International Disability Alliance (IDA)


IDA submission for the joint General Comment/Recommendation of the Committee on the Rights of the Child and the Committee on the Elimination of Discrimination against Women on harmful practices

The International Disability Alliance (IDA) is a unique, international network of global and regional organisations of persons with disabilities. Established in 1999, each IDA member represents a large number of national disabled persons’ organisations (DPOs) from around the globe, covering the whole range of disability constituencies. IDA thus represents the collective global voice of persons with disabilities counting among the more than 1 billion persons with disabilities worldwide, the world’s largest – and most frequently overlooked – minority group. Currently comprising eight global and four regional DPOs, IDA’s mission is to advance the human rights of persons with disabilities as a united voice of organisations of persons with disabilities utilising the Convention on the Rights of Persons with Disabilities (CRPD) and other human rights instruments. IDA also aims to promote the effective implementation and compliance with the CRPD within the UN system and across the treaty bodies.

IDA welcomes the initiative of the Committee on the Elimination of Discrimination against Women and the Committee on the Rights of the Child (hereinafter “the Committees”) to draft a joint General Comment/Recommendation on harmful practices.

Harmful practices violate the rights of women and children with disabilities

Persons with disabilities have frequently and consistently been the targets of harmful practices in efforts to hide, alleviate or correct disabilities, and to the extent of eliminating individuals with disabilities altogether. Children with disabilities are particularly vulnerable to harmful practices exercised by their family or communities; newborns with disabilities are murdered in different regions across the world for want of a family’s capacity or willingness to take care of a child considered to be a burden. In some parts of the world, children with disabilities are viewed as a sign of bad luck or evil and they may be accused of spirit possession or witchcraft and subjected to starvation, isolation, neglect and abuse in efforts to exorcise evil spirits from the body of the child. In certain regions of east Africa, persons with albinism have been seen as representing both bad luck and good luck, with both superstitions leading to violence and murder. Children with albinism are especially targeted due to their defencelessness by persons seeking to eradicate them in the belief that they are cursed, and others seeking to dismember their limbs for use in traditional healing in the belief
that their body parts transmit magical powers which will bring good health or prosperity to the user.

Girls and women with disabilities, and mothers of children with disabilities, are subjected to multiple forms of discrimination on the basis of gender and disability, the latter often being blamed for giving birth to a child with a disability as punishment for their personal wrong doing, which, in the eyes of the community, justifies the departure of their spouse and the withdrawal of family support. Several States have engaged in the eugenic practice of forced sterilisation of women and girls with disabilities, which still persists today in many modern democracies.\(^1\) In many countries, substituted decision making regimes, in law or in practice, permit a guardian to take the decision for the forced sterilisation or contraception of the woman concerned without consultation with her and sometimes without her knowledge.\(^2\) Parents, legal guardians, doctors and judges take decisions authorising interventions on women and girls with disabilities without their informed consent under the pretext that it is in their best interest.\(^3\) The best interest approach has often acted as a guise for the interests of others and the society at large to the detriment of persons with disabilities.\(^4\) The best interest principle and the institution of guardianship act to perpetuate discriminatory attitudes against persons with disabilities as incapable and in need of care or treatment, and continue to facilitate the practice of forced interventions (sterilisation, contraception and abortion) of women and girls with disabilities.

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\(^1\) Compulsory sterilisation programmes of women with disabilities took place at the beginning of the 20\(^{th}\) Century until the mid-1970s in the United States, resulting in the forced sterilisation of approximately 60,000 people (Lombardo, P., *Eugenic Sterilization Laws*, Dolan DNA Learning Center, Cold Spring Harbor Laboratory; available at: [www.eugenicsarchive.org/html/eugenics/essay8text.html](http://www.eugenicsarchive.org/html/eugenics/essay8text.html)) Principle targets of this programme were people perceived as “mentally ill, epileptic, blind, deaf, orphans, homosexuals...”), while in Sweden the eugenic sterilisation programme was set up in 1934 and abolished in 1976; during these years tens of thousands of women with mental disabilities and women otherwise considered “inferior” were sterilized. The CEDAW and CRC Committees, and the Human Rights Council through the UPR process has as recently as March 2011 recommended to Australia to prohibit the forced sterilisation of women and girls with disabilities ([Concluding Observations, CRC/C/AUS/CO/7, 30 July 2010, para 43; Report of the Working Group on the Universal Periodic Review: Australia, A/HRC/17/10, 24 March 2011, para. 86.39).\(^2\)


\(^3\) For example, in *Suchita Srivastava v Chandigarh Administration*, AIR 2010 SC 235, the Indian High Court adopted the best interest approach by ordering the abortion without consent and against the will of a woman with a mental disability who had fallen pregnant through rape, claiming that this was in her best interest, Raadhika Gupta, *Twin Tracking for Women with Disabilities in Disability Legislation*, Centre for Disability Studies, Nalsar University of Law, [http://www.disabilitystudiesnalsar.org/bcp/wwd.php](http://www.disabilitystudiesnalsar.org/bcp/wwd.php).

