppers & Elizabeth Sloss, *Recent Developments: Legislative Reforms in Reproductive Technology*, 18 OTTAWA L. REV. 663, 678–81 (1986); Carol Smart, “There is of Course the Distinction Dictated by Nature”: Law and the Problem of Paternity, in *REPRODUCTIVE TECHNOLOGIES: GENDER, MOTHERHOOD AND MEDICINE* 98, 98–117, (Michelle Stanworth ed., 1987). See Note, *Reproductive Technology and the Procreative Rights of the Unmarried*, 98 HARV. L. REV. 669, 669–85 (1985) (evaluating whether there is a valid state interest for US constitutional purposes in restricting the reproductive choices of unmarried persons). In the 1980s, feminists in the “developed” world often remarked on the myopic vision brought to analysis of reproductive issues by mainstream authors. See Joan Bercovitch, *Civil Law Regulation of Reproductive Technologies: New Laws for the New Biology?*, 1 CAN. J. WOMEN & L. 385 (1986); Somer Brodribb, *Off the Pedestal and Onto the Block? Motherhood, Reproductive Technologies, and the Canadian State*, 1 CAN. J. WOMEN & L. 407 (1986); Mary Anne Coffey, *Of Father Born: A Lesbian Feminist Critique of the Ontario Law Reform Commission Recommendations on Artificial Insemination*, 1 CAN. J. WOMEN & L. 424 (1986); Abby Lippman, *Access to Prenatal Screening Services: Who Decides?*, 1 CAN. J. WOMEN & L. 434 (1986); Janice Tait, *Reproductive Technologies and the Rights of Disabled Persons*, 1 CAN. J. WOMEN & L. 446 (1986); Christine Harrison, *Report on Human Artificial Reproduction and Related Matters by Ontario Law Reform Commission*, 1 CAN. J. WOMEN & L. 561 (1986).

- For a philosopher’s perspective a decade later, see Bambi E.S. Robinson, *Birds Do It. Bees Do It. So Why Not Single Women and Lesbians?*, 11 *BIOETHICS* 217, 217–27 (1997). Cf. Luna, *supra* note 4; Simone Bateman, *When Reproductive Freedom Encounters Medical Responsibility: Changing Conceptions of Reproductive Choice*, in *CURRENT PRACTICES*, *supra* 1, at 320–32, acknowledge the cultural, religious, and political dimensions of the debate at the regional and international levels. This literature shows there is a widespread and long-standing tendency to assume that the *status quo* (whatever it happens to be) is “natural,” and ought to be and remain as it is, is widespread even though the effects violate human rights. See Siobhán Mullally, *Debating Reproductive Rights in Ireland*, 27 *HUM. RTS. Q.* 78 (2005) (examining the conflict between religious-cultural beliefs and practices and women’s human rights).
8. Sozos J. Fasouliotis & Joseph G. Schenker, *Ethics and Assisted Reproduction*, 90 *EUR. J. OBSTET. & GYNECOL. & REPROD. BIOLOGY* 171 (2000); Yvon Englert et al., *ART in HIV-Infected Couples: Has the Time Come for a Change in Attitude?*, 16 *HUM. REPROD.* 1309 (2001); Judy E. Stern et al., *Access to Services at Assisted Reproductive Technology Clinics: A Survey of Policies and Practices*, *AM. J. OBSTET. GYNECOL.* 591 (2001); Judy E. Stern et al., *Attitudes on Access to Services at Assisted Reproductive Technology Clinics: Comparisons with Clinic Policy*, 77 *FERTILITY & STERILITY* 537 (2002); Judy E. Stern et al., *Determining Access to Assisted Reproductive Technology: Reactions of Clinic Directors to Ethically Complex Case Scenarios*, 18 *HUM. REPROD.* 1343 (2003); F. Shenfield et al., *ESHRE Taskforce on Ethics and Law, Taskforce 8: Ethics of Medically Assisted Fertility Treatment for HIV Positive Men and Women*, 19 *HUM. REPROD.* 2454 (2004).

judgment” about non-medical questions that impinge on individual choice. Even in jurisdictions where the law explicitly protects equality of access, the attitudes and practices adopted by healthcare providers can serve as an effective informal barrier and deterrent to defeat access by some would-be users of reproductive technologies and materials. The attitudes of healthcare professionals are most influential in jurisdictions where the applicable law is unclear or is not enforced.⁹ The ethical and political framework for the resolution of questions about access to reproductive technologies and materials requires clarification.¹⁰ We need a principled foundation for both legal rules and professional protocols on access and all related questions.

-
9. Consider this example: on 14 June 1988, the Saskatchewan Human Rights Commission initiated a complaint in its own name alleging discrimination on the basis of marital status against single women applying to the AID program of the Royal University Hospital, Saskatoon, Saskatchewan, Canada. Section 12 of the Saskatchewan Human Rights Code prohibits discrimination on the basis of race, marital status, etc., in services offered to the public in the province. The complaint stated:

In order to be accepted into the AID Program, single women must submit to more onerous social and psychological testing and questioning than is required of married women. These different procedures constitute discrimination because of marital status against single women in violation of Section 12 of the *Saskatchewan Human Rights Code*.

