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Open letter to the Council of Europe

After reading the Recommendation issue 2191 of the Parliamentary Assembly of the Council of Europe (PACE), published 12 October 2017, we would like to compliment the authorities that compiled this report for their dedication and effort into this complex and comprehensive dossier on DSD. This statement lists many thorough proposals, like the call to concentrate treatment of patients with DSD in specialized centers for multidisciplinary patient-centered care. We would like to extend this concept to:

‘multidisciplinary patient- and family-centered care’, as will be substantiated below. In many countries this objective is already largely implemented into medical practice, as evidenced by some recent surveys [1-3].

As medical professionals active in these specialized centers for multidisciplinary, patient- and family-centered care, we also recognize the call to break any secrecy, shame and stigmatization. We support the committee’s advice to provide full disclosure to patients and their parents, and to facilitate physical, psychological and social conditions for children and adolescents to grow and develop, and enabling them to fully participate in society, both while growing up and in adulthood. This is in line with the recommendations made in 2005 by an international consortium of medical and scientific professionals as well as patient representatives during the so-called Chicago consensus meeting [4].

This report however also includes some important caveats. We oppose to the use of the terminology: ‘intersex people’ and ‘intersex children’, as these terms are poorly defined and not synonymous with DSD, the latter being clearly defined as a group of distinct congenital conditions in which development of chromosomal, gonadal or anatomical sex is atypical.

Moreover, most DSD patients prefer the use of the specific etiological name when referring to their condition, and disapprove of the term intersex, which they perceive as annoying, confusing, and stigmatizing [5,6].

Soon after the introduction of the term DSD in 2005, intended to overcome at least some of the objections against the old nomenclature, including the term intersex, it became clear that this substitution also elicited negative perceptions. As especially the word: ‘Disorders’ had a negative connotation, the terms: ‘Differences’ and ‘Variances’ are at present increasingly used as alternatives to meet this demur [6]. Recently the term: ‘atypical genital development’ was proposed as an alternative to address to DSD-conditions as a group [7].



There is however a more worrying issue than semantics, namely paragraph 7, in particular 7.1.1, 7.1.2 and 7.5, dealing with medico-surgical care for children with DSD. Indicating that surgical interventions in children with DSD should only be applied in emergency conditions is discordant with the definition of health according to the World Health Organization (WHO), stating that health is not merely the absence of disease, but is a much broader concept, including physical, mental, and social domains. This especially applies to children, as favorable physical, social and emotional conditions are all critical factors for their optimal growth and development, which enables them to reach their full potential at adult age. As social and emotional interactions with the parents, being the most important adults in a young child's life, form the basis for their future, treatment of children with DSD can best be organized in a patient- and family-centered multidisciplinary setting, in an atmosphere based on openness, commitment and trust. We, physicians who daily take care of children with a variety of congenital conditions, alike their parents, are committed to the current as well as the future health and well-being of all children entrusted to our care. In contrast to what is alleged in this recommendation, parents implicitly act in the best interest of their children and should be respected as their outstanding representatives, and should not be put aside by claiming prohibition regulations regarding the well-informed decisions they make on their behalf.

We are aware that society is in motion and constantly changing, and welcome the current evolution, to which this report has made a significant contribution, towards a less divided and polarized humanity, where everyone is respected. However medical treatments are evolving too, and it may happen that therapies that were once standard are nowadays no longer applied. These changes are mainly based on scientific progress, continuous evaluation and resulting adjustments of treatments. Retrospective judgement of treatments applied in the past, although regrettable for all people who experience negative experiences or harm, is therefore incorrect.

Counseling parents and children with DSD in a patient- and family-centered multidisciplinary setting should be complete and unbiased, and based on available scientific and condition-related outcome information. We also encourage patients and parents to obtain information from other sources, especially from patient support societies. We have learned that a 'one size fits all' treatment does not exist for patients with DSD: treatment should be tailored to individual needs, taking into account all medical, psychological, social, and cultural considerations of the patient and its parents. All treatment options, including the pros and cons of each choice, are discussed extensively and repeatedly to ensure a well-considered shared decision. Advocating a ban on medico-surgical treatment contradicts the atmosphere of equality, openness and trust as is currently provided in the various patient- and family-centers for DSD care, and is actually a step backwards in evolution rather than forwards. We call society to entrust the care of children with DSD to their well-informed, committed parents and dedicated professionals of a multidisciplinary center.

We advocate to keep the dialogue open with the professionals active in specialized centers for multidisciplinary, patient- and family-centered care as well as with patient societies, for which the present resolution is recognized as being a solid starting base.

Board of the ESPU
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Document prepared by Wolffenbittel KP and Hoebeke P, approved by the board of the ESPU.



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