Legislation to End IGM – A Social Movement Whose Time has Come?
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Abstract  In 1950, systematic early cosmetic genital surgeries on children with variations of sex anatomy were introduced in North America and Europe, and eventually became the de-facto medical standard allover the ‘developed world’. 1993, survivors started organising against this practice, deploiring loss of sexual sensation, framing the non-consensual surgeries as grave human rights violations, namely against the right to physical integrity, and as Intersex Genital Mutilations (IGM), calling for legislation.

Since 2012, after a resurgence of political intersex activism including use of nonviolent action, human rights mechanisms, and lawsuits against perpetrators, this call for legislation has finally been recognised as legitimate and necessary by national and international ethics and human rights bodies, and echoed in parliament.
I’ll analyse the ongoing 20-year-struggle to end IGM in terms of grassroots’ models of social movements, and discuss how an emerging global intersex social movement can succeed in banning IGM within the next decade.

A. Intersex and IGMs
This section will provide an overview of intersex, genital differentiation, and the most frequent forms of IGM.

Variations of Sex Anatomy
Intersex persons, also known as hermaphrodites, or persons with Differences of Sex Development (DSD),¹ are people born with “atypical” sex anatomies (or “atypical” reproductive anatomies), or variations of sex anatomy, including

a) “ambiguous genitalia”, e.g. external genitalia, secondary sex markers; and/or

b) atypical hormone producing organs, or atypical hormonal response, e.g. a mix of ovarian and testicular tissue in gonads (ovotestes), the adrenal gland of the kidneys (partly) producing androgens instead of cortisol, low response to testosterone, little active testosterone producing Leydig cells in testes, undifferentiated streak gonads; and/or

c) atypical genetic make-up, e.g. XXY, X0, different karyotypes in different cells of the same body (mosaicism).

Variations of sex anatomy include

- “atypical characteristics” either on one or on more of the above three planes a)–c),

- or, while individual planes appear “perfectly normal”, together they “don’t match”, e.g. a newborn with male exterior genitals but an uterus, ovaries and karyotype XX, or with female exterior genitals but (abdominal) testicles and karyotype XY.

While many intersex forms are usually detected at birth or earlier during prenatal testing, others may only become apparent at puberty or later in life. What’s more, when talking about “the intersex people”, it’s important to keep in mind that persons with variations of sex anatomy are a very inhomogeneous group encompassing many different forms and variations. Between the different forms and “diagnoses”, there are practically more differences than similarities. However, one central commonality remains: About 90%² of intersex people are victims of unnecessary forced medical treatments (but also here there are big differences).


Genital development before birth.³

Genital Development

To understand how so called ambiguous genitals develop, we have to consider a fact of life usually omitted in biology classes: All people were hermaphrodites – until the 7th week of pregnancy. Yes, we all started out with precursors for ovaries and testicles in our bellies, and we all had “ambiguous genitals.”

Only after the 7th week of gestation, usually male or female genitals develop – out of the very same “basic parts”, including

- the genital bud, which in typical females forms the clitoris, and in typical males the penis
- the labioscrotal development, which in typical females forms the labia, and in typical males fuses to form the scrotum
- the urogenital fold, which only during the last stage in typical females divides into the urethral and vaginal openings, and in typical males fuses with the urethral opening ascending to the tip of the penis (in case you ever wondered why male private parts have a fission, this is the explanation).

However, it’s also possible that the genitals develop along a less common pathway, e.g. due to unusual level of certain hormones, or an unusually high or low ability to respond to them, resulting in “ambiguous”, “indeterminate”, or in-between genitals at birth.

Also, the bipotential gonads in typical females develop into ovaries, and in typical males into testicles (which usually, but not always, later descend into the scrotum). And regarding the basic duct structures, in typical females the Müllerian ducts develop into an uterus plus uterine tubes, while the Wolffian ducts vanish, and in typical males the Wolffian ducts develop into spermatic ducts, while the Müllerian ducts vanish.

However, again less common development pathways are possible, for example one or both of the bipotential gonads may develop into a mixture of both ovaries and testicles (ovotestes), or stay undifferentiated (streak gonads), and/or the “wrong” or both basic duct structures develop.

In medicine, genital variations are usually classified in so called stages on the Prader scale, with Prader 5 representing typical male appearance, Prader 0 representing typical female appearance, and Prader 1–4 representing in-between genitals. Some, but not all intersex children are born with “atypical” genitals. Children with genitals resembling Prader

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3 and 4 may arbitrarily be diagnosed as “boys with hypospadias” and submitted to “masculinising “hypospadias repair.” Children with genitals resembling Prader 1–5 may arbitrarily be diagnosed as “girls with an enlarged clitoris” and submitted to “feminising clitoris reduction” and “vaginoplasty.”

**Frequency of Intersex Variations**

Since hospitals, government agencies, and health assurances covering intersex surgeries on children still refuse to disclose statistics and costs, unfortunately there are no exact figures or statistics available regarding the frequency of intersex births.

In medical literature, often two different sets of numbers and definitions are given depending on the objective:

a) 1:1000 \(^5\) if it’s about getting access to new patients for cosmetic genital surgery; and

b) 1:4500 or less \(^6\) if it’s about countering public concerns regarding human rights violations, often only focusing on “severe cases” while refusing to give total numbers

However, from a human rights perspective, the crucial question remains: How many children are at risk of human rights violations, e.g. by non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries or other similar treatments justified by a psychosocial indication? Here, the best known relevant number is 1:500 – 1:1000 \(^7\) children are submitted to (often repeated) non-consensual “genital corrections”.

**The Three Most Common Forms of IGM**

According to leading human rights and ethics bodies and experts, Intersex Genital Mutilations (IGMs) can generally be defined as including non-consensual, medically unnecessary, irreversible, cosmetic genital surgeries, and/or other similar medical treatments, including imposition of hormones, performed on children with variations of sex anatomy, without evidence of benefit for the children concerned, justified by “psychosocial indications” shaped by societal and cultural norms and beliefs.

