



## NOTES AND COMMENTS

### HUMAN GENOME AND HUMAN RIGHTS: AN OVERVIEW

THE BIOTECHNOLOGICAL developments relating to human genome<sup>1</sup> have made great strides in recent years. The biology-based technologies with significant socio-politico-economic, ethical, moral and legal implications have led to dramatic transformations in the society. No single discovery has had such a great impact on mankind during the last 50 years than the discovery of the structure of DNA by Watson and Crick. Then came the breaking of the genetic code and introduction of the recombinant DNA technology.<sup>2</sup> With this, mankind stepped from the *slow* Darwinian evolution to the uncertain future of human determined artificial evolution.<sup>3</sup> Emerging techniques in genetic testing and manipulation of the genes can transform the framework that underpins the practice of clinical medicine, from one of “diagnosis and treatment” to one of “prediction and prevention.”<sup>4</sup>

These radical transformations made by genetic advances have launched us into a bio-society or what critics call a ‘bio-technocracy.’<sup>5</sup> In such a society biological advances often dictate our life on their own terms, affecting the basic human rights and traditional social structure. In a society that has come to view its members as just so many cells or molecules to be manufactured or rearranged at will, one wonders how easy it would be to recall all the shouting about “human rights” was supposed to mean.<sup>6</sup> Modern biotechnological advances relating to human genome have posed various new challenges before law, giving rise to a plethora of ethical, legal, social and cultural issues with far reaching implications for humanity. These have

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1. The sum total of the human genetic material present in a particular organism is known as human genome.

2. Recombinant DNA is DNA from two different sources that has been combined *in vitro* (outside living organisms). It is used for genetic transformation to produce genetically modified organisms. Recombinant DNA products include insulin, growth hormone, oxytocin, vaccines etc.

3. V. Ramalingaswami, “Scientific Opportunity and Ethical Quandary” in M.G.K. Menon *et al* (Ed.), *Human Genome Research: Emerging Ethical, Legal, Social and Economic Issues* 11 (1999).

4. “Mapping the Human Genome: Genetics Revolution” 391 *British Medical Journal* 1282 (1999).

5. Bartha Maria Knoppers, “Who Should have Access to Genetic Information?” in Justine Burley (Ed.) *The Genetic Revolution and Human Rights* 39 (1999).

6. L.H. Tribe, “Technology Assessment and the Fourth Discontinuity: The Limits of Instrumental Rationality” 46 *South California Law Review* 648-9 (1973).



a great impact on basic human rights e.g. right to life, right to privacy, right to dignity, individual autonomy, procreative liberty etc. The present paper is an attempt to locate various human rights issues relating to human genome, discussing the nature of the problem and the role of law, covering some important developments – genetic information, patenting of human genome, assisted reproductive technologies viz. artificial insemination, surrogacy and reproductive human cloning.

### **Problems and Prospects**

The neo-natal technologies relating to human genome are still premature and their efficiency is not beyond doubt. Against this backdrop, wide promises are being made by multinational companies which are funding human genome research. Sceptics argue that the knowledge gleaned from the human genome may, paradoxically render us less human if we use it to embark on a wholesale tinkering with the very process of evolution.<sup>7</sup> The exciting chain of events carries with it profound ethical, social and regulatory responsibilities along with progress.<sup>8</sup>

### **Pace of the technology and social change**

So rapid are the advances and so sophisticated and complex are the details of science and explanations of the technology, that even an informed person finds it difficult today to comprehend exactly what is happening. Today, the difference between the rate of scientific and technological change and the rate of social change in which there is real assimilation of scientific and technological discoveries of the time has become large and continues to increase. This situation has created an ideal environment for exploitation of the society by scientists and technologists.<sup>9</sup>

### **Economic concerns relating to human genome**

This is the age of “Homo economicus”. Human genetic material is increasingly becoming an object of commerce. The issues raised by human genetics reveal confusion and concern among policy makers and the general public about the appropriateness of commercialization.<sup>10</sup> The enormous

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7. *Supra* note 4.

8. *Supra* note 3.

9. P.M. Bhargava, “Ethical Issues in Modern Biological Technologies” available at <http://www.rbmonline.com/Article/915> (visited on 2 Mar 2007).

