

The Road to Hell. Intersex People, Sexual Health and Human Rights.

Keynote lecture by Mauro Cabral Grinspan at the 24th Congress of the World Association for Sexual Health and XII Congreso Nacional de Educación Sexual y Sexología. *Building Bridges in Sexual Health and Rights*. October 12-15, World Trade Center, Ciudad de México, Mexico.

I am not a sexologist. I am an historian and, as many other historians, I am obsessed with time. Time, I have to tell you, it's a quite fascinating subject. Sometimes it makes things look different just because one thing came before another; other times, it makes things to look the same even when separated by days, years or even decades. Let's consider, for example, this Congress. In its Program there is a session called "The John Money Lecture"¹. It was an honorific session; doubly honorific, in fact. The lecture honors John Money, and it honors the invited speaker by asking her to lecture about her area of expertise, but in John Money's honor. It was delivered yesterday. Today is another day, we are in a completely different lecture, and I am a completely different speaker. This lecture is not a John Money's lecture, except that, well, *it is* a John Money's lecture. It can't be anything else but a John Money's lecture.

Originally, my presentation was going to be focused on the sexual health and human rights issues faced by intersex people -that is to say, those people whose inborn sex characteristics vary from both male and female standards. Sex characteristics are defined as "each person's features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones and secondary physical features emerging from puberty".² Therefore, intersex people are those born with variations of sex characteristics. As a specific population when it comes to be about bodily diversity, there is much to be said about intersex people's sexual health and sexual rights.

As I said, that was my topic... before I opened the Program and saw that there was going to be a John Money's lecture. I must say it, at the very beginning, as it is: I am an intersex person, an intersex people who invited to speak at a Congress where John Money was going to be celebrated giving his name to central session. To be honest, my first feeling when I saw that was the urge to cancel my presentation; it was also my second and my third, it was my feeling yesterday after attending the lecture, which was focused on pleasure, and it was my feeling just moment ago, before starting to speak, and the reason is very simple: John Money's legacy stands for the *opposite* to intersex people's

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¹ Retrieved from www.was2019.org

² ***The Yogyakarta Principles Plus Ten. Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to Complement the Yogyakarta Principles*** (2017).

sexual health and human rights. Oversimplifying his perspective on intersex people, Money maintained that only people with normal bodies can have happy lives, and therefore, those born with so-called ‘abnormal’ bodies must be ‘normalized’ to be happy, or at least to look ‘more normal’³. Because of that legacy, all around the world, intersex people, like myself, are routinely subjected to gross human rights violations. We are genetically deselected, selectively aborted, prenatally treated, forced to undergo medically unnecessary procedures, procedures whose only aim is to “normalize” our sex characteristics, to make our bodies conform normative ideals about human bodies, and how they should look like. Those procedures include clitoridectomies, vaginoplasties, labioplasties and other genitoplasties, so-called “hypospadias repairs”, gonadectomies and many other hormonal, surgical and mechanical interventions, such as neovaginal dilations. Most of them are performed in infancy and early childhood; therefore, they are performed, by definition, without the full, prior and informed consent of the child.⁴ In other cases, intersex teenagers and adults are misinformed, or not informed at all, about our sexual anatomies, about the risk they pose for our health, and about our chances of overcoming the consequences of medical procedures to avoid such risks.⁵ Consequences include permanent genital and sexual insensitivity, sterility, chronic pain, chronic bleeding and infections, massive internal and external scarring, metabolic imbalances, osteoporosis, trauma, internalized shame, depression, suicidal ideations and suicide. Many of us deal with related health consequences, as doctors are too often not prepared to deal with the iatrogenic outcomes of previous ‘normalizing’ medical interventions; because many times there is nothing else to be done once our bodies have been damaged; or because the experience of abuse in medical institutions have been so traumatic that we avoid hospitals even when seriously sick. Many intersex people are not able to complete our education, or to keep our jobs, because of repeated hospitalization and extended recovery time, but also because of the chronic pain and trauma caused by medical treatment.⁶ And just to be clear I am not talking about very rare cases, ones that are difficult to find: we are *everywhere*. An estimated range of 0.05% and 1.7% of the population is born with sex characteristics varying from male and female standards.⁷ This long list of horrors is inextricably linked to John Money; to his name,

³ **Karkazis**, Katrina (2008). *Fixing Sex. Intersex, Medical Authority and Lived Experience*. Durham: Duke University Press. **Downing**, Lisa, **Morland**, Iain and **Sullivan**, Nikky (2015) *Fuckology. Critical Essays on John Money’s Diagnostic Concepts*. Chicago and London: University of Chicago Press.