In 1990, the complaint was settled by agreement between the Commission and the respondent Hospital. The director of the program is reported to have stated that he “started to do psychological testing on unattached women because he was uncertain about the social implications of single women having babies.” *Single Women will no longer be Tested for Emotional Stability*, CALGARY HERALD, 16 Dec. 1990, at D5. Because the Commission had initiated the complaint in its own name, individuals and couples who had contacted the Commission or filed formal complaints with the Commission alleging discrimination by the Hospital and AID program staff on the basis of one or more of the characteristics listed in Section 12 of the Code were not consulted about the terms of settlement. Those terms required the Hospital to forego *differential* screening of applicants in the future. The effect was to permit applicants to be subjected to social and psychological screening as a prerequisite to consideration for acceptance into the AID Program *if* they were *all* screened. Such a screening program was indeed established even though it: (1) increased program costs, as in the past few applicants were referred for screening and, of these, some declined to be subjected to screening procedures or to participate further in the Program; (2) is not formally required by law; and (3) arguably contravenes Sections 7 and 15 of the Canadian Charter of Rights and Freedoms, 1982, which protect individual liberty and security of the person against infringement by law and guarantee equal protection and benefit of the law, respectively. To date, there appears to have been no attempt to use the Charter to challenge the constitutionality of the screening program in the courts. Constitutional rights are not self-executing. CAN. CONST. (Constitution Act, 1982) pt. I (Canadian Charter of Rights and Freedoms), reprinted in THE CANADIAN CHARTER OF RIGHTS AND FREEDOMS: COMMENTARY 530 (Walter S. Tarnopolsky & Gérald-A. Beaudoin eds., 1982) [hereinafter CAN. CONST.].

10. Stern *et al.*, 2003, *supra* note 8, at 1351, finding wide variation in access policies and rationale and concluding that “most clinicians practicing ART [in the U.S.] are struggling with access issues . . . [and] further discussion of access-to-services issues as well as some training in systematic approaches to solving complex ethical problems could be very useful to clinicians in this field.” Similarly, the WHO report on assisted reproduction recommended that: “Procedures need to be established to ensure continuing multidisciplinary debate to shape the ethical framework of ART. This debate must include public participation.” CURRENT PRACTICES, *supra* note 1, at 394.

III. USING A HUMAN RIGHTS LENS TO REEXAMINE COMMON ASSUMPTIONS AND DEFINITIONS

A. Legacy of Unexamined Assumptions

Screening practices are typically based on assumptions about the general social effects of access policies. These assumptions seldom appear to have been critically examined or tested for validity. There is scant attention to the political implications and human significance of access screening even though access screening is a form of social control through which social dominance is expressed. As a result, there are gaps in the discourse and flaws in the logic of policy arguments dealing with access issues. The actual impact of screening on the lives of individuals, families, groups, and communities is rarely considered. Yet the view appears to be widely held that access screening serves general public policy objectives and is legitimate.

In this discussion, by contrast, the ethical and political interests of individuals and groups affected by access screening have a central place. The examples discussed do not exhaust all variations on basic themes or encompass the multifaceted circumstances of all individuals. However, they do serve to raise the fundamental issues, and point to the conclusion that many characteristics commonly used to distinguish groups and individuals for general public policy purposes have no significance within the ethical and political framework that must govern any policy on reproductive choice that is consistent with international human rights principles. Such a policy must be developed with attention to the effects of the policy as these are *experienced by* individuals and by the social and cultural groups to which individuals belong. The focus must be on the *human significance* of the effects of policy for those affected, not the quantifiable effects of the policy at the general societal level as measured by socioeconomic indicators. The change in focus results from adopting what I shall refer to as a "human rights lens." Once this shift is made it becomes apparent that many past discussions of access screening have not asked the questions that a human rights focus demands. We should not be surprised to find that new questions reveal different issues, require attention to evidence that was previously ignored, and generate new answers.

B. Equality of Persons

Central to a human rights focus is the assumption that all persons, as moral and political agents, are equal, without distinction by reference to social, economic, cultural, or any other characteristics by which individuals and groups may be identified or described from time to time. Factors that place

an individual or group of individuals in a relatively disadvantaged social or economic position in a society may provide grounds to argue that those individuals have claims for special assistance or other consideration from other members of that society. Such factors, however, do not diminish or detract from the equal status of individuals as moral and political agents.

C. “Inter-subjectively Constituted” Families

A human rights focus also requires that the definition of the term “family” reflect the significance individual participants attach to a broad range of social arrangements and kinship ties established by choice, marriage, birth, and adoption (formal or informal). A “family” is therefore defined here as consisting of all individuals who identify themselves as mutually responsible for one another’s physical and emotional well-being on the basis of a personal relationship that *those individuals* regard as “familial.” This definition is based on the view that families are “inter-subjectively constituted,” constituted by choice, not in accordance with the “objective” criteria commonly used in legal rules designed to draw clear lines between what is and is not a family. The proposed definition is far more useful for analytic purposes in an international, multicultural, and rapidly evolving social context than a definition based on the historically contingent social patterns of a particular society. By identifying choice and mutuality of responsibility as the defining features of a familial relationship, the definition recognizes that the family takes diverse institutional forms and is primarily the creation of human subjectivity interacting in the social environment rather than the product of biological processes. Biological relationships are the necessary condition of only some aspects of some families; they are never a sufficient condition of a family in the inter-subjective sense used here.

IV. REPRESENTATIVE ACCESS SCREENING POLICIES

The assumptions and definitions adopted in the preceding sections provide an alternate perspective or lens, congruent with human rights principles, with which to examine representative access screening policies. Policies on access may be set out in the form of rules, such as:

Rule 1: Access on request; no eligibility criteria;

Rule 2: Access subject to eligibility criteria based on medical or socioeconomic factors selected to protect the interests of the patient or the public;

Rule 3: Access subject to eligibility criteria to protect the “best interests” of the child;

Rule 4: Access limited to selected groups. / No access by members of specific groups.

Policies providing for access on request without reference to eligibility criteria (Rule 1) and those barring access by persons who are, for example, disabled or ill, unmarried, or poor, for example (Rule 4), appear to be unambiguous. Yet even when rules of Type 4 reflect a deliberate rationale based on assumptions related to the public interest or the well-being of children, they may nonetheless be over-inclusive, under-inclusive, or counter-productive, and to this extent ineffective as a means to achieve specific objectives.¹¹ There is no guarantee that the actual characteristics or circumstances of persons who qualify for access under the rule will correlate, now or in the future, with a specific set of social or personal situational factors. Some traditional families are not optimum environments for raising children. By contrast, some family or social networks or groups provide emotional, social, and economic security to an extended network of individuals. At the same time, specific individuals may or may not make the decision to reproduce in a deliberate and responsible manner under either Rule 1 or Rule 4.