The three most common forms of IGM are “masculinising genital corrections”, “feminising genital corrections”, and sterilising procedures. Other harmful treatments include forced mastectomy, imposition of hormones, forced excessive genital exams, medical display and (genital) photography, human experimentation, denial of needed health care, prenatal “therapy”, selective (late term) abortions, preimplantation genetic diagnosis (PGD) to eliminate intersex fetuses, as well as misinformation and directive counselling for parents, and systematic lies and imposition of “code of silence” on children. \(^8\)

While doctors promise to produce “normal looking genitals”, persons concerned still report being teased also in the so called “successful” cases because of scars and unusual appearance, let alone in cases of admittedly “bad results.”

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\(^5\) Rainer Finke, Sven-Olaf Höhne (eds.) (2008), Intersexualität bei Kindern, Preface, at 4
\(^6\) e.g. “fewer than 2 out of every 10,000 births”: Leonard Sax (2002), How common is intersex? a response to Anne Fausto-Sterling, The Journal of Sex Research 39(3):174-178, at 178
\(^7\) Intersex Society of North America (ISNA), How common is intersex?, http://www.isna.org/faq/frequency
IGM 1 – “Masculinising Genital Corrections”

“Hypospadias”, i.e., when the urethral opening is not at the tip of the penis, but somewhere on the underside between the tip and the scrotum, is arguably the most prevalent diagnosis for cosmetic genital surgeries. “Hypospadias repair” procedures include dissection of the penis to “relocate” the urinary meatus. Very high complication rates are common, as well as repeated “redo procedures” — as a medical presentation states, “5.8 operations (mean) along their lives … and still most of them are not satisfied with results!” Nonetheless, clinicians recommend these surgeries without medical need explicitly “for psychological and aesthetic reasons.” Most hospitals advise early surgeries, usually “between 12 and 24 months of age.”

While survivors criticise e.g. impairment or total loss of sexual sensation and painful scars, doctors still fail to provide evidence of benefit for the recipients of the surgeries. The main justification for hypospadias surgery is that a real man must be able to pee standing, and to be able to impregnate women via “normal” penetrative sex. In comparison, a numbed glans due to repeat surgeries is considered a minor obstacle. Tiger Howard Devore, one of the first survivors to speak out publicly, states,⁹

“My childhood was filled with pain, surgery, skin grafts, and isolation. And I still have to sit to pee. It would have been just fine to have a penis that peed out of the bottom instead of the top, and didn’t have the feeling damaged.”

On the other hand, I have personally spoken to several persons with hypospadias who are grateful for having escaped “corrective” surgery.

Many children have major surgeries every year until they’re old enough to resist further treatments. The language of the doctors is telling, see for example the official iatrogenic diagnosis “hypospadias cripple” for persons with repeat “failed” surgeries given up as hopeless cases. For decades, doctors again and again have been stating the lack of outcome studies, but still prefer to just go on with more and more surgeries by hook or by crook, relishing the “Surgical Challenge.” This is typical for all forms of IGM.

IGM 2 – “Feminising Genital Corrections”

Partial amputation of clitoris, often in combination with surgically opening or widening of the vagina, is arguably the second most prevalent cosmetic genital surgeries on intersex children today, with “46,XX Congenital Adrenal Hyperplasia (CAH)” being the most common diagnosis (further diagnoses include “46,XY Partial Androgen Insufficiency Syndrome (PAIS)” and “46,XY Leydig Cell Hypoplasia”). Despite numerous findings of loss of sexual sensation caused by these cosmetic surgeries and lacking evidence for benefits for the persons concerned, current guidelines nonetheless advise surgeries in the first 2 years of life”, most commonly “between 6 and 12 months,” and only 10.5% of surgeons recommend letting the persons concerned decide themselves later.

Until the second hypospadias repair boom in the 1990s, feminising corrections were the most frequent procedure due to surgical limitations, according to the infamous surgeon’s motto, “You can dig a hole, but you can't build a pole.”

Since the 1930s, the gist of the rationale given by doctors to justify cosmetic clitoris

surgery on intersex children has been the same until today: An ‘enlarged clitoris’ may appear bothersome and may lead to embarrassment for these girls in the changing room or while swimming, therefore, its amputation or cutting is surely justified. Clitoris amputations, or even more radical clitoridectomies were common until the 1990s. While doctors today employ more modern techniques, aiming at sparing the main nerves, they still cut away most tissue and persons concerned still deplore loss of sensitivity. Intersex activist Daniela “Nella” Truffer:  

“According to my medical records, my micropenis was reduced to a ‘very small clitoris’, i.e., my penis was dissected, most thrown in the garbage can, and the remains were stuffed inside me and sewn shut. I’ll suffer for the rest of my life from the consequences of this inhumane treatment.”

Other “feminising procedures” include surgical opening and/or widening of the vagina (“vaginoplasty”), followed by forced vaginal dilatation, usually for children with “46,XX Congenital Adrenal Hyperplasia (CAH)”, or surgical creation of an artificial vagina (“neovagina”), also followed by forced vaginal dilatation, for example on children with “46, XY (Complete) Androgen Insensitivity Syndrome ((C)AIS)" or “46, XX Congenital Absence of Vagina”, also known as “Mayer Rokitansky Küster Hauser Syndrome (MRKH)”. These surgeries are again done on little children with the rationale of allowing for later “normal intercourse”, often at the same time as the clitoral cuttings.

