

## References

1. Kass NA. An ethics framework for public health. *Am J Public Health*. 2001 Nov; 91 (11):1776-82.
2. Turolfo F. Responsibility as an ethical framework for public health interventions. *Am J Public Health*. 2009 Jul; 99 (7): 1197-202.
3. Mocherla, S, Raman, U. and Holden, B. , 2010-06-21 "A Mixed-Method Study Examining Patient Expectations in a Tertiary Eye Care Centre in India". Paper presented at the International Communication Association Annual Conference, Singapore, 2010 Jun 21.
4. Coughlin SS. How many principles for public health ethics? *Open Public Health J*. 2008 Jan 1; 1: 8-16.
5. Emanuel EJ, Emanuel LL. What is accountability in health care? *Ann Intern Med*. 1996 Jan 15; 124 (2): 229-39.
6. Roberts WA. Virtue ethics and public health: a practice-based analysis. *Monash Bioeth Rev*. 2004 Jan; 23 (1): 10-21.
7. Jecker N S, Pearlman RA. An ethical framework for rationing health care. *J Med Philos*. 1992 Feb; 17(1): 79-96.
8. Shickle D. The ethics of public health practice: balancing private and public interest within tobacco policy. *Br Med Bull*. 2009; 91: 7-22.
9. Roberts JM, Reich MR. Ethical analysis in public health. *Lancet*. 2002 Mar 23; 359 (9311): 1055-9.
10. Fletcher AE, Donoghue M, Devavaram J, Thulasiraj RD, Scott S, Abdalla M, Shanmugham AK, Murugan PB. Low uptake of eye services in rural India: a challenge for programs for blindness prevention. *Arch Ophthalmol*. 1999 Oct; 117 (10):1393-9.
11. Brilliant GE, Brilliant LB. Using social epidemiology to understand who stays blind and who gets operated for cataract in a rural setting. *Soc Sci Med*. 1985; 21(5):553-8.
12. Gupta SK, Murthy GV. Where do people with blindness caused by cataracts in rural areas of India seek treatment and why? *Arch Ophthalmol*. 1995 Oct; 113(10):1337-40.
13. Brilliant GE, Lepkowski JM, Zurita B, Thulasiraj RD. Social determinants of cataract surgery. The Operations Research Group. *Arch Ophthalmol*. 1991 Apr; 109(4):584-9.
14. Dandona R, Dandona L, Naduvilath TJ, Nanda A, McCarty CA. Design of a population-based study of visual impairment in India: The Andhra Pradesh Eye Disease Study. *Indian J Ophthalmol*. 1997 Dec; 45(4):251-7.
15. Dandona L, Dandona R, Srinivas M, Giridhar P, Vilas K, Prasad MN, John RK, McCarty CA, Rao GN. Blindness in the Indian state of Andhra Pradesh. *Invest Ophthalmol Vis Sci*. 2001 Apr; 42 (5):908-16.
16. Dandona L, Dandona R. What is the global burden of visual impairment? *BMC Med* 2006 Mar 16; 4:6.
17. Uncorrected refractive error: the major and most easily corrected form of avoidable blindness. *Community Eye Health*. 2007 Sep; 20 (63): 37-9.
18. Resnikoff S, Pascolini D, Mariotti SP, Pokharel GP. Global magnitude of visual impairment caused by uncorrected refractive error in 2004. *Bull World Health Organ* 2008 Jan; 86(1): 63-70
19. Marmamula S. Rapid assessment methodology for detection of refractive errors (RARE) 2011 [dissertation]. [Sydney]: University of New South Wales, Australia; 255 p.
20. Kovai V, Rao GN, Holden B, Bhattacharya SK, Marmamulla S, Khanna R. An estimate of patient costs and benefits of the new primary eye care model utilization through vision centers in Andhra Pradesh, India. *Asia Pac J Public Health*. 2010 Oct; 22 (4): 426-35.

