



Infertility: Why can't we classify this inability as disability?

Abha Khetarpal,¹ Satendra Singh²

1. Counsellor for students with disability at Enabling Unit, UCMS & President Cross the Hurdles
2. Coordinator, Enabling Unit, Equal Opportunity Cell, founder 'Infinite Ability', University College of Medical Sciences, Delhi

REVIEW

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Corresponding Author:

Dr Satendra Singh
Coordinator, Enabling Unit, Equal Opportunity
Cell, founder 'Infinite Ability', UCMS, Delhi
[Email: dr.satendra@gmail.com](mailto:dr.satendra@gmail.com)

Abstract

Disability is a complex phenomenon. It reflects an interaction between features of a person's body and features of the society in which he or she lives. International Classification of Functioning, Disability and Health (ICF), lays stress on the functional as well as the structural problem of a person. All the definitions of disability also include the disorders of the reproductive and endocrine system. So infertility and impotency should also be included in the category of disability. It affects the participation in areas of life and can have a disabling affect on an individual. Like any other disability the couple has to adapt and integrate infertility in their sense of self thus infertility comes as a major life crisis. Medically, infertility, in most cases, is considered to be the result of a physical impairment or a genetic abnormality. Socially, couples are incapable of their reproductive or parental roles. On social level, infertility in most cultures remains associated with social stigma and taboo just like the social model of disability. Couples who are unable to reproduce may be looked down upon due to social stigmatisation. Infertility can lead to divorces and separation leading to a broken family life. Without labelling infertility as a disability, it is difficult for the people to access services and welfare benefits offered by the government. Infertility treatments are highly sophisticated so they are very expensive and are even not covered by insurance and government aid.

In the light of all this it becomes imperative to categorise infertility as disability.

Key Words

Infertility; Disability

A good definition means disambiguation. Likewise the definition of disability ought to bring its clearest and nearest meaning. It must include the extensive gamut of attributes rather than it being a narrow and shrunken one. All its essential attributes must be encompassed in its definition that forms its essential nature.

Disability defined

The World Health Organization (WHO) has been continuously working on a general definition of *disability*. It defines disabilities as "an umbrella term, covering impairments, activity limitations, and participation restrictions. An *impairment* is a problem in body function or structure; an *activity limitation* is a difficulty encountered by an individual in executing a task or action; while a *participation restriction* is a problem experienced by an individual's involvement in life situations".¹ Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.

The International Classification of Impairments, Disabilities and Handicaps (ICIDH), which has been doing pioneering work in understanding and defining disability, reviewed its classification system in the late 1990s and set up the International Classification of Functioning, Disability and Health (ICF) in 2002.² The ICF now lays more stress on the functional as well as the structural problem of a person without relating it with being healthy.

Other terms of the new perspective of ICF are categorised in Table 1.³

The perspective of the ICF document relates not only to individuals with disabilities but to everyone. Its universal



value comes to the surface level due to its coverage of all aspects of human health.

In the understanding of the *ICIDH*, “impairment” refers to the physical situation of the person; “disability” means the restriction of activities due to the *impairment*; and “handicap” expresses the limitations in terms of fulfilling a social role. Impairment refers to the level of an organ as a functional or structural abnormality of the body;

Similarly, the American Disability Act (ADA) describes a disabled person as one who: (1) has a physical or mental impairment that substantially limits one or more major life activities; or (2) has a record of such impairment; or (3) is regarded as having such an impairment.⁴ And a *physical impairment* is defined by ADA as "any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, haemic and lymphatic, skin, and endocrine."⁵ To clarify, simplify and to broaden the definition of disability even the US Equal Employment Opportunity Commission (EEOC) has announced the changes in the ADA Amendments Act (ADAAA).⁶

Table 1: International Classification of Functioning, Disability and Health³ Reproduced with permission from: Towards a Common Language for Functioning, Disability and Health. In: ICF, The International Classification of Functioning, Disability and Health. World Health Organization. Geneva 2002 flowchart. Accessed on 8 December, 2011. URL: <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>

systems	endocrinal systems
Genitourinary and reproductive functions.	Structures related to genitourinary and reproductive systems
Neuromusculoskeletal and movement-related functions	Structures related to movement
Functions of the skin and related structures	Skin and related structures.
Activities and Participation	
Learning of knowledge and its application	
Homework and requests of general character	
Communication	
Mobility	
Self-care	
Domestic life	
Interpersonal interactions and relationships	
Major life areas	
Community, social and civic life	
Environmental factors	
Products and technology	
Natural environment and human-made changes to environment	
Support and relationships	
Attitudes	
Services, systems and policies	

The US Department of Justice,⁷ explains physical disability as: “(1) any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, lymphatic, skin, and endocrine; or (2) any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities”.

