

Medical Resistance to Criticism of Intersex Activists: Operations on the Frontline of Credibility¹

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SUMMARY

Since its establishment in the early 1990s the intersex movement has been attempting to enforce the respect for intersex children's human right to physical integrity and self-determination, as well as the non-pathologization of intersexuality. However, this has met with strong resistance from the medical community which prefers to reject criticism as subjective and unfounded. Credibility is a central issue in this debate, but it is rarely openly addressed. If the medical profession puts so much store in the quality of its analysis, what happens if we take a closer look?

INTRODUCTION

"The birth of a child with ambiguous genitalia constitutes a social emergency." This statement is taken from the recommendations of the American Academy of Pediatrics from the year 2000 (p. 138) on dealing with children with atypical sex characteristics. It illustrates preconceptions on our social system – an area, however, for which medicine has developed few if any analytical instruments, having consistently kept the subjective social sciences at a distance. In reaction to the criticism of adult intersex people who have now the means to speak their minds about the medical interventions prescribed for them, some doctors, psychiatrists or psychoanalysts are developing a counter-argumentation that subverts the credibility of intersex activists and aims to reinforce their

1 | Original in French.

own position as carriers of disinterested and objective expert knowledge (see Aaronson 2004; Chiland 2008; Meyer-Bahlburg 2004).

As social scientists, we want to examine the core arguments with which the medical community continues to pathologize persons with a sex they deem ‘ambiguous’ and attempts to brush aside the criticism of a number of intersex activists. Since in our view scientific rigor calls for making visible the situated standpoint from which we develop our thoughts, we would like to point out here that the first author of this contribution combines sociological expert knowledge with a situated experience as a politicized intersex person who was subjected to the medical normalization process.² The second author is also a politicized intersex person who in the course of over a decade has acquired comprehensive experiential knowledge, which she has formalized and documented.³ She holds a Master in Gender studies. We would however also like to emphasize that the position of an intersex person is in our view no more subjectively coloured than that of non-intersex people. The latter can also be aiming to defend their own interests and fear the consequences of our political ascent, for instance when urologists and endocrinologists see their financial interests compromised, as has already come to light (Davis 2011).⁴ Furthermore, non-intersex people cannot completely grasp the realities of intersex people, since they are not confronted in their everyday lives with the various elements that these realities are based on. Claiming to be objective is nothing more than a hollow self-ascription of credibility that is only founded on its performative assertion.⁵ To this claim we prefer intellectual rigor, which requires a capacity for reflexivity, honesty, and transparency about our research process and results.

Paradigmatic deletion of intersex in medicine and protest movements

Even though there are some differences in medical approaches to intersex people depending on country and institution, certain assumptions and practices predominate throughout. The Hopkins paradigm essentially formulated by John Money in 1955 was widely accepted in the so-called west until the end of

2 | Situated standpoint is here used as a term for a theoretical concept. See Harding, S. (Ed.) (2004): *The Feminist Standpoint Theory Reader*. New York/London: Routledge.

3 | Observatoire Des Transidentités, ODT: Independent information and analysis website on trans, intersex and gender issues. Besides the permanent staff (the ODT team) it relies on a network of actors in various areas of expertise, partner associations and academics. Once a month an article by a writer is published. URL: <http://www.observatoire-des-transidentites.com/> [05.09.2013].

4 | This statement may sound shocking, but it has been conveyed to us by three different sources who are in contact with doctors and who have heard such concerns from practitioners in Germany, France and the United States. Davis (2011) has documented such statements in interviews with doctors who treat intersex children.

5 | This topic has already been addressed by many scientific investigations. Due to lack of space we cannot reproduce them here.

the 1990s. According to this paradigm, both the biological sex and the social gender are malleable, but it is crucial that a child's body fits medical norms for male and female, and that he/she develops a 'matching' traditional male or female gender identity and behavior to ensure his/her positive psychosexual development and protecting it from rejection by its peers. But this sex/gender-related malleability, so the argument, only exists in the first two years of life, which is why early surgery is necessary. With the assumption that any uncertainty about the assigned sex/gender would limit the parents in their ability to rear their child in the corresponding social gender and cause confusion in the child, it is recommended to share only partial information with the parents and leave the child completely in the dark (Money 1994 [1968]). Early surgery is also – and sometimes primarily – recommended to relieve the suffering of the parents who are supposedly clueless about how to deal with their unusual child and would like nothing more than for her/him to develop like a normal girl or normal boy (Aaronson 2004; Holmes 2008, 2011; Karkazis 2008).