Rules 2 and 3 are overtly complex and ambiguous. Values and empirical assumptions must be used to construct the eligibility criteria in each rule and to justify the creation of the rule. The validity of the empirical assumptions and the propriety of the process used to select the values relied on may be controversial, however, whether a rule is simple or complex in form. Rules 2 and 3 are indistinguishable in this respect from Rule 4, despite the apparent differences. Interpretation and application of any rule requires elaboration of the eligibility criteria used in the rule and the exercise of discretion in interpreting and applying those criteria. In exercising discretion, decision makers necessarily rely to some extent on personal values and beliefs. Public authority is to that extent privatized. The phenomenon of privatization, inevitable in any legal system based on the rule of law, is arguably a serious flaw. But it is a systemic flaw that is commonly accepted as the unavoidable and not intolerable price of doing justice through the application of rules on the ground that some guidance is preferable to the exercise of untrammelled discretion. Making a rule more complex does not eliminate the need to exercise discretion in applying it. If a large number of eligibility criteria are included—in an attempt to avoid arbitrariness and limit the exercise of private authority—the decision maker must refer repeatedly to his or her values and beliefs in the process of assessing the facts, interpret-

11. Rules are designed with reference to specific patterns of fact and value. A "hard case" can always be found to test the adequacy of a rule. Most rules may appear consistent with more than one policy rationale depending on the set of background values and assumptions adopted. As a result, there may not always be unanimity about which cases actually are "hard cases" or when a rule is exhausted.

ing the criteria, and applying the rule to the facts.¹² Complex rules simply shape the expression of those values and beliefs and may even obscure or conceal their influence.

A. Eligibility Criteria and “Rationality”

The potential weaknesses of complex access rules based on multiple eligibility criteria must be balanced against the more “rational” and “enlightened” approach that they may appear to entail. Complex eligibility rules may specify race, ethnicity, marital status, or other social or formal legal status or characteristic, as a necessary or sufficient requirement for access. In the alternative, a number of criteria may be identified, each of which is believed to have a material relationship to specific social policy objectives. Such objectives typically include ensuring the health and well-being of each child and sometimes the health and well-being of the mother and her other children as well. This approach appears less arbitrary and more rational and enlightened precisely because it permits access decisions to be based on the existence of circumstances that are believed to have a direct empirical relationship, as causes or conditions, to the goals the screening policy is designed to promote. Access screening utilizing “objective” eligibility criteria based on “facts” that are deliberately selected for their relationship to individual and collective well-being is therefore widely viewed as a progressive and justifiable use of state power, even though one consequence is to limit individual self-determination and enhance the decision making power of agents of the state, whether they are healthcare providers or other state functionaries.

B. Access Policy and Systemic Values

From this overview, the four types of rules are seen to be subject to evaluation and comparison with respect to, at minimum: (1) clarity and ease in application versus vagueness and complexity in interpretation and application; (2) “arbitrariness” versus “rationality”; (3) protection or curtailment of individual self-determination; and (4) the apparent immediacy of the relationship between the rule and public policy objectives. The decision to adopt an access rule of a particular type, if it is a considered and deliberate decision, not an *ad-hoc* one, will tend to reflect the relative weight attached to the above characteristics by the policy maker.

12. Rule application always requires the exercise of some discretion; the content and structure of the rule merely determine which points require it.

Advocates of rules in the form of Rule 4, designed to limit access by members of specific groups, clearly must be prepared to curtail individual self-determination with respect to procreation. Although many feminists and classical liberals would support Rule 1, some would qualify their support for and reliance on self-determination and advocate instead on behalf of Rule 2 or Rule 3. Likewise, many liberal utilitarians would support Rule 2, if they attach more weight to the achievement of egalitarianism within the limits permitted by policies intended to protect individual and collective social welfare, or Rule 3, if they place a higher priority on protection of the interests of the most dependent members of the community, as those interests may be defined from time to time by and for the state. Yet, as most legislators know all too well, the interpretation and implementation of a rule may frustrate the intent of those who originally advocated its adoption. A complex rule offers multiple opportunities for the exercise of discretion by the decision maker interpreting and applying the rule. In addition, the operation of both simple and complex rules is often affected by unpredictable social and economic factors. For all these reasons, many policy makers, both those who initially favor rules of Type 2 or 3 because the content of those rules appears to be congruent with the goal of maximizing human well-being, and those who initially prefer rules of Type 4 because they appear to ensure certainty, will, on reflection, advocate adoption of Rule 1 as the most reliable means to achieve positive outcomes in the vast majority of cases over the long term.

Rule 1 bars screening and affirms a policy of unrestricted and equal access. In jurisdictions in which legislation affecting individual rights is subject to challenge in the courts on constitutional or human rights grounds, judicial review of primary or secondary legislation that mandates screening may result in its curtailment or prohibition. Where no legislation exists, decisions and guidelines that restrict access and have discriminatory effects still may be subject to challenge on constitutional grounds if state action is alleged or on public law grounds if legislation guarantees equal access to healthcare or prohibits discrimination by all institutions and associates of institutions receiving public funds. The fundamental question, however, is whether restrictions on access to reproductive services and technologies are ever legitimate, and if so, when.

