



# Social Justice and Human Rights Principles for Global Deliberations on Heritable Human Genome Editing

## DEVELOPED BY

The Gender Justice and Disability Rights Coalition of the Center for Genetics and Society's Missing Voices Initiative

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# Preamble

## BACKGROUND

Heritable human genome editing<sup>1</sup>—using genetic modification tools such as CRISPR on embryos or gametes—would alter the genes and traits of future generations. It could change societies in ways that further entrench inequities and discrimination and undermine human rights. Yet public narratives and official deliberations are typically based on claims that it would eliminate disease and disabling conditions and rarely acknowledge the social implications. Debate has centered on a narrow, individualized notion of bioethics with little regard for how the use of heritable human genome editing could undermine justice, equity, bodily autonomy, self-determination, and commitments to valuing the lives of all people. Social justice and human rights are necessary frameworks to apply to these deliberations. The [Missing Voices Initiative](#) (MVI), a project organized by the US-based organization [Center for Genetics and Society](#), contributes to that effort by highlighting a range of perspectives that have been largely absent from debate and policy making.

This document was developed by MVI's [Gender Justice and Disability Rights Coalition](#). Motivated by fundamental justice and rights commitments, the principles center women and pregnant people's health, rights, and freedom from exploitation, and affirm the worth and full inclusion of all people with disabilities. The principles address a range of essential social justice concerns that intersect with gender, reproductive, and disability rights and justice—including racial, LGBTQ+, economic, intergenerational, and environmental justice and Indigenous sovereignty.

***Debates about heritable genome editing have rightly emphasized the urgent need for a global and inclusive public dialogue.***

This includes the call made in 2015 by organizers of the First International Summit on Human Gene Editing for "[broad societal consensus](#)" as a prerequisite for deciding whether or not this technology should be used. The stakes are high, and although many agree on the need to engage the public, stakeholders in the

social justice fields named above are rarely consulted; their perspectives remain downplayed or unacknowledged altogether. Furthermore, the funding and resources necessary for broadly inclusive and meaningful public deliberation have not been allocated by national science academies, organizers of the Summit process, or other leadership bodies.

Public understanding and policy making on heritable genome editing requires robust discussion among governing bodies, scientific entities, and wide-ranging public sectors, including voices across a range of rights and justice fields. Organized civil society groups grounded in social justice and human rights, with feminist and anti-eugenic perspectives, are essential to this process. We will need to think expansively and creatively about engaging civil society in its many and varied forms, particularly in the Global South, where "civil society" may look or operate differently than what is acknowledged in the Global North. Global South countries may disagree with how "scientific progress" is defined or understood in the Global North, stemming in part from the history of harm done to Global South countries for the benefit of the Global North.

<sup>1</sup> In this document, all discussions of genome editing refer to genome editing in humans.

Robust and meaningful public engagement must also be based on complete and accurate information about heritable genome editing. This begins with clear and understandable definitions of technologies and distinctions among them. Many discussions of human gene editing conflate heritable genome editing with somatic gene editing and muddy the public discourse. Somatic gene editing would change the genes in one individual. Heritable genome editing, on the other hand, would alter the genes of any child born through this technology and subsequent generations. Among countries that have considered the technology, a [widespread global policy consensus](#) exists on prohibiting the use of heritable human genome editing. At least 70 countries categorically prohibit it, including the 29 that have signed and ratified the Council of Europe's [Oviedo Convention](#), a legally binding international treaty. No country in the world explicitly permits it.

Popular press, public discussions, and policy debates must acknowledge that there is no unmet medical need that would justify heritable genome editing. It would not save any lives, cure any disease, treat any patient, or prevent any illness, because it could only affect human beings who do not yet exist. Nor would it prevent health inequities, which stem from social and economic inequalities and systemic and institutional factors. Heritable genome editing is instead a tool that privileges genetic relatedness in family formation and intends to “design” children to have—or not have—particular gene variants. Furthermore, investing in an expensive technology that is not needed, may have too high a safety risk to individuals, and could be harmful to humanity as a whole, is not only a poor use of limited scientific, medical, and social resources but also diverts attention away from the true sources of health inequities and other forms of inequality.