In the 1990s the first generation of persons medicalized according to the Hopkins paradigm became adults. Therefore, they are now in a better position to voice their impressions and experiences. Contrary to the wishes of the medical practitioners acting according to the Hopkins paradigm, a number of them have succeeded in getting access to information about the surgery performed on them, to assess what has happened and in some cases making contact with other persons with similar experiences. (Gosselin 2011; Holmes 2008; Kessler 1998; Still 2008). In the social sciences this making contact is considered the crucial element for the development of a social group. Making contact enables people to talk about themselves, to invent their own words, to analyse shared or similar experiences as well as sometimes design alternatives, and in a next step, formulate demands. In the analyses of intersex people who actively demand enabling full consent to the respective treatments or the depathologization of the great variety of sex/gender-related bodies, one finds some theoretical principles of feminist researchers, activists of the women's health movement, lesbian, gay, queer and trans researchers.

These groups did much to initiate social change on various levels, to increasingly question medical authority and address the cultural foundations of its practice, and without them the recent intersex movement would not be as strong as it is (Karkazis 2008). In addition, intersex people have even shown great creativity in shaping their criticism: they have combined artistic productions with the publication of essays and theoretical observations, they are

represented in all social spheres and active on all continents. Through their involvement and the dissemination of their perspectives they are gaining more and more strategic supporters such as parents, sympathizing clinicians, ethics experts, jurists, researchers, students and artists. In the last three years, around 13 international treaty bodies, NGOs and States have spoken out in favour of the demands of intersex persons or put them into law. Among them the Swiss national ethics commission in the field of human medicine, the special rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez (A/HRC/22.53; 2013), the Council of Europe through its 1952 on Children's right to physical integrity, the UN Committee on the Rights of the Child (CRC/C/CHE/CO/2-4), the Maltese act. XI forbidding non-consensual, non life-saving medical interventions on intersex children, and the UN High Commissioner for Human Rights (A/HRC/29/23), to name but a few.⁶

Medical resistance

Exchange with the medical community on the other hand is less productive. Since the very beginning, the majority of doctors have considered the demands of intersex people as irrelevant. The two main arguments for this refusal are first, the alleged emotionality or lacking rationality and scientificity of the intersex activists' discourse, and second, the disregard on the part of the supposedly small minority of intersex activists of the interests of an overwhelming majority of people who, though being subjected to normalizing surgery and hormone therapy without their consent, are purportedly nevertheless very happy with the results. Accusations such as lack of rationality and scientificity of intersex activists claims, along with the way doctors describe these activists, are not very complimentary. Some call them zealots, like John Gearhart does in an interview in 1996 with N. Angier for the New York Times, as green-wellied loonies⁷ (Toomey 2001: 39, quoted from Karkazis 2008), as tortured souls (Chiland 2008), or as egocentric (Tremblay, 2014). They are accused of relying only on their passions, having no hard data and not being able to present any scientific research findings to refute the assertion that they constituted an exception in the mass of persons happy with their fate. Likewise some of these doctors have made the following remarks (we quote here excerpts from interviews by Karkazis (2008) with various surgeons):

6 | The corresponding statements are available in French on the website of OII-Francophonie: URL: www.oii-francophonie.org [15.08.2013]. See contribution by Vincent Guillot in this publication.

7 | Green-wellied refers to the green Wellington boots worn by persons regarded as hippies or ecos.

"ISNA is the disaffected few, but there's all these happy women out there who've had babies. They're the quiet majority." (Dr. S.) (Karkazis 2008: 266). "These people are very angry. The patients who are happy don't want to be spoken to; the parents don't want it. They say 'That's in the past, we don't want to discuss it. My kid is well adjusted. Everything is fine.' (Dr. O.)" (Karkazis 2008: 266)

In 2004 Meyer-Bahlburg et al. published the findings of a research project which examined via questionnaires in how far patients were satisfied with the medical approach their treatment was based on. Although the questions were phrased in such a way as to elicit an approval of the medical perspectives (Holmes 2008), two members of the journal's staff threw their support behind the article's contents in a commentary reproduced in the same edition. One of them, Aaronson (2004: 1619), states:

"For much of the last decade those called upon to advise on the management of an infant born with ambiguous genitalia have been under assault from patient advocates who have vociferously maintained that feminizing genitoplasty is a mutilating procedure. [...] Consequently, we are now in a state of virtual therapeutic paralysis, which does no service to the many parents who ask that something be done to normalize the appearance of their infant's genitalia."

