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Special Rapporteur on the right to health
Office of the United Nations High Commissioner for Human Rights
United Nations Office at Geneva,
CH-1211 Geneva 10, Switzerland

Dear Special Rapporteur,

Attached please find my comments on the "**Public consultation on sport and healthy lifestyles and the right to health."** I have primarily responded to Question 2. My comments are grounded in my 18-year experience conducting empirical research on controversies over medical care for people born with intersex traits as well as my more recent research on international sports policies that restrict the eligibility of intersex women, which has been a central focus of my research and advocacy over the last 4 years. I have spoken out against the regulations about which I write on a number of occasions and have authored a number of articles and papers on this subject. Most recently, I served as an expert witness at a 2015 challenge to these policies heard at the Court of Arbitration for Sport (CAS) in Lausanne, Switzerland—an appeal which suspended one of these policies. A selection of my written work in this area includes the following, which I have also attached:

Karkazis, K., Jordan-Young, R.M., Davis, G., and S. Camporesi. "Out of Bounds? A Critique of Policies on Hyperandrogenism in Elite Female Athletes." *The American Journal of Bioethics* 12(7): 3-16. Published online June 14, 2012.

Karkazis, K., and Jordan-Young, R.M. The Harrison Bergeron Olympics. Response to Letter to the Editor, *The American Journal of Bioethics,* 13(5): 66–69*,* 2013.

Jordan-Young, R., Sonksen, P. and Karkazis, K. Sex, Health, and Athletes. *BMJ* 28 April 2014; 348:g2926 doi: 10.1136/bmj.g2926.

Karkazis, K. and R. Jordan-Young, "Debating a Testosterone 'Sex Gap,' " *Science*, May 2015; 348(6237): 858-860. doi: 10.1126/science.aab1057.

Do you know of any State that has introduced legislation or policy in relation to sport and/or health lifestyles? If so, please provide a brief description and evaluation of the laws or policies adopted.

I want to begin my response by providing an explanation of a current policy at the international level of sport affecting women who are intersex or who exhibit signs of hyperandrogenism (that is, high natural levels of testosterone). Though not enacted by States, the policies put in place at this level are incredibly significant because they operate across all nations and supersede what nation states might do to promote participation in sport. Top athletes aspire to compete at this level, and nation states lack the ability to make

this a reality for their athletes without the support of international governing organizations. Even at this highest level, there has been ongoing debate in the athletic community concerning whether intersex women can be considered to be unfairly advantaged in a way that should bar them from competition in the women's category in their respective sports. What's more, however, these policies have a trickle down effect to the non-elite level as national organizations seek to comply with the policies as athletes climb the ranks. Thus although these apply at the elite level, their effects are felt at almost every level of sport.

The International Olympic Committee (IOC), the International Association of Athletics Federations (IAAF), as well as numerous other sports governing bodies have created policies that bar some intersex women from competition, and have done so by creating a ceiling for women's natural testosterone levels that would render them ineligible to compete should they exceed this ceiling. The testosterone level that the IAAF chose for women as the cutoff was 10 nmol/L. Any woman whose natural levels of the hormone fell above this were ineligible for competition unless they were able to reduce their levels below this threshold (via surgery or drugs). Setting the threshold here effectively ensured that the vast majority of those excluded under the policy were intersex women. Testosterone levels vary greatly among women, but the presence of testes are generally necessary to push naturally occurring levels up to the 10nmol/L threshold. (The IOC policy has no ceiling effectively applying to even more women.)

The fairness of this policy was recently challenged when Dutee Chand, a teen Indian sprinter who had been excluded under the policy, brought her case to the Court of Arbitration for Sport (CAS) in Lausanne, Switzerland. CAS ruled that the IAAF had failed to provide sufficient evidence that its policy was scientifically justified, and it was given a period of two years to gather more evidence to support such discrimination against women. Meanwhile, Dutee Chand and other women in her situation are now permitted to compete in IAAF governed sports. Despite the temporary victory for the athletes, the IAAF stands by its policy, and it is quite possible that it will come back into play in the near future.