10. Bartha Maria Knoppers, “Commercialization of Genetic Research and Public Policy” 286 *Science* 2277 (1999).



and rapid developments in biotechnology and genetic engineering, sometimes qualified as a pre-requisite for a third industrial revolution have a profound impact on human rights.<sup>11</sup>

### **Challenges before law**

Unless the information unleashed by the human genome research is subjected to the control of law, there are great chances of evil. There is an intimate relationship between science, law and society. Science cannot tell us how to live our lives. It is silent on ethical and moral issues. It is the scientist's job to find the ways in which technology can serve humanity but it is not his responsibility to determine whether a nuclear weapon should be used or not. It is the society as a whole that must frame and enforce moral as well as legal codes of human conduct. But the problems relating to law-human genetic interface are so complex that it is not easy to identify the legal issues relating to human genome. These problems are not purely legal but intertwined with ethical, moral, social and economic problems. So, it is difficult to get correct answers without posing the correct questions. This is a task which law can only fulfil – if it is adequately informed and illuminated by scientific knowledge and ethical conduct.

### **Genetic information**

In the 'human genome-human rights' debate, genetic information becomes a vital issue to be discussed in detail. Genetic information is ultra-sensitive. Unlike other medical information, genetic information holds distinct characteristics. Genetic tests divulge information not only about the person concerned but also his genetic relatives. These tests are predictive in nature. The information gained from genetic tests may predict future risks for healthy individuals and can also reveal both present and future health information about biological relatives of the individuals tested in a way that no medical information can. It is prone to be abused by the governments and others who control resources. From the human rights point of view genetic information raises issues of privacy, confidentiality, employment and non-discrimination. The discussion in the present paper revolves around the fundamental concepts of privacy and confidentiality. Here genetic privacy becomes a debatable issue but before discussing genetic privacy, it becomes pertinent to have a brief discussion about right to privacy as a human right.

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11. Virginia A. Leary, "Globalization and Human Rights" in Janusz Symonides (Ed.), *Human Rights: New Dimensions and Challenges* 18 (1998).



### Right to privacy

Privacy as a fundamental human right is recognized in the Universal Declaration of Human Rights,<sup>12</sup> the International Covenant on Civil and Political Rights<sup>13</sup> and many other national and international treaties. Nearly every country in the world recognizes right to privacy explicitly in their Constitution. In others, where privacy is not explicitly recognized in the Constitution, such as the United States, Ireland and India, courts have found that right in other provisions and have adopted international agreements that recognize privacy rights.<sup>14</sup>

### Right to genetic privacy

The fundamental postulate of right to genetic privacy is that an individual's genetic information is intrinsic to the individual and cannot be introduced in the public domain without the consent of the individual in question.<sup>15</sup> The ability of genetic information to provide both identification and sensitive information related to health and other predisposition has led to a lively debate about appropriate privacy protections. Proponents of "genetic exceptionalism" claim that genetic information deserves explicit and stricter protection under the law.<sup>16</sup> In the US, Genetic Privacy Act is a proposal for federal legislation. The Act is based on the premise that genetic information is different from other types of personal information in ways that require special protection. The DNA molecule holds an extensive amount of currently indecipherable information. The major goal of human genome project is to decipher this code so that information it contains is accessible. The privacy question is - accessible to whom?<sup>17</sup> Laws in every state of the US protect the privacy of medical records to some degree. In addition genetic-specific privacy protections exist in 28 states, although the measures vary widely.<sup>18</sup>

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12. Art. 12.

13. Art. 17.

14. "Privacy and Human Rights : An International Survey of Privacy Laws and Practice" available at <http://www.epic.org/privacy/survey/intro.html>.

15. Shyam Krishna Balganes, "Genetic Privacy: The Emergence of New Paradigm in Medical Confidentiality" 7 *Health Care: Policy Ethics and Law* 6 (2000).

16. "Genetic Privacy" available at <http://www.epic.org/privacy/genetic/> (visited on 4 Mar 2007).

17. "The Genetic Privacy Act and Commentary" available at <http://www.ornl.gov/sci/techresources/HumanGenome/resourse/privacy/privacy.lhtml>. (visited on 6 Aug 2004).

18. Sheetal Asran Dann, "The Right to Privacy in the Era of Smart Governance: Concerns raised by the Introduction of Biometric – Enabled National ID Cards in India" 47 *Journal of Indian Law Institute* 62 (2005).