## Impact of UNCRPD on the status of persons with disabilities

SMITHA NIZAR

Research scholar, NALSAR University of Law, Hyderabad, AP 500 078 INDIA e-mail: smithanizar@gmail.com

### Abstract

*The sanctity of human life is a fundamental human value and the medical profession has been ethically charged with respecting and enhancing the value of all human beings' lives. However, disability-selective abortion has been perceived as an acceptable health intervention to eliminate disabilities, and is provided for in law as well as in policies and healthcare programmes related to disability. Advanced medical technologies are being utilised not to maximise the lives of persons with disabilities but to prevent the birth of disabled people by medically terminating fetuses diagnosed with disability. Evidently, disability is seen as undesirable per se by society, and life with disability as not worth living.*

*The disability rights perspective argues that such laws, policies and programmes deny persons with disabilities the right to life and thereby discriminate against them. They violate the United Nations Convention on the Rights of Persons with Disabilities that recognises the inherent human dignity of all human beings and treats persons with disabilities on an equal basis with all other human beings.*

*This paper examines the question of whether disability-selective abortion as a prevention strategy diminishes the value of persons with disabilities, in the context of the right to life and dignity of*

*life accorded by the UNCRPD to persons with disabilities. This is discussed in the context of a selected summary of international and Indian policy and law on this subject.*

### Introduction

The sanctity of human life is a fundamental human value recognised by all societies, their social institutions and legal systems. The medical profession is one such social institution which has been ethically charged with respecting and enhancing the value of life of all human beings. It is assumed that the ethics of protection or preservation of human life should be applied equally to all without discrimination. Healthcare interventions are intended to promote the health of human beings and thereby to protect human life.

Yet in the healthcare system's approach to disability, disability-selective abortion is perceived as an acceptable health intervention. Laws, health policies, and healthcare programmes focus on the strategy of prevention of disability through prenatal diagnosis and disability-selective termination of pregnancy. Healthcare programmes related to prenatal care have routinised prenatal screening for fetuses with disabilities. The law has sanctioned its use and the subsequent termination of such fetuses. This unquestioned acceptance of disability-

linked abortion shows that disability is seen as undesirable *per se*, and life with disability as not worth living. This diminishes the value of persons with disabilities by presenting the prevention of their birth as a justifiable healthcare intervention.

This strategy is contrary to ethical and legal principles that recognise the value of every human life as equal, including the life of persons with disabilities. In particular, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognises the inherent human dignity and the right to life of persons with disabilities.

## Background

The principle of the sanctity of life has been asserted in legal decisions relating to claims for damages for 'wrongful life' and 'wrongful birth'. In both cases, the cause of action arises because the birth of a disabled child could not be prevented because the medical professional was negligent in failing to inform the parent of the presence of genetic disabilities of the foetus, thereby denying the option of seeking an abortion. These claims were in accord with both prevailing health intervention policies and the law that permits disability-selective abortion.

## Sanctity of life or value of human life

Sanctity of life refers to the intrinsic value of human life. Philosophical writings introduce two approaches to this concept. The first views sanctity of life as a God-given value, one that is external to man (1). The other derives the sanctity of life from experiential or psychological foundations internal to man (2). According to the philosopher John Keown, each human life is sacred or inviolable, and therefore has intrinsic worth (3). He also proposes 'vitalism' as an integral doctrine of sanctity of life. Vitalism holds that human life is an absolute moral value and considers it wrong to shorten the life of a human being or to fail to preserve it. It also holds that life should be preserved no matter what the cost and the suffering caused.

The 'duty of care' principle of medical professionals towards their patients implies a recognition of the value of human life. In the case of the law, the universal recognition of the right to life and the prohibition of intentional taking away of one's life are based on the principle of sanctity of life, and are expressed in international conventions on human rights. Article 2(1) of the European Convention on Human Rights, for example, provides:

Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law (4: Section 1, Article 2, 1).

The principle of sanctity of life prohibits the unjustified taking of human life (5). Human life is regarded by the law as both sacred and precious, and every nation has an interest in the preservation of life which prevails over all other interests (6). This principle is non-discriminatory in the sense that every

human life is valuable, regardless of social category, ability or disability since each person's life is of equal value in law. It is this principle which operates as the determinative factor in prenatal legal actions such as wrongful life and wrongful birth.

## Wrongful life claims

The sanctity of life principle has been bestowed with legal recognition in wrongful life claims cases. A wrongful life claim is a tort action by a disabled child against the medical professional who failed to warn of the unborn child's disability, and thereby denied the mother the choice of abortion. Wrongful life cases fall within the ordinary medical malpractice paradigm when a doctor fails to comply with a professional standard of care, resulting in pain, suffering, and unplanned costs (7). In such claims, the disabled child asserts that, but for the negligent behaviour of the doctor, s/he would not be in existence, and hence would not be suffering pain and impairment associated with her disability. The cause of action in such claims is the failure of the doctor to diagnose the presence of a foetal abnormality. The operable injury would be the disabled life. The plaintiff or the disabled child would argue that non-existence would be preferable to life with disabilities. The disabled child herself has to deny her dignity by arguing that she would have been better off *not* to have been born.

