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Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Rights of persons with disabilities****Report of the Special Rapporteur on the rights of persons with
disabilities***Summary*

In her report, the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, provides an overview of the activities undertaken in 2019 and a thematic study on the impact of ableism in medical and scientific practice. The Special Rapporteur explores how ableism is reflected in legislation, policies, customs and practices related to prevention, cure and assisted dying. The report contains recommendations to assist States to develop and implement legal and policy reforms oriented to embracing disability as part of human diversity, in line with the standards set forth in the Convention on the Rights of Persons with Disabilities. They include adopting measures to raise awareness, implementing rights-based prevention policies, respecting and protecting personal autonomy, the right to life and the right to personal integrity of persons with disabilities, and promoting their participation in decision-making.



I. Introduction

1. The Special Rapporteur on the rights of persons with disabilities submits the present report to the Human Rights Council pursuant to resolution 35/6. It contains a description of the activities she undertook in 2019 and a thematic study on the impact of ableism in medical and scientific practice, research and experimentation. In the report, the Special Rapporteur aims to provide guidance to States on how to adopt a human rights-based approach to disability in legislation, policies, customs and practices related to prevention, cure and assisted dying.

2. In preparing the study, the Special Rapporteur commissioned a background paper, convened an expert group meeting in Geneva on 16 and 17 September 2019 and analysed the 45 responses received to a questionnaire sent to Member States, national human rights institutions, bodies of the United Nations system, persons with disabilities and their organizations, and other civil society groups.¹

II. Activities of the Special Rapporteur

A. Country visits

3. In 2019, the Special Rapporteur visited Canada from 1 to 11 April and Norway from 2 to 11 October. She thanks both Governments for their cooperation prior to, during and after her visits. She has agreed to undertake visits to Botswana and China in 2020.

B. Engagement with stakeholders

4. On 5 March 2019, the Special Rapporteur presented her thematic report to the Human Rights Council on the right to liberty and security (A/HRC/40/54) and on 21 October 2019 her report to the General Assembly on older persons and disabilities (A/74/186). Both reports are available in accessible formats.²

5. In 2019, the Special Rapporteur continued to actively promote a process to strengthen system-wide accessibility, inclusion and mainstreaming of the rights of persons with disabilities in the United Nations. The findings of her 2018 baseline review of United Nations action to mainstream accessibility and disability inclusion – conducted at the request of the Executive Office of the Secretary-General – informed the development of the United Nations disability inclusion strategy in 2019.³ During this process, the Special Rapporteur engaged with the Secretary-General and the Deputy Secretary-General and collaborated with the Inter-Agency Support Group on the Convention on the Rights of Persons with Disabilities. The strategy was endorsed by the Chief Executives Board for Coordination in May and launched by the Secretary-General in June. Following its adoption, the Special Rapporteur continued to advocate with the Secretary-General's Senior Adviser on Policy, the President of the General Assembly, United Nations entities and Member States on the need to secure the long-term sustainability of the strategy and maintain it as a top-level priority across all pillars of the United Nations system.

6. The Special Rapporteur participated in numerous conferences and expert meetings, including a Security Council Arrria formula meeting on persons with disabilities in armed conflicts; the annual day on the rights of the child and the interactive debate on the rights of persons with disabilities at the Human Rights Council; a hearing of the General Assembly of France on protected adults; a hearing of the Committee of Ibero-American Affairs of the Senate of Spain; and the twelfth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities. She also organized an expert group meeting on the intersections between women's rights and the rights of persons with

¹ See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/BioethicsDisabilities.aspx.

² See www.ohchr.org/en/issues/disability/srdisabilities/pages/reports.aspx.

³ See www.un.org/en/content/disabilitystrategy/.

disabilities; commissioned a study on access to justice for persons with disabilities; and contributed to the United Nations global study on children deprived of liberty.

7. The Special Rapporteur continued to collaborate closely with the special procedures system, the treaty bodies and other United Nations experts and entities, including the Office of the United Nations High Commissioner for Human Rights (OHCHR), the Office for the Coordination of Humanitarian Affairs, the United Nations Development Programme, the United Nations Children’s Fund, the World Health Organization and the United Nations Partnership to Promote the Rights of Persons with Disabilities. She also engaged with regional organizations, national human rights institutions, organizations of persons with disabilities, other non-governmental organizations, universities and the diplomatic community.

C. Communications

8. Summaries of communications sent and replies received during the period covered by the present report are available in the communications reports of the special procedures (A/HRC/40/79, A/HRC/41/56 and A/HRC/42/65) and in the public communications database of OHCHR.

III. Lives not worth living

9. Despite the significant advances in the recognition of the rights of persons with disabilities at international and national levels, the deeply rooted negative perceptions about the value of their lives continue to be a prevalent obstacle in all societies. Those perceptions are engrained in what is known as ableism; a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives.⁴

10. Ableism leads to social prejudice, discrimination against and oppression of persons with disabilities, as it informs legislation, policies and practices. Ableist assumptions lie at the root of discriminatory practices, such as the sterilization of girls and women with disabilities (see A/72/133), the segregation, institutionalization and deprivation of liberty of persons with disabilities in disability-specific facilities and the use of coercion on the basis of “need of treatment” or “risk to self or to others” (A/HRC/40/54), the denial of legal capacity on the basis of mental capacity (A/HRC/37/56), the denial of treatment on the basis of disability (A/73/161), or the failure to consider the extra costs of living with a disability (A/70/297).

11. The eugenics movement was born out of, and grew on, the basis of ableist premises during the late nineteenth and early twentieth centuries. Under this widely accepted approach, thousands of persons with disabilities, including children, were prevented from reproducing through forced sterilization programmes in North America and Europe.⁵ In Germany, Nazi eugenic practice was responsible for the murder of approximately 300,000 persons with disabilities who were considered to have “lives unworthy of life”.⁶ Unlike the widespread moral revulsion and outrage against comparable atrocities of the twentieth century, the significance of the eugenics movement and its impact on how societies

⁴ See Ron Amundson, “Disability, ideology, and quality of life: a bias in biomedical ethics”, in *Quality of Life and Human Difference*, David Wasserman, Jerome Bickenbach and Robert Wachbroit, eds., (New York, Cambridge University Press, May 2005).

⁵ See David Pfeiffer, “Eugenics and disability discrimination”, *Disability & Society*, vol. 9, No. 4 (1994); Daniel J. Kevles, “Eugenics and human rights”, *BMJ*, vol. 319 (7207) (August 1999); and Ayça Alemdaroğlu, “Eugenics, modernity and nationalism” in *Social Histories of Disability and Deformity*, David M. Turner and Kevin Stagg, eds. (Abingdon, Oxon, Routledge, 2006).

⁶ See Michael Robertson, Astrid Ley and Edwina Light, *The First into the Dark: the Nazi Persecution of the Disabled* (London, Ubiquity Press (UTS ePress), 2019).

continue to dismiss the value of the lives of persons with disabilities has long remained confined to disability circles.