In India, as of now, there is no comprehensive privacy legislation. The right to privacy is not explicitly enumerated in the Indian Constitution and hence judicial pronouncements of the Supreme Court of India provide the basic source for both the purposes and the content of the right to privacy. With a zeal to translate the philosophy of the right to life and liberty into reality, the Supreme Court has recognized privacy as fundamental right and defined it in cases<sup>19</sup> involving police surveillance, phone tapping, media attention and so on. However, the jurisprudence of the court is still evolving. While some facets of privacy have been defined, the need for privacy of personal data in public and private sector databases has not been adequately addressed.<sup>20</sup> Thus, there exists a huge gap between the privacy needs of individuals and existing legislative protection in India.<sup>21</sup> In such a situation genetic privacy seems to be a far cry. But, to keep pace with the technology, some sort of specific treatment is a *sine qua non*. Privacy undeniably has great value, but policy makers also should recognize the effects of privacy laws on other social goods, such as health care, medical research and public health. The future challenge for policy makers lies in striking an equitable balance among privacy protections and other worthy goals.<sup>22</sup>

#### **Genetic counseling and informed consent: Law and ethics**

Genetic counseling requires more responsible role of the health professionals. However, the regulation of genetic counseling involves not only stringent legislations but some ethical conduct. The medical professionals, scientists etc. do not always need an external agency to monitor and enforce it. This is what makes the difference between law and ethics. Both have the same objects but operate in different ways. One (law) puts down the minimum standards while the other (ethics) presents a goal to which at least elite in the society must endeavor to conform with higher and higher levels of value orientation that civilized societies are aspiring to give to human life and existence. But because of the breakdown of conventional control systems in many societies, it has come to the lot of the legal system not only to take care of rights but also the requirement of the ethical conduct on the part of those exercising power.<sup>23</sup>

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19. *Govind v. State of M.P.*, AIR 1975 SC 1378; *People's Union for Civil Liberties (PUCL) v. Union of India*, (1997) 1 SCC 301; *R. Rajgopal v. State of T.N.*, AIR 1995 SC 264.

20. *Supra* note 18 at 65

21. *Ibid.*

22. Alissa Johnson, "Genetic Privacy" available at <http://www.astho.org/templates/display/>

23. N.R.Madhava Menon : "Role of Law in Human Genome Research and Applications" in *supra* note 3 at 186.



The issue of informed consent has become very complex because human genetics is highly advanced technology and its complexities are proved to be a great hurdle in obtaining an informed consent. In such a situation the condition of poor and illiterate people becomes vulnerable. From the patient's point of view there is very strong expectation that privacy and strict confidentiality are at the heart of therapeutic relationship, with confidentiality an important tool for protecting privacy. Medical confidentiality reflects the importance placed on this privacy and special protection of genetic information.

### **Genetic discrimination**

Genetic discrimination may be defined as discrimination against otherwise healthy individuals on suffering from a disease or condition in future. It creates fear about the formation of a new underclass based on genetic discrimination, the asymptomatic or "healthy ill" whose abnormality only lies in their genes. Employers may use the information to deny employment to individuals who may have potentially expensive future health problems. Health insurers may use the information in risk-rated health insurance to increase insurance rates substantially or to deny insurance altogether.<sup>24</sup> So the terms and conditions determined by insurers and employers on the basis of the genetic tests certainly violate the basic human rights. A breach of privacy can result in economic harm if a person is refused insurance on the basis of genetic tests and results.

Here the interests of insurers and employers also cannot be ignored because unless the insurers have access to some information as to the applicant, they are at a disadvantage and may suffer from adverse selection. Employers also have an economic interest in the health of their employees. When employees are in poor health they are less productive. The challenge is to anticipate the possible abuse of genetic information and to ensure that appropriate ethical and legal safeguards are in place. In analyzing privacy issues the extent and circumstances in which it is appropriate to invade the privacy of another must be considered. Crucial to any reforms at the national level is the adoption and integration of guiding principles of both UNESCO's Declaration on Human Genome and Human Rights, 1997 and Council of Europe's Convention on Bio-medicine.