Courts and legislations are reluctant to accept this life-diminishing contention. Consequently, nearly all western jurisdictions have categorically denied wrongful life claims on considerations of the sanctity of life, and the impossibility of comparing a disabled life with non-existence. The courts' rejection has also been influenced by other policy considerations. For one, such claims devalue the lives of disabled people, and encourage discriminatory treatment of persons with disabilities. Further, there can be disagreement on whether the disability is of a severity that merited the advice of abortion (8).

The above concerns have been voiced by courts in various jurisdictions whilst rejecting claims of wrongful life actions. Nations have enacted legislations providing for prohibition of wrongful life actions, in recognition of the value of human life. The widespread hostility to wrongful life claims can be ascertained from the following examples of case law emanating from courts across jurisdictions.

## United States

The United States judiciary holds that a child born with congenital disabilities cannot claim damages from the medical professional whose negligence resulted in his birth. This was laid down by the Supreme Court of New Jersey in *Gleitman v. Cosgrove* in 1967 (9). In that case, a pregnant woman informed her obstetrician that she had suffered from rubella during the first month of her pregnancy. The doctor assured her that this would not affect her foetus although he knew that 20 per cent of foetuses exposed to the virus during the first trimester would be born disabled. The woman consequently gave birth to a child who suffered from vision, hearing, and

speech disabilities. The lawyer for the child alleged that the "injury" caused by the physician's negligence was "be[ing] born to suffer with an impaired body," since the child's mother would have aborted him had she been fully apprised of his impairments (9). Concluding that it was "logically impossible" to "measure the difference between his life with defects against the utter void of nonexistence," the court rejected the claim as not cognisable at law (9). Ultimately, the court in *Gleitman* refused to recognise the claim for wrongful birth or wrongful life because of the "countervailing public policy supporting the preciousness of human life" (9).

In *Becker v. Swartz* (10), a similar case, the court stated:

The action was fundamentally flawed, primarily because the infant plaintiff could not be shown to have suffered a legally cognizable injury in the absence of a corresponding right to "be born as a whole, functional human being."

Many states in the US have denied wrongful life claims following *Gleitman* (11). Several state legislatures have explicitly barred wrongful life claims (12). Some statutes provide that there shall be no cause of action based on the claim that, but for the conduct of another, the claimant "would not have been conceived or, once conceived, would not have been permitted to have been born alive" (13). Many courts have reasoned that a life burdened with defects is better than no life at all; thus the plaintiff child suffered no legally cognisable injury in being born (14). Except three state jurisdictions, courts in the US have consistently rejected wrongful life claims citing the value of life principle and the above mentioned policy concerns of diminishing the value of disabled life.<sup>1</sup>

### **United Kingdom**

The seminal English decision of *McKay v Essex Area Health Authority* in 1982 laid the foundation for the wrongful life claim and its rejection. In *McKay*, a pregnant woman infected with rubella was unaware of the risk because the defendant's laboratory failed to diagnose her illness through blood tests. She gave birth to a girl with a disability. The girl filed a wrongful life action against her mother's doctor. The Court of Appeal unanimously rejected the child's action for wrongful life (15).

In 1976, following the recommendations of the Law Commission, the British Parliament enacted the Congenital Disabilities (Civil Liability) Act (16). The Act stipulates that a child born with disabilities attributable to another person's fault may claim damages from that person. The Act explicitly limits the liability of medical practitioners for prenatal injuries. Section 1 (6) of the Act states:

Liability to the child under this section may be treated as having been excluded or limited by contract made with the parent affected, to the same extent and subject to the same restrictions as liability in the parent's own case; and a contract term which could have been set up by the defendant in an action by the parent,

so as to exclude or limit his liability to him or her, operates in the defendant's favour to the same, but no greater, extent in an action under this section by the child.