The comments are surprising: Why does the medical community introduce such heated statements concerning the treatment of intersex people if it purports to develop its practices and treatment standards according to supposedly disinterested, objective and rationally conducted research? This of course is a purely rhetorical question because this assessment of intersex activists has no influence anyway on the confirmation or refutation of the Hopkins paradigm. Unless the doctors' aim here is to discredit them through the use of *argumentum ad hominem*. By depicting the activists as aggressive and impulsive – or even as zealots, tortured souls etc., the doctors elegantly avoid their responsibility to examine their own discourse, experiences and arguments and fail to deliver answers when the consequences of their actions come under critical review. Such a denial of alternative viewpoints – which at its worst is based in a non-representation of these standpoints, and at best on a sophistic oversimplification in the sense of a straw man argument – invalidates *de facto* the doctors' claim to objectivity, if such a thing as objectivity is at all possible. Here one could argue that we are dealing only with individual statements that do not reflect the official stance. But such statements are also found in scientific journals in which emotional outbursts are frowned upon. Aaronson (2004) for instance published his comment as editor of the official Journal of the American Urological Association.

Ignoring the interests of a broad, satisfied silent majority?

The wrathful positions of intersex activists are contrasted with a silent mass of intersex people who see no fault in the Hopkins paradigm. The activists are accused of representing their own position and thus that of a minority, providing no hard data, and merely personal impressions and anecdotes. Indeed, only a small minority of persons whose sex is described as atypical by medicine makes its voice heard publicly – but this is the case in every social movement. Also, there is disagreement among intersex persons concerning the paradigms that should be used for understanding our lives. Among those who have experienced the phase of socialization with peers there seems to be a general difference between political activists and members of patient groups (Karkazis 2008; Spurgas 2009; Still 2008). Even if the standpoints of these two groups differ concerning the rejection or approval of an intersex identity and pathologization, they still agree on their criticism of medicalization without previous consent. In addition, some intersex activists are particularly careful not to disadvantage other intersex persons by their stances and to remain in contact with patient groups. We don't expect from everyone affected by medicalization that they define themselves as an intersex person or as someone beyond the sexes – which does not exactly correspond to our understanding of intersex identity⁸ – contrary to all prejudices to this effect. Neither do we want to impose an identity beyond the sexes on intersex children, but merely ensure that they have the possibility to determine for themselves which identity they have. We do not demand that all intersex persons should refrain completely from physical modification, but rather that they should be able to determine themselves the modalities of such surgery or hormone therapy. However, with regard to the politics of silence and the medical interventions performed without the consent of the children one could say the following:

If the intersex persons concerned were really of the opinion that this is a better approach which allowed them to enjoy better psychological development, the logical consequence would be that they are less vulnerable or injured than we are, and it would also be easier for them than for us to mobilize. Their critical voices against the demands which they would regard as harmful for the majority of us would also be more numerous.

8 | The intersex identity mainly expresses the consciousness of having one's body's sex characteristics subjected to medical invalidation, regardless of one's gender identity. It cuts across diagnoses, since the invalidation process and the protocols used on intersex people share many common denominators. To some extent, it is often political, since people who use it are critical of medical judgment passed on them, and affirm the beauty of physical diversity. Some intersex people, however, also have another gender identity as a man and woman and will use 'intersex' to designate this other identity as well. In an effort to disambiguate, some intersex people identified as non-woman, non-man use a 'herm' gender identity.

In December 2012 the Second International Intersex Forum organized by the International Lesbian, Gay, Bisexual and Trans Association (ILGA) brought together 37 representatives from 33 organizations of intersex persons or their allies. Even though their aims and perspectives diverge they formulated a joint declaration which denounced the pathologization of intersex persons.⁹ If the blissful, satisfied majority really existed it would have been visible in greater numbers.

Tamar-Mattis (2012), who regularly engages in awareness-raising for doctors, psychiatrists and lawyers involved in the treatment of intersex persons, remarks:

“There’s a theory floating around the world of medicine that goes like this: while it is widely known that patients with disorders of sex development (DSD) [sic] are unhappy with the treatment they have received – cosmetic genital surgery, unwanted hormone treatment, and humiliating genital exams top the list – they can be safely ignored because there is actually a silent majority of patients out there who are doing just fine. This is a comforting idea. It justifies the mistakes of the past, and it allows current practice to continue without all the discomfort of change.”

“Those of us who work in DSD advocacy hear the theory of the satisfied silent majority all the time. But no one can find them. After almost two decades of patient advocacy and active debate, decades in which hundreds of affected people have spoken out against the treatment they received, not one person with a DSD has spoken out publicly to say that normalizing treatment is just great. Not one.”