### **Patenting of human genome**

The most common objection regarding the patenting of human genome is that human genes occur naturally; they are there to be discovered and not

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24. World Health Organization, *Genomics and World Health, Report of the Advisory Committee on Health Research* 157 (2002).



invented. The foundational case for the patenting of living organism is the much-debated *Diamond v. Chakraborty*.<sup>25</sup> In this case the US Supreme Court decided that genetically engineered (modified) bacteria were patentable because they do not occur naturally in nature. While recognizing living organisms as patentable subject matter, the court gave the widest possible interpretation to the term ‘manufacture’ and ‘composition of matter’ in section 101 of the U.S. Patent Act by stating that it could include ‘anything under the sun made by man’. The court adopted the test of ‘human intervention’ in making a difference between discovery and invention. Human genes and gene fragments became common subjects for patents in the years following *Chakraborty*.<sup>26</sup> TRIPs agreement contains no definition of ‘invention’ and it leaves members free to draw the line between discoveries and actual inventions in the biological field. The TRIPs agreement excludes the plants and animals from patentability but makes it obligatory to provide patents for “microorganisms” and “microbiological processes.” The word “microorganism” has not been defined in the TRIPs nor does the agreement specify any parameters concerning the scope of its protection. No international convention defines the word “microorganism” or lays down criteria regarding the nature and extent of its protection. However, it is clear that the term “microorganism” will be understood in its widest sense to include any biological material that is self replicable or replicable via a host organism.<sup>27</sup> This leads to wide patenting of human genome including gene fragments, proteins gene tests etc. It is well accepted by many countries that the human genome and other naturally occurring genomes are *res communis* – the common heritage of mankind – and, therefore, should not be subject to patents. UNESCO’s Universal Declaration on Human Genome and Human Rights, 1997 states that the human genome is the heritage of humanity and in its natural state it should not be used for financial gain. The implication is that the genome and its elements are patentable when not in the natural state. The European Union’s Directive on the Legal Protection of Biotechnology Inventions adopts a similar approach, stating that neither the human body nor its components are patentable subject matter while within the body but that they become patentable when removed from the body.<sup>28</sup>

However, the US patent laws are too lax, allowing patents on gene fragments, the real functioning of which is yet to be fully known. Patenting

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25. 447 U.S.303 (1980); 65 L2d144.

26. Linda J. Demains & Aaron Xavier Fellmeth, “Reinventing the Double Helix : A Noble and Non Obvious Reconceptualization of the Biotechnology Patent” 55 *Stanford Law Review* 319-20 (2002).

27. S.Vedraman, “Human Genetics- Bioethics Symposium : Emerging Ethical, Legal, Social and IPR Issues” in *supra* note 3 at 161.

28. *Supra* note 26 at 444.



of gene fragments, gene tests etc. require great concern because the knowledge derived from these are not always full. There is a great need to ensure that the economic developments that occur in relation to patent protection over essential advances affecting the human genome happen in a harmonious way with human rights development that advance accessibility to the tests and therapies of people in all countries not just in the developed world.

### **Assisted reproductive technologies (ART)**

Assisted reproductive technologies such as artificial insemination, *in vitro* fertilization, surrogate motherhood have been proved to be a blessing for many infertile couples. The new reproductive technologies have given hope to many women and helped many women to have children that they would not have had otherwise.<sup>29</sup> But along with potential benefits, modern reproductive technologies have posed various complex legal problems relating to family law and basic human rights. Assisted reproductive technologies have raised a number of human rights issues, including right to dignity, individual autonomy, right to know, procreative liberty etc.

#### **Artificial insemination**

Artificial insemination is the insertion of sperm into a woman's vagina to cause pregnancy using a method other than sexual intercourse. Where the male genetic material of the husband is introduced artificially into the woman's body, it is known as "Artificial Insemination Homologous" or Artificial Insemination Husband" (AIH). Where the genetic material is obtained from male other than the woman's husband, it is called "Artificial Insemination Donor (AID)". From the human rights point of view AID generates much heated debates.