### **France**

In 1996, the Supreme Court for civil and criminal matters quite surprisingly allowed recovery for a wrongful life claim. In *Perruche*, the court allowed the wrongful life claim of a boy born with severe mental illness and physical disabilities (17). The contention was that the medical personnel were negligent in incorrectly informing the boy's mother that she did not have rubella during pregnancy. The error resulted from the combined negligence of her physician and the laboratory that examined her blood. The Court held that:

Since the faults of the doctor and the laboratory committed in the performance of their contracts with the mother had prevented her from exercising her choice to abort a severely handicapped child, the latter could claim compensation for the loss resulting from the handicap and caused by the faults.

However, this French revolution was short lived. The court's rulings sparked intense criticism from two different directions. First, disabled people claimed that the court treated their lives as inferior to nonexistence. Second, gynaecologists, obstetricians, and ultra-sonographers argued that those rulings induced them to recommend an abortion even where the foetus had a low probability of congenital disability. These reactions resulted in a legislative response and on January 10, 2002, the National Assembly adopted a bill whereby no person might claim that he or she was damaged by being born (18). The Act placed France in line with the majority of western jurisdictions.

### **Australia**

A wrongful life claim was first considered by an Australian court in *Harriton v Stephens* (19) and *Waller v James* in 2002 (20). In *Harriton*, the plaintiff's disabilities resulted from her mother's exposure to rubella during pregnancy. In *Waller*, the plaintiff's disabilities resulted from a genetic blood clotting disorder. In both cases, the plaintiffs owed their very existence to the doctor's conduct. The cause of action was the negligence of the doctors in not informing the parents about the risk of congenital disability. In both cases, the plaintiffs contended that the defendant owed a duty of care to diagnose the mother's illness and to advise the mother that the only way to prevent the serious congenital disabilities was to terminate the pregnancy. The court held that the defendant did not have this duty. First, establishing damage in wrongful life cases would require an impossible comparison between existence and non-existence. Second, the recognition of wrongful life actions would be contrary to sound legal policies (21) of equality and non-discrimination. The court also raised policy concerns about: the 'risk of a parent being sued by the child' for wrongful

life; devaluing the lives of the disabled; the possibility of claims for trivial disabilities; differential treatment of the disabled; and infringement of the principle that the killing of disabled and non-disabled people is equally culpable (22).

These case laws encapsulate the absolute preference for life in wrongful life claims which has been derived from the general principle of sanctity of life. The rejection of wrongful life claims on the ground that they diminish the value of a life with disability also implies the recognition of the value of life of persons with disability. The fact that many courts and legislatures have persistently refused to recognise these actions suggests that there are lingering concerns about the impact of these actions on the community of people with disabilities. But the very existence of wrongful life claims, along with wrongful birth claims, demonstrates the way in which disability is treated by society. The same is true of the formulation of policies and laws that discriminate against one section of people, despite the recognition of the general principle of sanctity of life of all human beings.

### **Wrongful birth claims and wrongful life claims**

Wrongful birth claims are the claims brought by the parents of a child against the negligence of the medical professional who did not inform the parents of the risk or presence of deformities in the foetus, and thus did not offer them the choice of abortion. In wrongful birth claims, the injury identified is the "denial of parental autonomy" or the "lost choice" - they could not exercise the choice of aborting of a foetus on grounds of disability.

The case law discussed in the earlier part regarding wrongful life actions were brought along with wrongful birth claims by the parents. Here, contrary to wrongful life claims, courts have accepted claims for wrongful birth. The courts have allowed such claims on rationales such as deterring negligence in genetic testing, preserving parental autonomy, and compensating parents for medical expenses associated with disability. Wrongful birth as a cause of action was not popular (23) until *Roe v. Wade* was decided (24). In *Roe's* case the US Supreme Court recognised the reproductive choice of women to decide whether or not to continue the pregnancy.

It is ironical that many courts have recognised wrongful birth claims whilst rejecting wrongful life claims. Wrongful life is controversial because it identifies the impaired child's life as the operable injury, a concept contrary to many deeply held beliefs in society. Wrongful birth, on the other hand, seems significantly more appealing because the identified injury is the parents' lost choice over the future of the pregnancy. The "lost choice" is the label in wrongful birth cases, and a "life with disability" is the label in wrongful life claims.