V. ARE RESTRICTIONS ON ACCESS DEFENSIBLE WITHIN A HUMAN RIGHTS FRAMEWORK?

The social policy objectives adopted by a state and the means used to advance those objectives may be regarded as progressive, enlightened, or simply good public policy. Indeed, access screening often may be adopted in

large part because it is simply assumed to be an effective means to achieve valuable social objectives. Nonetheless it is necessary to ask what impact differential access has on individual and group interests. Here the frameworks for evaluation are ethical and political. The individual who seeks access (which here represents a chance to reproduce) and the immediate and wider communities whose interests are affected by that individual's reproductive activity may all have claims that require ethically sound responses. The other aspect of the evaluative framework is political. The inquiry then focuses on the relationships between the individual, the social and cultural groups to which the individual belongs, and the community as a whole. Policy on access to reproductive services and materials may have significant implications for those relationships.

We saw above that all rules and guidelines to restrict access are vulnerable to criticism. Indeed most rules, whether legislated or not, are generally subject to some of those types of criticism. What remains to be considered is whether such flaws are fatal *in the context of* legislation or guidelines restricting access to reproductive services, technologies, and materials. If legislation or regulatory guidelines could be crafted to achieve selected policy objectives with precision, would that suffice to legitimate the imposition of restrictions on access to reproductive materials, services, and technologies? Is it the blunt and faulty instruments used to implement restrictive policies that are objectionable, or is it the imposition of restrictions of any type that is indefensible? Are the individual and group interests affected by policies of differential access to reproductive services, technologies, and materials so fundamental that either the collective interest or respect for persons, or both, requires that individuals be protected against state imposed restrictions? Is it instead the case that the collective public policy objectives purportedly served by differential access outweigh the negative impact of procedural and substantive measures on individual and group interests? It is likely that legislators and judges in many jurisdictions will need to consider these questions in the near future?¹³

Differential access based on social or legal characteristics implies that the state, acting in the public interest, may limit reproduction by certain men and women. Other individuals may reproduce without restriction. In theory, it can always be argued that the collective social good or the welfare of potential children will be served by restricting reproduction by persons with the characteristics specified in a rule, whether it is income level, profession, education, religion, race, ethnicity, marital status, sexual preference, citizenship, or something else.¹³ Whether such arguments are persuasive

13. For example, if education is a scarce resource but children are not, the prevailing view might be that it is inappropriate for educated individuals to assume child-bearing or rearing responsibilities.

depends on social conditions, dominant cultural values, and the prevailing political ideology. Yet any restrictive access policy has discriminatory effects. In each case, the interests of the society as a whole and of the child or children whose possible future existence is at issue, *as these interests are perceived by decision makers empowered or permitted to act on behalf of the society*, determines the content of the rule and its interpretation. The effect of the rule is to deny specific men and women access to reproductive services and materials they require to achieve pregnancy and parenthood. To the same extent, the social and cultural groups to which these individuals belong are disadvantaged in their chances for expanding their membership through the birth of biologically related children. In all but the most homogeneous societies, any set of eligibility criteria will have a disproportionate impact on identifiable social, economic, ethnic, and racial groups. Insofar as differential access poses a threat to the continued existence and vitality of some cultural and social groups, it is compatible with political principles that devalue social and cultural diversity and support the creation of social and cultural homogeneity through the gradual assimilation and extinction of selected groups.

Access screening has significant impact on the lives of individuals. Parenthood and family relationships have long formed one of the central dimensions of cultural life. Cultural values are transmitted through the intimate relationships of family and immediate community. To restrict or deny reproductive options is to limit individual and group opportunities to create intimate personal relationships. To deny or limit a group's reproductive choices is therefore to increase the chance that its unique values, experiences, and world view will vanish, and that surviving members of that group will inhabit a social world that is increasingly alien. As the pool of shared economic resources and cultural capital shrinks, the material and spiritual lives of the survivors are impoverished. The restriction of access to reproductive services and technologies is therefore neither morally or politically innocuous. It is an affront to the "personhood" of the individual and is therefore inegalitarian in a fundamental rather than superficial sense.

If differential access based on social and legal criteria (Rule 4) is morally and politically unacceptable because it does not respect the equality of persons, then perhaps Rule 3, focusing directly on the "best interests" of the child, or Rule 2, requiring screening of all potential recipients to protect individual and collective welfare, is to be preferred. On reflection, however, it is apparent that before such rules are applied they must be expanded to include specific eligibility criteria. If these eligibility criteria refer to social, economic, and legal factors, the rules are subject to all the criticisms of rules in the form of Rule 4, discussed above. Criteria that are socially constituted, as all criteria based on social and legal characteristics are, tend to have a disproportionate and discriminatory impact on marginalized individuals and

the social and cultural groups to which they belong. Access rules incorporating such criteria cannot be justified on the ground of the “collective” or “public interest” or with reference to the “best interests of the child.” Any purported justification will tend to be a spurious representation of the values and interests of socially dominant groups in the guise of the “interest of the child” or the “public interest.”

Medical criteria, rather than social criteria, could provide the basis for eligibility in Rules 2 and 3. At first, this appears to be a promising approach. Medical criteria, *per se*, appear to be more objective than social criteria. Rules based on such criteria may therefore be less controversial. The living conditions associated with poverty may trigger the active onset of some medical problems, but otherwise inheritable medical conditions have no social or economic boundaries and appear to have no socially constituted elements. However, I argue below that because the significance attached to the probability that a particular characteristic will be genetically transmitted is socially constituted and value-laden, medical criteria are ultimately no more neutral than social or legal criteria. Eligibility rules incorporating either type of criteria are equally subject to criticism.