Thanks to a broad network in the internet intersex persons and persons identifying themselves as DSD patients were able to collect valuable knowledge about the experiences of others. Thus they could also establish the non-existence of this ‘silent majority’ and respond to the doctors clinging to this myth (Karkazis 2008: 266):

“Let them do their own studies interviewing all the happy intersex people out there, recruiting them through a special themed happy campaign to indicate that they are looking for satisfied people who want to fade into the woodwork, not carp and complain about monster doctors and their unhappy lives.”

What is surprising is the admission of doctors found in numerous scientific articles and joint declarations that there are no data on the results of the Hop-

⁹ | One can access the third statement, which includes the second, at this address.

URL: <http://oieurope.org/public-statement-by-the-third-international-intersex-forum/> [08.09.2015].

kins paradigm or on later performed surgery. This is the case with an article authored by medical professionals regarding themselves as intersex experts (2006: 496):

"In terms of psychosexual management, studies are needed to evaluate the effectiveness of information management with regard to timing and content. (...) It is essential to evaluate the effects of early versus later surgery in a holistic manner, recognizing the difficulties posed by an ever-evolving clinical practice. The consensus has clearly identified a major shortfall in information about long term outcome."

There is no evidence that non-operated adolescents who had no surgery are subject to more harassment than ones who have.¹⁰ There is no study that could attest to an improvement of the parent-child relationship as a result of surgical procedures, or an impairment if left intact. The advocacy of secrecy is equally unfounded. Tabooing, silence and half-truths can be identified as such. The parents cannot ignore the physical integrity of the child and its condition at birth. Despite the call for early medical interventions these have in many cases to be repeated in the course of childhood, so that they become ingrained in the child's memory. It is in fact these surgical and hormonal procedures that cause the trauma, because they convey to the child that its genitals – while causing him/her no pain nor discomfort – generate such aversion in their parents that corrections have to be made, even before it can deal with it itself (ISNA document, quoted from Holmes 2008: 56; Roen 2009). The child notices that it has something unspeakable that arouses its curiosity, which spurs it on a quest to gain the information on what has happened, but at the same time puts it at risk of experiencing a deep sense of betrayal by his/her parents and the doctors (Karkazis 2008; Intersex experiential knowledge).

The very ethics at the basis of the pathologizing approaches can be questioned. Holmes (2008), Kessler (1998), Roen (2009) and Streuli et al. (2013) argue that the parents consent to the surgery on their children primarily because intersex is portrayed by doctors as a medical disorder or illness – even when there is no danger for the health of the child. In this respect one can say that the parents are misled (Holmes 2008: 54; Kessler 1990).¹¹ Not only do the doctors make it impossible for the parents to perceive their child as healthy, but in their explanations they also rely on the assumption that the child has

10 | Here the testimonies by Hida Viloria und Nthabiseng Mokoena as unharmed intersex persons provide powerful examples for the possibility of self-development without surgery and hormone therapy.

11 | Also: "The question I am posing is whether or not this way of explaining intersexuality constitutes a failure to provide all the necessary information required to obtain consent that is truly informed" (p. 55).

to be either a he or a she, without leaving room for a development as s/he or neither-nor. (Holmes 2011).

In order to establish an approach of voluntary consent doctors need to rectify parents' expectations and beliefs concerning sex/gender diversity. In addition one has to ask oneself how far children in particular are able to give a truly free and fully informed consent under a paradigm that depicts its sex/gender-related constitutiveness as an error (of nature), disorder or syndrome. Some people might feel confused by this criticism of pathologization. But the assumption that intersex persons have an incomplete, over- or under-developed, deficient, dysfunctional or abnormal sex is based on a teleological perspective that has substituted God with nature – with the belief in an intention that is read from supposed aims, goals and functions (Bastien Charlebois 2011). In addition, this attitude prevents a thorough analysis of sex development. (Voß 2010).

In 1999 a group emerged from the American Urologist Association, comprised of medical specialists and 'patients' advocates'. Under the name NAFTI (North American Task Force on Intersexuality) it has set itself the goal to conduct studies on the long-term effects of surgery on the patients' psychosexual condition in order to remedy the lack of information in this regard.¹²

