

Opinion of the Central Ethics Committee of the SAMS on «differences of sex development»

Bern, 16 December 2016

1. Introduction

From an ethical perspective, there is broad agreement that any treatments or interventions in children with differences of sex development (DSD) must be guided by the welfare of the child concerned. Here, however, determination of the child's welfare is no easy matter. It is not enough to define the child's welfare solely on the basis of the current interests of the (essentially healthy) infant or child. Consideration needs to be given not only to the protection of the child's physical and psychological integrity but also to the implications for the identity, fertility and sexual experience of the future adult. Options will vary depending on how these goals are weighted in the context of the child's family, cultural and religious background.

The Central Ethics Committee (CEC) of the SAMS first addressed the topic of «intersexuality» in 2012, in response to an Opinion issued by the Swiss National Advisory Commission on Biomedical Ethics¹. The Commission had recommended that guidelines on education and training for the professionals involved should be prepared by the SAMS and other competent professional bodies. In 2012, the CEC concluded that responsibility for this task lay with the professional associations or international expert groups.

In 2016, two articles² were published in the *Schweizerische Ärztezeitung* concerning the implementation in Switzerland of the UN Convention on the Rights of the Child and medical interventions relating to sex assignment. The 2015 report on the implementation of this Convention had expressed concerns about medically unnecessary procedures performed on intersex children in Switzerland.³ On the basis of this report, the SAMS was called on to ensure, by issuing ethical recommendations, that no unnecessary medical or surgical treatments are carried out during infancy or childhood.

¹ Cf. Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE), On the management of differences of sex development: Ethical issues relating to "intersexuality", Opinion no. 20, Bern 2012, www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/.../NEK_Intersexualitaet_En.pdf

² Cf. Heller Y, Narring F, Recommendations made to Switzerland by the UN Committee on the Rights of the Child, SÄZ/BMS 2016;97(16):604 (German: www.saez.ch/docs/saez/2016/16/de/SAEZ-04414.pdf; French: www.bullmed.ch/docs/saez/2016/16/fr/BMS-04414.pdf) and Werlen M, DSD: no medically unnecessary treatment in early childhood, SÄZ/BMS 2016;97(32):1089–1090 (German: www.saez.ch/docs/saez/2016/32/de/SAEZ-04793.pdf)

³ Cf. UN Committee on the Rights of the Child, Concluding observations on the combined second to fourth periodic reports of Switzerland (CRC/C/CHE/CO/2–4), 26 February 2015, No. 42, www.humanrights.ch/upload/pdf/150317_Concl_Obs_rights_children.pdf

The CEC was thus prompted to re-examine this issue, seeking the views of experts⁴ and consulting both the Swiss Medical Association (FMH) and the Federal Office of Justice (FOJ).

2. Background

2.1. Legal situation

Under the existing legal regulations, a child's sex has to be recorded as male or female within three days after the birth.⁵ The Swiss legal system does not recognise a third sex. For the official registration, the register office records the sex indicated by the medical personnel on the birth certificate. Subsequent amendment of the recorded sex involves considerable effort and requires a court judgement. In 2014, to accommodate families with affected children, the Federal Office for Civil Registration (EAZW) declared that the recorded sex can be modified by register offices if they receive a birth certificate amended on the basis of medical investigations.⁶ In addition, the Federal Office of Justice is currently considering a simplified procedure for amendment of the recorded sex.⁷

Among others, the following points are relevant in the current discussion:

- Plausibility of the medical criteria for the determination of sex in the birth certificate;
- The recommendations of the NEK-CNE: retention of the binary system and facilitation of unbureaucratic subsequent amendment of the recorded sex;
- Developments in neighbouring countries (deferral of determination of sex and/or introduction of a third sex) and activities of the Council of Europe and the UN in the area of DSD.

⁴ Professor Dagmar l'Allemand, Consultant Paediatrician specialising in paediatric endocrinology and diabetology, Children's Hospital of Eastern Switzerland; Professor Rita Gobet, Consultant Paediatric Urologist and Surgeon, Zurich Children's Hospital, member of the Zurich Children's Hospital DSD Working Group.

⁵ Cf. Art. 35 Civil Status Ordinance (ZstV) of 28 April 2004 (SR 211.112.2).