Even if access screening is rejected in principle, these issues will reemerge whenever technological expertise and other scarce resources must be allocated among potential recipients other than by an unregulated market. Triage will be required with respect to some of the more complex and expensive procedures because only a portion of the healthcare resources allocated to reproductive medicine will be available for the most resource intensive reproduction cases.¹⁴ In theory, triage can be by criteria, lots, or a combination of the two. Even most recipients competing for scarce resources would probably agree that the prognosis for success should have some bearing on how scarce resources are allocated. Some potential recipients will withdraw on the ground that they do not choose to undergo medical procedures that are unlikely to be beneficial or are unnecessary.¹⁵ However, when access

14. Funding policies generally distinguish between “essential” and “elective” health services. When “health” is defined as encompassing the emotional and interpersonal dimensions of health and well-being, reproductive services and technologies are easily classified as essential health services, *e.g.*, the WHO definition and the psycho-social implications of infertility as discussed by Daar & Merali, *supra* note 1, at 17–18. Within reproductive medicine, however, services used to maintain general reproductive health may have priority over highly resource intensive procedures.

15. Opinions can vary as to when services are “required” rather than “elective.” For example, although both single women and married women whose sexual partners are infertile may seek assisted insemination by donor, some physicians appear to view AID as socially appropriate only for married couples. See *Single Women will no longer be Tested for Emotional Stability*, *supra* note 18. The attitudinal difference may reflect a desire to protect marital stability while affording infertile husbands an opportunity to assume the social role of parent. The psycho-socio interests and physical health of single women and their families surely merit equal protection.

is not clearly counter-indicated on *medical* grounds because the treatment would be hazardous for the patient or futile, the patient's informed decision to seek access to a particular treatment or service should be determinative.¹⁶ Although the potential recipients of scarce treatment or services could be compared by reference to medical criteria chosen to reflect the relative probability of a successful outcome based on existing empirical studies, such predictions involve much uncertainty. Individuals are not responsible for all the health factors that form the basis for probable success rates, nor are they responsible for the collective decision to allocate total healthcare resources in a particular way. It is therefore not justifiable to use the projected probability of success to defeat the equal eligibility of potential recipients.¹⁷ This leads to the conclusion that the equitable allocation of scarce resources among the group of potential recipients for whom a resource intensive treatment is neither hazardous nor futile requires a randomized selection process, such as a lottery, based on chance, not criteria.

Are there other factors that should be considered when determining how medical resources are to be distributed? Family medical history, evidence of chromosome damage (from occupational exposure to toxic substances or environmental pollution), and recessive genes for inheritable diseases, some of which—Tay-Sachs, thalassemia, and sickle cell anemia, for example—are most prevalent among the members of particular ethnic groups, are considered in genetic counseling. Is it appropriate to use such information to deny a potential recipient access to reproductive services and technologies? Such policies are not self-implementing, however. Implementation requires that healthcare providers or other functionaries act in the name of the state as agents for the “public interest.” Guidelines need to be developed and standards for application of the guidelines devised. And finally, decisions have to be made in individual cases. What of a personal or significant family history of diabetes, cancer, heart disease, short-sightedness, obesity, or even flat feet?¹⁸ Environmental factors, over which the “public” but not the individual has control, may be identified as co-contributors with genetic factors in the etiology of particular diseases and conditions. Can agents acting in the “public” interest deny individuals medical and technical assistance in pursuing their reproductive objectives on the ground that any offspring

-
16. Access to impartial information about treatment options, risks, and success rates is essential. Independent counseling should also be available to patients. See Deech, *supra* note 3.
 17. Equality may be measured by outcome or opportunity. When distributing scarce resources, however, the crucial question is—what, if any, limit is to be imposed on the *total* resources allocated to *each* recipient?
 18. And what about flat feet? See Germaine Greer, *A Modest Proposal*, SPECTATOR, 14 Jan. 1978, reprinted in GERMAINE GREER, *THE MADWOMAN'S UNDERCLOTHES: ESSAYS AND OCCASIONAL WRITINGS, 1968–1985*, at 204–06 (1986).

may be predisposed to hypersensitivity to an environmental factor (which may exist only as a consequence of “public” choice) and therefore may be somewhat more likely than “average” to develop a disabling disease or condition? Any such policy would be socially divisive. Persons subject to one or more of the identified conditions could see it as a backhanded way of stigmatizing them as undesirables, persons who “better hadn’t been,” and might well regard such a policy as reason to believe government and the medical research establishment had abandoned them.

The key argument against restricting access by reference to such criteria is the simple one of equality, however. Few jurisdictions license people for procreation by reference to these or other criteria.¹⁹ Many jurisdictions that at one time had sterilization laws designed to limit reproduction by selected individuals and groups have repealed those laws on the grounds that they: (1) violate individual human or constitutional rights; (2) lack a sound empirical basis; and (3) invite abuse against which even complex procedural protections are insufficient. Oppressive social conditions, incarceration, institutionalization, and execution also have secondary effects that limit reproduction, but the use of such measures to limit or control reproduction by selected groups violates human rights.²⁰

The human significance of reproduction is fundamental. Any regulatory approach that curtails access to reproductive materials, services and technology, also curtails reproductive choice. As long as reproductive choice is at least in theory an individual matter,²¹ not controlled by the community or

19. In effect, adoption and child apprehension and protection laws create “licensing” and “suspension” powers with respect to parenthood. In reproduction, the issue is who shall determine whether potential children shall exist, not who shall determine the care children shall receive. Concerns about the *welfare* of children are best directed towards measures to enhance the general quality of life of all existing children.

20. Consider the treatment of aboriginal peoples under colonial and post-colonial governments and the strategic abuse of women’s reproductive capacities in ethnic conflicts.