\(^4\) In the context of best interests, the vocabulary used includes terms such as non/therapeutic, in/voluntary, un/authorised, un/lawful and non/consensual sterilisation. Each of these terms derive from particular perspectives which take as their starting point the gendered, disciplinist view that the menstruation, sexuality and reproductive lives of disabled women and girls are the legitimate domain of legal, medical or other experts to determine... these terms and the underlying assumptions that drive their use actively undermine the lived experience of disabled women and girls and creates the conditions for the infringement of their human rights. This kind of terminology sanitises the nature of forced or coerced sterilisation which occurs without consent.” L Dowse, Women with Disabilities Australia (WWDA), *Moving Forward or Losing Ground? The Sterilisation of Women and Girls with Disabilities in Australia*, (Sept. 8-10, 2004), [http://www.wwda.org.au/steril3.htm](http://www.wwda.org.au/steril3.htm).
Without minimising the criminal responsibility of perpetrators of harmful practices, the State has an essential preventive role to play in ensuring that steps are taken to facilitate the enjoyment and exercise of the reproductive and sexual rights of women and girls with disabilities, including by providing better support to families and carers, making available education programmes and information on sexual and reproductive health for persons with disabilities, developing inclusive public health and awareness raising campaigns about sexuality and parenthood,\(^5\) in an effort to eliminate resorting to the practice of forced sterilisation, forced contraception and forced abortion.

Women and girls with disabilities are also subjected to the same harmful practices committed against women and girls without disabilities, with consequences which sometimes aggravate existing disabilities, create new ones, or which magnify their existing vulnerability and social exclusion. Practices such as female genital mutilation (FGM), forced marriage, and rape (including marital rape and rape committed by persons living with HIV/AIDS on the basis of the myth of virgin cleansing\(^6\)) are commonly exercised on women and girls with disabilities with impunity. In some cultures, parents and families arrange the marriage of women and girls with disabilities who have no say or choice in the matter.\(^7\) The reason predominantly cited by parents for these forced arrangements is to ensure a form of security for their...
disabled kin for when it will no longer be possible for parents and/or family members to fulfil the caregiving role. Other reasons for forced marriage of women and girls with disabilities include: obtaining assistance for ageing parents; obtaining financial security for the person with a disability; believing the marriage will somehow “cure” the disability; a belief that marriage is a “rite of passage” for all young people; mistrust of external (e.g. social care/health) carers; a fear that younger siblings may be seen as undesirable if older sons or daughters are not already married. The consequences of forced marriage can be the same for women and girls with disabilities as for those without disabilities: marital rape, domestic violence exercised by their spouse or extended family, domestic servitude, abandonment by their spouse, and exploitation of an individual’s finances and property. For all victims of forced marriage, leaving their marriage, family and community may be the only alternative, but many will require support to do this. People with disabilities may require greater levels of support for longer periods of time, and for many they may have no experience of life outside the family and may lack the financial, physical, social or moral support to leave and start anew.

Where mechanisms may exist to combat and prevent harmful practices, in the form of reporting to the police, or through the provision of support services and hotlines, frequently children and adults with disabilities are either not aware of them, or such mechanisms are not accessible to them. Reporting by persons with disabilities, in particular persons with intellectual disabilities, may not be taken seriously by the authorities. In many jurisdictions, adults with disabilities placed under a substituted decision making regime are not entitled to bring complaints, or to participate in legal proceedings concerning them without the authorisation of their legal guardian, who may either be the perpetrator or be complicit in the commission of the harmful acts. A recent study concluded that the access to rights and justice across Europe by people with intellectual disabilities and persons with psychosocial disabilities is by no means guaranteed. It identified the lack of special measures available within the justice system to facilitate their access, including accessibility of the procedures and of information. Cases of rape of women and girls with disabilities are commonly dismissed across jurisdictions due to their credibility being challenged in court. Lack of

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8 Id, p 13.
9 Id, p 14
10 Id, p 14
13 Id, p 28 (These findings are corroborated in a Comparative Study on Access to Justice in Gender Equality and Anti-Discrimination Law produced at the request of the European Commission in February 2011. Available on request from the European Commission DG JUST. These studies, as well as the report on Access to Justice in Europe: an Overview of challenges and opportunities published by the European Union Agency for Fundamental Rights around the same time, identifies ten EU and EEA countries – Austria, Cyprus, Czech republic, France, Latvia, Liechtenstein, Norway, Poland, Romania and Sweden – where the conditions for legal standing are considered to be excessively strict, requiring people to pass a double threshold: that of having a full legal capacity and of proving their direct interest in the matter. See European Union Agency for Fundamental Rights, Access to Justice in Europe: An Overview of Challenges and Opportunities, 2011, available at http://www.fra.europa.eu/fraWebsite/media/pr-230311_en.htm.)
training of the police, social support services and the judiciary in addressing the needs of persons with disabilities, and how to communicate with persons with disabilities creates barriers to their protection and to access to justice. The inability to access justice inevitably leads to impunity for the perpetrators, and the continuation of harmful practices against persons with disabilities.

**Standards protecting against harmful practices in the Convention on the Rights of Persons with Disabilities**

With the entry into force of the Convention on the Rights of Persons with Disabilities came the important paradigm shift from the medical model of disability, viewing persons with disabilities as objects of treatment or passive recipients of aid, to persons with disabilities emerging as subjects of their own rights and active participants and contributors to society. Several rights of the CRPD uphold the rights of women, girls and boys with disabilities in the face of harmful practices:

- **Article 10 - Right to life**
  Every human being has the inherent right to life and persons with disabilities, including newborns, children, women and men, should be protected to ensure the enjoyment of this right on an equal basis with others.

- **Article 17 – Protecting the integrity of the person**
  Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others. Acts which are committed without the full and informed consent of the individual is a clear violation of their individual integrity. This includes any form of forced treatment including forced sterilisation, contraception and abortion, and forced marriage.

- **Article 16 – Freedom from violence, exploitation and abuse**
  This provision requires States Parties to take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. This includes all forms of non-consensual treatment such as sexual violence, forced marriage, FGM, etc. perpetrated by both private and public actors.

- **Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment**
  Harmful practices constitute cruel, inhuman or degrading treatment or punishment and persons with disabilities and States Parties must take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

- **Article 6 – Women with disabilities**
  Recognising the multiple discrimination to which women and girls with disabilities are subjected, this provision guarantees that measures are to be taken to guarantee their full and

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14 For example, a recent petition communicated to the CEDAW Committee concerns the rape of a deaf girl who was denied access to justice in the Philippines on account of the lack of sign language interpreting in the trial proceedings.
equal enjoyment of all human rights and fundamental freedoms, including their right to protection against harmful practices.

- **Article 7 – Children with disabilities**
  States Parties must take all necessary measures to ensure to children with disabilities the full enjoyment of all human rights and fundamental freedoms on an equal basis with other children. The best interests of the child shall be a primary consideration in all actions concerning children and this principle should be equally applied to children with disabilities. This means that in assessing the best interests of the child, children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity on an equal basis with other children., on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise this right. Children with disabilities must have the same rights to information and education on sexual and reproductive health rights, and to access services and assistance on an equal basis with other children.

- **Article 5 – Equality and non-discrimination**
  All persons are equal before and under the law and entitled without any discrimination to the equal protection and equal benefit of the law. In particular, States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds, and in order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided. Practices which may be widespread in a community but which are harmful to the individual and committed on the grounds of disability, gender, age, ethnicity, etc cannot serve as a pretext to acceptance of these acts and constitute discrimination.

- **Article 23 – Respect for the home and family**
  This provision requires States Parties to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships to ensure that persons with disabilities exercise their right to
  - marry and found a family on the basis of free and full consent,
  - decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education and the means necessary to enable them to exercise these rights are provided,
  - retain their fertility on an equal basis with others (including children with disabilities)
  - adopt and receive appropriate assistance in the performance of their child-rearing responsibilities,
  - receive early and comprehensive information, services and support for children with disabilities and their families,
  - not be separated from their child on the basis of a disability of either the child or one or both parents,
  - ensure that, where the immediate family is unable to care for a child with disabilities, every effort is undertaken to provide alternative care within the wider family and failing that within the community in a family setting.