Communicating these basic points is a prerequisite for effectively engaging the public.

The development of policy governing heritable genome editing requires international attention and coordination, including full recognition of established human rights and any human rights principles that are at stake. Like other human biotechnologies and assisted reproductive technologies, if heritable genome editing were permitted, it would routinely cross borders, whether incidentally as part of scientists' and clinicians' collaborations or in deliberate attempts to evade restrictions. Patients and consumers would also travel across borders for medical and reproductive services in the already flourishing global fertility industry.

Science does not occur in a vacuum; we must acknowledge the broader political economy and the geopolitics of knowledge in which human genome editing would develop. A feminist, anti-eugenic lens can illuminate a global context shaped by unequal power and resources. A truly democratic process for engaging the public and for reaching genuine global societal consensus requires understanding these political, economic, and geographic differences.

## WHO WE ARE

The **Gender Justice and Disability Rights Coalition** is part of the **Missing Voices Initiative** (MVI), organized by the **Center for Genetics and Society**. MVI brings together civil society advocates and socially engaged scholars in a process aimed at amplifying social justice and human rights perspectives in debates about heritable human genome editing, as well as modeling meaningful inclusion of these key voices in policy making. MVI's Gender Justice and Disability Rights Coalition is a group of 16 advocates and scholars from 10 countries from a range of civil society organizations and academic institutions who are committed to feminist, disability rights, anti-eugenic, and intersecting justice-oriented perspectives.

The Gender Justice and Disability Rights Coalition developed the 11 principles below to guide policy making and public engagement with heritable human genome editing. We hope that they can be adapted to many country, regional, and international contexts and that those adaptations can be translated into multiple languages.

## IMPLICATIONS FOR POLICY

Like climate change and artificial intelligence, heritable human genome editing is a global challenge that could exacerbate inequality and change humanity as we know it. The prospect of its use has prompted worldwide recognition of the need for societal action before it's too late. **In light of the principles enumerated here, it is clear that there is no persuasive justification for pursuing heritable human genome editing.**

We call on governments to prioritize the social justice and human rights principles detailed in this document in policy making related to heritable human genome editing. We urge scientific and international bodies to incorporate these 11 principles as they develop policy recommendations. It is essential to apply the frameworks of gender, disability, racial, reproductive, economic, environmental, and LGBTQ rights and justice, human rights, Indigenous sovereignty, and the rights of children and future generations in all policy concerning heritable human genome editing. Our future depends on it.

# Gender Justice and Disability Rights Coalition on Heritable Genome Editing

## PRINCIPLES

01.

### Principle 1: Ensure the reproductive health and safety of women and pregnant people and avoid the potential harms of human experimentation

Acknowledging that heritable genome editing is new and experimental and would only be made possible with the participation of women and pregnant people, and would constitute human experimentation;

And because safety cannot be verified and unintended consequences cannot be identified before experiments are carried out, and the site of any “mistakes” would therefore be the bodies of women and pregnant people and people born through this technology;

And because there can be no reversals once modifications are made to the human germline, and any harms are therefore made to the entire human genome;

And because current discussions conflate heritable genome editing (genetic changes passed down to future generations) with somatic gene editing (changes that take place in one person’s body), and this obfuscation prevents wide public awareness of the enormous stakes of heritable genome editing for future generations and curtails public engagement:

**We call for a profoundly deliberate, inclusive, and global process to consider whether heritable genome editing should be pursued.**

02.

### Principle 2: Safeguard gender justice and reproductive justice for all people

Acknowledging that women have historically been—and continue to be—exploited for reproduction and that people of all genders have been sterilized to prevent reproduction;

And that the current global reproductive context prevents women and gender expansive people—especially poor women, Black and brown women, Indigenous women, women with disabilities, young women, and transgender and nonbinary people—from controlling their reproductive lives;

And because women’s voices have been marginalized in this debate;

And because women and people who are or who can become pregnant have many other identities and are affected by multiple forms of oppression (reproductive, gender, disability, LGBTQ, and economic injustice; racism; genocidal practices; xenophobia; ethnic, caste, and religious discrimination; and more):