**IGM 3 – Sterilising Procedures**

Arguably the 3rd most common form of IGM is castration of female-assigned children diagnosed with “46, XY Complete Androgen Insensitivity Syndrome (CAIS)”, whose healthy abdominal testes are removed under the pretext of an alleged high cancer risk, followed by Hormone “Replacement” Therapy (H“R”T) with artificial estrogens, despite the fact that the removed testicles produced testosterone, which by androgen insensitive bodies is then changed into natural estrogens via aromatasis. Consequently, many survivors complain of serious negative side effects, e.g., depression, adiposity, metabolic and circulatory problems, osteoporosis, limitation of cognitive abilities and of libido, and many report being better off with a HRT with testosterone.

What’s more, the supposedly blanket high cancer risk has been debunked by medical studies, emphasising the need to differentiate between different diagnoses, and stating effective cancer risks for CAIS at 0.8%, e.g., significantly lower than the risk for breast cancer in “normal women”, or prostate cancer in “normal men”. Also, unnecessary castrations have been criticised by some doctors for decades, however to little avail: “The castration of patients without a tumour converts symptomless individuals into invalids suffering from all the unpleasant consequences of castration.”

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Other common sterilising procedures include removal of reproductive structures “discordant to Sex of rearing”. For example, if a child is raised male, but has an uterus and/or ovaries, those are cut out in reverse. Other relevant procedures include removal of “persistent duct structures”, partial removal of ovotestes, etc. Again, despite that there is no medical need for early removal, doctors insist on doing so for psychosocial reasons.

**History and Frequency of IGMs**

Since 1950, starting in Baltimore and Zurich, IGMs have been practised systematically and on an increasingly industrial scale all over the “developed world”. For example, in a 1950 medical textbook by renowned paediatric endocrinologist Lawson Wilkins, a child described as “Normal age 9 years” is juxtaposed to 4 children numbered A–D aged 2–9 years diagnosed with “Congenital Adrenal Hyperplasia – Female Pseudohermaphroditism”, all of them having their “clitoris amputated” or “excised” respectively, or being submitted to “Plastic operations on hypospadias repair”. Until today, for children considered “not normal” by doctors, it’s been either clitoris amputation/“reduction” or “hypospadias repair”, depending on whether they were (often arbitrarily) assigned female or male.

Also, since 1950 until today, it’s paediatric endocrinologists together with paediatric surgeons leading the treatments, despite the obvious fact that medicalisation inevitably results in more and even more unnecessary genital surgeries on defenceless children. For example, a 2013 exploratory study found medicalised counselling as offered by paediatric endocrinologists resulting in 65.9% of prospective parents “consenting” to “corrective genital surgeries”, while demedicalised counselling as demanded by intersex advocacy groups resulting in 77.1% of prospective parents refusing medically unnecessary “genital corrections”.

Today, despite public denials by doctors, still about 90% of all children concerned get submitted to IGMs, with total numbers of unnecessary surgeries still rising.

Obviously, IGM is a glaring example of social injustice – but how to end it?

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14 Lawson Wilkins, “The Diagnosis and Treatment of Endocrine Disorders in Childhood and Adolescence,” Springfield 1950, p. 238


B. Social Movement Basics
This section will provide an overview of social movement history and strategies.

Power concedes nothing voluntarily

Most basic principles of modern, nonviolent social movements can be traced back to earlier struggles, for example to abolitionists, suffragettes, anti-colonial independence struggles, and the civil rights movement – all born from the hands-on experience of “No struggle, no progress!”

Or, as the former slave and abolitionist Frederick Douglass famously put it in 1857\(^{18}\) (my emphasis):

> “Let me give you a word of the philosophy of reform. The whole history of the progress of human liberty shows that all concessions yet made to her august claims have been born of earnest struggle. [...] If there is no struggle there is no progress. Those who profess to favor freedom and yet deprecate agitation are men who want crops without plowing up the ground; they want rain without thunder and lightning. They want the ocean without the awful roar of its many waters.

> This struggle may be a moral one, or it may be a physical one, and it may be both moral and physical, but it must be a struggle. Power concedes nothing without a demand. It never did and it never will. [...] If we ever get free from the oppressions and wrongs heaped upon us, we must pay for their removal. We must do this by labor, by suffering, by sacrifice, and if needs be, by our lives and the lives of others.”

Another related crucial intuition broached by Douglass is the realisation, nobody will be waging your struggle for you – the only way of getting it done is doing it yourselves.

In the case of the intersex movement, it’s obvious that, if doctors were inclined to be swayed by mere complaints and pleas by IGM survivors to change their ways, they would have done so 20 years ago, and tasking, e.g., LGBT groups to lead the intersex fight doesn’t work but in contrary results in political appropriation that alienates both the public and mainstream politicians, and which doctors are only too happy to successfully turn against IGM survivors speaking out.

Monolithic Model of Power vs. Pillars of Support
A cornerstone of modern social movements is the people’s power model. While in the monolithic traditional power model\(^{19}\) all power resides with the powerholders at the top, social movements recognise that the powerholders in fact are dependent on support and compliance by institutions and the public – and can be toppled by nonviolent withdrawal of this support.

In classic movement models these “pillars of support”\(^{20}\) include, e.g., the police, worker’s

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 organisations, military, media, political parties, and civil servants.

For the intersex movement, central pillars of support which need to be removed include the ignorance and silent assent of the public, complicity by government bodies and umbrella medical associations, lack of persons concerned speaking out in public due to traumatisation, silence on IGMs in the media, and lack of pressure from national and international human rights and ethics bodies.

Different Forms of Activism: Bringing it all together
Social activists employ all the different modes and forms of activism for awareness raising, mobilising and applying pressure, including

- having an online presence (own top level domain website, including additional contingency domains at different providers in case of lawsuits – not only, e.g., a Facebook page or a blog on blogger or wordpress, which can be taken down / deleted at any time without notice)
- regular press releases to all regional, national and international media
- media appearances and interviews
- publications in peer-reviewed journals
- contributions to parliamentary proceedings on a local / municipal level, state level, federal or national level
- participation in international human rights mechanisms, for example in reviews of international covenants by the United Nations
- participation in or active support of legal suits against perpetrators, for example litigation
- confronting perpetrators and colluding politicians with nonviolent protests

While these different modes of activism by themselves and in isolation are old news, contemporary social movements are unique in combining ALL of them into a unified coordinated strategy, which is their defining characteristic – i.e., else it's no social movement!