The International Olympics Committee (IOC) is a major driver of sport policy at the international level. Much like the IAAF, the IOC seeks to regulate eligibility of intersex women. The IOC policy, which was developed in conjunction with the IAAF's, states, "If, in the opinion of the Expert Panel, the investigated athlete has female hyperandrogenism that confers a competitive advantage (because it is functional and the androgen level is in the male range), the investigated athlete may be declared ineligible to compete."[1] Much like with the IAAF policy, this policy will primarily target intersex women because they are most likely to have androgen levels in the so-called male range. However, unlike the IAAF policy, this regulation has not been suspended and still serves to bar these women from competition. The Olympic policy applies to all those sports included at the Olympics.

There also exist a number of other international sports governing bodies that have enacted similar policies (e.g., FIFA). Not surprisingly, there exists a wide variety in the way in which these organizations handle eligibility of intersex athletes. As a general trend, we see more restriction being placed on eligibility in endurance sports such as running, where there exist clear, objective performance differences between men and women and widespread concern about athletes having unfair performance advantages.

Quite significantly, certain states (e.g., Australia) have relied on the rationales for these policies to allow for exceptions in anti-discrimination laws that permit discrimination on grounds of sex in the context of competitive sport, on the basis that the biological differences between the sexes make it unfair to permit men to compete against women.[2]

Now that I have outlined some of these policies, I want to go into detail about some of the harms they impose on intersex athletes and some of the ways in which they actively discourage them from participating in their sports.

Medical Harm

Firstly, I want to address possible medical harm. If an athlete is deemed ineligible to compete pursuant to the IAAF policies, for example, the Expert Medical Panel "may further recommend conditions under which it would be acceptable for the athlete to compete in women's competition; and a schedule of monitoring of the athlete's prescribed medical treatment with a view to the athlete returning to competition once she meets the conditions so determined."[3] In other words, the athlete must undergo medical interventions to "normalize her androgen levels."[4]

Medical interventions used to lower testosterone are controversial and raise health sequelae in the near and long term. The process is not simple—it is not always possible to lower testosterone

pharmacologically—and can take months. Long-term maintenance of low levels may produce side effects that diminish quality of life and can be medically serious. Among a large cohort of women receiving androgen suppressive therapies, roughly two thirds experienced significant side effects.[5] These side effects can be serious for anyone, but especially an athlete, and can include:[6]

- diuretic effects that cause excessive thirst, urination, and electrolyte imbalances;
- disruption of carbohydrate metabolism (such as glucose intolerance or insulin resistance);
- headache;
- fatigue;
- nausea;
- hot flushes; and
- liver toxicity.

Moreover, liver function and blood chemistry must be carefully monitored during and after interventions because some anti-androgens have the potential to damage the liver, disrupt other necessary steroid production, and occasionally cause serious cortisol deficiency.[7] Balancing these and other side effects with efficacy in lowering testosterone can also be difficult. Medical care requires that physicians weigh patients' discomfort from symptoms and concern about metabolic indicators (such as insulin resistance and cholesterol levels) against the presence and future risk of side effects. The approach called for in the policies, however, is to lower testosterone irrespective of symptoms, complaints, or potential adverse effects.

Gonadectomy involves the surgical removal of the gonads and is a method by which testosterone levels can be lowered in certain cases. Gonadectomy was until recently the standard care for some women because of the risk of a germ cell tumor of the gonads. However, because tumor risk varies with specific diagnoses, together with the serious health consequences of gonadectomy, a recent review in BJU International concluded that the tumor risk is low enough in most cases that gonadectomy is not warranted.[8] Notably, gonadectomy is not mentioned as a treatment option for hyperandrogenism in the guidelines of the American Association of Clinical Endocrinologists.[9] Gonadectomy is associated with significant side effects. It will cause hypogonadism, compromising bone and muscle strength and risking chronic weakness, depression, sleep disturbance, poor libido, adverse effects on lipid profile, diabetes, and fatigue. It will necessitate lifetime hormonal replacement and will also sterilize women who may be fertile.