**We call for women from diverse ability, ethnic, caste, geographic, national, religious, and economic backgrounds and contexts to play primary leadership roles in national and international processes regarding policy making in relation to heritable genome editing.**

### **03. | Principle 3: Value all lives and diversity in bodies, intellect, and ability**

Acknowledging that certain groups of people—particularly people with disabilities, Black and brown people, Indigenous peoples, women, people of “lower castes,” ethnic and cultural minorities, poor and working class people, immigrants, and trans and nonbinary people—have been targeted by eugenic policies;

And that promotion of heritable genome editing perpetuates assumptions that some people’s lives are more valuable than others;

And that individuals are more than a collection of genes or traits; and an individual’s or group’s value is not determined by their genes;

And rejecting the assumptions that people with disabilities lead lesser lives and that having a child with a disability is unquestionably something to be avoided; and highlighting that these ideas ignore the reality of varied experiences and perspectives of people with disabilities themselves;

And affirming that “All human beings are born free and equal in dignity and rights,” as articulated in the first Article of the Universal Declaration of Human Rights:

**We affirm the worth of all people and call for this premise to undergird the development and use of all human biotechnologies, including the question of whether to pursue heritable genome editing.**

### **04. | Principle 4: Dismantle eugenic legacies and confront eugenic temptations**

Acknowledging the catastrophic history of eugenics and the ways in which eugenic beliefs continue to inform policies and practices around the world;

And recognizing the eugenic implications of the rapidly expanding array of genetic tests and embryo selection technologies that are already incorporated into routine pregnancy care and assisted reproduction without critical reflection, generally accompanied by anti-disability biases from medical professionals and society as a whole;

And concerned that individuals and couples using assisted reproductive and genetic technologies are unwittingly part of a new market-driven consumer eugenics, distinct from state-sponsored eugenics;

And recognizing that inaccurate beliefs about social categories being genetically determined (for example, with regard to race, gender identity, sexual orientation) could revive and reinforce discriminatory ideas, and encourage efforts to use heritable genome editing to “edit out” marginalized peoples and traits;

And that heritable genome editing, if permitted, would most likely be offered through the assisted reproductive technologies industry:

**We call for scientific and medical research bodies involved in human genome editing work to reckon with the eugenic histories of their disciplines—in particular with regard to disability, gender, race, class, and indigeneity—and how this legacy continues to affect their discourse, goals, practices, and outcomes;**

**And for education in a variety of forms about eugenic histories and legacies, relevant to each country and region, to accompany public engagement around whether heritable genome editing should proceed;**

**And for education and public policies that address stigma and discrimination against people with disabilities and other marginalized groups and that value and affirm the lives of people with disabilities and of all peoples;**

**And for policy that ensures that a person’s genes—or an assumption of a genetic basis, whether accurate or not—should never be used as a reason for discrimination;**

**And for training of genetic counselors to include contact with people with disabilities outside of a clinical setting;**

**And for genetic counseling programs and genetic testing companies to adopt a model that provides comprehensive information and unbiased counseling to prospective parents, including accurate information about what it might be like to raise a child with a disability or genetic condition identified in their testing of an embryo or fetus, incorporating perspectives from people with that condition or disability and/or their families.**

## **05.** | **Principle 5: Promote a comprehensive understanding of health; guarantee access to health and related resources and ensure non-discrimination toward people with disabilities**

Recognizing that health is often narrowly defined as the absence of disease and disability; and that people with disabilities are often perceived as “unhealthy” or “defective” in medical and social settings just for having a disability;

And that a social model of disability understands institutional and societal barriers as the key obstacle to people with disabilities functioning and thriving in their communities;

And that promises of “healthy children” who are “free” of genetic conditions are being used to promote heritable genome editing without consideration of these institutional and societal dynamics:

**We call for policy and societal changes to end discriminatory practices toward people with disabilities, to ensure environments that provide needed accommodations for people with a range of disabilities, and to allocate resources to do so;**

**And for a range of solutions that address the needs articulated by people with disabilities and disability rights advocacy organizations rather than potentially dangerous solutions determined by medical and scientific establishments and by commercial interests, such as heritable genome editing;**