⁴ **Cabral Grinspan**, Mauro and **Carpenter**, Morgan (2017) Gendering the lens. Critical Reflections on Gender, Hospitality and Torture. *In Gender Perspectives on Torture: Law and Practice*. Washington: American University :183-197

⁵ **Tamar-Mattis**, Anne (2014) Medical Treatment of People with Intersex Conditions as Torture and Cruel, Inhuman, or Degrading Treatment or Punishment. *In Torture in Healthcare Settings: Reflections on the Special Rapporteur on Torture’s 2013 Thematic Report*. Washington: American University :91-105.

⁶ **OHCHR** (2019) [Background Note on Human Rights Violations against Intersex People](#). Geneva: OHCHR.

⁷ **Blackless M.**, **Charuvastra A.**, **Derryck A.**, **Fausto-Sterling A.**, **Lausanne K.** and **Lee E.** (2000) “How Sexually Dimorphic Are We? Review and Synthesis. *American Journal of Human Biology* 12(2): 151-166.

to his research, to his language, to his publications, his students, his colleagues; it is linked to the intersex healthcare protocols that he created and that many others reproduced (and even today keep reproducing around the globe), it is linked to the unacceptable politics of evidence that informs those protocols. It is linked to his entire legacy.

Of course, John Money and his followers did not promote human rights violations against intersex people. They were just building theories, crafting new conceptual tools, making science in times when professional practices, epistemological concerns and bioethical rules maybe were different than ours. And yes, decades later, his actions and those of his followers have been identified as human rights violations against intersex people, but it can be said: all of that happened in the past, and that past was an entirely different world. My problem today, however, is not with that past and that world; it is with *this* present and *this* world. After *all* the evidence on the suffering caused by him and his legacy since the mid` fifties to date not only he is still being celebrated, but intersex people keep still being subjected to the *same* kind of treatment. As intersex British philosopher Iain Morland wrote “Despite recent clinical policies that endeavor to distance current practice from Money’s recommendations, his foundational assertions continue to haunt treatment decisions by doctors and parents alike; we are not post-Money.”⁸ And I can’t agree more with him: we are not post Money at all. Let me introduce a local and very recent example. In the shadow report produced by Brujula Intersex, Vivir y Ser Intersex, Dr. Eva Alcántara and StopIGM.org/Zwischengeschlecht.org to the 6th Periodic Report of Mexico on the International Covenant on Civil and Political Rights (CCPR) in 2019, the Mexican Ministry of Health is denounced as recommending “*genital reconstruction*”, namely “*clitoroplasty*”, “*vaginoplasty*” and “*perineoplasty*”, “*usually between 2 and 6 months*” in order to “*reduce parental anxiety*” and to “*avoid stigmatisation*” and “*psychological problems*”, despite openly admitting to the lack of evidence supporting early surgery, as well as to the increased risk of vaginal stenosis requiring dilation in case of early “*surgical correction*”.⁹ I am not sharing this information as a foreigner in the land of human rights violations against intersex people: my own country, Argentina, has been already denounced to the Committee Against Torture and the Committee on the Rights of the Child precisely because of the same issues.¹⁰

Starting in the 1990s, intersex people have organized in a quite strong political movement.¹¹ We have not only questioned medical protocols, but the very classifications naming and

⁸ Morland, Iain (2018) Afterword: Genitals are History. In *Postmedieval*, 9-2: 209-215.