#### *Anonymity and non-anonymity of gamete donor*

One of the most problematic human rights aspects relating to AID is concerned with the anonymity of gamete donor. At the international level, the vast majority of countries endorse anonymous gamete donation and some countries such as France, Denmark and Norway do not allow offspring any information. In England, the Human Fertilization and Embryology Act, 1990 stipulates that gamete donation should be anonymous; the identity of the donor cannot be given to either the donor offspring or the couple receiving the gametes. There is, however, in recent years a discernible

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29. Belinda Bennett, "Reproductive Technology, Public Policy and Single Motherhood" 22 *Sydney Law Review* 631 (2000).





trend towards allowing children access to identifying information about their gamete donor. The first country to remove the anonymity of gamete donor was Sweden, allowing the child, when sufficiently mature, to find out the identity of sperm donor. Austria also allows the child to gain identifying information. In the US, there is no legislation, at either federal or state level, that either prohibits or enforces anonymous gamete donation. The matter is regulated by non-legally binding professional guidelines, which recommend the anonymity of gamete donors.<sup>30</sup>

*Child's right to know vis-à-vis parent's right not to tell the genetic origin*

Many societies in the present time have begun to place greater emphasis on the rights of child. Article 7 of the UN Convention on the Rights of the Child, 1989 can be seen as being of fundamental importance as it provides for the right to know one's parents. In the context of donor anonymity it has been expressed as the child's right to know the identity of gamete donor. In our contemporary culture young people have strong moral claims to know the genetic identities. It has been contended by some that now it is time for these moral claims to convert to legal rights. Such a right-based argument has been used by various legislators to justify policies of non-anonymous gamete donation. There are some people who argue that in case of gamete donation there are compelling reasons for not telling the child. It has been contended that it is not in the best interest of child to tell about the gamete donation because there is a fear that telling a child how they were conceived would cause severe social and psychological problems. A further reason for not telling the child is that parents should have a right to privacy and if they keep such information confidential that is their prerogative.

It is clear that balancing of these competing interests is a difficult matter that requires a full debate, discussing the merit of each case. However, in future it might well be the choice to be made between a reduced, non-anonymous programme that respects the child's right to know and a much wider anonymous programme that seeks to benefit a greater number of childless couples.<sup>31</sup>

### **Surrogate motherhood**

Surrogate arrangements<sup>32</sup> have created a lot of confusion in legal

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30. Lucy Frith, "Gamete Donation and Anonymity" 16 *Human Reproduction* 819 (2001).

31. *Id.* at 823.

32. Surrogacy arrangements are agreements under which a woman agrees to bear a child for a couple (or, less frequently, a single person) often called the "commissioning" couple or person. The woman is either artificially inseminated with the sperm of the commissioning man (or a donor) or she is implanted with the embryo produced *in vitro*



circles, posing new challenges. The bifurcated role of woman in surrogate arrangements is prompting renewed assessment of the meaning of motherhood and the designation of maternal rights.<sup>33</sup> From the human rights point of view the underpinning issues involve right to individual autonomy, procreative liberty, right to dignity, right to privacy, commercialization of human body etc.

#### *Individual autonomy*

The principle of autonomy is often invoked as a justification for allowing surrogacy. This principle states that people have the freedom to decide what to do with their bodies provided that no harm is caused to others. The fundamental fallacy of the autonomy argument lies in the fact that the decision a woman makes to have a child (*i.e.* to do something with her own body) is not the issue in case of surrogacy but rather the decision to give the child to someone else who happens to want it.

#### *Procreative liberty*

As courts have struggled to define the parameter of procreative choice, the right of procreation has received its most extensive legal expression as a right not to procreate.<sup>34</sup> Included in the right to procreate is the right to conceive. Abortion is a right to conceive followed by a protected option – a right not to procreate. Surrogate motherhood is the inverse: a right to conceive that should also be followed by a protected option – a right to procreate. In the abortion case, the mother's conception is only biological in origin. In the surrogate mother's case, the initiating mother's conception is only mental. Different kinds of protection are required for conceiver to realize different kinds of procreative intent.<sup>35</sup> Courts in abortion cases must balance the rights of a mother and a child, whereas courts in surrogate cases must balance the rights of two mothers and a child. However, in both cases, the fundamental right of conception as a predicate of the right to procreate is at stake. Because even infertile mothers can exert their right of psychological conception, they too have a procreative right that courts should preserve. Conscious and intentional exertion of the right to procreate

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from the gametes of one or both of the commissioning couple (or from donated gametes). Less frequently the woman is inseminated by sexual intercourse with the commissioning man.