**And for these actions to be implemented as alternative solutions to heritable genome editing.**

## **06.** | **Principle 6: Prioritize societal and policy changes to eliminate health inequities, end discrimination, and foster thriving for all**

Affirming that health is a human right, as recognized in the 25th Article of the Universal Declaration of Human Rights and the International Covenant on Economic, Social, and Cultural Rights;

And recognizing that marginalized peoples all over the world have little or no access to health care;

And that health inequities are deep and widespread, with social and structural causes that could not be addressed by heritable genome editing; and that pursuing heritable genome editing would divert resources from societal changes that could improve health and well-being for all:

**We call for policies in every country and region that address and eliminate the roots of health inequities and create environments where all people can thrive, including ensuring access to comprehensive health care over the lifespan.**

## **07.** | **Principle 7: Safeguard the rights, interests, and welfare of future generations and any people born through heritable genome editing in policy decisions concerning this technology**

Affirming that enabling the “design” of future children would fundamentally alter the relationship between generations;



And that heritable human genome editing, if permitted, would likely become part of the global fertility industry, in which commercial interests tend to be prioritized over the rights, dignity, and interests of children;

And that respect for human dignity requires that children are not treated as objects of design with genetically predetermined futures, but recognized as bearers of human rights both as individuals and collectively;

And that the principle of intergenerational equity means that current generations have a responsibility to safeguard the rights, interests, and welfare of future generations, parallel to the pressing need to end ongoing practices and policies that continue climate change:

**We call for regulation that takes into account the impact of human biotechnologies on the rights, interests, dignity, and health of future generations in assessing whether heritable genome editing should be permitted;**

**And for governments and lawmakers to take responsibility not only for those living in the present, but also for those who will be affected in the future, and for governing biomedical developments accordingly.**

## **08.** | **Principle 8: Ensure the right to self-govern genetic material and biological data**

Recognizing that Indigenous nations and peoples have historically been and continue to be deceived and exploited to obtain their genetic material for biomedical research to benefit dominant groups, without any benefit or return to them;

And that numerous ethnic minorities, marginalized groups, and small populations have had their genetic material used and misused in ways to which they did not consent:

**We support Indigenous peoples' call for ownership and tribal control regarding use of their genetic material and biological data in relation to all human biotechnologies;**

**And for recognition that all peoples should have greater control over and fully informed consent regarding intended-and potential future-uses of their genetic material and biological data;**

**And for genuine and meaningful involvement of peoples and communities whose genetic material and biological data are used, in the areas of research agenda setting, implementation, and results;**

**And for sharing with those peoples and communities and the public the results of and benefits achieved by the research.**

## 09. | Principle 9: Apply a precautionary approach in policy making

Recognizing the precautionary principle—adopting precautionary action to prevent harm in the face of scientific uncertainty and high stakes, developed in the field of environmentalism and also applied in the fields of health protection and bioethics—as a relevant guide to policy making around heritable genome editing;

And that the full effects of heritable genome editing on future generations and society are entirely unknown and difficult to predict;

And that there is compelling evidence that harms may come to individuals, families, communities, and societies from heritable genome editing, both in terms of unsafe outcomes and deepened social inequality;

And that researchers' and clinicians' claims that they will only introduce the technology into humans once it is deemed safe ignores the social and ethical consequences as well as health risks that will likely continue for pregnant women and pregnant people and for future generations:

**We call on regulatory bodies to apply a precautionary approach when developing policy around heritable genome editing as well as future (not yet developed) biotechnologies, in particular taking anticipatory action to avoid potential harm to populations and to society, which can include prohibition or moratoria on heritable genome editing.**

## 10. | Principle 10: Prioritize people over profit

Noting the accelerating commercialization of human biotechnologies and assisted reproduction;

And that consumers are often presented with misinformation and misled about the need for and impacts of human biotechnologies;

And that financial conflicts of interest are built into the research institutions where the researchers developing biotechnologies often stand to profit from their commercialization:

**We call for prioritization of the health and well-being of individuals, communities, and nations, and of principles of social justice, equity, and human rights in considering heritable genome editing;**

**And for regulation that includes provisions to prevent conflicts of interest in the development and use of human biotechnologies;**