12. Contrary to common belief, persons with disabilities can experience a good quality of life. They consistently report a quality of life as good as, or sometimes even better than, that of persons without disabilities.⁷ The earlier in life that the impairment is acquired, the higher the resulting quality of life reported.⁸ Furthermore, evidence indicates that differences in quality of life perceptions of persons with disabilities are largely associated with contextual factors such as social connectedness, employment opportunities, access to quality services and community inclusion.⁹ No significant differences have been found between degrees of severity of impairment. What determines the quality of life of persons with disabilities is not the impairment, but the same things that determine the quality of life of persons without a disability. As for anyone else, persons with disabilities can have fulfilling and happy lives and will also be confronted with losses and adversity, particularly in the face of discrimination, oppression and barriers.

13. The contrasting assessments of the quality of lives of persons with disabilities reflect both ableist views of disability and a lack of understanding of the role of social and environmental barriers in the experience of disability. As research has shown, the lower estimation of the quality of life of persons with disabilities by external observers, including many bioethicists, are caused by unconscious biases towards persons with disabilities.¹⁰ Fear, ignorance and prejudices permeate the understanding of the disability experience, a process that is constantly reinforced by dominant cultural representations of disability. Many persons have never had direct experience of persons with disabilities, owing to the long-standing practice of segregation and institutionalization.

14. Some persons with disabilities themselves hold negative and prejudiced attitudes towards disability. This internalized oppression is the result of the pervasive stigma and stereotypes of persons with disabilities that abound in society. Society systematically delivers degrading and dehumanizing messages about their appearance, behaviour and worth, which can distort the perceptions of persons with disabilities about themselves and their value. Internalized oppression can lead to disempowerment but also to harmful emotions, such as shame and self-loathing, which could increase the risk of isolation and self-harm.

15. Over the last 50 years, the disability rights movement has been challenging these deeply rooted negative perceptions, stating that the real problem is the failure of society to eliminate barriers, provide the required support and embrace the disability experience as part of human diversity. However, the claims of persons with disabilities to have their rights recognized are often dismissed and the underlying power imbalance invalidates their lived experiences. Their narratives are considered to be subjective and ill-suited to informing objective decision-making and thus are not given the space to be genuinely weighed or to challenge ableism. Access to the platforms on which discussions are taking place is limited, rendering the disability movement unable to share information on an equal basis with others.

⁷ See Tom Shakespeare, "Nasty, brutish, and short? On the predicament of disability and embodiment" in *Disability and the Good Human Life*, Jerome Bickenbach, Franziska Felder and Barbara Schmitz, eds. (New York, Cambridge University Press, 2013).

⁸ See Sharanjit Uppal, "Impact of the timing, type and severity of disability on the subjective well-being of individuals with disabilities", *Social Science & Medicine*, vol. 63, No. 2 (July 2006).

⁹ See Ron Amundson, "Quality of life, disability, and hedonic psychology", *Journal for the Theory of Social Behaviour*, vol. 40, No. 4 (November 2010); Bernd Fellinghauer and others, "Explaining the disability paradox: a cross-sectional analysis of the Swiss general population", *BMC Public Health*, vol. 12 (August 2012); and Carli Friedman and Laura VanPuymbrouck, "The impact of people with disabilities choosing their services on quality of life outcomes", *Disability and Health Journal*, vol. 12, No. 2 (April 2019).

¹⁰ See Ron Amundson, "Quality of life, disability, and hedonic psychology".

IV. Bioethics and disability

16. Ableist positions continue to dominate important debates that impact on the rights of persons with disabilities. Outdated notions about normality still dominate medical, legal and philosophical deliberations, including sensitive discussions related to scientific and medical developments and practice, such as prenatal screening; gene editing; withholding and withdrawal of life-sustaining treatments; the permissibility of invasive, painful and/or irreversible interventions; and assisted dying. Often, these debates have taken place primarily in the field of bioethics.

17. Bioethics is a broad interdisciplinary field in which ethical issues raised by developments in medicine and biology are explored, studied and resolved. It draws from a wide range of subjects, including philosophy, law, social science, social policy and medicine, applying a variety of theoretical and empirical approaches.¹¹ Although much of bioethics is academic, it helps to address very practical issues ranging from clinical decisions to public health innovations and social policy and contributing to judging whether an intervention is ethically right and how research and practice should be regulated. Furthermore, bioethics is concerned with the ethical consequences of the ways that advances in medicine and biology impact upon how societies consider human lives and values. It reflects on the modern dilemma between individual liberty and social responsibility.

18. Bioethics emerged in part in response to the brutalities that took place in the Second World War, in order to protect the human dignity and human rights of all by addressing the power and morality of scientific and technological developments.¹² Anchored in the indivisibility of ethics and human rights, as reflected in the Nuremberg Code and the Universal Declaration of Human Rights, the relationship between bioethics and human rights was later strengthened by the Declaration of Helsinki (1964), the International Covenants on Civil and Political Rights and on Economic, Social and Cultural Rights (1966), the Universal Declaration on the Human Genome and Human Rights (1997), the International Declaration on Human Genetic Data (2003) and the Universal Declaration on Bioethics and Human Rights (2005). At the regional level, only the Council of Europe has a specific treaty on the issue, the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo Convention) (1997).

19. Historically, bioethics and disability have had a close but conflictual relationship. Despite a common interest in facilitating good medical care and individual choice, disability rights activists and bioethicists often differ considerably in their approaches. From a mainstream bioethical perspective, preventing or curing impairments is a morally good thing to do. Since disability is perceived as a deviation from a norm of health, restoring impaired bodies and minds to normal functioning and health, or ideally preventing such an occurrence, is valued positively. However, from a disability rights perspective, disability is part of the continuum of the human experience. The question is not about preventing or curing impairments, but how to ensure that all persons with disabilities enjoy the same rights and opportunities as everybody else.

20. Much of the work in bioethics to date has been based on a thin or inaccurate understanding of the diversity, complexity, and socially embedded nature of disability. While some bioethical writing on disability has begun to take into account the perspective of persons with disabilities, it is still overwhelmingly produced from the standpoint of outsiders. Ableist views, including the assumption that persons with disabilities are of lesser value than others, or that their lives are not worth living, dictate most bioethical discussions, from prenatal testing to assisted dying. They therefore fail to address the bioethical questions that actually concern persons with disabilities and their families.

21. When discussing issues such as prenatal testing, selective abortion and pre-implantation genetic diagnosis, there is a shared concern among disability rights activists

¹¹ Alicia Ouellette, *Bioethics and Disability. Towards a Disability-Conscious Bioethics* (New York, Cambridge University Press, 2011).