Body	
Function:	Structure:
Mental functions	Structure of the nervous system
Sensory functions and pain	The eye, ear and related structures
Voice and speech functions	Structures involved in voice and speech
Functions of the cardiovascular, haematological, immunological and respiratory systems	Structure of the cardiovascular, immunological and respiratory systems
Functions of the digestive, metabolic, endocrinal	Structures related to digestive, metabolic and



Medicalisation of infertility

All the above definitions, if seen carefully, include the disorders of the reproductive as well as endocrine system. So, why have infertility and impotency not been included in the category of disability? According to the International Committee for Monitoring Assisted Reproductive Technology and the WHO, infertility is defined as the "failure to achieve a clinical pregnancy after twelve months or more of regular, unprotected sexual intercourse".⁸

Is infertility in women or impotency in men not a kind of impairment? It definitely affects the participation in areas of life. These disorders influence the domestic life of an individual. The three dimensions of disability as recognised in ICF: body structure and function (and impairment thereof), activity (and activity restrictions) and participation (and participation restrictions) also hold true in the case of infertility in females and impotency in males. AADA's definition of disability includes the term "major life activities" that includes "major bodily functions". Reproductive and endocrine systems too are major bodily functions playing a significant role in the "major life activities". Infertility can have an adverse impact on the sense of identity of a female as femininity and motherhood are usually intrinsically related. There can be identity crisis. It can have a disabling affect on an individual if there is conflict between the ideal sense of self as a woman and the real sense of self being infertile. Like any other kind of disability the couple has to adapt and integrate infertility in their sense of self. Infertility comes as a major life crisis and can profoundly and permanently alter a couple's life. Childlessness can bring chronic sorrow.

The difficulties of measuring infertility are amplified by the multiple definitions given to describe the situation. The latest systematic review highlights the fact that terms such as 'infertility', 'subfertility', 'subfecundity', 'primary permanent infertility', 'unresolved infertility', 'childlessness' and 'primary unresolved infertility' are used without being clearly defined.⁹ The absence of an established definition of infertility results in varying estimates of its prevalence within and between populations.

Infertility is being regarded as a disease due its 'medicalisation'. It is not less than a disability.¹⁰⁻¹³ It "is a chronic condition that meets biopsychological, social role and legal criteria for disability".¹² Medically, infertility, in most cases, is considered to be the result of a physical impairment such as blocked fallopian tubes or a genetic abnormality. Socially, couples are incapable of their reproductive or parental roles.

Interlinking of models

The incapacity to bear children fits into the criteria of both the major conceptual models of disability i.e. the *medical model and social model*.

The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. So according to this model a person needs medical or other treatment or intervention, to 'correct' the problem with the individual. If we look at infertility as a disability from the perspective of the medical model, it needs treatment. Assistive technology here too plays an important role like that in other kinds of physical disabilities. Here assistive technology is commonly known as reproductive technologies (ARTs). The major ART procedures include in vitro fertilisation (IVF), embryo cryopreservation, and micromanipulation techniques as far as female infertility is concerned. All these are rehabilitation methods and "rehabilitation dominates the medical model."¹⁴

In about 7% of couples, unable to conceive, male infertility is ascribed as the cause.¹⁴ Male infertility can be caused by a number of factors including anatomical problems, hormonal imbalances, and genetic defects.¹⁶

More than 90% of male infertility cases are due to low sperm counts, poor sperm quality, or both.¹⁷ Male infertility affects 10% of reproductive aged couples worldwide; 1-10% of male factor infertility is a result of an underlying, often treatable, but possibly life-threatening medical condition. Genetic male infertility and congenital or acquired obstruction are even untreatable. So is this not a kind of permanent disability?

On the other hand, the *social model* of disability views disability as a socially created problem.³ This model considers that disability is the result of society's response to the people with impairments. It considers that the health and welfare systems tend to make them socially isolated and oppressed. Barriers of all kinds prevent disabled people from participating in various situations.

A woman's body is structured basically to be a child bearer. So her reproductive health may often be the most important part of her well-being. A woman's health has often been located in her capability to reproduce. The main focus on her health is related to the fact that she is able to menstruate and bear children. If something prevents her body's ability to perform these activities she is seen as faulty, deviant or incomplete and it becomes a



kind of disability for her. Thus the societal pressure to have children has forced the medicalisation of infertility.¹⁸

Infertility, especially in women, leads to oppression by society. So, infertility is nothing less than a disability even from the point of view of social model.

