

dsdfamilies response to the World Athletics Consultation – Recommendation to the eligibility conditions for the Female Category, March 2025.

Our response relates only to women athletes with 46,XY DSD

a. How will the new eligibility conditions impact you or the interests of athletes with whom you are affiliated? We want to learn about both positive and negative impacts from all consultees.

Explanatory context

dsdfamilies is a UK-based charity, with global recognition, that supports families, young people and children living with Disorders/Differences of Sex Development (DSD). By asking us to be a stakeholder in this consultation, World Athletics acknowledges that these proposals have real life consequences for our population, and for that we are grateful.

Throughout our response we will strongly object to the proposed merger of DSD and transgender regulation. These are two distinct populations which require two different sporting policies attuned to different circumstances and characteristics.

Disorders/Differences of sex development (DSD) are a group of rare congenital conditions involving atypical development of chromosomal, gonadal, or anatomic sex. DSD can be inherited, but there is often no clear reason why it happens to someone. Sometimes a baby is diagnosed shortly after birth (especially in resource rich settings in the Global North), and sometimes a young woman will be diagnosed when puberty does not occur, does not progress, or when she develops unexpected secondary sex characteristics. Some people describe DSD as 'intersex'.

DSD refers to a physical variation that is innate, meaning you are born with it. The overwhelming majority of people with DSD are not 'gender diverse' and do not experience gender dysphoria.

In the context of sport eligibility rules, the relevant population are babies registered as female at birth and raised as girls and women. They share the umbrella diagnosis of 46,XY DSD, which includes a range of biologically different conditions, from complete androgen insensitivity syndrome and 46,XY gonadal dysgenesis to 5-alpha reductase deficiency, and everything in

¹ Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., & Group, L. E. C. (2006). Consensus statement on management of intersex disorders. *Archives of Disease in Childhood*, 91(7), 554-563. https://doi.org/10.1136/adc.2006.098319

between. Learning how their bodies develop differently is complex, varies between individuals, and can be a deeply traumatic experience.

Transgender is about <u>gender identity</u>. It describes someone whose gender identity (how they experience themselves) is different from their registered sex at birth. For example, a trans woman would be someone registered at birth as male based on their biological sex characteristics, and raised as a boy, but who comes to identify as a trans woman.

In its preamble, World Athletics commits to not questioning or judging 'gender identity.'
However, combining DSD and transgender regulations and equating the puberty and biology of individuals with a 46,XY DSD to male biology is tantamount to questioning their legal registration from birth as female and it risks prompting others to do so. This is already evident in online discussions regarding this consultation.

We understand the concerns about potential advantages that some women with 46,XY DSD may have in sport. We encourage, and urge, sports scientists and clinical specialists with expertise in DSD to meet and reach an evidence-based, humane agreement on eligibility criteria tailored to these conditions.

dsdfamilies is a UK-based charity with a strong global record in producing evidence-based educational resources to support families, children and young people living with DSD. Our objective is to support the development of confident young people who accept and understand their different biological make-up and can talk about this with loved ones and others, if and when they choose to.

To achieve this, we have taken a three-pronged approach since our foundation in 2011:

- We work with DSD clinical specialists in developing communications and resources, and to improve healthcare for new families, children and young people; we have worked with many of the world's leaders in this field, spoken at medical conferences in various medical disciplines, and sat on research and registry boards. Our resources are used in clinical settings worldwide, and one of our resources is available in 14 languages.
- We work with families and young people on understanding their medical condition and to provide peer support, and
- We work with third parties to help public understanding of this highly diverse range of medical conditions affecting the process of biological sex development.

We have noted the problematic impact on those with DSDs of often poorly-informed media coverage of women athletes with 46,XY DSD.

DSD healthcare professionals are observing the impact of this in clinical settings. Many have expressed a deep concern that the expertise and perspectives of paediatric and adult clinical endocrinologists, medical psychologists and other DSD clinical specialists have not been at the heart of the consideration of World Athletics that have produced these recommendations, and have encouraged us to argue strongly against the proposed merger of DSD regulations and transgender regulations. We would welcome the opportunity to follow this up with WA.

Response to Question a of the consultation

We are grateful that, in asking us to be a key stakeholder, World Athletics recognises that this consultation may have a detrimental impact on the wellbeing of children, young people and adults living with DSD conditions – especially women with 46,XY DSD and their families and loved ones.

At the same time, we recognise that anxiety on this subject exists among many female elite athletes and their families and loved ones, and that we have a responsibility to everyone in helping to inform these discussions. We also recognise the concern around the disproportionate representation of women with 46,XY DSD in elite sports.