⁶ Cf. EAZW Official Notice No. 140.15, 1 February 2014, Intersexuality: recording and amendment of sex and first names in the civil register: www.bj.admin.ch/bj/de/home/gesellschaft/zivilstand/weisungen/mitteilungen.html

⁷ Cf. Right to protection against discrimination, Federal Council Report of 25 May 2016 in fulfilment of the postulate of Martin Naef 12.3543 (available in German: www.ejpd.admin.ch/dam/data/bj/aktuell/news/2016/2016-05-25/ber-br-d.pdf and French: www.ejpd.admin.ch/dam/data/bj/aktuell/news/2016/2016-05-25/ber-br-f.pdf)

2.2. Medical practice

Although no national guidelines on the management of DSD exist to date in Switzerland, an international consensus statement⁸ has offered useful medical guidance since 2006. In an article published in 2016⁹, the COST Action DSDnet expert group notes that current best practice involves a holistic, multidisciplinary approach, actively engaging with the individuals concerned and their families, so as to ensure that any medical interventions are appropriate.

The experts consulted by the CEC believe that the care provided for affected families in Switzerland has improved in recent years, and that the recommendations of the NEK-CNE and international standards are complied with as far as possible. For care centres with small numbers of “cases”, however, implementation can be challenging as a result of a lack of expertise or experience. In general, parents who find themselves in this difficult situation now receive advice and support from a multidisciplinary team from the birth onwards¹⁰. All decisions concerning treatments and interventions are guided by the child’s welfare and are based on shared decision-making.

One unresolved difficulty lies in the fact that it is not clearly defined which of a heterogeneous group of more or less serious congenital variations are to be classified as disorders of sex development. While it is agreed that the question whether or not a treatment or intervention should be performed can only be assessed in specific cases, taking all relevant factors into account, opinions differ among medical and other experts as to what measures are medically necessary or unnecessary in DSD.

This is partly due to the inadequate evidence base: there is a lack of studies of long-term outcomes which would permit a sound assessment of what is necessary or unnecessary. Registry-based studies could help to determine what interventions at what stage lead to what medical outcomes and effects on physical and psychosocial development, development of gender identity, and quality of life. The design (and financing) of meaningful studies in this area is, however, challenging.

⁸ Cf. Hughes IA et al., Consensus statement on management of intersex disorders. Arch Dis Child 2006;91:554–563, www.ncbi.nlm.nih.gov/pmc/articles/PMC2082839/

⁹ Cf. Cools M et al., Response to the Council of Europe Human Rights Commissioner’s Issue Paper on Human Rights and Intersex People. European Urology (2016), www.sciencedirect.com/science/article/pii/S0302283816301798

¹⁰ The costs of psychosocial care are not, however, covered by social insurance; here, in the view of the CEC, action is required.

3. Conclusions of the CEC

In the present situation – given the inadequate evidence base and the state of legislative flux – the CEC does not consider it appropriate to issue comprehensive medical-ethical guidelines on this topic. However, it offers the following recommendations:

- The CEC recommends that **register offices should extend** the period for the determination of sex **from 3 to 30 days in unclear cases**. In the vast majority of cases, the necessary medical investigations can be completed within this period. For other cases, the arrangements announced by the EAZW in 2014 appear to be appropriate.
- The CEC recommends that **psychosocial care** for parents should be **financed** from the birth onwards.
- In the medium term, it would be advisable to develop **national guidelines** or adapt international guidelines for Switzerland. These should be jointly prepared by experts and the people concerned, taking national and international developments (including the legal framework) into account.
- Guidelines must be based on an **improved evidence base**. To obtain a baseline, a survey of the centres providing support and treatment for people with DSD should be considered. In the medium term, plans should be made to develop and finance a registry, or to join an existing international registry, and to carry out studies of long-term outcomes.
- In view of the small numbers of people affected, the CEC recommends that counselling and treatment should be **concentrated** at a few centres in Switzerland, and that **networks** should increasingly be established, bringing together professionals from different disciplines (e.g. medicine, nursing, psychology, ethics).
- While the CEC is responsible for the preparation of medical-ethical guidelines, the professional associations are responsible for the **preparation of professional guidelines**. Various associations and subgroups should be involved: paediatric endocrinology, surgery and urology, paediatric and adolescent gynaecology and psychiatry, genetics, fetal medicine and neonatology. If so desired, coordination by the FMH and the CEC could be considered.
- Insofar as medical questions need to be evaluated for the **legislative process** as part of the overall revision of family law, the CEC is prepared to examine these questions in consultation with the FMH.