Like the models of disability, there are models of infertility too, which can be definitely and convincingly linked to the models of disability. In the case of infertility, models including biological, psychological and social aspects were developed and these were based on the opinion that infertility, in most cases, has physical causes; that there are medical interventions to treat it (biological aspects), there are individual reactions to infertility such as depression and anxiety (psychological aspects) and there are social implications such as the stigma and taboo associated with infertility. As a result, various psychosocial interventions were adapted to help and support individuals and couples experiencing infertility. These include crisis intervention, grief and bereavement approaches, (family) systems theory, cognitive behavioural, solution-focussed and psychodynamic approaches, identity theory, stress and coping theories, and stigma theory.^{1,6-8}

On a social level, infertility in most cultures remains associated with social stigma and taboo just like the social model of disability. Couples who are unable to reproduce may be looked down upon due to social stigmatisation. Infertility can even lead to divorces and separation and often the main sufferer in all such cases is the female. The stigma of infertility can affect every aspect of human life. Discrimination occurs if she is considered inauspicious and, in some cultures may not be allowed to attend social gatherings or take part in rituals or festivities. The consequences of infertility can be consistent ostracism, physical abuse and even suicide. Thus it can even become a human-rights issue.

Tagging infertility as a disability

Giving a label of disability to those who face infertility, might be objected to by some persons. However, without surrendering to such a tag, it is difficult for the people to access services and welfare benefits offered by the government. There is negligible or limited public funding available for medical treatment. Infertility and its treatment can be a major financial burden for couples. Moreover infertility treatments which involve highly technological and sophisticated treatment procedures are almost uncovered by insurance or by government aid. Developing and underdeveloped countries are already struggling with problems such as dirty drinking water, tuberculosis, malaria and AIDS, so they may find IVF expenditures hard to justify. Infertility, if categorised as a disability by the government,

would get due attention in the policies and agendas, as far as course of treatment is concerned.

In developing countries, infertility is regarded as a personal failure, sometimes seen as evil or even a curse.¹⁸ Islam dictates that if one wife cannot bear the children, the man should go for another marriage. A woman who has not gone through labour is considered as an incomplete woman. Likewise in Haiti, a woman is not considered a social adult unless she bears a child. Infertility can culminate in her forfeiting all her support and benefits of a conjugal relationship. Similarly in Asian countries like Japan, Singapore and South Korea the situation is no better.¹⁹ In China womanhood and motherhood are synonymous. Though China has a one-child policy, the stigma attached to childlessness is enormous. They even have enforced pro-birth policies. In China and Vietnam there is a traditional belief that the souls of childless people can not easily rest. In Islamic cultures, women without children are not always allowed to be buried in graveyards or sacred grounds.

According to Genesis 30:1 "*Give me children or I shall die.*" The line expresses how important children are to married couples.

Infertility can result in stress in a marriage and can be the cause of marital and sexual dissatisfaction within a marriage. Infertility is prone to produce a feeling of being defective and not being part of the 'fertile world'. Thus there is an added pressure on couples to reproduce and follow what society has prescribed as normal. Couples, who have not reproduced, feel that they have failed to live their lives the way society has prescribed as normal.¹² It is perceived as something deviant and against societal norms. All this has led to infertility becoming a medical problem.¹⁰ Being a social problem too, especially in many developing and underdeveloped countries, there have been many medical advances such as synthetic drugs to control ovulation. In response to the social stigma attached to being infertile and not being a mother, the number of couples seeking medical help has increased, and because of this the number of physicians specialising in reproduction has increased.

Many countries formally accept the UN Convention on the Rights of Persons with Disabilities (Disability Convention) which marks a formal shift from the archaic medical model to the social model. The Article 1 of the United Nations Convention on the Rights of Persons with Disabilities²⁰ summarises the overall objective of the Convention as: "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental



freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

The Disability Convention recognises that “disability is an evolving concept” and avoids listing specific conditions and severities and broadly casts that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.²⁰ Thus infertility can very well fit into this definition of disability. There is inadequate focus on infertility in many developing and underdeveloped countries’ reproductive health programme. The number of infertile persons remains significant and the impact on women’s lives is considerable. Care-seeking options continue to be few and services available in the public sector are very much inadequate. Stigmatising beliefs, limited male participation, cost, indifferent quality of care and lack of services in the public sector are major barriers to prompt and appropriate treatment seeking. The more broadened the definition of disability, the more measures would be taken up by the state for its prevention and treatment.