21. In practice, reproductive decisions are subject to significant systemic influences. It is naïve to assume that reproductive choices are ever as fully “free” and “voluntary” as classical liberal theory presumes choice to be; the exercise of patient autonomy is inevitably constrained by socioeconomic circumstances and shaped by cultural values and expectations. In a multicultural society individuals’ choices will differ, even under socioeconomic conditions that are consistent with substantive equality. Achieving conditions of socioeconomic equality remains a challenge in most jurisdictions, however, and therefore some policy makers seek to protect individuals from exploitation by curtailing “free choice.” See April L. Cherry, *Choosing Substantive Justice: A Discussion of “Choice,” “Rights” and the New Reproductive Technologies*, 11 *WIS. WOMEN’S L. J.* 431, 431–41 (1997). However, transformation of the socioeconomic and political conditions that make exploitation possible, not protective legislation, arguably remains the most promising long term strategy to secure meaningful liberty. The role of government is then to foster the conditions required for the exercise of meaningful individual choice while continuing to protect the right of the individual to choose. See also Joan C. Callahan & Dorothy E. Roberts, *A Feminist Social Justice Approach to Reproduction-Assisting Technologies: A Case Study on the Limits of Liberal Theory*, 84 *KY. L. J.* 1197,

the state, principles of substantive equality clearly prohibit the restriction of access to reproductive services and technology by individuals who are competent to consent to medical treatment and choose to use reproductive technologies to achieve pregnancy. It would be arbitrary to limit the exercise of reproductive self-determination by those who use specialized medical services and technology but not by those who do not use them. The distinction would be contingent on whether an individual did or did not seek to use medical services and one or more of the simple or complex reproductive technologies as a means to achieve pregnancy. The use of such a distinction as a basis for selecting persons whose decision to reproduce is subject to veto by the state is irrational and opportunistic, at best. Any community that strives to function in accord with principles of equality and self-determination will necessarily reject restrictions on access to reproductive services and technologies on the ground that access screening infringes personal liberty and is morally and politically indefensible.

VI. IMPLEMENTATION OF EQUAL ACCESS

The resources required to review and make determinations under access screening policies should be redirected to provide reproductive information and counseling programs for *all* persons of reproductive age. Personal reproductive decisions made by well-informed persons with easy access to user-centered testing and counseling services will generally be carefully made and reflect concern for the interests of all significantly affected parties. Under these circumstances, the general welfare will be better served, as reflected in the overall quality of all the decisions made by all persons faced with reproductive choices, than it can be by a public or professional regulatory mechanism designed to curtail individual choice. In cases involving uncertainty, decisions would reflect the factors deemed relevant by the potential parent or parents. Faced with situations that were identical in

1197–1234 (1995). In the interim, autonomy arguably nurtures responsible agency, while protectionism may encourage deference to authority and delegation of responsibility. See Peggy Cooper Davis & Carol Gilligan, *A Women Decides: Justice O'Connor and Due Process Rights of Choice*, 32 McGEORGE L. REV. 895, 895–915 (2001). See also Alison Harvison Young, *New Reproductive Technologies in Canada and the United States: Same Problems, Different Discourses*, 12 TEMPLE INT'L & COMP. L. J. 43, 79 (1998), which compares some representative discussions of abortion and surrogacy and observes that: "Such choices are every bit as socially conditioned as a choice to serve as a surrogate might be, but we do not think of that as a very good argument in the abortion context for not allowing the woman to choose." This perspective supports the conclusion that genuine multiculturalism and the affirmation of the equal dignity and value of all persons requires respect and support for the reproductive choices made by each individual. After all, why should my social conditioning and religious-cultural values and beliefs trump yours or *vice versa*?

risk and prognosis from a medical point of view, not all potential parents would make identical choices. A user-centered process that supports and ensures a place for expression of the priorities and values of the individuals directly affected by each decision has legitimacy within an egalitarian political framework that is necessarily absent when individual decisions are generated by a regulatory mechanism. In a regulatory approach, the only cases reviewed are those in which the patient seeks medical intervention. The decision in each such case must be justified by reference to the interpretation and application of a rule. The results are necessarily somewhat arbitrary, despite all best efforts, and the process is subject to all of the criticisms raised above.

By contrast, individual control over reproductive choices protects social diversity and pluralistic values. It avoids the social divisiveness and alienation inevitably produced by even the most carefully administered state imposed regulatory scheme, affirms the equal personhood of individuals, and recognizes that even in jurisdictions that provide significant social welfare programs on behalf of children, the primary interest in and immediate responsibility for children lies with their parent or parents and families. Individuals are in the best position to make decisions that reflect their cultural values and socioeconomic circumstances. Within the framework of the principles and assumptions adopted and applied here, it is therefore clear that the only legitimate access policy is the unrestricted policy formulated in Rule 1. Of the four policies discussed, this is the only one that is consistent with: (1) the definition of the "family" as "inter-subjectively constituted," created by the choices of the participants and thus the product of human subjectivity interacting in the social environment, and (2) the principle that all persons, as moral and political agents, have equal rights of self-determination.

It is further apparent that the four types of access policy rules examined above have different social effects and political implications. The adoption and use of any of these rules inevitably shapes the community's consciousness of itself, its self-identity, and contributes to the cultural and political ideology and world view that characterizes the community as a whole. If, for example, it is assumed that only males are capable of making responsible decisions with respect to reproduction, a version of Rule 4 that prohibits access to reproductive services by single women will be preferred and informed consent by a male partner may be explicitly required. Rules of Type 2 and 3 will appear desirable if members of the community assume that an agent authorized directly or indirectly by the state should be the decision maker. Rules of Type 2 and 3 require collective deference to the values and assumptions held by the individuals who act as decision makers on behalf of the state, including their assumptions about the probable impact of the existence of potential individuals on the interests of the community. Even the most responsible decision makers acting in good faith may be influ-

enced to some extent by the social ignorance and prejudice found in most communities. By adopting rules of Type 2 or 3, the community acquiesces in the social effects of those rules, including any discrimination that results from their interpretation and application.