In summary, regardless of whether the recommended conditions for return to competition pursuant to the regulations involve pharmacological or surgical procedures, the physical risks are significant, over both the short and long term. These risks are imposed even though the procedures may not be medically necessary. Indeed, the first report of implementation of the IAAF regulations' return to competition conditions describes four young athletes (aged 18-21) from developing countries who underwent gonadectomy and "partial clitoridectomy," procedures that were stated to be unrelated to health risks and beyond the scope of what the regulations mandate.[10]

One major concern with policies such as those created by the IAAF and IOC is that they can coerce intersex individuals into receiving unwanted or unneeded medical intervention. It is true that intersex individuals have unique medical needs, and that they often undergo surgery for a wide variety of reasons. This can be acceptable when the purpose of the procedure is to prevent an even greater risk to health or because it is desired. However, it is unethical to require athletes to incur such risks simply to bring them into line with various criteria for athletic eligibility. The consequence of this has been the creation of a system that coerces intersex women into undergoing medical interventions to compete in a category in which they have always competed and to continue their careers. For athletes who reach this highest level, their sport is their life, their passion, and their primary occupation. They have little choice, but to do what is necessary in order to compete as women.

Stigma to women from having eligibility questioned

Underlying the policies are assumptions that sex segregation in sports requires that athletes must and can be scientifically segregated into two distinct categories of male and female. The policies imply that classifying an athlete according to the sex indicated on her legal documents is not sufficient for the purpose of eligibility in athletic competition and that there must be an additional way to mark females that is only in use and pertinent for the purpose of sport (something I have called "athletic sex"). The policies ostensibly

move away from previous approaches to so called sex testing and assert that testosterone is an appropriate and scientifically valid marker for sex segregation. Despite this messaging, many individuals consider the policies to be "gender verification" or "sex testing" policies. This understanding can be explained by a fundamental lack of understanding of the complexity of sex and the ways the policies point to sex segregation as a reason for their existence (women who fail to comply may compete with men pursuant to the IOC policy), as well as by the fact that in practice they are carried out in the same manner as prior "gender verification" and "sex testing" policies. This widespread interpretation of the policies as existing for the purpose of "gender verification" or "sex testing" has led to stigma for those athletes who have been subject to investigation who have been subjected to intense public scrutiny, including claims that they are not women. The assumption that these investigations are to determine sex in earlier prominent cases under predecessor policies has carried over to the present.

The manner in which investigations are commenced also leads to stigma. By stating that women with hyperandrogenism "often display masculine traits and have an uncommon athletic capacity in relation to their fellow female competitors,"[11] the IAAF regulations raise concerns about particular scrutiny of exceptionally talented women athletes and all women athletes whom others may deem insufficiently feminine in behavior or appearance. (The IOC policy also notes that each National Olympic Committee should "actively investigate any perceived deviation in sex characteristics" prior to registering women athletes for competition.[12]) Women who have lived and competed as women their whole lives can no longer compete as women, and as such coming under investigation is shocking and stigmatizing. It also sends a message that women who are investigated are not women, or not women enough. Voyeuristic media reports of investigations only intensify this stigma and harm. The investigation may not only affect an athlete's self-concept and identity as a woman, but may also lead others in the athlete's life to question this as well. These harms are not trivial and may affect the athlete's family, sport, and community relationships.

Disproportionate effect on women from the Global South

One of the least discussed aspects of the regulations and other similar policies is how they affect women differently based on ethnicity, race, class, and nation. Poor women from the Global South appear to be those most affected,[13] amplifying concerns over threats to autonomy, lack of informed consent, and the possibility for coercion. In the cases I know of, namely those of Ms. Chand, Caster Semenya, Santhi Soundarajan, and the four young women from 'rural and mountainous regions of developing countries" mentioned in the article by Fenichel et al,[14] the women investigated under the policies have all been brown or black women from the Global South. Most, or perhaps all, of the individuals requiring medical work-up since the implementation of the IAAF regulations have come from developing countries.

