**Mandate of the Special Rapporteur on the rights of persons with disabilities**

23 August 2019

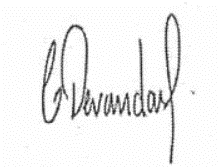
Dear Madam/Sir,

In my capacity as Special Rapporteur on the rights of persons with disabilities, pursuant to human Rights Council resolution 35/6, I am currently preparing a report for the 43rd session of the Human Rights Council on *Bioethics and Disability.* The study aims to explore bioethical responses to disability and to discuss areas where potential tensions could emerge.

In this connection, I am pleased to transmit to you the questionnaire attached on *Bioethics and Disability,* in English, French and Spanish. I would be most grateful for your response to be sent electronically, in accessible formats (Word Document), to [sr.disability@ohchr.org](mailto:sr.disability@ohchr.org) no later than **30 September 2019**. I would appreciate if your response may be as concise as possible and if annexes could be attached where necessary.

Whenever possible, I would also encourage you to provide copies of relevant laws, policies, programme outlines, evaluations, and any other information relevant for the topic. Please also indicate if you have any objections with regard to your submission being posted on the website of the Office of the High Commissioner for Human Rights.

I take this opportunity to thank you in advance for your contribution.



Catalina Devandas-Aguilar

Special Rapporteur on the rights of persons with disabilities

**Questionnaire on bioethics and disability**

1. Please provide information on the legislative and policy framework in place in your country in relation to:
   1. Prenatal diagnosis

There is no specific legislation or policy for prenatal diagnosis during pregnancy specifically to detect disability but general women undergo regular medical examination during pregnancy to understand the growth of the foetus and risks involved during delivery time.

Section 25, sub-section (2) and clause (f) of “Rights of Persons with disabilities Act (2016) of India provides provision for prenatal, perinatal and postnatal care of mother but not diagnosis which reads as follows:

(*f*) Take measures for pre-natal, perinatal and post-natal care of mother and child;

* 1. Disability-related abortion

Medical termination pregnancy act 1972 has the provision to terminate the pregnancy on the basis of disability in case the foetus has gross disability or the disability is the threat to the life of the mother or major risk factor during delivery time which may cause death of the pregnant.

* 1. Informed consent to medical treatment and scientific research

Section 10, sub-section (1-2) of Rights of Persons with Disabilities Act (2016) of India in someway shall endeavour to protect persons with disabilities from medical treatment and research without consent. The appropriate provisions are as follows:

**10.** (*1*) The appropriate Government shall ensure that persons with disabilities haveaccess to appropriate information regarding reproductive and family planning.

1. (*2*) No person with disability shall be subject to any medical procedure which leads to infertility without his or her free and informed consent.

Section 25, sub-section (1) clause (k) reads as follows:

(*k*) sexual and reproductive healthcare especially for women with disability

1. Protection of persons with disabilities undergoing research

Section 6, sub-section (2) and clause (i-ii) of “Rights of Persons with disabilities Act (2016) of India protects persons with disabilities from conducting research without the informed consent in accessible formats and undergoing research by persons with disabilities. The appropriate provision in this regard reads as follows:

(*2*) No person with disability shall be a subject of any research without,—

(*i*) his or her free and informed consent obtained through accessible modes, means and formats of communication; and

(*ii*) prior permission of a Committee for Research on Disability constituted in the prescribed manner for the purpose by the appropriate Government in which not less than half of the Members shall themselves be either persons with disabilities or Members of the registered organisation as defined under clause (*z*) of section 2.

1. Euthanasia and assisted suicide

There is no specific legislation or policy on the above subject either to encourage or to prevent or discourage. Generally the constitution of India does not allow even sui cide of any of its citizens including persons with disabilities. Attempt to sui cide or committing sui cide is a punishable offence.

There is no concept of euthanasia in the country but in rare cases mercy killing is done which is not legal.

2. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) in relation to:

* 1. The availability, accessibility and use of prenatal diagnosis
  2. The availability, accessibility and use of disability-related abortion
  3. The practice of informed consent to medical treatment and scientific research
  4. The existence of measurements of quality of life which affect both clinical decision-making and health policy
  5. The practice of experimental, controversial and/or irreversible treatments
  6. The practice of euthanasia and assisted suicide on persons with disabilities

There were no surveys conducted on the above mentioned subjects and there is no data available on these aspects.

1. Please provide information on discrimination against persons with disabilities on research involving humans.

Generally the medical colleges and universities dealing medical science conduct research and experiment on humans particularly on persons with disabilities without their informed consent in most accessible formats in order to advance the medical science in terms of diagnosis, treatment, prevention and curing of diseases. Even this is good for human beings to combat deadly diseases but conducting such experiment without consent is considered as discriminatory practice. This occurs relatively more with persons with disabilities due to their impairment which hinder them to express or voice their concerns to the concerned.

1. Please describe how national ethics committees address the rights of persons with disabilities. Please provide information on protocols, guidelines, decisions, investigations or publications in relation to persons with disabilities.

National ethics committees look at the issues related to rights of female foeticide, female infanticide and killing of girls. There are legislations and specific policies to promote the rights of women and girls with regards to bio ethics and prevent unethical practises such as female foeticide, female infanticide and killing of girls but not for persons with disabilities.

1. Please describe to what extent and how persons with disabilities are involved in the work of national ethics committees.

We have not come across any evidences and instances of involvement of persons with disabilities and their representative organisations in the work and activities of national ethics committees.

1. Please refer to any innovative initiatives that have been taken at the local, regional or national level to promote and ensure the rights of persons with disabilities in bioethical discussions.

The civil society organisations and Disabled people’s Organisations have been striving to raise the issues related to bio ethics with regard to persons with disabilities. There are campaigns, advocacy initiatives and media engagement with regard to bio ethics of persons with disabilities. Many have filed petitions in the court of law against the violation of bio ethics of persons with disabilities.