33. Andres E. Stumpf, "Redefining Mother: A Legal Matrix for New Reproductive Technologies" 96 *The Yale Law Journal* 186 (1986).

34. See *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973).

35. *Supra* note 33 at 200.



should be accorded more protection than an accidental and unintended procreation.<sup>36</sup>

### *Inviolability of surrogate mother*

Once the embryo is implanted in the womb of the surrogate the process enters a realm of privacy which entails substantial personal freedom for gestating mother. The inviolability of this personal realm prohibits enforcement of the surrogate contract through specific performances during gestation. Damage remedies against the surrogate mother for non-performance must be severely limited to preserve the fundamental rights of privacy and procreative autonomy. The terms of the contract should serve primarily as indications of the parties' intent including a willingness on the part of the surrogate mother to abide by the terms. However, punishing the surrogate mother for "inadequate" birth is misplaced in the traditional scheme of maternity, which accords pregnant woman the freedom to lead their life without fear of sanction.<sup>37</sup>

Surrogacy arrangements have different implications on different societies having distinct culture, social values, religious and social set up etc. But human rights issues relating to surrogacy arrangements have universal character. These issues can be addressed by effectuating the basic human rights through legislation. The human rights instruments should be translated in tune with the current pace of assisted reproductive technologies.

### **Reproductive human cloning and human rights**

Reproductive human cloning<sup>38</sup> is seen as a flagrant violation of basic human rights. It is usually taken for granted that reproductive human cloning is a clear violation of basic tenets of life – individual autonomy, procreative liberty, identity, individuality etc. This presumption, without a wholesale inquiry into the domain of human cloning is never justified in the age of human rights. The logical battle in pros and cons over this issue requires a deep discussion in the light of recent transformations in the human values and social norms. As things stand now in animal models, cloning technology is not feasible. The recent death of 'Dolly', the first cloned sheep due to problem of ageing and genetic abnormality reveals this fact. However, human cloning, if realized, would force us to redefine the notions of individuality,

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36. *Id.* at 201.

37. *Id.* at 202-03.

38. In reproductive cloning an entire animal or human being is produced from a single cell by asexual reproduction. The creation of Dolly falls in this category. Human reproductive cloning would involve the creation of human being who was genetically identical to another.



human dignity, personal identity, family and procreative liberty etc.

The central contention used to support legislative prohibitions against human cloning is that creating an individual with a genome nearly identical to a living or dead person is an affront to human dignity. For example, article 11 of UNESCO's Universal Declaration on the Human Genome and Human Rights states: "Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted". Arguments used to support this view are that a clone would not have a "genetic individuality" and that his or her individual autonomy would be greatly compromised.<sup>39</sup> It is, however, a fallacy because in the case of naturally occurring twins it is explicitly clear that genetically identical individuals are far from being identical people, they may differ from one another physically, psychologically and in personality. People's uniqueness and individuality is a normative belief in the intrinsic value of each individual person.<sup>40</sup>

The potential danger relating to human reproductive cloning is that it will lead to children being treated as means to parental ends and not as end in themselves, thus violating the Kantian maxim to treat people as ends and not merely means.<sup>41</sup> Human reproductive cloning also creates confusion regarding the family lineage and kinship. Michael Freeman, however, argues that while concerns about the commodification of children in the era of new reproductive technologies are legitimate, they are mostly, 'speculative and alarmist.'<sup>42</sup> Here it is important to know that despite the fact that first *in vitro* fertilization baby, Louise Brown, was born only twenty five years ago in 1978, the resulting forms of kinship and family to which *in vitro* fertilization has given rise have been largely assimilated by our culture.

Another human right issue concerned with the reproductive human cloning is procreative liberty. Procreative liberty is generally thought to be an important instance of personal liberty. It has been argued by some scholars that human cloning might seem like a weak candidate for constitutional protection because it does not implicate the full range of liberty interests normally associated with natural reproduction, such as bodily integrity and intimate association. The right to an abortion, for example presents a compelling liberty interest in bodily integrity.<sup>43</sup>

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39. Timothy Caulfield, "Cloning and Genetic Determinism – A Call for Consistency" 19 *Nature Biotechnology* 403 (2001).