⁹ [NGO Report to the 6th Periodic Report of Mexico on the International Covenant on Civil and Political Rights \(CCPR\)](#)

¹⁰ [NGO Report to the 6th and 7th Periodic Report of Argentina on the Convention against Torture \(CAT\)](#); [NGO Report to the 5th and 6th Report of Argentina on the Convention on the Rights of the Child \(CRC\)](#)

¹¹ [Astraea Lesbian Foundation for Justice \(2016\) *We Are Real. The Growing Movement Advancing the Human Rights of Intersex People*](#). New York: Astraea Lesbian Foundation for Justice.

defining our bodies.¹² We have been heard by human rights institutions at the local, regional and international levels.¹³ We have been heard by the World Health Organization itself, on sexual health and human rights and on forced sterilization.¹⁴ Even when my own presence here, as an intersex keynote speaker, could be considered an example of how things are changing. However, when it comes to be about clinical practice, things are not changing that much. As I said, surgical, hormonal and mechanical interventions keep being the rule, not the exception.

And, in fact, Intersex people are still affected by one of the most pervasive and long-lasting consequences of the past and present pathologization of bodily diversity. Following English philosopher Miranda Fricker, we can define our experience as a clear example *epistemological injustice*, in its two key forms.¹⁵ One of them, *testimonial injustice* happens when a negative stereotype introduces prejudices that cause a deficit in the credibility of the person. Intersex people have been structurally affected by *testimonial injustice*, and not only because of our credibility deficit but also because of the *credibility excess* generally attributed to doctors. Quoting an Australian intersex bioethicist and advocate, Morgan Carpenter said: Human rights violations of intersex individuals persist, deeply embedded in a deliberate history of silencing. ... silence gave people with intersex traits no words to describe our sutures, scars and lack of sensation, and no words to understand commonalities shared across the diversity of lives and histories".¹⁶ Having no words to describe what happened to us, and having our words dismissed, ignored or denied, is what Miranda Fricker calls *hermeneutical injustice*, the one that arises when some people are systematically excluded from the collective process of making sense of the world. The combination of both forms of *epistemic injustice* affecting intersex people provides a good explanation for why the concrete evidence about the extremely negative consequences of medical protocols keep being ignored, why those medical protocols keep being performed in spite of the absence of evidence supporting them. It can explain why so many people committing human rights violations against us seem to be so sure about their present and future impunity: it seems that no one will hold them accountable. It can explain, for example, why it could have seem a great idea to have, at the same Congress, a session honoring John Money *and* to invite an keynote speaker, who was tortured because of exactly what

¹² [GATE Submission to WHO on Intersex Issues in the process of ICD Reform](#).

¹³ OHCHR (2019) [Background Note on Human Rights Violations against Intersex People](#). Geneva: OHCHR.

¹⁴ OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO (2014) [Eliminating forced, coercive and otherwise involuntary sterilization. An interagency statement](#). Geneva: World Health Organization.
WHO (2015) [Sexual health, human rights and the law](#). Geneva: World Health Organization.

¹⁵ Fricker, Miranda (2009) *Epistemic injustice. Power and the Ethics of Knowing*. Oxford: Oxford University Press.

¹⁶ Carpenter, Morgan (2016) The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change. *Reproductive Health Matters* 24 (47): 74–84.

John Money's stood for, and having a John Money's lecture focused on sexual pleasure without even saying a word about his involvement in intersex genital mutilation and about its impact in our ability to enjoy sexual pleasure.

And I get it. John Money, and his followers, only had, and only have, good intentions. the *best intentions* in the world, actually. No one wanted, or wants, to *harm* anyone. However, as the saying goes, the road to hell is paved with good intentions. And just in case it is not clear, practicing hormonal treatments, surgical procedures and mechanical interventions - without any medical necessity, with irreversible consequences on people who cannot consent to them, with only the purposes of conforming to social gender and sexual expectations, avoiding stigma and discrimination, treating parental anxiety, or increasing someone's chances being adopted, being desired, getting laid or getting married, as good as all of that clearly sound to many people, is *never* a good practice, and it is never in the best interest of intersex people in general and of children in particular. It wasn't the case eighty years ago, it wasn't the case yesterday, it is not the case now, it won't be the case later, it won't be the case tomorrow, it won't be the case ever.

In 2006 I had the opportunity of being part of the Experts' Group that produced the *Yogyakarta Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity*. In that document, we managed to include a paragraph on intersex. under Principle 18 on Protection Against Medical Abuses. It calls States to:

“take all necessary legislative, administrative and other measures to ensure that no child's body is irreversibly altered by medical procedures in an attempt to impose a gender identity without the full, free and informed consent of the child in accordance with the age and maturity of the child and guided by the principle that in all actions concerning children, the best interests of the child shall be a primary consideration”¹⁷

Ten years later, the *Yogyakarta Principles Plus 10* introduced another set of Principles, with very strong language on intersex issues, including sex characteristics as a protected ground from human rights violations.¹⁸ Principle 30 on the Right to Bodily and Mental Integrity, for example, provided a very needed standard of interpretation to Principle 18, by adding that States shall “ensure that the concept of best interest of the child is not manipulated to justify practices that conflict with

¹⁷ *The Yogyakarta Principles. Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity* (2007).

¹⁸ *Yogyakarta Principles Plus Ten. Additional Principles and State Obligations on the Application of International Human Rights Law in Relation to Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics to Complement the Yogyakarta Principles* (2017). Members of the Drafting Committee were Morgan Carpenter, Julia Ehrt, Sheherezade Kara, Arvin Narrain, Pooja Pate, Chris Sidoti, Monica Tabengwa and Mauro Cabral Grinspan.

the child's right to bodily autonomy". It can't get clearer, right? We also introduced two additional State Obligation related to Principle 10 on the Right to Freedom from Torture and Cruel, Inhuman or Degrading Treatment or Punishment, calling States to

"Recognize that forced, coercive and otherwise involuntary modification of a person's sex characteristics may amount to torture, or other cruel, inhuman or degrading treatment" and to "Prohibit any practice, and repeal any laws and policies, allowing intrusive and irreversible treatments on the basis of sexual orientation, gender identity, gender expression or sex characteristics, including forced genital-normalising surgery, involuntary sterilization, unethical experimentation, medical display, "reparative" or "conversion" therapies, when enforced or administered without the free, prior, and informed consent of the person concerned."

However, when it comes to be about the *Yogyakarta Principles* my favorite one is Principle 37 on the Right to Truth. Its introduction affirms:

"every victim of a human rights violation on the basis of sex characteristics has the right to know about the facts, circumstances and reasons why the violation occurred. The right to truth includes effective, independent and impartial investigations to establish the facts, and includes all forms of reparation recognized by international law. The right to truth is not subject to statutes of limitations and its application must bear in mind its dual nature as an individual right and right of the society at large to know the truth about past events."

As you can see, The Right to Truth has a fascinating relation with time. it applies not only to the past, but also to the present and to the future. When it comes to be about John Money, it is not only about his research and writing on intersex issues, but also about those who came after him and follow his teachings. It is also about those who saw the evidence of wrongdoing, and kept doing wrong; it is about those who, even today, keep defending genital cutting as the right -and, actually, as the only- approach to intersex bodies, even when that approach has been identified by UN mechanisms as torture and ill treatment in medical setting, as harmful practices, and as comparable to female genital mutilation. I am very proud to share with here that at the Argentinian Senate there is right now a law protecting intersex people's human rights, including the creation of a Truth Commission to investigate those human rights violations, including those committed in medical settings and inspired by John Money's work and its followers¹⁹.

Some people have asked me in the past days about my opinion on whether WAS should get rid of the John Money's lecture, but speaking of truth, truth is it is not even *that* important. The problem with John Money is not the lecture yesterday, or the lectures in previous congresses, or the

¹⁹ [Proyecto de ley de protección integral de las características sexuales.](#)

lectures in the congresses to come. Actually, it doesn't matter at all if WAS will have or won't have a John Money lecture in the future. What matters is what is WAS going to do with John Money's legacy. As Jacques Derrida said, the only way of inheriting a legacy is to acknowledge the disputes that come with it.²⁰ What matters, then, if it WAS will accept or reject the sexual health and human rights disputes that cannot be dissociated from John Money's legacy. What *really* matters here is if WAS (and all and each of you) will respect, promote and defend intersex people's human rights, or not.