The Four Roles of Social Activism
Social movement pioneer Bill Moyer details four roles of social activism, and he also distinguishes between effective and ineffective ways to play the four roles:

1. **The Concerned Citizen.** Promotes positive, widely-held values, e.g., democracy, freedom, justice, non-violence; is grounded in the centre of society; protects the movement against charges of ‘extremism’.

2. **Ineffective: Naive citizen:** Does not realise the powerholders and institutions serve elite interests; super-patriot: Blind obedience to powerholders and country.

3. **The Rebel.** Protests: Says “NO!” to violation of positive values; uses nonviolent direct action and civil disobedience; puts problems in public spotlight; strategic; exciting, courageous, risky.
   
   *Ineffective: Self-identifies as ‘being on the fringe’; ‘any means necessary’, including violence and property destruction; acts from strong negative emotions such as anger, desperation and powerlessness; anti-organisation, opposed to any rules or

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21 Practical experience by the author
22 Bill Moyer with JoAnn McAllister, Mary Lou Finley, Steven Soifer, “Doing Democracy. The MAP Model for Organizing Social Movements,” Gabriola Island 2001, p. 21–41
structure; personal needs outweigh movement needs.

4. The Reformer. Uses official channels to make change; uses variety of means: lobbying, legal action, elections; monitors success to assure enforcement, expand success and guard against backlash.  
   *Ineffective:* Promotes minor reforms; co-optation: identifies more with official powerholders than grass roots; limited by hierarchical/patriarchal structure; does not advocate paradigm shifts.

5. The Change Agent. Uses people power: educates, convinces and involves majority of citizens: mass-based grassroots organising; employs strategy and tactics for waging long-term movements; promotes alternatives and paradigm shifts.  
   *Ineffective:* Utopian: promotes visions of perfectionism disconnected from current movement needs; dogmatic: advocates single approach while ignoring others; ignores personal needs of activists; disengages from movement to live isolated, alternative lifestyle.

In a successful social movement, all of these four roles must be played effectively and as one, i.e., every activist should at least know about all different roles to be in a position to support them effectively. Ideally social activists are able to play all four roles effectively, and according to the movement’s needs.

**The Need for Constant Ongoing Coordinated Pressure on All Levels**

In addition to employing all the different modes of activism and playing all four activist roles effectively, for a social movement to succeed, ongoing and coordinated pressure is needed on all levels, including:

- Pressure in the Media
- Pressure in Parliaments
- Pressure in the Courts
- Pressure on the Streets

If a social movement succeeds in mounting such coordinated continuing pressure for long enough and doesn’t forget that ultimately it will need winning over the support of a significant majority of the public to force the powerholders (i.e., in the case of the intersex movement, the doctors) to change their practice, victory will ultimately only be a question of time.

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23 Practical experience by the author. See also Alinsky’s “The eight rule: Keep the pressure on, with different tactics and actions, and utilize all events of the period for your purpose,” as well as “The tenth rule: The major premise for tactics is the development of operations that will maintain a constant pressure on the opposition.” Saul Alinsky, “Rules for Radicals,” New York 1971, p. 128–129
Winning the public in three ways: Bill Moyer's Movement Action Plan (MAP).\textsuperscript{24}

### The Long Run: Movement Action Plan (MAP)

Nonetheless, social change doesn't come over night, but takes years and decades, and needs lots of tenacity. Unfortunately, social activists often despair despite successes, ironically regularly when they're actually winning important battles along the way.\textsuperscript{25}

Bill Moyer's Movement Action Plan (MAP)\textsuperscript{26} was devised to counteract this perceived failure. It distinguishes eight stages of a successful social movement to give activists an idea of where the movement stands, what might be the powerholders next moves and what activists can to do to further advance the cause. It's vital for social movements and activists to be prepared for the long run.

What's more, MAP puts people's power front and centre, analysing crucial increases in public awareness of the problem, public opposition to powerholder policies, and public support for movement alternatives as cornerstones in social movement development.

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\begin{tabular}{|c|c|c|c|c|}
\hline
Steady State & Build-up of Stress in the System & Seen as a General Problem & Resolution \\
\hline
1 Business-as-usual & 2 Normal Channels Fail & 3 Conditions Ripen & 4 Take Off! \\
& 5 Activist “Failure” & 6 Win Majority of Public & 7 Success! \\
90\% & & & \\
80\% & & & \\
70\% & & & \\
60\% & & & \\
50\% & & & \\
40\% & & & \\
30\% & & & \\
20\% & & & \\
10\% & & & \\
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\textsuperscript{25} Bill Moyer with JoAnn McAllister, Mary Lou Finley, Steven Soifer, “Doing Democracy. The MAP Model for Organizing Social Movements,” Gabriola Island 2001, p. 87–98
\textsuperscript{26} Bill Moyer with JoAnn McAllister, Mary Lou Finley, Steven Soifer, “Doing Democracy. The MAP Model for Organizing Social Movements,” Gabriola Island 2001, p. 42–86
C. Towards an Intersex Social Movement

This section will review the intersex movement based on the above-outlined movement theories, and show how in some recent developments victories were achieved by putting grassroots-based social movement theory into action.

1993: First Organised Public Criticism by Survivors

For 21 years now, intersex people from all over the world and their organisations have been publicly denouncing IGMs as destructive of sexual sensation, and as a violation of basic human rights, notably the right to physical integrity. For 18 years, they have lobbied for legislation against IGMs to end the impunity of perpetrators due to statutes of limitation. For 17 years, they have been invoking the UN Convention on the Rights of the Child to fight IGMs, and for 10 years they have been reporting IGM to the UN as a human rights violation.