### **Disability prevention through prenatal diagnosis and abortion**

Prevention is considered preferable to the treatment of disease. This approach is also used for disability which is considered

undesirable by society. In the context of disability, this involves strategies to prevent conception of a disabled individual, as well as screening for disability before it becomes manifest, including by identifying disability prenatally, or by early identification of disabling conditions followed by appropriate medical intervention to minimise the development of disability and the risk of related complications. Other strategies encompass the actions taken after the occurrence of disability to prevent complications of disability and restore functionality.

Selective abortion is a major prevention strategy in the context of disability. Relevant laws, policies and medical programmes support disability-selective abortion for this purpose. This practice implies that people with disabilities should not be welcomed into the family or the world (25). This also suggests that abortion is the morally correct choice when a foetus is diagnosed with disability. Health professionals and policy makers may hold that prenatal testing followed by pregnancy termination if the foetus is diagnosed with disability promotes public health. For them disability-selective abortion is simply one more legitimate method of averting disability in the world (25). Thus advanced medical technologies and related health policies, along with legitimisation of abortion, try to prevent disability by preventing such births.

All the countries where claims for wrongful life and wrongful birth have been filed have affordable diagnostic techniques and permit abortion. For instance both Britain and France allow abortions on the ground that 'the foetus is handicapped in some way'. In Great Britain the Abortion Act 1967, legalises the termination of pregnancy where there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped (26 Section 1(1) (b)). In France, terminations of pregnancy were first legalised by the Abortion Act, 1975, the provisions of which are now found in the code of public health (27).

Technological advances have made it easy to identify serious problems at an earlier stage of pregnancy. The first scan at 11-13 weeks can pick up more than 50 per cent of structural abnormalities, screen for Down's syndrome and identify multiple pregnancies (28). Parents (supported by society) are anxious to find out if the child has birth defects and may request termination even for curable defects. Such perceptions arise due to the low threshold of acceptance of even the most minor deviation from what is viewed as normal, and the great desire for a 'perfect' child. This mindset has been promoted by law and medicine. This seems contradictory: both medicine and law on the one hand uphold the ethical principle of sanctity of life, but on the other hand, permit the use of technologies to select foetuses with disabilities to terminate them, which results in discrimination against the life of persons with disabilities.

### **Prenatal technologies and abortion in India**

Though wrongful life and wrongful birth claims have not so far been brought before Indian courts, disability-linked abortions are explicitly permitted by law. The Medical Termination of Pregnancy Act, 1971, and the Pre-natal Diagnostic Techniques

(Regulation and Prevention of Misuse) Act 1994, are the two Indian laws that permit the detection of disability and abortion of fetuses diagnosed with disability.<sup>2</sup> The MTP Act permits abortion within 20 weeks of the pregnancy on the ground of saving the life of the mother or preventing the birth of an abnormal (in terms of physical and mental health) child (29 Section 3(2)(ii)). The PNDT Act permits the use of prenatal technologies to detect chromosomal abnormalities, genetic metabolic diseases, haemoglobinopathies, sex-linked genetic diseases and congenital anomalies. A careful reading of the PNDT Act shows that while selection on the grounds of sex is unambiguously banned, it legitimises selection on the basis of disability (30). Thus the PNDT Act and the MTP Act together provide a legal framework to use pre-natal tests to detect foetal abnormalities and terminate pregnancies of fetuses with disabilities. These laws are used within policies and programmes that prescribe abortion as a solution when prenatal testing reveals a birth anomaly.

In this context, it would be appropriate to describe the implications of the UNCRPD on the value of the life of persons with disabilities.

### **The implications of UNCRPD on the value of disabled life**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), together with its Optional Protocol, was adopted on December 13, 2006 and came into force as international human rights law on May 3, 2008. As the first human rights convention adopted in the 21<sup>st</sup> century, the UNCRPD seeks to protect the rights of all persons with disabilities. It treats the life of persons with disabilities as equally valuable to that of any other human being. The Convention makes a paradigm shift from current approaches to disability. It is a shift from a model in which persons with disabilities are treated as objects of medical treatment, charity and social protection, to one in which persons with disabilities are recognised as having a standing which is accountable in the human rights arena.

The UNCRPD provides a wide range of basic rights to persons with disabilities. It recognises the inherent human dignity of all human beings. Along with equality and non-discrimination as the general principles informing the Convention, Article 3 provides for dignity, individual autonomy, full and active participation and inclusion, respect for difference, and accessibility. Article 5 of the Convention explicitly addresses the right to equality and non-discrimination. This article embraces both formal and substantive approaches to equality. The formal approach recognises that all are equal before the law. The substantive approach specifically prohibits discrimination on the basis of disability. The Convention also asserts the right to life, freedom from torture or cruel, inhuman or degrading treatment or punishment, freedom from exploitation, violence and abuse, protecting the integrity of persons, and respect for privacy.