40. Dan W. Brock, "Human Cloning and Our Sense of Self" 296 *Science* 315 (2002).

41. John A. Robertson, "Liberty, Identity and Human Cloning" 76 *Texas Law Review* 1418 (1998).

42. Dean Bell, "Human Cloning and International Human Rights Law" 21 *The Sydney Law Review* 219 (1999).

43. *Planned Parenthood v. Casey*, 505 US 833 (1992) at 852, 857, 896.



Freedom from government intrusion into the matters of intimate association and sexual conduct is another important liberty interest that supports the protection of some reproductive activities. Arguably, human cloning does not implicate the same quantity of liberty interests as do other forms of reproduction.<sup>44</sup>

In debates around human rights and cloning, human dignity is used to describe the essential quality which cloning is seen to violate. But what is human dignity? Surprisingly – for such a central concept in international law, there has been virtually no commentary on human dignity, its source, content and boundaries. Traditionally this has not been of great importance because international human rights law has not relied on violation of human dignity, but rather on the breach of a specific right which itself derives from the duty to respect human dignity.<sup>45</sup> Human dignity has been retained as the conceptual keystone in international instruments, namely, the Council of Europe's Convention on Human Rights and Biomedicine and UNESCO's Universal Declaration on Human Genome and Human Rights.

So in the case of reproductive human cloning, at present, the risk outweighs the benefit. However, if it becomes feasible it will pose various problems regarding private laws relating to marriage, divorce, maintenance, inheritance etc and destabilize established social norms and family lineage. However, the opposition against reproductive human cloning is largely predictive. Therefore, the situation warrants a deep analysis of the problem. Any legislation regarding the reproductive human cloning should not be made in haphazard way but taking into account its potentials and pitfalls. So far as the legislative efforts are concerned, in U.K. reproductive human cloning is prohibited under Human Fertilization and Embryology Act, 1990. Similarly, many other countries have banned the reproductive human cloning. However, there are countries that do not currently have legislation relating to cloning, which provides ample opportunities for the misuse of cloning technology. So there requires an international consensus and co-operation for a uniform regulatory mechanism in this regard.

### Conclusion

The biotechnological advances relating to 'human genome' have opened new vistas in the medical field, promising great human progress. Despite the concerns that some people have expressed about research and development in the biosciences, the potential advantage for human health care is considerable, but rapid commercial activities involved in the biotechnological research raise several human rights issues. Biotechnology

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44. "Human Cloning and Substantive Due Process" 111 *Harvard Law Review* 23-57 (1998).

45. *Ibid.*



is a technology so intrinsically related to human life, if remains unregulated, has the potential to invade the basic human rights. Human rights have become indispensable to the contemporary understanding of how human beings are treated by one another and by national and international political bodies. So human rights discourse may be a guide in formulating the policies for the regulation of biotechnological developments and maintaining a morally compelling world order.

The potential of biotechnology necessitates its legal regulation but the problem lies in the fact that there is lack of proper interaction between lawyers and scientists. Lawyers do not know the implications of the emerging science and scientists are not fully posted with the discipline that human rights impose on governance. So there requires interdisciplinary discussions and debates to have an integrated look at the problem. There lies a great responsibility on legal scientists to structure the compromises which man will make in adopting the new technologies.

Coming to the regulatory fora, we need policies that promote and respond to a rational discourse about the benefits and risks of biotechnological developments relating to human genome. Law is ill-equipped, confining itself to the traditional role while the situation demands a more sophisticated role on its part to deal with the challenges posed by biotechnology. The human rights issues relating to human genome can be properly addressed by redefining the human rights instruments in tune with the current pace of technology. Human rights instruments highlight the human rights concerns but the protection of human rights needs great legislative efforts, guided by ethical concerns. Keeping in view the sensitive nature of biological advances relating to human genome the concerned policies should be backed by the interdisciplinary and multidisciplinary discussions, giving paramount importance to the human rights concerns. The premature opposition, without any reasonable basis impedes research, which may in the long run be benevolent to humankind. So there requires a balanced approach on the part of law. It should not only act as a regulator but as a facilitator to the scientific developments. It is, however, equally important to ensure that while facilitating the scientific developments the basic tenets of law and the basic human values on which the whole concept of human rights relies should not be compromised. Law should not lose its real character while making adjustment with biotechnological developments.

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