Intersex movement pioneers ISNA (USA 1993) and AGGPG (Germany 1996) profited from the rise of the internet to overcome the “code of silence” imposed by IGM doctors and compounded by trauma, organising survivors internationally, and successfully employing social movement strategies and tactics. However, virtually all early groups didn’t make the long run, and most activists ceased being active. In addition to the “usual activist burn out”, survivors of IGM report retraumatisation and frequent political appropriation.

27 Source: http://www.isna.org/books/chrysalis

2007: First Trial against IGM Surgeon – Won!
German survivor Christiane Völling was the very first intersex person to succeed in bringing her former surgeon to court in Cologne. Ultimately she won not only 100,000 Euros damages, but the first court session on 12.12.2007 and the ongoing case led to mass media coverage in European German language countries. The trial also led to a resurge in intersex social activism, and hopefully to an ongoing global movement.

In 2014, a state and federal lawsuit against IGM doctors, IGM clinics and social service employees is proceeding in the US, and in Germany another is pending against an IGM surgeon and an IGM university hospital.

2012: Swiss National Ethics Body Calls for Legal Review
For many, many years, survivors in the Americas, in Europe, and in New Zealand and Australia reported the human rights violations of intersex people to state human rights and ethics bodies, calling for legislation to end IGM, however to no avail.

29 (German) http://blog.zwischengeschlecht.info/post/2008/02/07/Sieg-fur-Christiane-Voellung
30 http://aiclegal.org/programs/project-integrity/
31 (German) http://blog.zwischengeschlecht.info/post/2013/11/11/N%C3%BChrberger-Nachrichten-Zwitterprozess-Uniklinik-Erlangen
32 See e.g. San Francisco Human Rights Commission (2005), Australian Human Rights Commission (2009), German Ethics Council (2012)
Nonetheless, in November 2012 the Swiss National Advisory Commission on Biomedical Ethics NEK-CNE condemned “medical practice […] guided by sociocultural values which […] are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination” of “children with a sex variation”, and explicitly demanded:

- Suffering of survivors should be acknowledged by society
- Psychosocial indication cannot in itself justify irreversible genital surgery in a child who lacks capacity
- Legal review of:
  - Liability implications of unlawful interventions in childhood
  - Limitation periods
  - Criminal law re: Assault and Genital Mutilation

This first-time inclusion of crucial intersex movement demands was also the result of a five-year campaign employing social movement strategies (see below). For this, the Commission’s report was recognised globally not only by intersex organisations, but also by other human rights bodies also calling for legislation against IGM.

**2013: Special Rapporteur on Torture, Council of Europe**

The UN Special Rapporteur on Torture, Juan E. Méndez, in his report on torture and other cruel, inhuman or degrading treatment or punishment in health-care settings dated 01.02.2013, was the first UN body to explicitly call for legislative measures to end “involuntary genital normalizing surgeries” and “sterilization” of “children who are born with atypical sex characteristics”. Again, the foundation had been laid in four years of partaking in human rights mechanisms, as well as media coverage, parliamentary procedures, nonviolent protests, submissions, etc., by intersex advocates.

In the same year, the Council of Europe (COE) in its Resolution 1952 (2013) “Children’s right to physical integrity” followed suit, condemning “unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood” of “intersex people”. Again, this was a result of years of awareness-raising and lobbying by intersex organisations.

**2014: WHO Interagency Statement**

In May 2014, UN bodies World Health Organisation (WHO), Office of the High Commissioner for Human Rights (OHCHR), UN Children’s Fund (UNICEF), UN Women, UNAIDS, UN Development Program (UNDP), UN Population Fund (UNFPA) in their interagency statement “Eliminating forced, coercive and otherwise involuntary sterilization” condemned “forced, coercive, involuntary sterilization” and “cosmetic and other non-medically indicated surgeries performed on [the] reproductive organs” of

35 Including Advocates for Informed Choice (AIC), Zwischengeschlecht.org / Stop IGM.org, Intersexuelle Menschen e.V.
37 Including OII Europe, Zwischengeschlecht.org / StopIGM.org and Intersexuelle Menschen e.V.
“Children who are born with atypical sex characteristics”, calling for

- Independent and impartial investigation of all incidents
- Recognize past or present policies, patterns or practices
- Issue statements of regret or apology to victims
- Collection of data and monitoring
- Provide appropriate and humane notification to people concerned
- Access, including through legal aid, to administrative and judicial redress.

Once more, this didn’t fall out of the sky, but was the result of ongoing hard work by intersex activists and organisations. 39

The Hidden Power of Nonviolent Confrontation

Unfortunately, intersex organisations employing the full spectrum of social movement strategies and tactics are still few and far between. What’s more, many intersex organisations of all things still shy away from the single most effective tool, granting the movement a decisive edge if used as part of an overall strategy: Nonviolent Action.

This lack is mostly down to two conflicting albeit popular misconceptions of the theory and practice of social movements in general, and particularly of nonviolent action:

1. An underlying fear of nonviolent action due to the lack of recognition of the difference between effective and ineffective or negative rebels, i.e., the misconception “there is no such thing as a nonviolent protest, every protest will escalate and end in chaos eventually.”

2. The misconception that nonviolence means absolute pacifism, and therefore is cowardly and ultimately futile anyway.

In the case of the intersex movement, the paralysing effect of these popular misconceptions are again aggravated by increased trauma and the lifelong (after-)effects of the “code of silence”, e.g., the internalised commandment “keep a low profile, do not stand out, do not attract attention”.

While of course above misconceptions have been debunked again and again by every social movement in existence, they remain nonetheless widespread, notably amongst powerholder representatives antagonistic to people’s power interfering with their agenda, as well as in commercial media representing powerholders’ interests, but unfortunately also amongst way too many activists and potential allies. However, the seeming popularity of this misconceptions still doesn’t make them true.