Conclusion

Infertility is an illness, which is caused by various medical causes resulting in the abnormal functioning of the reproductive systems such as blocked fallopian tubes or low sperm count. It can become a hindrance to building a family and is capable of posing a serious threat to the existence of marriage. Couples are brought to complete devastation because of this. The dream to procreate thus remains unfulfilled and unfulfilling, which gives rise to a lot of stress and anxiety in a marriage, bringing an individual, a family or a relation to the brink of disintegration.

There is saying: “A human embryo is not a potential human being, but a human being with potential”.²¹ Thus being infertile pertains to no procreation which would further mean the loss of some potential which would have otherwise been a part of this world or mankind. So why should infertility not be regarded as a disability?

References

1. World Health Organization. Disabilities. URL: <http://www.who.int/topics/disabilities/en/>. [Internet]. Accessed on 8th December, 2011.
2. World Health Organization. International Classification of Functioning, Disability and Health (ICF). [Internet]: <http://www.who.int/classifications/icf/en/>. Accessed on 8th December, 2011.
3. Towards a Common Language for Functioning, Disability and Health. In: ICF, The International Classification of Functioning, Disability and Health. World Health Organization. Geneva 2002 flowchart. Accessed on 8th December, 2011. [Internet]: <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>
4. Thomas VL, Gostin LO. *The Americans with Disabilities Act: shattered aspirations and new hope*. JAMA. 2009; 301(1): 95-7.
5. Americans with Disabilities Act. Public Law 101-336, 42 USC [sections] 12101.1990.
6. US Equal Employment Opportunity Commission. Fact sheet on the EEOC’s final regulations implementing the ADA. [Internet]: http://www.eeoc.gov/laws/regulations/adaaa_fact_sheet.cfm. Accessed on 9th December, 2011.
7. United States Department of Justice. URL: <http://www.justice.gov/>. [Internet]. Accessed on 9th December, 2011.
8. Zegers-Hochschild F, Adamson GD, de Mouzon J, Ishihara O, Mansour R, Nygren K, Sullivan E, Vanderpoel S, International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organization (WHO) revised glossary of ART terminology, 2009. *Fertil Steril* 2009;92:1520-4
9. Gurunath S, Pandian Z, Anderson RA, Bhattacharya S. Defining infertility--a systematic review of prevalence studies. *Hum Reprod Update*. 2011; 17(5): 575-88.
10. Becker G, Nachtigall RD. Eager for medicalisation: the social production of infertility as a disease. *Sociology of Health & Illness*. 1992; 14(4): 456-471.
11. Malin M, Hemminki E, Raikkonen O, Sihvo S, Perala ML. What do women want? Women’s experiences of infertility treatment. *Soc Sci Med*. 2001; 53: 123-133.
12. Miall CE. The stigma of involuntary childlessness. *Social Problems*. 1986; 33(4): 268-282.
13. Woouett A, Boyle M. Editorial introduction: Reproduction, women’s lives and subjectivities. *Feminism & Psychology*. 2000; 10(3): 307-311.
14. Finkelstein V. The commonality of disability, in: J. Swain, V. Finkelstein, S. French & M. Oliver (Eds) *Disabling Barriers - Enabling Environments*. London: SAGE Publications. 1993.
15. Templeton A, Fraser C, Thompson B. The epidemiology of infertility in Aberdeen. *BMJ*. 1990; 301:148-152.



16. Miyamoto T, Tsujimura A, Miyagawa Y, Koh E, Namiki M, Sengoku K. Male infertility and its causes in human. *Adv Urol*. 2012:384520. Epub 2011 Oct 20.
17. Shefi S, Turek PJ. Definition and current evaluation of subfertile men. *International. Bra J Urol*. 2006;32:385-397
18. Forsythe S. Social stigma and the medicalization of infertility. *Journal of the Manitoba Anthropology Students' Association*.2009;28:22-36
19. Jones GW. Delayed marriage and very low fertility in Pacific Asia. *Population and Development Review* 2007; 33(3): 453-478.
20. Convention on the Rights of Persons with Disabilities. 2007 URL:
<http://www.un.org/esa/socdev/enable/rights/convtexte.htm> Accessed on 25th June 2012.
21. Princeton University. Prolife. Human Rights for All. Available at:
<http://www.princeton.edu/~prolife/articles/humanrightsgen.pdf> Accessed on 26th June 2012

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests