

Submission to the Special Rapporteur on the rights of persons with disabilities Sexual Rights Initiative

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This submission is made by the Sexual Rights Initiative (SRI). The SRI is a coalition of national and regional organizations based in Canada, Poland, India, Egypt, Argentina and South Africa, that work together to advance human rights related to sexuality, gender and bodily autonomy at the United Nations.¹

Introduction

1. This submission reviews bioethics and how it has related to the rights of persons with disabilities. It first highlights how bioethics constitutes its own authority and experts to have a say in the lives of persons with disabilities. Secondly it provides a brief overview of a global feminist approach to bioethics and its contributions to a critique of the field. After highlighting the contributions of women with disabilities to the so-called “bioethical discussions,” the submission recommends to move away from bioethics to examine human rights issues.

Who decides and who is decided upon in bioethics?

2. Bioethics is a discipline² that, in practice, sets the scope of human dignity, personhood and autonomy. Hence, it is paramount to question the selectivity of whose lives are deemed to be a “bioethical issue” and therefore a matter of bioethical discussion and research. Often, bioethicists dive into the realms of vulnerability “to pick out greater than ordinary vulnerability”.³ And even when concepts like vulnerability are questioned,⁴ it is the same persons who see their lives’ worth or dignity discussed and the scope of their rights to legal capacity and bodily autonomy limited by, for example, setting different standards for informed consent and decision-making.
3. Bioethics is a study of problems and inquiry into those problems, usually translated to bioethical “dilemmas”.⁵ Bioethics’ “theoretical orientation and methods for approaching problems have been shaped by the moral philosophers, theologians, attorneys, physicians, and biologists.”⁶ The ideas of normalcy, challenged for so long by persons with disabilities themselves, including through disability studies, are tightly embroidered into current medical, legal, psychological and philosophical perspectives. Yet, professionals coming from these fields are the ones who can legitimately access and participate in bioethics.

¹ <http://www.sexualrightsinitiative.com/>

² Different authors hesitate to clearly call it a discipline and use more nuanced approaches. Without ignoring those perspectives, for brevity we will refer to bioethics as a discipline. See e.g. “As the reader will note, this defines a field of interest. [...] There are long-standing debates about the status of bioethics as an actual or emergent academic discipline, given the protean nature of the field, and its complex interweaving into a wide range of institutional and professional settings...” Richard E. Ashcroft, *Could Human Rights Supersede Bioethics*, 10 Hum. Rts. L. Rev. 639 (2010), pp. 640-641.

³ Wendy Rogers, Catriona Mackenzie and Susan Dodds, *Why bioethics needs a concept of vulnerability*, International Journal of Feminist Approaches to Bioethics, Vol. 5, No. 2, (Fall 2012), pp. 11-38

⁴ Critiques on the concept and use of vulnerability are part of the bioethics debate. “In particular, the relations between respect for autonomy, the demands of justice, and vulnerability remain opaque.” See e.g. *Id.*; Miguel Kottow, *Vulnerability, Human Rights, and Bioethics. Turbulent Relationships, Unsolved Conflicts*, 69 Derecho PUCP 25 (2012); Thiago Cunha; Volnei Garrafa, *Vulnerability A Key Principle for Global Bioethics?*, 25 Cambridge Q. Healthcare Ethics 197 (2016).

⁵ *Supra* note 2 at 643.

⁶ Jessica H. Muller, *Anthropology, Bioethics, and Medicine: A Provocative Trilogy*, 8(4) Medical Anthropology Quarterly, New Series, (1994), p. 450.

4. Bioethics places its experts in a position where they can discuss someone else's dignity and humanity on an unlevel field. Through professional expertise, it is easier to rationalize debates about the worth of someone's life and present "authoritative" opinions on these "controversies". Hence, the lives and rights of marginalized people, in particular of persons with disabilities, are turned into a legitimate debate. These debates are based on biased perceptions and fail to address the root causes found in material conditions, stigma and structural discrimination.⁷ As disability rights advocate and attorney Harriet McBryde Johnson said when she was invited to a debate by Peter Singer, bioethics professor at Princeton University, "it sounds a lot like debating my life -- and on my opponent's turf, with my opponent moderating, to boot."⁸ Johnson further pointed out that she was "a participant in a discussion that would not occur in a just world,"⁹ but seized the opportunity to question "who should have the burden of proof as to the quality of disabled lives."¹⁰
5. Another layer of power found in bioethics is geopolitical power, highlighting not only the North-South divide, but also the ongoing problem of neo-colonialism.¹¹ This is usually addressed by considering that bioethics is different in the global South because of lack of access to technological advances, reducing the problem to economic capacity.¹² Such a simplistic approach fails to acknowledge the harm caused by neo-colonial powers, as well as regional and global financial institutions, through the imposition of privatized health, social security systems, and structural adjustment policies that simultaneously increase social protection gaps and defund social security programs essential to meaningful informed consent.
6. Unsurprisingly, one of the worst recent threats to the progress of the standards set by the Convention on the Rights of Persons with Disabilities (CRPD) was the draft Additional Protocol to the Oviedo Convention on bioethics. Equally unsurprising is that the opposition to the draft materialized in documents that did not engage with bioethics, but rather reminded States of their obligations under the CRPD.¹³
7. Feminists bioethicists have grappled with some of these power gaps by challenging the center-periphery dynamic of production of knowledge, inviting bioethicists from the global South to question the principlist

⁷ See, e.g. Adrienne Asch and Erik Parens, *Prenatal Testing and Disability Rights* (Hastings Center Studies in Ethics series) (Kindle Locations 164-167). Kindle Edition.: "The bioethics and medical literatures of the last decade also reveal misinformation and stereotypic thinking about what disability means for individuals, families, and society. Many clinicians and bioethicists take it for granted that health status is mostly responsible for the reduced life chances of people with a disability, largely ignoring the role of societal factors such as educational and employment discrimination. Furthermore, these clinicians and bioethicists often discount data indicating that people with disabilities and their families do not view their lives in solely or even predominantly negative terms; instead, they may insist that such data reflect a denial of reality or an exceptional ability to cope with problems."

⁸ Harriet McBryde Johnson, *Unspeakable Conversations*, The New York Times, February 16, 2003, <https://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html>.

⁹ *Id.*

¹⁰ *Id.*

¹¹ Sexual Rights Initiative and Coalition of African Lesbians, Statement on Item 3: Clustered ID with the Independent Expert on the promotion of a democratic and equitable international order, Human Rights Council Session 42 (2019).

¹² For example, it was often suggested during the Zika outbreak in Brazil in 2016 that the "bioethical discussions" were different because Brazil did not count with the same technology of other countries of the global North. While this might be true, it reduces the problem to poverty, missing several other factors for analysis. Helen Mekoosha, (*infra* note 15) mentions this briefly: "the technological fix will only be available to some disabled people and that the power relations between those with access to resources and those without will widen. The bioethical debate must encompass the concerns of disabled people beyond the countries of the global North. Decisions made there that impact negatively on the people of the global South carry major ethical and moral implications for scholars and activists. For instance, war, the arms trade, and the exportation of pollution..."

¹³ CRPD Committee, Statement by the Committee on the Rights of Persons with Disabilities calling States parties to oppose the draft Additional Protocol to the Oviedo Convention (2018); Parliamentary Assembly of the Council of Europe, Resolution 2291: Ending coercion in mental health: the need for a human rights-based approach (2019).

theory rooted in U.S., white, educated, middle class culture.¹⁴ Some of the proposed critiques, however, are still too embedded in the biomedical model to connect with elements beyond its own scope. For example, some feminist bioethicists consider that nurses, instead of doctors, are better placed to make decisions over “incompetent or largely incompetent patients.”¹⁵ By doing this, feminist bioethicists challenge the construction of “technical knowledge” and its authority by contextualizing and giving value to nurses’ expertise learned from direct interaction with patients. And while this might be true, at the same time it misses the point on why is decision making by third parties allowed through the attribution of “incompetency”, a proxy for disability.

8. By the time feminist critiques of bioethics were being articulated, disabled women like Anne Finger and Marsha Saxton had already engaged with feminism, bioethics, and disability.¹⁶ In the 80s, they addressed forced sterilization, prenatal genetic screening, fetal diagnosis, and fears of giving birth to a disabled child.¹⁷ Their pioneering work highlights the need to center the voices of women with disabilities. “Disabled women, who rank at the lower end of social and medico-legal power relations, know very well they have little choice and that their reproductive rights are still ignored and abused.”¹⁸

Bodily autonomy as a framework to ensure meaningful consent

9. The issues selected by the Special Rapporteur for this report (prenatal testing, abortion, informed consent for medical treatment and research, protection of persons with disabilities undergoing research, and euthanasia and assisted suicide) can be dealt with meaningful consent, when material conditions and determinants of health are ensured so they do not limit choice, and bodily autonomy. Both feminist and disability critiques claim that informed consent, under many circumstances, provides a cover for the illusion of choice.¹⁹ “Neoliberalism and individualist ideologies perpetrate the myth of choice by suggesting that we have options as never before.”²⁰ When someone is presented with a choice, different systems of oppression have already narrowed the possibilities and even limited the scope of the imaginable. Decisions depend on many other circumstances related to job stability, food security, availability of services in the community, and personal safety, amongst many others.
10. The abstraction of choice, when associated with the rational and individualist perspective, is incompatible with articles 12 (equal recognition before the law) and 19 (living independently and being included in the community) of the CRPD and with the feminist and communitarian critiques to “enlightenment notions of individuals as rational and atomistic beings who express preferences of their own volition and thereby lay claim to enjoying their rights.”²¹ The CRPD has also given a new depth to the rights to education, accessibility, equality and non-discrimination, all necessary to ensure meaningful consent and bodily autonomy.

¹⁴ See, e.g.: Ana Cristina González Vélez, Debora Diniz, *Feminist Bioethics: The Emergence of the Oppressed*, IN Globalizing Feminist Bioethics: Crosscultural Perspectives, Rosemarie Tong (ed.) (2000); Rosemarie Tong, *Feminist approaches to bioethics: Theoretical reflections and practical applications* (Boulder, CO: Westview Press, 1997).

¹⁵ *Id.* [Ana Cristina González Vélez & Debora Diniz].

¹⁶ Helen Meekosha, The complex balancing act of choice, autonomy, valued life, and rights: Bringing a feminist disability perspective to bioethics, *International Journal of Feminist Approaches to Bioethics*, Vol. 3, No. 2, Special Issue: Disability Studies in Feminist Bioethics (Fall 2010), pp. 1-8

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ This includes objections made to the framework of euthanasia and assisted suicide that argues that under the current state of structural discrimination, persons with disabilities do not have the right, but the duty to die.

²⁰ *Id.*

²¹ Janet Lord and Michael Ashley Stein. *Contingent Participation and Coercive Care: Feminist and Communitarian Theories of Disability and Legal Capacity*. In: *Coercive care: Rights, Law and Policy* (Eds. Bernadette McSherry and Ian Freckelton) 31-49 (2013).

11. Feminists, and black feminists in particular, through articulating reproductive justice have worked for the realization of the ability to make and exercise choices not limited by oppression, discrimination, stigma, coercion, violence, lack of opportunities or possible consequences.²² Feminist movements have advocated in international and regional human rights systems for the material conditions necessary to exercise reproductive rights. Reproductive justice also addresses the legacy of population control informed by white supremacy and replacement theory, which has resurfaced in current populist politics and has been historically based on race, gender and disability.²³
12. Feminist organizations in their interaction with human rights systems, particularly around health including maternal mortality and morbidity and abortion, have concurred with disability justice advocates, as also recognized by different human rights mechanisms²⁴, in their critical perspectives of the biomedical model. In recognizing its effects, feminists have argued that “over-medicalization can reduce women to object of interventions without agency,”²⁵ which necessarily means that “it is essential to move towards developing standards that surpass the biomedical approach and reach beyond [...] for a better understanding of the mental and social health and human rights.”²⁶ Materializing these rights concerns not only those advocating for the right to abortion, but anyone working to ensure meaningful consent and bodily autonomy.
13. While people’s individual circumstances may differ, their oppressions share a commonality in restrictions to bodily autonomy grounded in patriarchal gender norms and stereotypes that seek to subordinate women, girls’ and gender non-conforming persons’ decisions about their own bodies to the State, through laws, policies or their implementation. These practices, laws and policies are driven through institutions – State or non-state, that have a vested interest in maintaining these stereotypes – hence maintaining the status quo. Structural and compounded discrimination on the basis of disability, race, sexual orientation, gender identity, geography, ethnicity, faith and any other status, create stark protection gaps within the international human rights framework that must be addressed.
14. Treaty bodies and special procedures have echoed this need and recognized that the realization of women’s reproductive rights depends on the material conditions in which they are born, grow, live, work and age, and on power structures and resource distribution at all levels.²⁷ In doing so, they have laid out a framework for accountability for social and other determinants of health. For instance the Working Group on discrimination against women and girls affirmed that

“[a]utonomous access to health care means ensuring a woman’s right to make decisions concerning her health, fertility and sexuality free of coercion and violence. Key to this is the notion

²² Sexual Rights Initiative et.al., Joint civil society statement on the International Safe Abortion Day, 42nd Session of the Human Rights Council, (2019)

²³ Joint Statement / Ross, Loretta, and Rickie Solinger. 2017. Reproductive Justice: An Introduction.

²⁴ Several reports of the Special Rapporteur on the rights of persons with disabilities and the Special Rapporteur on the right to health have addressed the biomedical model as a source for power asymmetries. See, e.g.: Special Rapporteur on the rights of persons with disabilities, Report to the General Assembly on challenges experienced by persons with disabilities in the enjoyment of their right to the highest attainable standard of health, (2018) UN. Doc. A/73/16, para 29; Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Report on the right to mental health, (2017) UN. Doc. A/HRC/35/21, paras. 18-26.

²⁵ Liiri Oja; Alicia Ely Yamin, Woman in the European Human Rights System: How Is the Reproductive Rights Jurisprudence of the European Court of Human Rights Constructing Narratives of Women's Citizenship, 32 Colum. J. Gender & L. 62 (2016).

²⁶ Planned Parenthood, Stolen Lives: A Multi-Country Study on the Health Effects of Forced Motherhood on Girls 9–14 Years Old, (2019) available at: https://www.plannedparenthoodaction.org/uploads/filer_public/db/6d/db6d56cb-e854-44bb-9ab7-15bb7fc147c5/ppfa-stolen-lives-english.pdf

²⁷ WHO, About social determinants of health (2017), available at http://www.who.int/social_determinants/sdh_definition/en (last visited Oct. 16, 2017)

of choice. The rights to informed consent and confidentiality are crucial to ensuring that women can make decisions freely. These rights impose corresponding duties upon health-care providers, who are bound to disclose information about proposed treatments and alternatives in order to aid informed consent and to respect the right to refuse treatment; likewise, they are bound to maintain confidentiality to allow women to make private decisions without the interference of others”²⁸

15. Considering the aforementioned depth, States are required to ensure the availability of and access to underlying determinants for the right to health, including adequate sanitation and health care facilities. These obligations have often been articulated in the context of the right to health and have been expanded in the articulation of the rights to sexual and reproductive health.²⁹ Progress made in the broad understanding and implementation of these standards is as relevant to all health care, but particularly so in decisions where bodily autonomy is often disputed and that have been rightfully identified by the Special Rapporteur for the forthcoming report.
16. In 2018, several organizations came together to create the Nairobi Principles on Abortion, Prenatal Testing, and Disability.³⁰ The principles are a clear declaration of the importance of overcoming the false dilemma that suggests that we must choose between the rights of women and the rights of persons with disabilities. In fact, the only way forward is by ensuring the right to bodily autonomy for all and addressing the different systems of oppression.
17. Realizing bodily autonomy in this case means, amongst others, that providers should offer evidence-based information without bias in diagnostic process and treatment.³¹ Going back to the concept of reproductive justice, the principles clearly state a commitment to work on the realization of existing human rights standards for the realization of bodily autonomy

“not only with regards to pregnancy termination but within the full spectrum of reproductive justice, especially concerning violations that disproportionately affect women and girls with disabilities, such as forced and coerced abortion, contraception, and sterilization. We will support the autonomy and self-determination of women and girls with disabilities, including those deprived of legal capacity, to decide on matters related to their reproductive health, including whether to continue pregnancies. We will work to ensure that sexual and reproductive health goods and services are physically and financially accessible and that information and communication on sexual and reproductive health is provided in accessible formats. We will also work to ensure the support services needed to access sexual and reproductive health. We also support the right of persons with disabilities to parent, recognizing that parents with disabilities should not be limited in this right based on stereotypes about disability or economic or social

²⁸ Report of the Working Group on the issue of discrimination against women in law and in practice. (2016) A/HRC/32/44,

²⁹ See, e.g. CESCR Committee, General Comment No. 14 (2000): The right to the highest attainable standard of health (article 12 of the ICESCR), para. 4.: “The right to health embraces a wide range of socio economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition, housing, access to safe and potable water and adequate sanitation, safe and healthy working conditions, and a healthy environment.”

CESCR Committee, General Comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the ICESCR), para. 8: “In all countries, patterns of sexual and reproductive health generally reflect social inequalities in society and unequal distribution of power based on gender, ethnic origin, age, disability and other factors. Poverty, income inequality, systemic discrimination and marginalization based on grounds identified by the Committee are all social determinants of sexual and reproductive health, which also have an impact on the enjoyment of an array of other rights as well”.

³⁰ The Nairobi Principles on Abortion, Prenatal Testing, and Disability. Available at <https://nairobiprinciples.creaworld.org/>

³¹ *Id.*

obstacles and that persons with disabilities should have equal access to assisted reproductive technologies and adoption, as well as personal assistance and other supports for parenting.”³²

18. In order to begin to address the barriers to engagement by marginalized people there needs to be a concerted effort to dismantle systems of oppression such as patriarchy, ableism, racism and heteronormativity, neoliberal capitalism, as opposed to a tendency towards tokenizing the marginalized by inserting them into inequitable structures with the expectation that they will carry the burden of reforming them.³³ Including persons with disabilities in bioethics boards and discussions is not enough. Further, scientific research that includes persons with disabilities need to be determined by persons with disabilities themselves, including by scientists with disabilities. This can only be achieved by ensuring that the rights to education, work, health, independent living, bodily autonomy and legal capacity start being realized and fulfilled in a way that choice is no longer an illusion.

Conclusion

So far, bioethics has failed to address the power hierarchies of institutional structures and social relations over the experience of those marginalized.³⁴ It also lacks accountability in relation to those whose lives are deemed to be bioethical problems. Hence, other approaches are needed to engage with institutional cultures that mediate interactions and determine power negotiations in health and other related social instances.³⁵ A human rights-based approach provides mechanisms of accountability, as human rights have been used to “open authoritative institutions like medicine, and to challenge their entrenched hierarchies of power.”³⁶

Recommendations:

- Center and apply a human rights-based approach in the design and implementation of programs and services: ensuring participation, accountability and transparency. All disciplines, including bioethics, should adhere to human rights principles and are not a replacement for a human rights-based approach.
- Address social and other determinants of health in law and practice from an intersectional perspective to ensure that they enable all individuals to effectively enjoy their right to bodily autonomy.³⁷
- Reform national legal capacity frameworks to guarantee informed consent for persons with disabilities through supported decision making, when required by the person with disabilities, and reasonable accommodations in all aspects, including those necessary for the provision of accessible information and additional services.
- Ensure access to public, widely available, community-based mental health services.
- Deinstitutionalize and create transition programs for community living that include education, work and housing.
- Ensure access to available, accessible, acceptable and quality health services, including sexual and reproductive health services, as part of universal health coverage and public health systems, financed through taxation and free from control from other governments, multilateral agreements and transnational corporations.

³² *Id.*

³³ SRI and the Coalition of African Lesbians, Joint Statement on the Clustered ID with the Independent Expert on Equitable International order, 42nd Human Rights Council session (2019).

³⁴ Joanna N. Erdman, Commentary: Bioethics, Human Rights, and Childbirth, Health and Human Rights 17/1, available at: <https://www.hhrjournal.org/2015/06/commentary-bioethics-human-rights-and-childbirth/>

³⁵ *Id.*

³⁶ *Id.*

³⁷ WHO, About social determinants of health, *supra* note 23.

- Ensure access to comprehensive sexuality education that is inclusive and accessible to all.
- Remove all legal and social barriers to safe abortion, including its criminalization, including sanctions and no sanction regimes, and commit to providing safe abortion services on request.
- Hold private companies and multinational corporations accountable for unethical research practices, violations and abuses of women and girls' reproductive rights and bodily autonomy.
- Prioritize the meaningful participation of local movements, particularly of women with disabilities under CRPD article 4.3, for the implementation of human rights standards and center their demands and recommendations for the realization of reproductive justice.