To inform our response we have spoken with leading (sports) scientists, endocrinologists and psychologists – some who have a long record of working on discussions around female eligibility.

At heart, we want to work with World Athletics to achieve an outcome that combines evidence-based science with a commitment to the dignity of women athletes with 46,XY DSD. However, we do not believe the recommendations proposed in the consultation, nor the evidence used to justify them, will lead to a positive outcome.

- To reiterate the point made in the initial explanatory context: we strongly object to the
 proposed merging of DSD regulations and transgender regulations. This represents a
 category error that could cause harm by conflating two distinct populations. While there
 may be a need for rules, these rules must be tailored to suit different circumstances and
 populations.
 - In addition to the risk of harm, this conflation also threatens to hinder public understanding of eligibility criteria and the research required to support sound policies.
- 2. The naming of the Working Group on Gender Diverse Athletes is problematic as it fails to distinguish between these two very different populations. As set out above, DSD refers to biology, not gender diversity. Furthermore, upon reviewing the membership of the Working Group, we note that none of the voting members appear to have scientific qualifications in the field of DSD.

We respectfully propose the establishment of a separate working group on DSD, with membership that includes paediatric clinical endocrinologists, adult clinical endocrinologists, clinical/medical psychologists, sports scientists, and sports doctors. To maximize opportunities for rebuilding trust and ensuring clear communication, we suggest including non-voting representation from a female (XX) athlete and a 46,XY DSD/family representative or athlete.

Such a group would help build confidence that new DSD regulations are sound, evidence-based, and crafted with the dignity and respect of all athletes in mind.

3. We question the 'Key developments since 2023' that form the basis of the Recommendations:

None of the evidence presented directly relates to the distinct population of DSD athletes.

Furthermore, we question the authority and qualifications regarding Disorders/Differences of Sex Development of the Independent Special Rapporteur on Violence against Women, whose report on 'Violence against Women' has been submitted as a key development. In the past, we have similarly questioned the authority and qualifications of the 2017-2023 Independent Rapporteur on Sexual Orientation and Gender Identity because of the conflation of DSD/intersex issues with transgender issues.

We also note that all five surveys submitted as evidence regarding changing public attitudes are solely related to transgender athletes. The absence of equivalent evidence on women athletes with a DSD does not make the submitted surveys relevant to these two distinct populations. Combining the DSD and trans categories in this way will not improve public understanding of either DSD or the eligibility criteria. There is no justification for using public attitudes on transgender athletes with an assumption that they also apply to DSD.

4. We disagree with the assertion in the consultation that there is no distinction between 'androgen sensitive' women with 46,XY DSD and trans women athletes.

Trans women are not biological females. They are observed at birth as boys, legally registered at birth as male and are raised as boys and men.

Women with 46,XY DSD are diagnosed with a DSD because of diagnostic assessment confirming that they are NOT biologically the same as typical males.

People with DSD follow unique developmental pathways, including puberty, that differ from those of typical males or females. In this consultation, we focus on women with 46,XY DSD, who are observed as girls at birth, legally registered as female from birth, and raised as girls and women.

We understand that World Athletics aims for a 'strictly biological' approach with a focus 'on sports only'. But sport - by virtue of its global popularity and the resonance of sporting competition - does not exist in isolation. Indeed, World Athletics' 'landmark social responsibility programme' - 'Athletics for a Better World' (ABW) recognises the organisation's global responsibility and platform.

Debates prompted by the wide publicity that sporting competition receives can have implications well beyond sport itself. So well-intended interventions 'on sports only' may have **inadvertent**, **adverse real-world consequences**. **WA risks denying women with 46,XY DSD public recognition of their unique biological development**, **legal registration**, **and personal life stories as females**. To prevent this risk, WA must maintain separate regulations for women with 46,XY DSD, reviewed and agreed by a team of experts on DSD.

- 5. DSD is an 'umbrella term' rather than a uniform entity; it includes many rare and distinct diagnoses, each often associated with a range of different presentations. The oversimplification of splitting DSD into androgen insensitive and androgen sensitive athletes does not provide a sound basis for capturing the complexity among variations and within variations and cannot therefore resolve questions of eligibility. Again, we feel that these complexities would be better addressed through separate DSD regulations, agreed by an expert panel who would be able to differentiate among variations, including those that will need to be addressed on a case-by-case basis.
- b. Are there ways to minimise or remedy the adverse impacts of the new eligibility conditions, such as approaches to addressing reasonable reliance interests or the type of support that could be offered as Athletes go through the testing and compliance processes?