- **Article 25 - Right to health**
Article 25 guarantees the right to the enjoyment of the highest attainable standard of health including sexual and reproductive health and the obligation to provide persons with disabilities the same range, quality and standard of free or affordable health care and programmes as provided to other persons on the basis of free and informed consent. The requirement of free and informed consent therefore prohibits harmful practices in the form of coercion in medical treatment including forced abortion, forced contraception, forced sterilisation, and administration of all other non-consensual medical treatment. The provision supports access to consensual treatments, such as fertility treatment, on an equal basis with others. Implicit in this right is the availability of trained professionals who are aware of the sexual and reproductive health needs of women with disabilities and who are able to effectively communicate and render information accessible.

- Article 21 – Freedom of expression and opinion, and access to information
This provision requires States Parties to take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the right to seek, receive and impart information and ideas on an equal basis with others with others and through all forms of communication of their choice\(^\text{15}\) including by:
  - providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost,
  - accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
  - urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
  - encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
  - recognising and promoting the use of sign languages.

Article 21 requires States to make available and accessible information on human rights, the prohibition of harmful practices, emergency access to police and assistance, sexual and reproductive education including protective and contraceptive measures, family planning options and services to children and adults with disabilities.

- Article 9 – Accessibility
This provision provides for the elimination of barriers of accessibility in the physical and environment, including accessibility of information, communications and services. Article 9 reinforces the independence and participation of persons with disabilities by ensuring that information and services is made accessible, hence for information to be available in different formats which respond to the needs of persons with disabilities, for example information in Braille or easy to read formats, availability of sign language interpreters in related services and by providing appropriate training for police, the judiciary, medical professionals,

\(^{15}\) As defined under Article 2 of the CRPD, communication includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology.
educators, service providers and others to understand the rights of persons with disabilities, to foster respect for their decisions and to ensure the provision of support for their choices, instead of curtailing them.

- **Article 8 – Awareness-raising**
  Article 8 requires States Parties to adopt immediate effective and appropriate measures to
  - raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
  - combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
  - promote awareness of the capabilities and contributions of persons with disabilities.

This provision promotes greater social awareness and positive perceptions about persons with disabilities including promotion of the inherent dignity of children and adults with disabilities and their status as equal and active subjects of rights in all fields including health care, reproductive health, family life, etc, in order to foster an attitude of respect for their integrity and rights. In addition, awareness raising should encompass training programmes regarding persons with disabilities for all medical and health professionals, educators, police, judicial officers and social assistance personnel. Training must ensure that information, advice and treatment are provided to persons with disabilities in a respectful and professional manner which does not exert pressure or threats, or amount to judgments on the choices of persons with disabilities.

- **Article 13 – Access to justice**
  This provision ensures that women and girls with disabilities being subjected to harmful practices have effective access to justice on an equal basis with others, and for perpetrators to be brought to justice. In particular, women and girls with disabilities should be provided procedural and age appropriate accommodations to ensure their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages. To ensure their access to justice, appropriate training should be promoted for those working in the field of the administration of justice.

- **Article 31 – Statistics and data collection**
  Under this provision States Parties are obliged to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the rights of persons with disabilities. This includes an obligation to collect data which is disaggregated by sex, age, type of disability, geographical region. For example, data on the occurrence of violence, abuse and exploitation should distinctly address information relating to the women and children with disabilities, and their experiences in seeking and obtaining intervention by the police and/or public authorities and assistance, the alleged perpetrators (family members, carers, teachers, doctors, strangers, etc), charges filed, sanctions of convicted perpetrators and remedies for victims, and the involvement of persons with disabilities and their representative organisations in the development of policies and programmes aimed at combating harmful practices affecting them. Such data would facilitate the implementation of States Parties’ obligations to identify and address the barriers
faced by women and girls with disabilities in the effective enjoyment and exercise of their rights.