¹² See Paula Siverino Bavio, "Una bioética en clave latinoamericana: aportes de la Declaración Universal sobre bioética y derechos humanos de UNESCO", *Derecho PUCP*, vol. 63 (2009).

that bioethical analyses are often used to give an ethical justification to a new form of eugenics, often referred to as “liberal” eugenics.¹³ Contrary to the eugenics movement, liberal eugenics aims to expand reproductive choices for individuals, including the possibility of genetic enhancement. While there may be no State-sponsored coercive eugenics programmes, in a context of widespread prejudice and discrimination against persons with disabilities, the aggregate effect of many individual choices are likely to produce eugenic outcomes. Indeed, ableist social norms and market pressures make it imperative to have the “best possible child” with the best possible chances at life. Some utilitarian bioethicists have further argued that genetic enhancement is a moral obligation and that it is ethical to give parents the option to euthanize their newborns with disabilities.¹⁴

22. Emerging technologies raise important bioethical questions that it is increasingly urgent to answer. Advances in biotechnologies, such as gene therapy, genetic engineering, synthetic biology and nanotechnology, raise significant ethical issues concerning the nature, safety and appropriateness of such technologies, as well as their impact on the lives of persons with disabilities. These cutting-edge tools grant humanity unprecedented power to prevent and “repair” disability. There is a genuine concern that the result will not only be an increase in eugenic practices, but an overall decrease in social acceptance and solidarity in relation to diversity and difference.¹⁵ Besides these new challenges linked to emerging technologies, many practices that have been legitimized by traditional bioethics (i.e. coercive interventions) are still problematic from a disability perspective.

23. An existential worry lies beneath these concerns about bioethics and eugenics. When bioethics addresses the moral permissibility of using a particular medical or biological intervention to prevent or treat disability, it is also judging the quality of life and, ultimately, the value of persons with disabilities. What is being debated is the impact of an impairment on an individual’s lived experience against the ethical cost, and sometimes the economic cost, of making a particular intervention or not. Choosing between subjective measures of quality of life (what people with lived experience say) or objective measures (what economists, public health specialists or others say) will lead to different conclusions. As a consequence, when debating those issues, disability rights advocates often feel forced to justify their own worth and existence. That is a feeling shared by many persons with disabilities throughout their lives, while facing stereotyped assumptions about their individual abilities and rights to participate in and contribute to society.

24. The increased reliance on medical practice and policymaking by the work of bioethics committees is also of concern. Such committees systematically and continually address the ethical dimensions of the health sciences, the life sciences and health policies, issuing opinions and recommendations that play an important role in clinical practice, research and policy. However, as some have pointed out, persons with disabilities are not represented on those committees and their views are regularly dismissed.¹⁶ Furthermore, the increasing proceduralism in bioethics, as practised by bioethical committees, is transforming ethics into an “instrumental function” rather than a process of critical reflection.¹⁷ As such, ethical debates are reduced to an application of rules to situations in an oversimplified and legalistic manner, without a critical reflection of the role of human rights in bioethics and the power dynamics under which decisions are made.

¹³ See Robert Sparrow, “A not-so-new eugenics. Harris and Savulescu on human enhancement”, *Hastings Center Report*, vol. 41, No. 1 (January-February 2011); and Nicholas Agar, *Liberal Eugenics. In Defence of Human Enhancement* (Oxford, Blackwell, 2004).

¹⁴ See Julian Savulescu, “Procreative beneficence: why we should select the best children”, *Bioethics*, vol. 15, No. 5–6; and Peter Singer, *Practical Ethics*, 2nd ed. (New York, Cambridge University Press, 1993).

¹⁵ See Nuffield Council on Bioethics, “Genome editing and human reproduction: social and ethical issues”, (July 2018).

¹⁶ See Christopher Newell, “Disability, bioethics, and rejected knowledge”, *Journal of Medicine and Philosophy*, vol. 31, No. 3 (2006).

¹⁷ *Ibid.*

25. Against that background, there is a need to return to a bioethics informed by human rights. Bioethics should move toward a “disability bioethics”¹⁸ or a “disability-conscious bioethics”¹⁹ that recognizes the rights and concerns of persons with disabilities, paying close attention to their own voices, their needs and their ethical choices. To have a reliable basis for theoretical ethical reflection and policymaking, bioethics must have enough empirical grounding in the realities of the lives of persons with disabilities. The bioethical debate must be permeated by the human rights standards and concerns related to persons with disabilities. While bioethics has a commitment to promote respect for human dignity and protect human rights (Universal Declaration on Bioethics and Human Rights, art. 2), the rights of persons with disabilities, as informed by the Convention on the Rights of Persons with Disabilities, are yet to be embraced.

V. Contemporary challenges

26. There is a permanent tension between the notion of “curing disability” and that of supporting people to live with a disability. Persons with disabilities themselves have different perspectives on the issue. Some may find the notion of cure irrelevant or even offensive, particularly those who experience disability as part of their identity; whereas others are supportive of biomedical research aimed at curing or correcting impairments. Both views are equally valid and must be respected. Nevertheless, society biases towards “fixing” difference have a broad range of negative consequences for persons with disabilities.

27. While prevention of impairments and illnesses is an important element of public health policy, it is not an appropriate tool for protecting the rights or improving the quality of life of persons with disabilities, in particular when State efforts are focused on prevention instead of on fixing society to be accessible to, and inclusive of, persons with disabilities. Furthermore, many prevention programmes reinforce prejudice and stigma against persons with disabilities by conveying the message that life with a disability is not worth living.²⁰ In addition, biomedical research targeting certain conditions, such as autism, raises the important question as to whether prevention of such conditions is desirable, as it will result in a reduction of human diversity.

28. Many parents of children with disabilities experience enormous pressure towards cure. There is a growing number of interventions aimed at “fixing” a child’s impairments or, at least, making them less apparent to the outside world. Many of these interventions are invasive, painful and/or irreversible, and do not achieve any real benefit for the children, because they are performed with the sole objective of making them appear aesthetically normal and better accepted within society (for example, limb lengthening in children with restricted growth or cosmetic facial surgery in children with Down’s syndrome). Some interventions are potentially harmful, such as stem cell therapy, antifungal medications and chelation therapy for autistic children.²¹ There are also a number of surgical procedures and hormonal treatments intended to inhibit the growth of children with severe impairments, including hysterectomy and oestrogen treatment (see A/72/133).

29. Ableist views of disability also lead to coercive practices. While autonomy is a central value of bioethics, many groups of persons with disabilities, such as persons with intellectual disabilities, persons with psychosocial disabilities, persons with dementia and autistic persons, are regularly considered as “incompetent” to consent to treatment and are therefore subjected to forced and/or involuntary medical interventions, research and experimentation aimed at curing or correcting their impairments (and its consequences). These practices include, inter alia, sterilization, contraception and abortion; invasive,

¹⁸ See Jackie Leach Scully, *Disability Bioethics: Moral Bodies, Moral Difference* (Lanham, Maryland, Rowman and Littlefield, 2008).

¹⁹ See Alicia Ouellette, *Bioethics and Disability. Towards a Disability-Conscious Bioethics*.

²⁰ See Theresia Degener, “Disability in a human rights context”, *Laws*, vol. 5, No. 3 (2016).

²¹ See Susan E. Levy and Susan L. Hyman, “Complementary and alternative medicine treatments for children with autism spectrum disorders”, *Child and Adolescent Psychiatric Clinics of North America*, vol. 24, No. 1 (2015).

painful and/or irreversible medical interventions; electroconvulsive therapy; and the administration of psychotropic medication.

30. Many therapeutic interventions that are within broadly accepted standards of medical practice are nonetheless controversial from a disability perspective. For example, although psychotropic medications are now relatively commonplace, their use raises various ethical issues. They include the medicalization of human suffering and social problems; the medication of challenging behaviour, particularly in children; unknown side effects, including suicidality and medical complications; gaining informed consent in a context of biased information and structural discrimination; and profound questions of identity, such as the role of voice-hearing, visions and similar sensory experiences. As pharmaceutical interventions become more sophisticated (for example, “smart” pills), there is a need to include the voices of persons with psychosocial disabilities themselves in such ethical discussions.

31. Efforts to prevent disability include the use of genetic prenatal screening and genetic diagnosis pre-implantation. Thanks to technological advances, these options are increasingly available, take place earlier and are safer and more accessible. The cumulative effect of individual choice, the ideal of the perfect offspring and ableism, among both clinicians and wider society, has resulted in a steady rise of prospective parents choosing not to have a child with a disability. In some high-income countries, high uptake rates for screening have already been associated with significant reductions in the number of children born with some congenital disabilities.²²

32. From a disability rights perspective, there is a concern that such practices may reinforce and socially validate the message that persons with disabilities ought not to have been born. Legislative frameworks that extend the time frame for a lawful abortion or, exceptionally, permit abortion in the presence of fetal impairment aggravate this message. In addition, as the consequence is a smaller number of persons with disabilities being born, some fear a reduction in disability advocacy and social support for persons with disabilities.²³ Furthermore, health policies and abortion laws that perpetuate deep-rooted stereotypes and stigma against persons with disabilities also undermine women’s reproductive autonomy and choice.²⁴ In that regard, while the issue of disability-selective abortion requires greater attention, solutions must not compromise the right of all women, including women with disabilities, to decide whether or not they want to continue with a pregnancy. As interventions against sex-selective abortions have shown, abortion bans and restrictions on the use of technologies are not only detrimental to women’s rights but also ineffective.²⁵

33. As genetic research advances, the potential for genetic engineering to ensure the presence or absence of particular genes or characteristics is becoming a reality. Gene editing refers to the active “repair” of impairment-associated genes. Alongside the various ethical issues raised by this technology, including those related to safety, consent, inequalities and unintended mutations, there is concern among bioethicists and disability rights activists that it may lead to a significant decrease in diversity per se and fewer opportunities for those who are deemed different.²⁶ There are already worrisome reports related to ongoing experimentation to repair the gene linked to deafness.

²² See Maria Loane and others, “Twenty-year trends in the prevalence of Down syndrome and other trisomies in Europe: impact of maternal age and prenatal screening”, *European Journal of Human Genetics*, vol. 21, No. 1 (January 2013).

²³ See Elizabeth R. Schiltz, “Finding common ground in the disability rights critiques of selective abortions” in *In Search of Common Ground on Abortion: From Culture War to Reproductive Justice*, Robin West, Justin Murray and Meredith Esser, eds. (Farnham, Surrey, Ashgate, 2014).

²⁴ See Committee on the Rights of Persons with Disabilities and Committee on the Elimination of Discrimination against Women, joint statement (29 August 2018), available from www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDStatements.aspx.

²⁵ See World Health Organization, “Preventing gender-biased sex selection: an interagency statement. OHCHR, UNFPA, UNICEF, UN Women and WHO” (2011).

²⁶ See Nuffield Council on Bioethics, “Genome editing and human reproduction: social and ethical issues”.

34. Persons with disabilities often face discrimination in organ transplantation. Some medical professionals believe that a person's impairment will impact the likelihood of transplant success, while others consider that some persons with disabilities, particularly those with intellectual and psychosocial disabilities, will be unable to comply with the necessary post-operative care.²⁷ However, there is plenty of evidence debunking such myths and stereotypes about the medical suitability of persons with disabilities for organ transplants.²⁸ The impairment will generally have little or no impact on the likelihood of the transplant being successful and if a person with disabilities receives adequate support, there should be no impact on their ability to follow a post-transplant care regime.

35. The disability community has expressed significant concerns about the potential dangers of withdrawal and withholding of life-sustaining treatment on the basis of disability. While withdrawal and withholding of treatment can be ethical and medically appropriate in some circumstances, it has been reported that physicians may exert pressure on critically ill patients and their families to withhold or withdraw life-sustaining treatment based on the belief that further treatment would be futile, non-beneficial or potentially inappropriate, particularly for patients with severe impairments.²⁹ That subjective assessment, based on the physician's opinion and values, includes an assumption on the resulting quality of life of the individual and thus involves a risk that it is influenced by ableist views of living with a disability.³⁰ Similarly, cost-effectiveness considerations may also result in the denial of life-sustaining treatments to some persons with disabilities.³¹

36. Assisted dying, whether through euthanasia or assisted suicide, is a contentious issue within the disability community. Euthanasia generally entails the consented administration of a lethal substance by a third person, usually a physician, to end a person's life; assisted suicide refers to the prescription of a lethal substance for self-administration by the individual.³² To date, assisted dying is legal in only eight countries, but many others are considering its implementation.³³ The practice and requirements for assisted dying vary across jurisdictions; in some, euthanasia performed by physicians is predominant, whereas in others only assisted suicide is permitted. Additionally, while in some jurisdictions assisted dying is restricted to adults who are terminally ill, some countries offer assisted dying for anyone with a medical condition who experiences severe physical or mental pain and suffering. Countries where assisted dying is performed by physicians and that have broad access criteria have higher percentages of assisted dying and have experienced a significant expansion of the practice over the last decade.³⁴

37. From a disability rights perspective, there is a grave concern that legalizing euthanasia and assisted suicide could put at risk the lives of persons with disabilities. If assisted dying is made available for all persons with a health condition or impairment, regardless of whether they are terminally ill or not, a social assumption might follow that it is better to be dead than to live with a disability. Therefore, a first concern is that persons

²⁷ See National Council on Disability, *Organ Transplant Discrimination against People with Disabilities: Part of the Bioethics and Disability Series* (Washington, D.C., September 2019).

²⁸ See Katherine L. Cahn-Fuller and Brendan Parent, "Transplant eligibility for patients with affective and psychotic disorders: a review of practices and a call for justice", *BMC Medical Ethics*, vol. 18 (2017); Alexander N. Goel and others, "Heart transplantation in children with intellectual disability: an analysis of the UNOS database", *Pediatric transplantation*, vol. 21, No. 2 (March 2017).

²⁹ See John M. Luce and Douglas B. White, "The pressure to withhold or withdraw life-sustaining therapy from critically ill patients in the United States", *American Journal of Respiratory and Critical Care Medicine*, vol. 175, No. 11 (June 2007).

³⁰ See Maneka A. Braganza, Alastair J. Glossop and Vandana A. Vora, "Treatment withdrawal and end-of-life care in the intensive care unit", *BJA Education*, vol. 17, No. 12 (December 2017).

³¹ See Dominic Wilkinson, Stavros Petrou, Julian Savulescu, "Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care", *Monash Bioethics Review*, vol. 35, Nos. 1–4 (July 2018).

³² These practices differ from refusing treatment and withdrawing life-sustaining treatment where the disease process is what leads to the patient's death.

³³ Assisted death is legal in Belgium, Canada, Colombia, Luxembourg, Netherlands, Switzerland, the State of Victoria in Australia and 10 jurisdictions within the United States of America.

³⁴ See Trudo Lemmens, "Charter scrutiny of Canada's medical assistance in dying law and the shifting landscape of Belgian and Dutch euthanasia practice", *Supreme Court Law Review* (2nd series), vol. 85 (2018).

with a newly acquired impairment may opt for assisted dying based on prejudices, fears and low expectations of living with a disability, before even having the chance of coming to terms with and adapting to their new disability status. Second, persons with disabilities may decide to end their lives because of social factors, including loneliness, social isolation and lack of access to quality support services. A third problem is that persons with disabilities, particularly older persons with disabilities, may be vulnerable to explicit or implicit pressures arising from their context, including expectations from family members, financial pressures, cultural messages and even coercion.

38. Generally, when life-ending interventions are normalized outside the end stage of terminal illness, persons with disabilities and older people may increasingly feel the need to end their lives. For example, the available data from two countries show an increase in the demand for euthanasia among people who are not terminally ill, particularly persons with psychosocial disabilities and dementia.³⁵ Nevertheless, many disability rights advocates also oppose assisted dying in terminally ill contexts, as they fear it will put at risk persons with new or progressive disabilities or diseases, who may be mistakenly diagnosed as terminally ill but who have many years of life ahead of them.³⁶

VI. Embracing disability as part of human diversity

39. The Convention on the Rights of Persons with Disabilities, adopted in 2006, provides the most appropriate framework from which to approach the issues arising at the intersection of bioethics and disability. The Convention embodies a shift of paradigm in the way persons with disabilities are perceived, which entails a move from the medical model to the human rights model of disability. While the former reduces disability to a medical phenomenon of impairment, the latter recognizes disability as a social construct. In doing so, the Convention locates the “problem” of disability outside the person and within society by recognizing that social barriers are the main obstacles for the enjoyment of human rights by persons with disabilities. Persons with disabilities are considered as subjects of rights rather than objects of charity, protection or care. That entails recognizing their equal value and ensuring that all persons with disabilities enjoy all human rights and fundamental freedoms without discrimination.

40. The Convention embraces differences between human beings and underlines the importance of taking the diversity of the human experience into account. Society has traditionally ignored or discounted the difference of disability and thus societal structures have not considered the rights of persons with disabilities. The Convention restores the importance of the human being in the human rights discourse by emphasizing the individual and social aspects of the human experience. In that way, the Convention challenges traditional approaches to disability and has the potential to redress the legacy of disempowerment, paternalism and ableism.³⁷

A. General principles of the Convention on the Rights of Persons with Disabilities

41. The general principles of the Convention on the Rights of Persons with Disabilities are fundamental for ensuring a human rights approach to disability while medical and scientific practice concerning persons with disabilities are under discussion. The principle of respect for inherent dignity, individual autonomy, including the freedom to make one’s own choices, and independence of persons (art. 3 (a)) must, in particular, be of primary consideration. The term dignity appears in the Convention more often than in any other

³⁵ Ibid.

³⁶ See Marilyn Golden, “Why assisted suicide must not be legalized”, Disability Rights Education & Defense Fund, available from <https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized-2>.

³⁷ See Gerard Quinn and Anna Arstein-Kerslake, “Restoring the ‘human’ in ‘human rights’: personhood and doctrinal innovation in the UN disability convention” in *The Cambridge Companion to Human Rights Law*, Conor Gearty and Costas Douzinas, eds. (Cambridge, Cambridge University Press, 2012).

universal treaty.³⁸ It is included in its preamble, purpose and principles, and is referred to in relation to specific rights such as the right to health. “Inherent dignity” refers to the worth of every person. The recognition of inherent dignity serves as a powerful reminder that persons with disabilities, simply by being human, are equally worthy and deserving of respect.³⁹ It proclaims that persons with disabilities are ends in themselves and not means to the ends of others, challenging societal responses that treat them as objects to be pitied, protected or cured, or value their lives only from a utilitarian standpoint.

42. Individual autonomy and personal independence (art. 3 (a)) are essential values associated with human dignity. Autonomy means to have the freedom to make one’s own choices, independence and to be in charge of one’s own life. Traditionally, both individual autonomy and personal independence were based on ableist assumptions, such as possessing certain mental capacity or not needing assistance to carry out everyday activities. As a result, persons with disabilities were seen as less autonomous and independent than others and even as having no autonomy or independence. However, the human rights model of disability frames autonomy and independence in a way that takes into account the interdependence of human experiences and accepts reliance on others as a fundamental aspect of these values (see A/HRC/34/58). Respect for individual autonomy means that persons with disabilities are recognized as rights holders, capable of making their own decisions, with adequate support if required. Having high support needs cannot justify the denial of autonomy and self-determination.

43. The principles of non-discrimination (art. 3 (b)) and equality of opportunity (art. 3 (e)) are also important for ensuring the respect of the rights of persons with disabilities in medical and scientific practice. Those principles lie at the heart of the Convention and are evoked consistently throughout its text with the formula “on an equal basis with others”. The Convention embraces a model of substantive equality (“inclusive equality”) that seeks to address structural discrimination in addition to direct and indirect discrimination. It further provides for a framework for a positive response to human diversity in order to achieve equality, taking into account power relations and different layers of identity. The principles of equality and non-discrimination entail stopping all forms of discrimination against persons with disabilities, including discrimination by private actors, but also ensuring legal and policy frameworks that enable persons with disabilities to fully participate on an equal basis with others.

44. The principle of respect for difference and the acceptance of persons with disabilities as part of human diversity and humanity (art. 3 (d)) is a unique contribution of the Convention on the Rights of Persons with Disabilities to human rights theory. Respect for difference involves accepting persons with disabilities for who they are, rather than pitying them or seeing them as a problem that needs to be “fixed”. It further implies that impairment is not to be regarded as a deficit or as a factor that can be detrimental to human dignity.⁴⁰ Accordingly, persons with disabilities are recognized as part of human diversity and must be respected and embraced as such. This premise is fundamental to addressing ethical and policy questions that are triggered by how society perceives and treats impairment.

45. The principle of respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (art. 3 (h)) is also relevant for discussions related to medical and scientific concerns. The principle of respect for their evolving capacities affirms that children are rights holders under international law and recognizes the role of children’s agency in decision-making. The recognition of the right to preserve the child’s identity involves the protection of both the static and dynamic attributes of a child’s identity, including, inter alia, their disability.⁴¹

³⁸ Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018) on equality and non-discrimination, para. 6.

³⁹ See Gerard Quinn and Theresia Degener, *Human Rights and Disability. The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Geneva, United Nations Press, 2002).

⁴⁰ See Theresia Degener, “Disability in a human rights context”, p. 8.

⁴¹ John Tobin and Jonathan Todres, “Article 8. The right to preservation of a child’s identity” in *The UN Convention on the Rights of the Child. A Commentary*, John Tobin, ed. (Oxford, Oxford University Press, 2019).