Adverse impacts can be mitigated by maintaining separate DSD regulations and transgender regulations around eligibility, and by ensuring that DSD regulations are reviewed and decided upon by a dedicated working group of experts on DSD.

There is an additional risk concerning athletes from the Global South where DSD conditions are often less well understood and may remain undiagnosed. Accordingly, some athletes will have grown up without an understanding of how their body has developed and what that means. They may only discover their condition as a consequence of participation in elite sports and find themselves thrust into a media spotlight without preparation or support.

In contrast, androgen sensitive athletes growing up in the Global North are more likely to have had the medical support to be aware of how their body develops and may have had the opportunity to act upon that information (for example, through choosing a gonadectomy), or be better prepared to respond to the publicity their condition may generate.

To mitigate the risk of unequal treatment we recommend that World Athletics, in line with its <u>ABW mission</u>, works with national federations on an educational programme, working with established clusters of DSD clinical centres, especially those in the Global South.

c. For the preclearance requirement, which requires that World Athletics have on file both the athlete's genetic and hormonal status, please share whether you have a preference between (a) the cheek swab and (b) a dry blood spot test. The cheek swab would provide genetic information but not hormonal status and so would require follow-up in rare cases where the athlete is SRY positive. Dry blood spot tests can provide both genetic and hormone status.

We don't think that the proposed 'wholesale' testing for the SRY gene is either sensible, practical or ethical, nor based on (new) evidence that would justify this approach.

Ethically responsible genetic counselling ensures that people understand the potential consequences of receiving genetic test results before consenting and provides comprehensive professional follow-up.

We question WA's capacity to monitor its 214 members' ability to provide sensitive and humane follow-up care in the rare circumstances when female athletes are SRY positive. A sensitive and humane follow-up can be a challenge even when a diagnosis is made in a so-called resource-rich setting and with professionals totally committed to the wellbeing of their patients.

We would welcome a discussion and in meantime refer to the following editorial: <u>Fair and Safe</u> Eligibility Criteria for Women's Sport: The Proposed Testing Regime Is Not Justified, Ethical, or <u>Viable</u>

d. What is your sense of the public's understanding of the reasons athletes are divided in competition by sex?

We believe the public takes a common-sense approach to the reasons athletes are divided by sex and is aware of the debates surrounding trans women athletes. This explains why there are strong public opinions about the presence of trans women athletes in the female category, as reflected in the surveys you included in your evidence.

However, we think the public has little to no awareness or understanding of DSDs. In the first place **these are rare medical conditions**. And most of those who are aware of them only learn about DSD when they or their child—whether a baby, growing child, or teenager—is diagnosed. Many parents, even after years of dedicated support, still struggle to fully understand their child's condition. They often – understandably - find themselves carefully balancing openness about their child's condition with the child's right to privacy about atypical internal and external sex organs. Psychological support for girls and women with DSD focuses on providing emotional, mental, and social support to help them navigate the unique challenges they face, whilst fostering self-acceptance and resilience.

In these circumstances, ill-informed coverage and discussion of DSDs can be traumatic and stigmatizing.

Sports-related controversies and media coverage – such as those surrounding the women's boxing competition at the last Olympics – can compound this sense of stigmatisation.

So again, we argue for a carefully calibrated, <u>distinctive approach</u> to the regulation of female DSD athletes informed by experts in this field.

e. How can World Athletics best educate the public about its biological sex-exclusive design for the Female Category?

We regret to say that we predict World Athletics, by failing to address the transgender category separately from DSD, will fall short of its objective to educate the public.

This risks harming everyone.

f. Is there anything not mentioned in Recommendation 5 that the organisation can do to support transgender and DSD Athletes?

Recommendation 5 is titled: 'Consider forward initiatives, including to support elite gender diverse XY athletes'.

In the entire text of Recommendation 5 there is only reference to 'Gender Diverse Athletes'.

We reiterate our concern that the WA does not distinguish between DSD and transgender when using the term 'gender diverse.' DSD and transgender are two distinct populations and they - and any sport-related regulations - must not be conflated.

We understand that World Athletics is seeking a way forward, and we genuinely are grateful to have been asked to reflect and share the real-life consequences of these proposals.

We very much hope that WA's engagement with DSD athletes and related stakeholders such as dsdfamilies and medical professionals will not stop here.

g. Are there other athlete populations – in addition to gender diverse athletes – World Athletics should consider as it contemplates its programming?

Please note, and as per our comments above, the question does not distinguish between two distinct populations – DSD and transgender – and categorizes both within the 'gender diverse' category, which wrongly, and problematically conflates sex and gender.