

Denmark: Open letter on ensuring meaningful consultation of people with variations of sex characteristics

Dear Minister Ellen Trane Nørby,

As human rights and intersex rights organisations, we are concerned about the way that the Danish Health Authority organised the conference titled “Konference om variationer i kønskaraktæristika / Conference about differences in sex characteristics”, held on 30 January 2019 in Copenhagen. Although we welcomed the invitation made to a representative from OII Europe to speak at the conference and to Amnesty International to participate in a panel discussion, the failure to include intersex activists and organisations in the planning of this conference meant that they were not able to participate effectively.

Intersex organisations in Denmark were not invited to speak at the event. Several activists and individuals with variations of sex characteristics were not even able to attend the event as the registration costs of 400 Danish Krone were prohibitive, and no sponsorship option was offered for people with limited means. Furthermore, the patient organisations Klinefelter Foreningen and Triple X Foreningen, representing people with Klinefelter syndrome and triple X chromosomes, were not informed about, or invited to, the conference. There are many types of variations of sex characteristics and it is important that the voices, needs and concerns of people with such variations are heard, and that organisations which promote a human rights-based approach to supporting people with variations of sex characteristics are represented and heard.

We welcome the commitment made by the Danish Government in forming an LGBT Action Plan and understand that this conference formed part of the implementation of this Plan. However, we would like to reiterate that for such plan to be adequate, impactful and achieve real and long-lasting change, it needs to be developed with the meaningful consultation and participation of people with variations of sex characteristics. We understand that intersex organisations have already criticised the lack of inclusion of the process. Therefore, we urge you to include intersex-led organisations and activists in the design, development and implementation of the Action Plan.

We are also concerned that the factsheet titled ‘Spørgsmål og svar om variationer i kønskraktæristik og DSD’ (‘Questions and answers about sex characteristics, and about the term DSD’) that was distributed to MPs in November 2018 did not provide a full and accurate picture of the situation of individuals with variations of sex characteristics in Denmark by:

- Failing to recognise hypospadias as a variation of sex characteristics;
- Excluding many other variations from the statistics of the number of births of people with variations of characteristics every year in Denmark;
- Using the term “DSD” although it is largely rejected and perceived as pathologizing by people with variations of sex characteristics and intersex activists.

In addition, it is problematic that intersex organisations have not been involved in the

development of the nationwide clinical guideline by the Endocrinology Committee and under the Danish Paediatric Society. We further wish to contest your response to question 1147 in the Health and Senior Committee in which you state that current practice in the treatment of individuals with variations of sex characteristics is also in line with human rights. Amnesty International's 2017 report '[First, Do No Harm](#)' found evidence that current medical practices – in particular, the practice of non-emergency, invasive and irreversible surgeries with harmful effects – violate the rights to the highest attainable standard of health, to freedom from discrimination and from harmful gender stereotypes, to private life, physical and bodily integrity and self-determination, and the best interests of the child.

We continue to recommend that the Ministry of Health instruct the Danish Health Authority to:

- Develop human rights-based guidelines at the national level for responding to people with variations in sex characteristics;
- This should be done in consultation with individuals with variations in sex characteristics and activists working on these issues;
- The guidelines should be human rights-focused and include an emphasis on postponing non-emergency, invasive and irreversible genital surgery or hormone treatment on infants and children with variations in sex characteristics until they are able to meaningfully participate in decision making and give their informed consent, in line with the principle of evolving capacities of children and adolescents.
- To this end, we also wish to draw your attention to the following publications by InterACT in the USA, titled '[What We Wish Our Doctors Knew](#)' and '[Providing Ethical and Compassionate Healthcare to Intersex Patients: Intersex-Affirming Hospital Policies](#),' and we encourage you to use these resources when developing guidelines for medical professionals.

We further recommend that the Ministry of Health:

- In consultation with individuals with variations in sex characteristics and activists working on these issues, develop and provide mandatory training to medical and healthcare professionals on gender and bodily diversity, focusing on individuals with variations in sex characteristics;
- Ensure that resources are available to provide long-term psychological support to adults, adolescents and children with variations in sex characteristics and their parents – including by publicising and using the toolkit produced by OII Europe, IGLYO and EPA '[Supporting your intersex child - A Parents' toolkit](#)' when developing informational materials for parents;
- Ensure that individuals are able to access their medical records.

We welcome your attention to these issues and look forward to receiving your response.

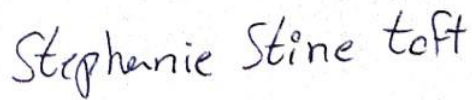
Yours sincerely,



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