The shift in focus between rules in the form of Rule 2 and those in the form of Rule 3 is only apparent. Both imply that patients may not make appropriate decisions and agents of the state know what is best. Such rules are not founded on principles of egalitarianism, individual responsibility, and self-determination, are inherently elitist, and easily lend themselves to authoritarianism. An institutional arrangement that does not give control over matters of fundamental importance to the persons who are most directly affected is socially dangerous. Benevolence easily disguises and conceals totalitarian impulses, even from the actor. Screening to determine which potential users may access reproductive technologies and related medical services as a means to achieve personal reproductive objectives is therefore indefensible from a moral and political perspective. This conclusion pertains to screening performed on behalf of the state pursuant to a legal mandate, as well as to screening by individual healthcare providers in reliance on either personal opinion or professional guidelines and protocols.²²

VII. ACCESS TO REPRODUCTIVE MATERIALS: AN EXCEPTION TO THE RULE?

In many jurisdictions, the relationship between donors and recipients, and between donors and resulting children, is one of anonymity mediated by healthcare providers. The donor has no direct control over selection of the recipients of his or her donated material and no right to knowledge of the identity or subsequent life circumstances of any biological children produced. Some donors have no interest in the quality of life enjoyed by these children; others do. People who are unwilling to relinquish responsibility for their biological children do not become donors. Some people are prepared to be donors only if they are confident that the well-being of the biologi-

-
22. Once the link between power, hierarchy, and beneficence is grasped, neither politics nor professionalism can ever be the same again. See Uma Narayan, *Colonialism and Its Others: Considerations on Rights and Care Discourses*, 10 *HYPATIA* 133, 134 (1995) (drawing upon the writings of Edward Said and observing that “benevolence” and the rhetoric of the “ethics of care” were used to make colonialism “morally palatable to those engaged in the infliction of domination”). Colonization was portrayed as conferring material, cultural and moral benefits, while issues of power and domination/subordination were neither acknowledged nor addressed. I suggest that members of professional elites, especially those in the “helping professions,” are as easily seduced into believing that the “benevolent” exercise of power is legitimate as Narayan suggests many colonial functionaries likely were.

cal children produced with the material they donate is likely to be secure. These are the only individuals subject to influence by the policy on access to donated reproductive materials. The concerns of this group of potential donors may appear to provide an independent rationale for access screening, especially if the participation of these donors is assumed necessary to maintain a supply of reproductive materials adequate to meet the requirements of the entire community, including members of minority groups.

This rationale for access screening requires careful scrutiny. If donors are reassured that all recipients are screened, a fiduciary relationship between the donor and the cryo-bank is created because donors who are concerned about the welfare of potential children may rely on that representation. This arguably makes the administrators of cryo-banks responsible for access screening. Thus an immediate consequence of advising donors that recipients are screened is the reemergence of many of the issues discussed above as healthcare professionals attempt to cobble together an approach to screening that fulfills what they assume to be their "duty" to the donors. The approaches that emerge may cover the entire spectrum, from little more than the minimalist approach proposed above to preclude frivolous use of donated material, to a highly personalized approach in which the decision maker attempts to assess the recipient as a potential parent using criteria he or she assumes a typical donor or society would use. It is often assumed that "social policy" and "typical donor preferences" reflect the preferences of the "average reasonable and prudent person." This description is notoriously vague and is easily interpreted to mean "someone like me." Even when such an assessment is undertaken in good faith using criteria the reviewer sincerely believes screening requires, those criteria usually reflect the personal values, preferences, and biases of the reviewer.

Thus the inevitable result of delegation by donors to cryo-banks of the power to determine who the recipients of reproductive material shall be, is the creation and legitimation of unrestricted power to determine which potential recipients of reproductive material shall be given an opportunity to reproduce. Some healthcare providers will seize this as an opportunity to engage in eugenics in accordance with the criteria they personally deem to be appropriate. The same objectives can be pursued using criteria drafted by a committee or clinic staff. Eugenics is eugenics whether it occurs through a collegial process or pursuant to the preferences and prejudices of a decision maker acting alone. Such screening, I submit, is open to all of the objections raised above. Unchallenged it facilitates the imposition by healthcare providers of controls over procreation in the absence of any medical justification in all cases that require the use of donated reproductive materials. This practice reinforces an ethos of expert authority in reproductive medicine and thereby invites the extension of screening practices to reproductive services that do not require the use of donated material.

In particular, in cases where reproductive material is required it is clear that if access screening is practiced on the ground of a fiduciary duty to donors, any policy of unrestricted access that may have been implemented, as proposed above, will be subverted and rendered wholly ineffective. It is therefore imperative to address donor expectations fully and in a manner that *eliminates any expectation* that donated reproductive material will only be available to recipients selected by a screening process.

To that end, potential donors should be provided with educational materials explaining the inherent limitations of screening and the negative social and political effects of screening programs and, where available, statistics and representative recipient profiles. Potential donors should be advised that recipients are not screened and that donors are not permitted to impose restrictions on the use of the donated material. The only exception would be when material was donated solely for use by a specific individual pursuant to an agreement between those parties. All other donors should be required: (1) to delegate to any potential recipient of the donated material irrevocable authority to determine whether and when the reproductive material the donor contributed is used, and (2) to provide comprehensive personal and family medical information, as well as detailed information about ethnicity, race, religion, education, etc. These profiles, together with any information obtained through genetic testing, should be available to patients who need to select donated reproductive material for personal use. Periodic donor recruitment campaigns should be conducted to ensure that sufficient reproductive material is available to meet the diverse needs and preferences of all potential recipients in the community, including those who are members of minority groups. This approach should generate adequate donations and eliminate pressure to accept reproductive materials from donors who insist on restrictive conditions.²³ The result will be to ensure that the apprehension that unrestricted access may result in an insufficient supply of donated reproductive material cannot be raised to justify or excuse a policy on access to reproductive materials that is more restrictive than the policy for access to reproductive services and technologies.