The right to life and right to health provided under the Convention are catalysts to achieve the human rights paradigm. Article 10 of the Convention states:

State Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

The term 'reaffirm and shall recognise' have been used to strengthen the text and to make it clear that 'right to life' includes the 'right to survive'. The right to life was included in the Convention mainly in view of the stereotypes prevailing in society against a life with disability.

Article 25 of the Convention states:

State parties recognize that persons with disabilities have the right to enjoyment of the highest attainable standard of health without the discrimination on the basis of disability.

It further provides for right of access for persons with disabilities for gender-sensitive, equal and non-discriminating health services. The reference to reproductive health in Article 25 (a) of the Convention is crucial as this concerns the international legitimisation of abortion. The Convention envisages prevention under the right to health as minimising further disabilities of persons with disabilities.

The Convention accords unequivocal rights to life, inherent dignity, equality and non-discrimination to the life of persons with disabilities, the same rights enjoyed by other human beings.

In the wake of the UNCRPD, is making disability-selective abortion a preventive strategy for disability ethically and legally justifiable? Does it not devalue the lives of persons with disabilities?

### **Disability-selective abortions devalue the lives of persons with disability**

The medical profession has been ethically charged to respect and enhance the value of life of all human beings. Ending a life is not a function of medical science, as a mode to prevent any disease. Yet, selectively preventing the birth of disabled fetuses is an approved medical mode for preventing disability. This strategy does not prevent or treat disability in an existing human being or in a foetus.

Advanced medical technologies are being utilised, not to maximise the lives of persons with disabilities, but to prevent the birth of disabled people by medically terminating fetuses diagnosed with disability.

While medical technology has made it possible to detect problems in the foetus; it has also made it possible to treat such problems in the womb. For instance, foetal therapy is an advancing medical field that aims to prevent disability through

the diagnosis and treatment of problems *in utero*. Though foetal care is still in its nascent stage, it is possible to make efforts to develop the field to treat the problems of foetuses. However, medical professionals justify termination of pregnancy for severe anomalies, because they consider non-treatable defects as lethal.

The right to disability-selective abortion is justified as it enables women to exercise their reproductive choice. However, this raises the ethical question of discrimination as this choice is not extended to choosing a particular sex. This unproblematic acceptance of disability-linked abortions shows that disability (unlike gender/sex) is seen as undesirable *per se* and life with disability as not worth living. The existing principles, policies and law diminish the value of persons with disabilities by presenting the prevention of their birth as a justified healthcare intervention.

This challenges the ethics of sanctity of life of persons with disabilities. It also infringes upon the right to life and right to health of persons with disabilities as accorded by the UNCRPD. This type of prevention is an explicit form of denial of the right to live to persons with disabilities. The right to health envisaged under the UNCRPD mandates States to spend resources to minimise further disabilities of persons with disabilities. But the health policy promoting prevention through disability-selective abortion diverts resources from minimising disability to diagnosing disability and terminating it. Resources and technologies are used not to empower the lives of persons with disabilities, but to diminish their value by denying them the right to life. Preventing the birth of an individual with a disease is morally different from preventing a disease. It sends the message that persons with disabilities are not entitled to the rights to life and equality and implies that the lives of persons with disabilities are not worth living.

## Conclusion

Human life possesses inherent value as recognised by law and ethics. The medical profession is responsible for promoting health and curing disease. Healthcare interventions promoting disability-selective abortion diminish the value of persons with disabilities. If the courts are of the view that a disabled child is not entitled to any compensation for his/her life with disability, as disability does not cause any harm to human life, then the selective killing of a foetus with disability is legally unjustifiable.

As prenatal diagnosis followed by disability-selective abortions is viewed as a legitimate medical and public health practice, there is an acknowledgement that the characteristic of disability is not desirable. If public health espouses the goals of social justice and equality for people with disabilities, it should reconsider whether it is ethically correct to promote this practice.