With regards to the first misconception, “nonviolent protests will escalate and backfire inevitably,” as Bill Moyer 40 pointed out in some detail, curbing “negative rebels” (including “true believers” overemphasising the rebel role, dogmatic “hard left” militants, “naive followers” unaware of the importance of playing all the different roles effectively, as well as paid for “agents provocateurs”, etc.) and preventing them from taking over and destroying social movements is crucial. Activists planning and facilitating nonviolent protests and

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39 Including Mauro Cabral, Advocates for Informed Choice (AIC), Zwischengeschlecht.org / StopIGM.org, cf. Acknowledgments, Interagency Statement p. 17
40 Bill Moyer with JoAnn McAllister, Mary Lou Finley, Steven Soifer, “Doing Democracy. The MAP Model for Organizing Social Movements,” Gabriola Island 2001, p. 32–38
especially mass protests really need to be aware of this specific problem and must be prepared to act decisively if the need should arise. However, as long as nonviolent intersex protests are not a mass phenomenon, this can be managed comparatively easily. In the current situation, preventing the budding intersex movement from being appropriated (often with “best intentions”) by third party interests and pressure groups, e.g., wanting to “fight homophobia, heteronormativity and the gender binary” but refusing to actually combat intersex genital mutilations, usually presents a far more urgent and frequent problem than “negative rebels”.

Regarding the second misconception “nonviolence is cowardly and futile”, of course on both counts the contrary is true. Not only are there countless examples of successful nonviolent movements and campaigns, but every nonviolent strategist worth his salt has stressed nonviolence is not an excuse for avoiding confrontation and nourishing “victim mentality”, but on the contrary a means to accelerate and escalate conflicts in order to actually make the powerholders change their practice whether they like it or not, although not by brute force or violence,41 and not with the ultimate goal of destroying the adversary, but of eventually winning justice and reconciliation.42


Nonviolence as Spiritual Confrontation

For generations of activists, Mohandas Gandhi remains the world’s arguably foremost teacher of nonviolent resistance (satyagraha) as a means to humiliate our oppressors by our own suffering, and to eventually make them mend their unjust ways by applying nonviolent non-cooperation and what Gene Sharp famously referred to as “political jiu-jitsu.”

Nonetheless, nowadays Gandhi is often publicly misrepresented as a poster boy for “doormat nonviolence” – while in fact Gandhi famously insisted, although nonviolence was “infinitely superior to violence,” if someone was not ready or strong enough yet to embrace nonviolence, then resorting to violence would be by far better than resorting to cowardly flight.

“Where there is only a choice between cowardice and violence, I would advise violence.” (Gandhi, 1920)

“Cowardice is worse than violence because a coward can never be nonviolent. [...] It is the duty of every believer in ahimsa [nonviolence] to see that cowardice is not propagated in the name of nonviolence.” (Gandhi, 1939)

Accordingly, in 21st century social movement theory, nonviolent action is often described as a form of spiritual confrontation, conflict, struggle, or even warfare.

(However, for social activists there is no requirement of being or becoming a religious person in order to be able to comprehend and apply the spiritual aspects of nonviolent struggle – basic empathy, common sense and love of life will do.)

“But I’m no surgeon!” So-not-amused Intersex Genital Mutilator Prof. Dr. Wieland Kiess shouting at protestors (see below Exhibit 1). Nonviolent Protests and Open Letter vs. “9th Joint Meeting of Paediatric Endocrinology” and Italian IGM Universities and Clinics, Milano 20.09.2013. Photo: Rolf Schmidt / StopIGM.org.

Naming, Blaming and Shaming the Perpetrators

“Pick the target, freeze it, personalize it, polarize it.” – When it comes down to direct nonviolent confrontation with IGM doctors, universities, clinics, medical societies, et al., legendary social organiser Saul Alinsky’s infamous thirteenth and final “Rule for Radicals”46 and the accompanying practical examples still prove to be most effective.

As Zwischengeschlecht.org / StopIGM.org demonstrated, all it takes is an ongoing nonviolent campaign applying social movement strategies and tactics – and in particular publicly naming, blaming and shaming IGM doctors, universities, clinics, societies, and congresses as Intersex Genital Mutilators

- on the net (using a legally “hardened” online presence including back-up domains)
- in mainstream newspapers, radios, ad on TV
- in local, state and federal parliaments
- in courts
- and last but not lest in front of their very own doorsteps during nonviolent protests.

For some reason, this proved to be something the perpetrators were definitively not prepared for, and obviously keep having a very hard time adapting to ever since – yet even more so after the statement by the UN Special Rapporteur on Torture. Explains IGM survivor Daniela Truffer, “Doctors need to feel the pain, too, or nothing will ever change.”47

In their obvious distress, so far the perpetrators and their institutions have resorted to

- expressing hurt feelings
- claiming to be innocent bystanders having their human rights violated by intersex activists levelling unjust accusations
- rousing their legal departments to send out cease and desist letters
- followed by legal threats, but no suits
- followed by moral accusations and more threats
- yelling at peaceful protesters
- announcing token policy changes
- promising consultation of intersex organisations.

Conclusion: IGM doctors and institutions are responding favourably to the treatment. Further therapy required.

**How the 21st Century Intersex Social Movement is Making History**

While still very limited in scope and means, a growing global intersex movement applying social movement strategies is already making a difference.

**Exhibit 1:** Prof. Dr. Wieland Kiess, President 2012 European Society of Pediatric Endocrinology (ESPE), Professor of General Paediatrics (Chair) and Director of the University Hospital for Children and Adolescents, Dean and Chairman of the Board, Medical Faculty, University of Leipzig, Germany. Previous positions as lecturer and clinician in Paediatrics and Neonatology at two more known German IGM University Hospitals. Editor-in-Chief, Pediatric and Adolescent Medicine Series, Editor-in-Chief, Journal of Pediatric Endocrinology and Metabolism, Editor-in-Chief, Kinder- und Jugendmedizin.