23. A recent Swedish study of donor recruitment concluded that the characteristics of recruits vary but are "typified by a strong desire to assist infertile couples." A. Lalos et al., *Recruitment and Motivation of Semen Providers in Sweden*, 18 HUM. REPROD. 212, 216 (2003). The motivation to help was strongest when the donor had infertile friends or acquaintances or had otherwise become aware of the social and psychological issues infertility posed for specific individuals.

VIII. FROM THEORY TO PRACTICE—THE IMPLICATIONS OF HUMAN RIGHTS FOR REGULATION OF FERTILITY CLINICS—A CANADIAN EXAMPLE

The practice of screening persons who seek access to reproductive services has profound social and political significance. Access screening affects individuals and families and shapes a community's social and political identity. Analysis of the methods used to screen potential users of fertility services showed that access screening often lacks a defensible rational basis, is inconsistent with the principles of equality and self-determination, and violates human rights. Human beings are quite capable of deciding whether and when they wish to reproduce and choosing the means they prefer to use to achieve that objective. Decisions to use treatments and technologies to enhance fertility and achieve and sustain pregnancy are no different in this respect from other types of reproductive decisions. All reproductive decisions are fundamental expressions of personhood. Egalitarian principles require equal respect for the personhood and fundamental human rights and interests of all human beings.

I submit that we must conclude that no community that strives to function in accord with those principles and to protect human rights should permit unregulated access screening by healthcare providers. To date Canada has not taken steps to address this matter though empirical evidence suggests that pro-active regulatory measures are required to protect the human rights of those who seek access to fertility services. The Saskatchewan human rights complaint, discussed above, dealt with the practices of a single Canadian clinic in the 1980s but those practices and the attitudes that gave rise to them are likely representative of a much broader phenomenon.²⁴ The results of research on access policies in the United States provide indirect support for that inference. Professional medical culture in Canada in relation to access to fertility services may be somewhat different from that found in United States due to Canada's adoption of principles of equal access to universal healthcare and the influence of the Canadian Charter of Rights and Freedoms²⁵ on professional norms in reproductive medicine generally. In both jurisdictions, however, reproductive choice continues to be a controversial subject that raises sensitive issues for many clinicians. Researchers found wide variation in access policies and rationale in the United States and concluded that "most clinicians practicing ART are struggling with access issues . . . and further discussion of access to services issues as well as some training in systematic approaches to solving complex ethical problems could be very useful to

24. *Single Women will no Longer be Tested for Emotional Stability*, *supra* note 18.

25. CAN. CONST., *supra* note 9, ch. 11.

clinicians in this field."²⁶ It would be useful to conduct similar research in Canada. In the meantime, there is every reason to believe that Canadian clinicians are also struggling with access issues. Indeed, based on the limited evidence that is available, I submit that we must assume this to be the case and prevail on government to take affirmative steps to protect the human rights of persons who seek access to fertility services in Canada.

In the current legal and political environment, it is obvious what those steps should be. In 2004, following more than a decade of research and broad consultation, Parliament enacted federal legislation to regulate the use of reproductive technologies and materials. As yet, however, only portions of the legislation are in effect and some elements of the projected regulatory mechanism have yet to be established.²⁷ And, although the legislation affirms that reproductive technologies are not to be used in a manner or for purposes inconsistent with human dignity and equality, the Act does not prohibit access screening. That issue remains open.

I propose that it be addressed in the regulations to be promulgated under the Act and in policies developed by the regulatory agency to be established pursuant to the Act. Federal regulations that impose strict conditions on clinic licenses should be enacted to ensure that access decisions are based on legal criteria. No lesser measure is adequate to ensure equal access to fertility services across the country. Until a well-articulated and principled legal framework for dealing with access issues is established, questions affecting access to fertility services will be routinely decided by clinicians solely on the basis of their personal and professional views, often without a coherent or principled rationale. Clinic policies, though they may be set down in writing, will not necessarily be the product of systematic and principled reflection or respect individual rights.

That is unacceptable and must not continue. It is morally repugnant and politically intolerable to subject individuals to access screening based directly or indirectly on social, ethnic, racial, cultural, or economic criteria to determine who shall be eligible to reproduce. A narrowly limited set of medical criteria, strictly defined in law and uniformly applied, will suffice to preclude the patently frivolous use of healthcare resources or criminally negligent treatment of patients.²⁸ In all other cases, reproductive materials,

26. Stern *et al.*, *Determining Access to Assisted Reproductive Technology: Reactions of Clinic Directors to Ethically Complex Case Scenarios*, *supra* note 8, at 1351. See also Daar & Merali, *supra* note 1, at 394.

27. ASSISTED HUMAN REPRODUCTION AND RELATED RESEARCH (AN ACT RESPECTING), c.2 (S.C. 2004), *assented to* 29 Mar. 2004; *entered into force* 22 Apr. 2004, *except* ss. 8, 12, 14–19, 21–59, 72, 74–77 (SI/2004-49).

28. Under Canadian law no one is a legal person with rights protected by law prior to his or her birth. Maternal decisions that may affect the health or well-being of a fetus are not within the *parens patriae* jurisdiction of the courts. Courts will not curtail maternal

services, and technologies should be accessible to everyone who is legally competent to consent to treatment and chooses to use them to become pregnant and give birth, in accordance with principles of equality and self-determination. The fundamental nature of the human interests affected by access screening requires deference to the principle of self-determination.²⁹

liberties to protect fetuses. To make decisions on behalf of unborn children would require the courts to intrude on the rights and liberties of women. *Winnipeg Child and Family Services (Northwest Area) v. D.F.G.*, 3 S.C.R. 925 (1997).

29. State regulatory action that violates human rights cannot derive legitimacy from the existence of legal rules mandating the activity. Either the inadequacy of the rule making and decision making processes to the gravity of the issues at stake or the nature of the individual interests affected, or both, may be grounds not to place certain decisions in the hands of agents of the state at all.