All other medical conditions or diseases are addressed with health interventions aimed at reducing the impact of, or treating, the condition. This approach is adopted even in relation to incurable diseases. Interventions which reflect the

preference for perfect bodies and minds offend the dignity of people living with various kinds of disabilities. Moreover, when abortion is promoted for one particular group to eliminate characteristics they receive in the natural lottery, this results in apparent discrimination.

This discrimination challenges ethics, especially when based on wrong assumptions or information of disability.

The medical profession will agree that it is not possible to make a 100 per cent prediction of the presence of disability. This uncertainty makes prevention through medical termination unethical and unjustifiable. The case of Niketa Mehta (31) illustrates the uncertainty of medical opinion as to the extent of disability. In this Indian case, Niketa Mehta was 26 weeks pregnant when her doctor diagnosed the foetus as having a congenital heart block. Since Ms Mehta's pregnancy had crossed the legally permitted time limit of 20 weeks under the Medical Termination of Pregnancy Act, 1971, the petitioners (Mr and Mrs Mehta and the doctor) approached the Bombay High Court seeking judicial interference in the specific provisions of the MTP Act in order to permit medical termination. The Court appointed a committee of doctors to submit a report, based on which it concluded:

"... taking into consideration the opinion expressed by the doctors' committee from J J Group of Hospitals as well as the two-expert committee of doctors constituted by the petitioners themselves, *there is no categorical opinion* before us from the medical experts to the effect that 'if the child were born, it would suffer from physical or mental abnormalities as to be seriously handicapped.' Apart from the fact that already the period of 26 weeks of pregnancy has passed, even the requirements of the provisions of law under Section 3(2)(ii) read with Section 3(2)(b) are not satisfied. In other words, even if the petitioners were to approach this Court before the expiry of 20 weeks of pregnancy, based on the medical opinion placed before us, it would not have been possible for this Court to issue direction for exercise of right in terms of Section 3 of the said Act."

It is clear that apart from the lack of power to legislate, the court has been driven by the fact of contradictory and uncertain medical opinions, to reject medical termination.

At this juncture, it is important to state that not all disability is preventable, and also that many disabilities are acquired during the course of one's lifetime. Is it not more desirable that the medical profession learns how to deal with diverse human minds and bodies? Is it not more desirable to give to humans the best kind of life with the kinds of minds and bodies they possess than chasing the mirage of the perfect mind and body? Is it not possible to accept disability as an integral part of the human condition?

Such policies and programmes also do not take into account the fulfilled lives lived by persons with disabilities. If disability is accepted as an integral part of the human condition as stated by the UNCRPD, policy makers can focus on planning for a society which would accommodate disabilities, as we do for many other human conditions. Then resources can be allocated for building a just society rather than being expended on waging a losing battle.

It is important that professionals learn much more than they know at present about a life with disability, in order to disseminate correct information to prospective parents and society at large. Practitioners and policy makers should allocate resources to changing social attitudes so that disability is accepted as an integral part of the human condition. If professionals recognise, respect, and affirm disability as part of the human condition, it would be easier to incorporate disability into the familial and social landscape. Disability would be one more aspect of human diversity. Disability-linked abortions need a re-examination because they impede the social acceptance of persons with disabilities. The UNCRPD has provided an opportunity to the medical profession and the policy makers to make this ethical-social choice.

**Declaration:** *I would like to see the issue of abortion from the perspective of 'right to life of the foetus', rather than 'women's right to reproductive choice'. I support women's right to choose abortion in certain circumstances, such as when the pregnancy arises from rape, but oppose the termination of a foetus that is termed 'unwanted' on the basis of its 'sex' or other physical conditions.*

**Acknowledgement:** *I would like to thank Amita Dhanda (Professor and Head, Centre for Disability Studies, NALSAR University of Law, Hyderabad) for her encouragement and guidance that enabled me to write this paper.*

#### References

1. Dworkin R. *Freedom's law: the moral reading of the American Constitution*. Cambridge, MA: Harvard University Press; 1996.
2. Cohen S. De-moralizing death: a humanistic approach to the sanctity of life. *Elder Law Journal*. 2006; 14 91: 101.
3. Keown J. Restoring moral and intellectual shape to the law after bland. *Law Quarterly Review*. 1997; 113: 482-503.
4. Council of Europe. Convention for the Protection of Human Rights and Fundamental Freedoms as amended by Protocols No. 11 and No. 14 [cited 2011 Aug 29]. Available from: <http://conventions.coe.int/treaty/en/treaties/html/005.htm>.
5. Lavi S. Euthanasia and the changing ethics of the deathbed: a study in historical jurisprudence. *Theoretical Inquiries in Law*. 2003; 4(2): 754.
6. Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990).
7. Belsky AJ. Injury as a matter of law: is this the answer to the wrongful life dilemma? *22 University of Baltimore Law Review*. 1993; 185 (2): 190.
8. *Harriton v Stephens* [2006] HCA 15.

