

(Translation: Morgan Carpenter, Laura Inter.)

Ministry of Health
Chile's government
Subsecretary of Public Health
Division of Prevention and Control of Diseases
Department of Life Cycle
DSC / JVC / GAG / CAA / PTE / YGR / gtc

CIRCULAR N ° 07

SANTIAGO, AUG 23, 2016

COMPLEMENT TO CIRCULAR N° 18 THAT INSTRUCTS ON CERTAIN ASPECTS OF HEALTHCARE FOR INTERSEX CHILDREN

On 22 December 2015, the Ministry of Health issued Circular No. 18 instructing on certain aspects of the treatment of intersex children.

It has been considered necessary to expand the information communicated through it, in particular with regard to the paragraph that states: *It is instructed that unnecessary "normalization" treatments of intersex children, including irreversible genital surgeries, be stopped until they have are old enough decide on their own bodies. Without disrespect of the above, we point out that the assignment of sex registration should be done according to best expectations.*

FIRST: Since integrating the human rights approach to health, intersex is a term that refers to *"all those situations in which an individual's sexed body varies from the cultural standards for female or male bodies"* and is considered that the term intersex would be technically, socially and legally the most appropriate (IACHR, 2013).

On the other hand, the medical term used on the basis of the 2006 Chicago Consensus, is Disorders of Sex Development (DSD) in English.

When informing the patient or his/her representatives about this condition, especially in the first consultation, appropriate use of language should be considered. If care is not performed in a specialist center, the information delivered should be general.

SECOND:

The recommendation that refers to not performing unnecessary genital surgery, does not refer to pathologies in which there is a clearly defined sex, both genetically and/or somatically, such as: cryptorchidism, isolated hypospadias, cloacal malformations and exstrophies.

THIRD:

In cases of people with 46XX DSD with classical congenital adrenal hyperplasia, surgeries such as clitoroplasty, uro-genital sinus surgery, and genitoplasty, should be agreed between the specialist multidisciplinary team and the family, and the opinion of the Ethics Advisory Committee following consultation, when the professionals or the patient consider it necessary. The final decision of the

patient and/or the patient's representative must be supported with the signing of a specific informed consent.

FOURTH:

Other forms of DSD/intersex, with potential for both sex assignments, should be analyzed in the same way, and the family must be clearly informed of this potentiality. Sex assignment and surgeries in these patients, such as gonadectomy and/or genital surgery, should be done by mutual agreement between parents and the multidisciplinary team; consulting the Ethics Advisory Committee, an entity that will act as a safeguard that all the options have been considered. The possibility should be explained of deferring surgery to an age where the patient may manifest or demonstrate tendencies of a sexual identity.

FIFTH:

When DSD/intersex is suspected in a neonate, it is recommended to defer sex assignment until an evaluation in a Reference Center takes place. Relatives should be informed of the health condition and have it clarified that the patient's reference is for a specialist diagnosis and to make an informed decision, shared between them and the experts. Children and adolescents with suspected DSD/intersex will also be referred for their care to these reference centers.

SIXTH:

In those patients who present with a surgical emergency due to complications derived from their underlying pathology, for example an obstruction or infection of the urogenital sinus, surgical procedures will be carried out to ensure the patient's physical integrity, as guaranteed by the current legal framework, and then be transferred to the relevant reference center.

SEVENTH:

DSD/intersex patients will be referred for care to specialist centers that have a multidisciplinary team with experience in the integrated [i.e. multidisciplinary] management of people with DSDs. The specialist professional team will ideally consist of a pediatric urologist surgeon, an endocrinologist, a clinical geneticist, a social worker, a psychologist, a psychiatrist, a pediatric radiologist, a pediatric gynecologist and a fertility doctor. On the other hand, the establishment where this specialist attention is carried out must be supported by an Ethics Advisory Committee.

EIGHTH:

The MINSAL (Ministry of Health) will define the reference centers according to standards that ensure the quality of care.

NINETH:

Considering the rapid changes and the advancing knowledge in these matters, updated technical guidelines will be elaborated and will be reviewed periodically, by a committee of specialists convened at ministerial level, with broad representation of the scientific societies involved in the subject.

TENTH:

This instruction establishes in each Health Service a work plan, reaffirming the need to nominate a reference person to lead the management and registration of the cases in the Health Services.

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