**And for accurate, comprehensive, and clear information (including acknowledgment of what we do not know) about heritable genome editing for the public and policy makers, informed both by science and by understandings of equity, justice, and human rights.**

# 11.

## Principle 11: Implement public empowerment programs to ensure inclusive decision making for the common good

Recognizing that there are numerous worldviews about how to conduct research and understand and implement scientific findings;

And that the voices of people most affected—and most likely to be affected—by inequities, marginalization, and discrimination are typically absent from or ignored in officially-sanctioned debates and policy making about science and technology;

And that there have been repeated published statements concerning the importance of public deliberation in determining whether to pursue heritable genome editing;

And that the human genome is a symbolically important part of our common human heritage, the future of which should not be decided by any small number of people:

**We call for implementation of concrete, comprehensive, and adequately resourced programs to ensure public empowerment<sup>2</sup> by actively involving members of the public in these discussions and debates, providing them with opportunities to meaningfully impact relevant policy making, and ensuring a broad range of public values, perspectives, experiences, interests, and priorities in research and policy agendas regarding these technologies.**

<sup>2</sup> As defined by the WHO Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing in their [Recommendations document](#).

# COALITION MEMBERS

## ORGANIZATIONAL MEMBERS



### Center for Genetics and Society (CGS)

United States  
Marcy Darnovsky, Emily Galpern, and Katie Hasson



### biorespect

Wir hinterfragen Biotechnik

### biorespect

Switzerland  
Gabriele Pichlhofer and Tino Plümecke



### Autistic Self Advocacy Network (ASAN)

United States  
Larkin Taylor-Parker



### Disability Rights Education and Defense Fund (DREDF)

United States  
Silvia Yee



### Genetic Support Foundation

### Genetic Support Foundation

United States  
Katie Stoll



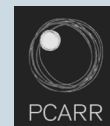
### Gen-ethisches Netzwerk e.V. (Gen-ethical Network)

Germany  
Isabelle Bartram



### Our Bodies Ourselves (OBOS)

United States  
Judy Norsigian and Sally Whelan



### Pro-Choice Alliance for Responsible Research (PCARR)

United States  
Susan Berke Fogel

## INDIVIDUAL MEMBERS

**Britta van Beers**, Department of Legal Theory and Legal History, Vrije Universiteit, Netherlands

**Alana Cattapan**, Department of Political Science, University of Waterloo, Canada

**Francine Coeytauz**, Plan C Pills, United States

**Hedva Eyal**, Ben-Gurion University of the Negev, Israel

**Florencia Herrera**, Escuela de Sociología, Universidad Diego Portales y Núcleo Milenio Estudios en Discapacidad y Ciudadanía (DISCA) (Millenium Nucleus Studies in Disability and Citizenship), Chile

**Maria Ní Fhlatharta**, Centre for Disability Law and Policy, University of Galway, Ireland

**Amrita Pande**, Department of Sociology, University of Cape Town, South Africa

**Laura Perler**, University of Bern, Switzerland

**Abril Saldaña Tejeda**, Department of Philosophy, Universidad de Guanajuato, Mexico

# ENDORSEMENTS

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## INDIVIDUALS

Affiliations are listed for identification purposes only; signees do not represent any position of their affiliated organizations.