That includes the need to support and safeguard the child's right to decide who he or she will become in the future.⁴²

46. The active participation of persons with disabilities in decision-making is a requirement of the human rights model of disability. Participation is addressed as a cross-cutting issue in the Convention; it is recognized as a general principle (art. 3 (c)) and as an obligation for consulting and actively involving persons with disabilities in decision-making processes of their concerns (arts. 4 (3) and 33 (3)). Efforts to involve persons with disabilities in decision-making processes are important, not only because they result in better decisions and more efficient outcomes, but also because they promote citizenship, agency and empowerment (see A/HRC/31/62).

B. Human rights obligations of the Convention on the Rights of Persons with Disabilities

47. Many human rights obligations of the Convention are relevant to medical and scientific debates concerning persons with disabilities from a human rights-based approach to disability. Article 8 recognizes the important role of awareness-raising for the implementation of human rights by providing for the adoption of immediate, effective and appropriate measures to raise awareness throughout society regarding persons with disabilities and to foster respect for their rights and dignity; combat stereotypes, prejudices and harmful practices used against them; and promote awareness of their capabilities and contributions. In article 8 (2), a set of measures to this end are recommended, including initiating and maintaining effective public awareness campaigns and promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities. Article 21 complements those obligations by recognizing the freedom of persons with disabilities to seek, receive and impart information and ideas on an equal basis with others.

48. Article 10 recognizes and protects the right to life of persons with disabilities on an equal basis with others, which is critical for contesting legislation, policies and practices whereby the lives of persons with disabilities have been put at risk because of perceived low quality of life. It reaffirms that every human being has the inherent right to life, which reflects the concern expressed in the Convention to consider the lives of persons with disabilities as being as valuable as those of any other human being. Article 10 calls on States to take "all necessary measures to ensure the effective enjoyment of the right to life by persons with disabilities on an equal basis with others". That entails a duty to protect the lives of persons with disabilities from all acts and omissions that are intended or may be expected to cause their unnatural or premature death,⁴³ as well as ensuring respect, dignity and quality of life of persons with disabilities on an equal basis with others in all spheres and at all stages of life. The right to life includes the right to survive and develop on equal basis with others. Disability cannot be a justification for termination of life.

49. Article 12 enshrines equal recognition before the law so that all persons with disabilities enjoy legal capacity on an equal basis with others. Legal capacity is recognized as a universal attribute inherent in all persons by virtue of their humanity.⁴⁴ Accordingly, States cannot restrict the legal capacity of persons with disabilities and must rather protect them against any interference in all aspects of life (see A/HRC/37/56). In article 12 the role of support in the actual implementation of the right to legal capacity is emphasized by establishing an obligation to provide persons with disabilities with access to the support they may require in exercising their legal capacity, including decisions regarding medical treatment and research. The recognition of full legal capacity and supported decision-making are necessary steps for providing persons with disabilities with the freedom and opportunity to live the lives they value, which must be a basic premise in all medical and scientific research and practice.

⁴² Ibid.

⁴³ Human Rights Committee, general comment No. 36 (2018) on the right to life (replacing general comment Nos. 6 and 14), para. 3.

⁴⁴ Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) on equal recognition before the law, para. 8.

50. Article 15 prohibits torture and cruel, inhuman or degrading treatment or punishment against persons with disabilities. Following the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, a broad range of actions committed against persons with disabilities may constitute torture or other forms of ill-treatment: inter alia, forced sterilization, contraception and abortion; forced medical procedures or interventions aimed at correcting or alleviating a disability, including invasive and irreversible surgeries, electroconvulsive therapy and the administration of psychotropic medication; the use of chemical, physical or mechanical restraints; and isolation or seclusion.⁴⁵ Article 15 (1) further clarifies the proposition that medical or scientific experimentation without free consent may amount to torture or other forms of ill-treatment.

51. Article 17 complements the prohibition of torture and ill-treatment by recognizing the right to the physical and mental integrity of persons with disabilities. It complements article 14 on the right to liberty and security of the person, which protects individuals against the intentional infliction of injury to the body or the mind, regardless of whether the victim is detained or not, and imposes a heightened duty of care to protect the integrity of individuals deprived of their liberty.⁴⁶ That is the first time such a right has been enunciated in a universal convention. Article 17 was intended to address coercive interventions “aimed at correcting, improving or alleviating any actual or perceived impairment”.⁴⁷

52. In article 22, personal and family privacy and the reputation of persons with disabilities are protected. That protection applies regardless of place of residence or living arrangements (i.e. institutions). Article 22 (2) further references the privacy of the personal, health and rehabilitation information of persons with disabilities, reflecting concerns about health-related information and the potential that its disclosure may lead to discrimination, including in the context of medical research.

53. Article 23 prohibits discrimination in all matters related to marriage, family, parenthood and relationships. Accordingly, persons with disabilities have the right to 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 are recognized and they are to be provided with the means necessary to enable them to exercise those rights. Persons with disabilities, including children, have a right to retain their fertility on an equal basis with others.

54. Article 25 reaffirms the right of all persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination. Among other obligations, article 25 (d) requires States to provide quality health care to persons with disabilities on the basis of free and informed consent, which precludes all forms of substitute decision-making.⁴⁸ Article 25 (d) further stresses the importance of raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care. In addition, article 25 (f) requires States to prevent discriminatory denial of health care or health services or food and fluids on the basis of disability. The reference to food and fluids refers directly to the medical practice of withdrawal of basic life-sustaining care to persons with severe impairments.

55. Article 26 provides for the obligation to guarantee access to habilitation and rehabilitation services to persons with disabilities. While traditionally habilitation and rehabilitation have focused on “fixing” a person’s impairment, these measures are reconceptualized in the Convention as enablers for attaining and maintaining maximum independence, full physical, mental, social and vocational ability, and full inclusion and

⁴⁵ See Tina Minkowitz, “A response to the report by Juan E. Méndez, Special Rapporteur on Torture, dealing with torture in the context of health care, as it pertains to nonconsensual psychiatric interventions” in *Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report* (Washington, D.C., Center for Human Rights and Humanitarian Law, 2014).

⁴⁶ Human Rights Committee, general comment No. 35 (2014) on liberty and security of person, para. 9.

⁴⁷ See daily summary of discussions at the fifth session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 28 January 2005.

⁴⁸ Committee on the Rights of Persons with Disabilities, general comment No. 1, para. 41.

participation in all aspects of life (see A/HRC/40/32). Article 26 reinforces a cross-sectoral approach to rehabilitation, recognizing that rehabilitation has social, educational, vocational and other non-health components.

56. The principles, rights and obligations enshrined in the Convention challenge previous international bioethics standards. While international bioethics declarations and instruments have made little reference to persons with disabilities, they have allowed some exceptions to their right to be free from non-consensual medical treatment, research and/or experimentation. For example, the Oviedo Convention, the Universal Declaration on Bioethics and Human Rights and the Universal Declaration on the Human Genome and Human Reproduction permit third persons to decide on interventions carried out on adults who do not have the capacity to consent under the principle of best interests. As evidenced, those standards have been superseded by the Convention.