9. 227 A.2d 689 (N.J. 1967), 690-694.
10. N.E.2d 807 (N.Y. 1978).
11. Perry R. It's a wonderful life. *Cornell Law Review*. 2008; 93:329:368.
12. IDAHO CODE ANN. § 5-334(1) (2004); IND. CODE ANN. § 34-12-1-1 (Lexis-Nexis 1998).
13. S.D. CODIFIED LAWS § 21-55-1.
14. *Lininger v. Eisenbaum*, 764 P.2d 1202, 1210 (Colo. 1988); *Garrison v. Med. Ctr. of Del., Inc.*, 581 A.2d 288, 294 (Del. 1989); *Blake v. Cruz*, 698 P.2d 315, 322 (Idaho 1984).
15. [1982] QB 1166, 1171-1174.
16. United Kingdom. Congenital Disabilities (Civil Liability) Act 1976. Chapter 28 [Internet]. 1976 Jul 22 [cited 2011 Sep 19]. Available from: <http://www.legislation.gov.uk/1976?title=Congenital%20Disabilities%28Civil%20Liability%29>
17. Cass. Ass. Plén., 17.11.00, J.C.P.G 2000, II-10438, p. 2309.
18. Assemblée Nationale, 11eme Legislature, texte adopte n° 757 2002 Jan 10 [cited 2011 Aug 30]. Available from : <http://www.assemblee-nationale.fr/ta/ta0757.asp>
19. (2006) 226 ALR 391.
20. (2006) 226 ALR 457.
21. Stretton D. *Harriton v Stephens; Waller v James: wrongful life and the logic of non-existence*. Melbourne University Law Review. 2006; 30(3): 449-52.
22. Hensal WF. The disabling impact of wrongful life and wrongful birth actions. *Harvard Civil Rights-Civil Liberties Law Review*. 2005; 40: 163.
23. Jennifer R. Granchi. The wrongful birth tort: a policy analysis and the right to sue for an inconvenient child. *South Texas Law Review*. 2002. 1261; 43: 1266.
24. 410 U.S. 113 (1973).
25. Asch A. Disability, bioethics and human rights. In: Albrecht GL et al, editors. *Handbook of disability studies*. 2001: 307.
26. Abortion Act 1967 (c.87), <http://www.legislation.gov.uk/ukpga/1967/89/section/1/enacted>
27. Morris A, Saintier S. To be or not to be: is that the question? Wrongful life and misconceptions. *Medical Law Review*. 2003 Summer; 11(2): 167-93.
28. Kritikha R. Understanding the unborn. *The Hindu* [Internet]. 2010 Jul 4 [cited 2011 Aug 29]. Available from: <http://www.hindu.com/mag/2010/07/04/stories/2010070450010100.htm>
29. The Medical Termination of Pregnancy Act, 1971. Act No. 34 of 1971. [cited 2011 Sep 16]. Available from: [http://www.medindia.net/indian\\_health\\_act/the-medical-termination-of-pregnancy-act-1971-introduction.htm](http://www.medindia.net/indian_health_act/the-medical-termination-of-pregnancy-act-1971-introduction.htm)
30. Ghai A, Johri R. Prenatal diagnosis: where do we draw the line? *Indian Journal of Gender Studies*. 2008; 15:2:291-316.
31. (2008)110BOMLR3293.

#### Notes

1 Only the California, New Jersey and Washington Courts recognised a cause of action for wrongful life. *Curlender v. Bio-Science Labs.*, 165 Cal. Rptr. 477, 489-90 (Cal. Ct. App. 1980); *Procanik v. Cillo*, 478 A.2d 755, 764 (N.J. 1984); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 496 (Wash. 1983). 985 (N.J. Super. Ct. App. Div. 1988)

2 The original law, the Pre-natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994, was amended and renamed as the Pre-conception and Pre-natal Diagnostic Techniques (Prohibition of Sex Selection) Act, in 2003.