Our demands to you are clear and simple, and expressed in several accessible documents.²¹

- Stop performing (or endorsing the performance of) medically unnecessary procedures to “normalize” our sex characteristics without our full, prior and informed consent, and provide full access to rehabilitation and reparations to the past victims of such procedures.
- Provide adequate information to intersex people, our parents and family, and ensure our full access to our own true medical records.
- Stop subjecting us to unnecessary physical examinations, psychological interrogations, and stop photographing and filming us without our consent.
- Support intersex people's sexual health, by ensuring our bodily integrity and our self-determination, by expanding scientific knowledge about our bodies and our sexualities, by challenging gender and sexual stereotypes, by debunking the myth saying that no one would ever desire us if our bodies are not medically “corrected” first, and also that other myth, the one saying that genital mutilation is fully compatible with a happy and healthy sexual life.
- Stop pathologizing bodily diversity, including the healthy variations of sex characteristics.

Actually, stop pathologizing *all* forms of sex, gender and sexual variations, including those in childhood and adolescence. When I checked the Program I pictured myself and my lecture presenting between the John Money's lecture and another lecture, still to be presented later today. In that case it won't be a lecture about intersex issues, but about trans issues. That means that it won't be about those of us who were born with variations of sex characteristics, but about those of us who identify in a gender identity different than the sex assigned to us at birth.²² For me, being here,

²⁰ **Derrida**, Jacques (1993) *Spectres de Marx: l'état de la dette, le travail du deuil et la nouvelle internationale*. Paris: Gallimard.

²¹ See, for example: [Malta Declaration](#) (2013); [Statement of San José de Costa Rica](#) (2018).

²² **Kara**, Sheherezade (2017) [Gender is not an illness. How pathologizing trans people violates human rights law](#). New York: GATE.

speaking between a John Money's lecture and the upcoming lecture on trans children and adolescents from the pathologizing perspective of gender dysphoria can only be described by a very technical term: it is what we call "a pain". But I am here, as many other intersex, gender diverse and trans activists and/or scholars are everywhere, not only to give testimony of that pain, but to do *something* about it. So, this lecture still has to happen; taking advantage to work and play with time, I invite you now to join our collective efforts to put for good intersex, gender diverse and trans psycho and medical pathologization, so-called reparative²³ and *cancellative* therapies where they belong: in the past and, more precisely, in that territory of the past called 'the never-again'.

I want to finish this presentation with a short explanation about what I am wearing today. This T-shirt has an open eye in its front. In medical literature, intersex people have been usually depicted fully naked, with our eyes covered. This *style* of visual representation has been justified as the only way of exposing intersex anatomies while supposedly protecting our privacy. In fact, however, covering intersex people's eyes only protects those who are seeing us, from us, the ones being seen. In the context of this representational game, the intersex open eye clearly marks the beginning of an end. It is an open invitation; it is inviting you to ask yourself and dare to answer, the question posed by Donna Haraway: "With whose blood were your eyes crafted?".²⁴ The naked intersex eye is also a radical challenge to that old scopic scene where you can see us but we can't see you seeing us. Now you know it. We are seeing *you*.

Abran sus ojos, gente. Open your eyes.

Thank you.

²³ **Paré**, Florence (2019) Homophobia, Conversion Therapy, and Care Models for Trans Youth: Defending the Gender-Affirmative Approach. *Journal of LGBT Youth*, DOI: [10.1080/19361653.2019.1665610](https://doi.org/10.1080/19361653.2019.1665610); **OutRight Action International** (2019) [Harmful Treatment. The Global Reach of So-Called Conversion Therapy](#). New York: OutRight Action International.

²⁴ **Haraway**, Donna (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*. Vol 14, pp 575-599; p. 585.