- Article 12 – Equal recognition before the law
  Article 12 embodies the paradigm shift of the CRPD by recognising that persons with disabilities enjoy legal capacity in all aspects of life on an equal basis with others. Many harmful practices occur as a result of decisions taken by an individual’s legal guardian or family member, and Article 12 prohibits the deprivation of an individual’s capacity to exercise their rights, and obliges the State to make available support, where it may be required, for decision making and exercise of rights in accordance with an individual’s wills and preferences. This provision prohibits health care decisions such as the use of contraception, abortion, sterilisation, etc to be taken by a third party against the will of the individual concerned. Equally, the right to marry, family planning decisions and the exercise of parental rights cannot be taken away or restricted on the basis of disability, and appropriate support is made available to persons with disabilities, where it may be required (and so long as it is accepted by the person concerned), for the full enjoyment of these rights.

IDA Recommendations for the General Comment/Recommendation

The CRPD therefore reinforces the provisions of the CRC and CEDAW in obliging States to respect, protect and fulfil the rights of women and children with disabilities against harmful practices. On the basis of these human rights instruments, IDA makes the following recommendations to the Committees:

- Elaborate and adopt a General Comment/Recommendation on harmful practices which comprehensively addresses the situation and concerns of women and children with disabilities by upholding the rights inscribed in the CRPD. Continue to consult closely with and actively involve persons with disabilities, including children with disabilities and their representative organisations in the drafting process of the General Comment/Recommendation (Article 4(3), CRPD).

- Call on States to take immediate steps to fulfil their obligation to protect women and children with disabilities (including newborns) from harmful practices committed by State agents and private entities or individuals through the adoption of laws, policies and programmes in which the rights and needs of women and children with disabilities figure as an integral part of all measures and initiatives. Ensure that women and children with disabilities and their representative organisations participate and play a central role in the elaboration, implementation and monitoring of laws, policies and programmes and related campaigns.

- Call on States to take steps to effectively prohibit in the law sexual violence and abuse including rape (also marital rape), forced marriage, FGM and other harmful practices which violate sexual and reproductive health rights and the right not to be subjected to torture or cruel, inhuman or degrading treatment or punishment, and to ensure effective protection of women and children with disabilities who are at a heightened risk due to the multiple discrimination exercised against them and their marginalisation in society.
• Call on States to ensure that the law provides for strong criminal sanctions for perpetrators of harmful practices and discrimination, and that traditional and customary beliefs do not mitigate the severity of the crimes and sanctions applied. Ensure that the law provides victims with access to both criminal and civil remedies, and that support and rehabilitation services are available and accessible to them.

• Call on States to adopt immediate measures to ensure that women and children with disabilities are provided procedural and age appropriate accommodations to ensure their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages. In order to guarantee and facilitate their access to justice and support services, appropriate training on the rights of persons with disabilities, on communication and the provision of reasonable accommodation should be promoted and conducted for personnel working in the administration of justice (including the police), social assistance and community services, healthcare and education.

• Call on States to adopt measures which ensure that all health care and services, including sexual and reproductive health, provided to persons with disabilities are respectful of the dignity and integrity of persons with disabilities and are therefore based on the free and informed consent of the individual concerned, and that all non-consensual treatment, including that for which consent is given by a third party (by a parent or legal guardian), is not permitted by law, including *inter alia* forced abortions, forced contraception, and forced sterilisation.

• Call on States to establish support services, including respite care, to assist families in the care of their children with disabilities (including those who have reached adulthood) in order to protect and promote the full and effective enjoyment of their rights on an equal basis with others. In addition, develop and implement community education programmes and the disseminate information targeted at persons with disabilities, and their families and carers, with respect to the rights of children and adults with disabilities, including the right to express their views, right to informed consent, sexual and reproductive health rights, right to privacy, and right to family, in an effort to eliminate recourse to certain forms of harmful practices.

• Call on States to conduct nation-wide and local awareness raising campaigns aimed at the government, public and families to promote the positive image of women and children with disabilities and their role as equal and active participants of and contributors to society. Undertake inclusive and accessible campaigns to educate and inform all public and private sectors of society about harmful practices, that they constitute a violation of the human rights and will not be tolerated, and how victims/potential victims may seek assistance and protection. Ensure that information and communications are accessible by making them available in age appropriate and easy to read formats, local languages including sign language and sign language interpretation, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology such as through websites and phone lines.
• Collect data (disaggregated by sex, age, type of disability, ethnicity, region) on the prevalence of harmful practices exercised on children and adults with disabilities, including women and girls with disabilities, conduct questionnaires and studies to identify trends in reporting, recourse to social support services, complaints filed, investigations, charges, convictions, sanctions and remedies, in an effort to develop laws, policies and programmes to prevent and combat harmful practices and to ensure effective responses for victims.

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