VII. Fighting ableism

57. The human rights model of disability provides a useful framework for challenging ableism and addressing ethical and policy dilemmas related to advances in medical practice, research and technology in the field of disability. States can implement a number of measures to guarantee the rights of persons with disabilities while considering these issues, including awareness-raising; adopting rights-based prevention policies; respecting the personal autonomy and integrity of persons with disabilities; and taking concrete measures to protect their right to life.

58. When advocating for change on such issues, disability rights advocates often find themselves in an uneasy alignment with various anti-choice groups. The Special Rapporteur wishes to depart from those positions and emphasize that the universality, indivisibility, interdependence and interrelatedness of human rights should inform all such discussions, which in no way aim to roll back rights to protect autonomy and self-determination that have been won. What the present report aims to address is how to uphold those rights without bringing into question the rights of persons with disabilities.

A. Awareness-raising

59. To combat ableism, States must raise awareness throughout society regarding the inherent dignity and rights of persons with disabilities. That involves both actively challenging negative stereotypes and prejudices and raising awareness of their value, capabilities and contributions. The multifaceted and multilevel nature of stigma renders the need for multilevel interventions, including for different target audience groups.⁴⁹ Awareness-raising strategies must be complemented by legislative and policy changes, since laws and policies that use derogatory language or discriminate against persons with disabilities reflect and reinforce stigma.

60. There are a number of awareness-raising strategies that have proved effective in combating stigma and prejudices against persons with disabilities. Information-based strategies, such as educational and media campaigns, are a useful tool for addressing the lack of or incorrect knowledge of living with a disability and thus to dispel myths, beliefs and/or stereotypes.⁵⁰ Promoting direct contact with persons with disabilities has also proved successful in reducing stigma, overcoming discomfort, distrust and fear, and facilitating connection and empathy between people with and without disabilities.⁵¹ Awareness-raising interventions should be accompanied by peer counselling and empowerment strategies to

⁴⁹ See Catherine Campbell and Harriet Deacon, “Unravelling the contexts of stigma: from internalisation to resistance to change”, *Journal of Community and Applied Psychology*, vol. 16, No. 6 (November–December 2006).

⁵⁰ See Wim H. van Brake and others, “Out of the silos: identifying cross-cutting features of health-related stigma to advance measurement and intervention”, *BMC Medicine*, vol. 17 (February 2019).

⁵¹ See Monica E. Kolodziej and Blair T. Johnson, “Interpersonal contact and acceptance of persons with psychiatric disorders: a research synthesis”, *Journal of Consulting and Clinical Psychology*, vol. 64, No. 6 (December 1996); and Heather Stuart, “Reducing the stigma of mental illness”, *Global Mental Health*, vol. 3 (2016).

reduce internalized oppression and self-stigma and boost self-esteem. Peer support, in particular, can help to counterbalance experiences of discrimination, rejection and isolation, and can play a key role in building skills and empowerment.

61. Inclusive education is one of the strongest tools for combating ableism. It is the primary avenue by which persons with disabilities can obtain the means to participate fully in their communities and challenge societal perceptions.⁵² It is also an effective way to build inclusive societies that value and embrace human diversity, helping children with disabilities to develop a sense of belonging and children without disabilities to develop positive attitudes towards disability. It is important that States foster an attitude of respect for the rights of persons with disabilities at all levels of the education system, including tertiary education. The renewal of the human rights paradigms in the training and practice of health professionals is essential to respecting the rights of persons with disabilities.

B. Rights-based prevention policies

62. States must ensure that prevention strategies and interventions are respectful of the dignity and rights of persons with disabilities. Viewing disability as a human rights issue is not incompatible with the prevention of health conditions, as long as prevention policies are not stigmatizing or discriminatory, for example through avoiding the use of language and imagery that may convey the message that a life with a disability is not worth living.⁵³ Likewise, the investment in prevention policies must not lead States to waive their primary obligation of promoting, protecting and ensuring all human rights for all persons with disabilities.

63. Prenatal genetic screening and testing should be implemented and made available in a manner that respects the rights of persons with disabilities and values them as equal members of society. Genetic screening must never be considered to be a cost-effective alternative to providing the highest attainable standard of care or service for persons with disabilities. The decision about having prenatal tests must be solely that of the pregnant woman, regardless of her age, reproductive history or disability status.⁵⁴

64. It is important that balanced and accurate information is provided, not just about the risks and limitations of prenatal tests, but also about life with the condition that is being screened for, in order to create a process for prospective parents to confront any personal or societal bias to which they may have been exposed. The use of counter-narratives of persons with lived experience could be important for combating the stigma and bias experienced by prospective parents. For example, the campaign run by the Down's Syndrome Association of the United Kingdom of Great Britain and Northern Ireland, "Tell it Right, Start it Right" offers an information pack, provides training to midwives and related health professionals on providing balanced information related to Down's syndrome to prospective parents and includes individuals with Down's syndrome and their parents in the training.⁵⁵ Ultimately, tackling ableism is a more effective way to address disability-selective abortion.

C. Respecting personal autonomy and integrity

65. States have an obligation to review their legal and policy frameworks and repeal all laws, regulations, customs and practices that discriminate against persons with disabilities in the context of medical or scientific procedures, research and experimentation. Legislation must expressly recognize the right of persons with disabilities to provide their free and informed consent in such circumstances. Substitute decision-making regimes for medical or scientific experimentation must be immediately repealed. Supported decision-making schemes must be subjected to an appropriate framework of safeguards to ensure respect for

⁵² Committee on the Rights of Persons with Disabilities, general comment No. 4 (2016) on the right to inclusive education, para. 10.

⁵³ See World Health Organization and World Bank, *World Report on Disability* (2011), p. 6.

⁵⁴ See Elizabeth R. Schiltz, "Finding common ground in the disability rights critiques of selective abortions", p. 140.

⁵⁵ See www.downs-syndrome.org.uk/about/campaigns/tell-it-right-start-it-right/.

the rights, will and preferences of individuals in the provision of support and protect them from conflicts of interest, undue influence and abuse (see A/HRC/37/56). Respect for autonomy and self-determination, including in situations which may not align with clinical best interests, is central to protecting the integrity of persons with disabilities on an equal basis with others.

66. States must immediately repeal all laws, regulations, customs and practices that allow sterilization or other surgical invasive, painful and/or irreversible procedures on girls, boys and young persons with disabilities without their free and informed consent, and/or when decided by a third party. The interpretation of a child's best interests cannot be used to justify such practices, which conflict with the child's human dignity, identity and right to physical integrity.⁵⁶ Furthermore, the child's best interests must be determined on a case-by-case basis and any assessment must include hearing the views of the child. States should consider adopting protocols to regulate and request the free and informed consent of children and adolescents with disabilities with regard to all medical and scientific procedures.