- **Diana Namumbejja Abwoye**, Our Bodies Ourselves, United States
- **Roberto Andorno**, Institute of Biomedical Ethics and History of Medicine & Faculty of Law, University of Zurich, Switzerland
- **George J. Annas**, Center for Health Law, Ethics & Human Rights, Boston University, United States
- **Alberto Aparicio**, University of Texas Medical Branch, United States
- **Gabriela Arguedas-Ramírez**, School of Philosophy, University of Costa Rica, Costa Rica
- **Françoise Baylis**, Dalhousie University, Canada
- **Emily Smith Beitiks**, Longmore Institute on Disability, San Francisco State University, United States
- **Ruha Benjamin**, Princeton University, United States
- **Rajani Bhatia**, SUNY at Albany, United States
- **Elisa Constanza Calleja Sordo**, Institute of Legal Research of the National Autonomous University of Mexico, Mexico
- **Daisy Deomampo**, Fordham University, United States
- **Donna Dickenson**, University of London, United Kingdom
- **Troy Duster**, University of California, United States
- **Erika Dyck**, Department of History, University of Saskatchewan, Canada
- **Nourbese Flint**, All Above All, United States
- **Rosemarie Garland-Thomson**, Emory University, United States
- **Sandra P. González-Santos**, Independent Researcher, Mexico
- **Robert M. Gould**, San Francisco Bay Physicians for Social Responsibility, United States
- **Sigrid Graumann**, Germany
- **Jyotsna Agnihotri Gupta**, University of Humanistic Studies, Netherlands
- **Lisa Ikemoto**, School of Law, University of California, Davis, United States
- **Matt James**, Centre for Bioethics and Emerging Technologies, St Mary's University, United Kingdom
- **Jallicia Jolly**, Amherst College, United States
- **Jaya Keaney**, Gender Studies, School of Social and Political Sciences, University of Melbourne, Australia
- **S. Eben Kirksey**, University of Oxford, United Kingdom

- **Sara Lafuente-Funes**, University of Frankfurt, Germany/Spain
- **Marc de Leeuw**, School of Law, Society & Criminology, University of New South Wales, Australia
- **Jessica Lehman**, Disability and Aging Consultant, United States
- **Alejandro Gustavo Martínez**, Fertilis Reproductive Medicine, Argentina
- **Bill McKibben**, Author: *Enough: Staying Human in an Engineered Age*, United States
- **Stephanie Meredith**, Georgia State University, United States
- **Monica Moreno Figueroa**, Department of Sociology, University of Cambridge, United Kingdom
- **Nchangwi S. Munung**, University of Cape Town, South Africa
- **Sarojini Nadimpally**, Public Health Researcher, Bioethicist, India
- **Michal Nahman**, University of the West of England, United Kingdom
- **Osagie Obasogie**, University of California, Berkeley, United States
- **Kavita N. Ramdas**, KNR Sisters, United States
- **Vardit Ravitsky**, Global Health and Social Medicine, Harvard Medical School, United States
- **Aleksandra Relić**, Hrvatska (Croatia)
- **Dorothy Roberts**, Departments of Africana Studies and Sociology and the Law School at University of Pennsylvania, United States
- **Loretta Ross**, Smith College, United States
- **Camisha Russell**, University of Oregon, United States
- **Natacha Salomé Lima**, National Scientific and Technical Research Council (CONICET), Argentina
- **Susanne Schultz**, Goethe University Frankfurt, Germany
- **Carolin Schurr**, University of Bern, Switzerland
- **Sue Schweik**, University of California, Berkeley (retired), United States
- **Alexandra Minna Stern**, University of California, Los Angeles, United States
- **Banu Subramaniam**, Women's and Gender Studies, Wellesley College, United States
- **Jantina de Vries**, Department of Medicine and Neuroscience Institute, University of Cape Town, South Africa
- **Peter Wade**, University of Manchester, United Kingdom
- **Sonja van Wichelen**, Arts and Social Sciences, University of Sydney, Australia
- **Wouter Vyvey**, OII Europe, Intersekse Vlaanderen, Intersex Belgium, Belgium
- **Joseph M. Yracheta**, Native BioData Consortium, Lakota Country, United States

## ORGANIZATIONS

- **appella**, Switzerland
- **Autistic People of Color Fund**, United States
- **Black Women for Wellness**, United States
- **Black Women for Wellness Action Project**, United States
- **Caminar Intersex**, España (Spain)
- **Disability Visibility Project**, United States
- **From Small Beginnings...**, United Kingdom
- **Healthcare Across Borders**, United States
- **Heinrich Böll Stiftung**, Germany
- **International Center for Technology Assessment**, United States
- **Intersex Venezuela**, Venezuela
- **kolekTIRV**, Croatia
- **Milton Reynolds Consulting**, United States
- **National Center for Disability, Equity, and Intersectionality**, United States
- **Organisation Intersex International Europe e.V. (OII Europe)**, Germany
- **OII Japanese / OII日本支部**, Japan
- **Sama Resource Center for Women and Health**, India
- **VIMÖ/OII Austria**, Austria

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