However, only a few years later this group had to end its activities for the following main five reasons: obstacles in the procurement of funds, failure to find a definition of acceptable ethical parameters for such research activities, difficulties in reaching the patients, problems with the representativity of data and fears of being criticized by intersex people and being sued. Before solid and representative data can be collected the silence around the situation of many intersex patients would have to be broken. How should the well-being of people who don't yet know that they have been subjected to surgery be measured without informing them about it? They cannot wholly consent to such a study since they have no detailed information about their past. It also seems to be impossible or too difficult to locate adult patients. Many have moved and no longer have any contact with clinical doctors. Furthermore, there is the difficulty of finding persons who have had bad experiences with surgery and no longer trust doctors. The very title of the research project could put off certain people, depending on whether the terms 'intersex' or 'DSD' are used. Finally, numerous senior physicians have voiced reservations about opening medical files of their patients, since they fear being held accountable by an entire group of people or being sued by them (Karkazis 2008). The politics of silence

12 | Further goals were: Determining rules for the support of intersex children, considerations concerning the ethical dimensions of current treatment standards and development of new principles for medical practice.

makes the medical practices irrefutable. It is not only bad faith but also naive to continue to adhere to the Hopkins paradigm and at the same time reject the experiences and analyses disseminated by intersex people, despite the fact that there is serious lack of evidence for the desirability of this paradigm and it is impossible to formally refute its position.

Furthermore Karkazis (2008) reports that the doctors interviewed by her resort themselves to anecdotal information. They either draw on their own clinical experience or that of their colleagues. And the latter are given more credibility than those persons who are directly affected by the medicalization. In this regard the case of John/Joan is particularly significant since it has contributed – despite being a single case – strongly to questioning the hypothesis of the malleability of the social gender. The following quote illustrates how a doctor can legitimize not working in a scientifically correct manner and rely on his general impression of a patient (Karkazis 2008: 278):

“I don’t need studies. I have my own clinical practice where I can see long-term outcomes when people come back and talk to me about their outcomes. A girl just came across my desk today I’d done a bowel vaginoplasty on. It was an intersex baby and she does very well – she’s a gender-reassigned individual, [and she] does beautifully.”

As Karkazis (2008) correctly underscores, according to which criteria does he assess that she does beautifully? According to his or hers? Does ‘she does beautifully’ mean that there were no surgical complications? That she is happy? That she has a female identity? That she has a sex life? That she is satisfied with the results of the surgery? How then is ‘she does beautifully’ defined? Could it also be that doctors filter information because they fear that they have failed or caused harm to a person? We would also add that given the doctors’ position of authority, many intersex persons would find it difficult to voice their discomfort, doubts or criticism regarding the surgeon’s actions. This, at the very least, has been the experience of the main author of this contribution.

Injured ego versus broken integrity – an outlook

A thorough analysis of medical positioning with regard to children with atypical sex characteristics must comprise an examination of the assumption it is frequently based on, i.e. that it is possible to act in a person’s best interest without their consent. In effect, this best interest implies that these other persons, who are capable of making their own decisions, are not listened to and not

acknowledged. Who can say whether an operation or a surgery was successful or not, if not the person concerned? For the medical authorities success can lie in the fulfilment of an esthetical norm. For intersex persons success does not necessarily mean that they are assigned to one gender in which they feel happy but rather that they retain their physical self-determination as well as their sexual and orgasmic responsiveness and know themselves to be desired and desirable. Some doctors and parents may have seen medicalization without the child's consent as the best way and may have been surprised to perceive the regret and the strong disapproval from intersex persons. For them it is undoubtedly easier to think that these negative results merely reflect bad treatment practices of their colleagues and not a fundamentally flawed approach. The notion that good intentions lead to good results or protect from criticism and from questioning one's own actions is very common in our society. Good intentions were indeed attributed to many actions with negative consequences. It is our view that good intentions lead to good results when they emerge from a full recognition of the capability of others to define their own aspirations. But this implies listening to others, acknowledging them as credible and not acting against them. From us as professors, researchers or professionals listening in this way requires the ability to doubt, the willingness to criticize ourselves and a humble attitude. As knowledge producers we command an enormous position of power. Criticism can harm – but it is important not to lose sight of the context in which it was formulated. Who is in the position of power within this dynamics? Which risks are doctors exposed to? Do these risks weigh more heavily than those intersex persons face, i.e. the violation of physical integrity, the degradation of their being, the emergence of serious feelings of shame, the loss of the ability to have an orgasm or the impairment of their sexual responsiveness, the loss of trust towards their parents, the isolation, the non-recognition of their injuries or the denial of their existence? The medical community will not be able for much longer to sustain the illusion that we do not inform ourselves as social actors and examine and analyse the medical discourses they build around us, that we do not develop our own ideas and critical analyses, and are not represented in the institutional spaces in which expert knowledge is created. And perhaps we will improve the situation, since the visibility of intersex persons will contribute to the dedramatizing of our existence and showing its beauty.

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