67. States must take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities from being subjected to torture and ill-treatment. In addition, they have an obligation to criminalize acts of torture and ill-treatment, prosecute perpetrators, impose penalties and provide redress to victims. The right to redress includes restitution, compensation, rehabilitation, satisfaction, guarantees of non-repetition and the right to truth.⁵⁷

D. Protecting the right to life

68. States must protect the rights of persons with disabilities on an equal basis with others. They must adopt legislation to expressly prohibit discrimination on the basis of disability in decisions to withhold or withdraw life-sustaining treatment. Those decisions must respect the rights, will and preferences of individuals, including advance directives.⁵⁸ States must also consider adopting legislation banning discrimination on the basis of disability in organ transplantation. Persons with disabilities must receive equal priority for organ transplants. Expedited complaint procedures and robust remedies are needed to protect the right to life of persons with disabilities adequately in both situations.

69. States considering legalizing any form of assisted dying should conduct extensive discussions with the active participation of organizations representing persons with disabilities. In such debates, States should pay particular attention to the social factors that may affect the decisions of persons with disabilities in relation to assisted dying, including ableism, social stigma and discrimination, societal views on the quality of life of persons with disabilities and the availability of community support and services, social protection programmes and palliative care. Assisted dying must not be seen as a cost-effective alternative to providing personal assistance and disability services for persons with disabilities, in particular those with high support needs.

70. If assisted dying is to be permitted, it must be accompanied by strong measures to protect the right to life of persons with disabilities.⁵⁹ First, access to assisted dying should be restricted to those who are at the end of life; having an impairment should never be a reason for assisted dying to be permitted. Second, the free and informed consent of persons with disabilities must be secured on all matters relating to assisted dying and all forms of pressure and undue influence prevented. Third, access to appropriate palliative care, rights-based support (see A/HRC/34/58), home care and other social measures must be guaranteed; decisions about assisted death should not be made because life has been made unbearable through lack of choices and control. Fourth, accurate information about the prognosis and availability of peer-support counselling must be provided. Fifth, accountability regulations

⁵⁶ Committee on the Rights of the Child, general comment No. 13 (2011) on the right of the child to freedom from all forms of violence, para. 61.

⁵⁷ Committee against Torture, general comment No. 3 (2012) on the implementation of article 14 of the Convention.

⁵⁸ See A/HRC/37/56, para. 44.

⁵⁹ Tom Shakespeare, *Disability Rights and Wrongs* (Abingdon, Oxon, Routledge, 2006), p. 169.

must be established requiring collection and reporting of detailed information about each request and intervention for assistance in dying.

E. Participation in decision-making

71. States must closely consult with and actively involve persons with disabilities and their representative organizations, including children and women with disabilities, in the adoption, implementation and evaluation of legislation and policies about medical and scientific research and experimentation, prenatal screening, assisted dying and other issues directly or indirectly related to the value of the lives of persons with disabilities. Girls, boys and adolescents with disabilities, even the youngest, are the experts on their own lives and thus also have the right to participate in decision-making and to be provided with disability- and age-appropriate support for that purpose (see A/72/133).

72. States must also promote the participation of persons with disabilities in the work of national bioethics committees. For example, in Sweden an expert nominated by the Swedish Disability Rights Federation represents persons with disabilities in the National Council on Medical Ethics. While bioethical debates are an important tool for critical reflection about ethical conflicts caused by science and medicine, States must primarily take into consideration the rights and concerns of persons with disabilities when considering legislation and policies at the intersection of bioethics and disability.

VIII. Conclusions and recommendations

73. **The hegemony of ableism in society has perpetuated the idea that living with a disability is a life not worth living. There is a deep-rooted belief, carved with fear, stigma and ignorance, that persons with disabilities cannot enjoy a fulfilling life, that their lives are incomplete and unfortunate, and that they cannot attain a good quality of life. Such ableist ways of thinking, reinforced by the medical model, have privileged prevention and cure over all other responses to disability, leaving persons with disabilities with limited opportunities to be included and participate in society. While the eugenic programmes of the late nineteenth and early twentieth centuries have disappeared, eugenic aspirations persist in current debates related to medical and scientific practice concerning disability, such as prevention, normalizing therapies and assisted dying. Notwithstanding all the progress achieved over recent decades concerning the rights of persons with disabilities, embracing disability as a positive aspect of humanity remains the final frontier to be conquered.**

74. **Life with a disability is a life worth living equal to others. Every person has a unique set of unrepeatable characteristics and experiences that make them irreplaceable and valuable. The lives of persons with disabilities are human lives and, consequently, endowed with inherent dignity. Persons with disabilities can live fulfilling lives and enjoy what gives life meaning. They share the same aspirations as everyone else, such as making friends, getting a job, living on their own, starting a family or accomplishing their dreams. Persons with disabilities bring talent, diversity and richness to their communities. While they may face more barriers in achieving their aspirations, their endeavours and accomplishments contribute to building more inclusive and diverse societies for the benefit of all.**

75. **Given the cultural and societal challenges posed by ableism, neither awareness-raising programmes nor the generalization of anti-discrimination measures will alone suffice. What is needed is a cultural transformation of the way society relates to the difference of disability. That is a commitment to the recognition of persons with disabilities as equals on all terms, with the same rights and opportunities as everyone else in society. It is thus vital to reduce the distance between society's views of disability and the narratives of those living with a disability. The devaluation of the lives of persons with disabilities comes partly from a historic inability to listen to what persons with disabilities have to say about themselves.**

76. **The Special Rapporteur makes the following recommendations to States, with the aim of assisting them in developing and implementing reforms that will lead to the recognition and acceptance of disability as part of human diversity:**

- (a) **Conduct a comprehensive legislative and policy review to abolish all laws, regulations, customs and practices that discriminate against persons with disabilities, including in the context of medical or scientific procedures, research and experimentation;**
- (b) **Recognize, in domestic legislation, the right of persons with disabilities to provide their free and informed consent prior to any medical or scientific procedure and provide them with access to the support they may require in exercising that right;**
- (c) **Explicitly prohibit, in domestic legislation, discrimination on the basis of disability concerning decisions to withhold or withdraw life-sustaining treatment and organ transplantation;**
- (d) **Guarantee access prompt and effective remedies to protect the rights to life and the personal integrity of persons with disabilities in the context of medical or scientific procedures, research and experimentation;**
- (e) **Ensure that prevention strategies and interventions are respectful of the inherent dignity and rights of persons with disabilities;**
- (f) **Where assisted dying is permitted, implement strong measures to protect the right to life of persons with disabilities on an equal basis with others;**
- (g) **Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to medical and scientific practice concerning them, including law reform, policy development and research. National bioethics committees must consult and include persons with disabilities in their work;**
- (h) **Raise awareness throughout society, particularly among policymakers, public officers, service providers and the media, regarding the inherent dignity and rights of persons with disabilities, including by challenging negative stereotypes and prejudices and raising awareness of their value, capabilities and contributions;**
- (i) **Promote and provide training on the rights and value of persons with disabilities in medical and science faculties within universities.**

77. **The Special Rapporteur recommends that the International Bioethics Committee of the United Nations Educational, Scientific and Cultural Organization consider the disability rights perspective in their work, including by consulting and engaging with persons with disabilities and their representative organizations.**