Prof. Dr. Kiess exhibits various symptoms and traits of a typical Intersex Genital Mutilator:

- becomes agitated when Intersex Genital Mutilations are mentioned
- claims he was never ever personally involved in any Intersex Genital Mutilations during his entire career
- claims never ever having referred any of his CAH patients to a surgeon for “genital correction”, but that all of his CAH patients who had surgery did so before he became involved and without his knowledge
- denies absolutely any responsibility for any IGM treatments done in any department or clinic when he was in charge
- can’t understand at all why anyone in the world would think he’s an Intersex Genital Mutilator, let alone send him Open Letters, or picket his IGM clinic or ESPE
- exhibits considerable distress, when neither legal nor personal threats nor the university nor the children’s hospital's lawyers can stop those nasty activists
- lost his nerve in public, shouting “You should be ashamed of yourselves!” and “I'm not a surgeon!” at yet another nonviolent intersex protest (see picture 7).

While Prof. Dr. Kiess represents our only on-camera example, various intersex organisations have reported testimonies by IGM doctors everywhere confessing how it’s getting to them every time they their institutions are named and shamed as Intersex Genital Mutilators or Perpetrators of Torture and other Inhuman, Cruel or degrading Treatments (CIDT), to the point of spoiling their fun doing IGM procedures.
“Stop Genital Mutilation in Children’s Clinics!” Christiane Völling protesting “ethics lecture” by serial IGM surgeon and future German guidelines speaker Susanne Krege (arrow) at her alma mater. Nonviolent Protest and Open Letter vs. Susanne Krege and Aachen University Clinic, Aachen 30.05.2011. Photo: Markus Bauer / StopIGM.org.

**Exhibit 2:** The proposed new German IGM guidelines claiming to “postpone” mutilations, citing “massive public protests”. In 2014, the three major German paediatric medical bodies German Society for Paediatric Endocrinology (DGKED), Paediatric Surgery (DGKCH) and Urology (DGU) announced upcoming new guidelines to recommend “postponing” IGMs “until before or at puberty”, or “10 to 12 years”, after then allegedly having “obtained informed consent” from the “patients”. Which of course merely underlines how doctors still chose to ignore basic human rights considerations regarding non-consensual unnecessary IGMs on children, as well as well-established prerequisites for giving informed consent (a 10–12 year old can’t make an informed decision on whether to risk losing sexual sensitivity possibly impairing orgasmic function or not). In addition, it is to be expected that the final guidelines will merely single out some comparatively rare procedures for “postponing”, while allowing the most frequent procedures to continue unchanged. Nonetheless, this obvious attempt at accommodating mounting public pressure remains arguably by far the greatest concession ever considered, let alone “voluntarily” announced to bring in effect, by any official perpetrator’s body worldwide.

What’s more, public statements by Dr. Susanne Krege, spokesperson and co-coordinator of the proposed guidelines, as well as outspoken serial IGM surgeon, leave little doubt on

what eventually tipped the scale:

- “Massive public protests” (Official DGU Press Release, 13.05.2014)\(^49\)
- “Massive accusations by persons concerned going public” (Rundfunk Berlin-Brandenburg, 16.05.2014)\(^50\)
- “Persons concerned coming to medical congresses, protesting against me and other surgeons” (Der Spiegel 22/2014, p. 102)\(^51\)

While from an activist’s perspective the scale of past and current nonviolent intersex protests can hardly be considered as “massive” (see picture 8), obviously for the bad conscience of the perpetrators such nonviolent protests are still sufficiently triggering every time they are unmistakably called on the illegality and human rights breaches of medically unnecessary and non-consensual IGMs, and their deeds exposed publicly.

“Human Rights For Hermaphrodites Too!” The first annual nonviolent protest in front of a local IGM university clinic in Switzerland, resulting in national news coverage used to build political pressure: Nonviolent Protest and Open Letter vs. Zurich University Children’s Clinic, Zurich 06.07.2008. Photo: Dominik Huber © dominikphoto.com.

Exhibit 3: The Swiss National Ethics Body calling for legal review of IGMs. While a certain amount of luck and fortunate circumstances is always welcome and needed to succeed in any social struggle, I maintain that the groundbreaking recommendations by the Swiss National Advisory Commission on Biomedical Ethics NEK-CNE recognising for the first time the pivotal intersex movement demand for legislation against IGMs where before various other ethics and human rights bodies had failed, was neither just a coincidence nor just pure luck, but arguably the result of four years of social movement strategies put into action.

49 (German) http://idw-online.de/pages/de/news586665
50 (German) http://www.kulturradio.de/programm/sendungen/140516/kulturradio_am_vormittag_0905.html
51 (German) http://blog.zwischengeschlecht.info/public/Kreg_Spiegel-22-2014.jpg
Our recipe:

1. Stage a nonviolent protest tailored for maximum media impact in front of a local IGM clinic, denouncing the ongoing mutilations and calling for legislation

2. Use the resulting media coverage to persuade and support local and state politicians of all colours to take non-partisan parliamentary action specifically focusing on IGM

3. Build your campaign from the ground up – work your way from local to federal and beyond

Like this, IGMs were always introduced into the political discourse as a non-negligible, non-partisan, fundamental children’s and human rights issue (as opposed to e.g. framing intersex as a sexual identity, LGBT, or discrimination issue), and constant pressure was applied on all levels. So when eventually the Swiss federal government tasked the National Ethics Commission in an attempt to accommodate the mounting pressure, this established framing finally prevented IGMs and the demand for legislation from being ignored and swept under the carpet once more, as well as triggering further recognition by other human rights bodies.