Especially given the potential disproportionate effects of the regulations on women athletes from the Global South, the decision of whether to undergo pharmacological intervention or gonadectomy in order to return to competition pursuant to the Regulations has effects that reach beyond the athlete herself: athletes are embedded in families, teams, organizations, and even nations that depend upon them to compete. An athlete is "regarded as vulnerable to undue, even extreme situational pressures arising from the decision-making environment,"[15] especially when a competitive career is also a way to improve economic status for her and her family. A recent newspaper report on Ms. Chand, for example, noted that she had to stop building her family a new home because she was no longer competing.[16] Ms. Semenya also had used prize money to build her family a home and there was question whether her forced hiatus would affect this and her financial future.[17] As the Regulations get implemented in more and more countries at the national level, as has happened in India, for example, more women could be affected in this way.

Coercing women athletes into pharmacological or surgical interventions as a prerequisite to return to competition can also give rise to decisional regret at some later point in their lives. Most of the literature that exists about decisional regret concerns parental decisional regret especially owing to lack of true informed consent.[18] It is reasonable to assume that decisional regret may also occur for women athletes that decide to undergo these interventions, including because the athlete may:

- not have provided adequate informed consent;
- feel pressure to comply to continue her career, but at the end of her career this pressure may reduce, leading her to re-evaluate the decision and its health consequences; and

- prioritize short-term effects and minimize long-term consequences of such interventions in order to return to competition as soon as possible.
- Some elite athletes have variations in the ACE gene that augment muscle growth and efficiency, and in the NOS gene that increase blood flow to skeletal muscles.[19]

Elite athletes thus already display myriad types of biological and genetic advantages. Hyperandrogenism is a naturally occurring phenomenon and therefore no different than any other exceptional biological variation in the human body. Aside from biology, there are many factors that are unregulated by sports governing bodies but that are important to athleticism and can provide advantages. These factors can be technological (access to high-tech training methods and equipment), environmental (access to clean air and water, good nutrition, and safe communities), financial (access to superior coaching, competition, training, and technical support), and social (access to cultural and legal support, social capital and status).

Considering these many harms, it seems necessary for there to be some significant and necessary benefit to the athletic community that results from these policies. However, this does not appear to be the case. There is a severe lack of scientific evidence suggesting that intersex athletes are unfairly advantaged, as CAS recently ruled. Studies on athletic benefit derived from hormones have focused almost exclusively on athletes who were doping. There are no studies that have shown conclusively that this benefit also applies to individuals who have naturally occurring levels of androgens that fall in the "male range." Even if there is some benefit, is is not clear why we should treat these athletes' natural advantages differently from those that benefit their competitors.

Bodies such as the UN can play a significant role in the move away from policies that scrutinize intersex individuals. These policies are a legitimate threat to the health and wellbeing of these athletes. Furthermore, they serve to perpetuate harmful stereotypes about female intersex athletes and to suggest that they are somehow not "real women." Instead, the international organizations should serve as models of tolerance and inclusivity that member states can aspire to emulate.

Sincerely,

Katrina Karkazis

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1 International Olympic Committee. IOC regulations on female hyperandrogenism. 2014. www.olympic.org/Documents/Commissions_PDFfiles/Medical_commission/IOCRegulations-on-Female-Hyperandrogenism.pdf.

2 Section 42 of the Australian Sex Discrimination Act 1984, amended by the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 notes that nothing in the Act "renders it unlawful to discriminate on the ground of sex, gender identity or intersex status by excluding persons from participation in any competitive sporting activity in which the strength, stamina or physique of competitors is important." The Explanatory Memorandum further explains that "It is legitimate to recognise that biological differences between men and women are relevant to competitive sporting activities. Limiting this exemption to situations in which strength, stamina or physique are important is a proportionate means of achieving this outcome."

3 International Association of Athletics Federations. IAAF regulations governing eligibility of females with hyperandrogenism to compete in women's competitions. 2011. www.iaaf.org/about-iaaf/documents/medical.

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6 Azziz R, Sanchez L, Knochenhauer E, Moran C, Lazenby J, Stephens KC, et al. Androgen excess in women: experience with over 1000 consecutive patients. *J Clin Endocrinol Metab* 2004;89:453-62.
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[11] IAAF Regulations, p. 1.

[12] IOC Regulations on Female Hyperandrogenism, 2014, p. 2.

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