In contrast, while – another global first! – in 2013 the German parliament discussed three motions calling for legislation against IGMs\(^2\), ultimately all three were nixed in favour of an IGM-friendly so-called “Intersex Gender Law” explicitly reassuring doctors sole authority\(^3\).

**Conclusion**

Intersex Genital Mutilations, framed correctly as non-consensual, unnecessary, irreversible, cosmetic genital surgeries and/or other similar medical treatments including imposition of hormoses, and as a fundamental children’s and human rights violation (as opposed to e.g. a sexual identity, LGBT, or discrimination issue), have all the potential of winning a majority of the public opposing them, and ultimately no place in an informed society. While the IGM doctors present not-to-be-underestimated, determined, monied and influential opponents, they’re still in a relatively weak and vulnerable position (e.g. compared to an army, a police force, or multinational corporations), and definitely no match for even a small scale intersex movement successfully harnessing people’s power and turning social movement strategies into action. Provided the budding global intersex movement succeeds in increasing constant pressure on all levels while keeping the demand for legislation against IGMs front and centre, it’s not unreasonable to expect substantial progress within the next decade.

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\(^2\) (German) http://blog.zwischengeschlecht.info/pages/Bundestag-CDU-CSU-fordert-Verbot-von-Intersex-Genitalverstummelungen

Intersex Genital Mutilations


«The doctors need to feel the pain, too»

Annexe:
Intersex Social Movement Primers
– Annotated Reading and Viewing Suggestions

Committee on the Rights of the Child (CRC)\textsuperscript{54}, endorsed by diverse intersex organisations in Europe, the US and Australia, includes the two essential thematic resources, “IGM – Historical Overview. Hermaphrodites in the ‘Developed World’: From Legal Self-Determination to IGM” (p. 49–62), and “IGM – The 17 Most Common Forms” (p. 63–81), as well as many references to essential intersex movement publications.


Walter Wink, “Jesus and Nonviolence. A Third Way,” Minneapolis 2003. This small volume set in an agreeably large font is arguably the best and most intuitive introduction to the topic. Don’t be put off by the religious background – you don’t have to be a believer to dig it, and the relevant knowledge distilled in this book is hands-on and not restricted to Christian sources, but also includes essentials by Gandhi, Saul Alinsky and Gene Sharp. What’s more, if you ever heard the expressions “turn the other cheek” or “go the extra mile” before and frowned, you’ll probably be in for a pleasant surprise. Wink’s also recommended complementing popular (as opposed to theologic) books “The Powers That Be,” New York 1998, and “When the Powers Fall,” Minneapolis 1998, cover the entire life cycle of nonviolent social movements (the first not to be confused with the theologic scholarly “Power Trilogy 1984–1992”).

Georges Monbiot, “An Activist’s Guide to Exploiting the Media,” online 1999.\textsuperscript{55} “*The only chance we have of reaching people who haven’t yet heard what we’ve got to say is through the media. [...] Whether we use the media or not, our opponents will.*” Neglecting presswork is arguably the second most fatal, as well as the second most common mistake of virtually any social movement (usually because there’s always so many more and so much more pressing “real” things to be done first). In addition to delivering what its title promises, George Monbiot’s short but most instructive piece provides intuitive understanding of how the different tribes of journos and news corporations a.k.a. “the media” tick and why, in order to make the most of it. “*It’s the follow-up call, stupid!*” Additionally recommended: Jason Salzman, “Making the News. A Guide for Activists and Nonprofits, Revised & Updated,” Boulder 2003.

Steve York, Peter Ackermann, Jack DuVall: “Nashville – ‘We were Warriors,’” PBS / DVD 2000. Moving and gripping episode of the TV series “A Force More Powerful” on the nonviolent campaign ending segregation in Nashville 1959–1960. An intuitive and instructive introduction to a little known but highly successful Ghandi-inspired nonviolent campaign – including a “Nonviolent Academy,” rock solid campaign planning and action footage that has to be seen to believed. There is also a same-titled companion book to the series by Ackermann and DuVall, New York 2000.

Bob Hercules, Bruce Orenstein, “The Democratic Promise – Saul Alinsky and His Legacy,” Chicago Video Project / IndieFlix DVD 1999. Powerful documentary on Saul Alinsky and his incredibly effective firebrand tactics, including archival footage of Alinsky personally explaining it all, as well as 1990s examples of Alinsky-founded or inspired groups fighting on. Somewhat more intuitive and accessible than Alinsky’s authoritative

and recommended classic “Rules for Radicals,” New York 1971. In addition, there’s an extensive 1972 Playboy Interview available online.  

(It’s such a shame how nowadays Tea Party organisers have to be considered the ones most successfully adapting Alinsky’s book, distributing it to their cadres, and a sanitised version to all members, while at the same time demonising Alinsky in public.)

**Gene Sharp**, “The Politics of Nonviolent Action, Vols. I–III,” Boston 1973. The classic synthesis on the topic and originator of the modern social movement people’s power model, based on Sharp’s 1968 dissertation. Authoritative to this day (although perhaps somewhat less intuitive than above suggested primers), only this 1973 edition includes the famous unabridged list of no less than 198 distinctive methods and techniques of nonviolent action analysed and described.

Unfortunately, all later condensations in a single volume (e.g. “Waging Nonviolent Struggle,” Boston 2001, including an updated overview of basic nonviolent principles and some case studies), only list the bare titles of the 198 methods, but omit the essential descriptions and historical examples.

While some recent critiques of the disproportionate focus of Sharp and his Albert Einstein Institution on foreign nonviolent struggles but ignoring nonviolent struggles in western countries do have merit, other discrediting accusations levelled against Sharp are unfounded – and both shouldn’t distract from making the most of this powerful classic. An UK documentary on Sharp by Ruaridh Arrow, “How to Start a Revolution,” TVF Media DVD 2011, was screened at Occupy camps in Europe and the US.

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