

On the management of differences of sex development

Ethical issues relating to "intersexuality"

Opinion No. 20/2012

Berne, November 2012

Members of the Commission:

Professor Otfried Höffe (Chair), Dr Ruth Baumann-Hölzle, Professor Annette Boehler, Professor Alberto Bondolfi, Dr Kurt Ebnetter-Fässler*, Carlo Foppa, PhD, Professor Olivier Guillod, Dr Bertrand Kiefer, Dr Margrit Leuthold, PD Dr Jean Martin*, Dr Judit Pók Lundquist**, Franziska Probst, lic. iur et lic. phil.,* Professor François-Xavier Putallaz, Maya Shaha, PhD, RN*, Professor Brigitte Tag*

* Member of the working group responsible for preparation of the Opinion,

** Chair of the working group responsible for preparation of the Opinion

Publication details

Published by: Swiss National Advisory Commission on Biomedical Ethics NEK-CNE

Editorial responsibility: Susanne Brauer, PhD

Production management: Dr. Jean-Daniel Strub

Design and layout: Künzle-Druck AG, John Huizing, Zurich

Address for orders: www.nek-cne.ch or NEK-CNE Secretariat, c/o FOPH, CH 3003 Bern

Contact: nek-cne@bag.admin.ch

Print versions of this Opinion are available in French, German and Italian. The online English version is available at: www.nek-cne.ch

© 2012 Swiss National Advisory Commission on Biomedical Ethics, Bern

Reproduction permitted with citation of source.

Contents

| | |
|---|-----------|
| Summary of mandate and definition of problem. | 5 |
| 1 Introduction | 7 |
| 1.1 Definition of terms | 7 |
| 1.2 Current state of the debate | 8 |
| 2 Professional counselling and support for affected parents and children | 9 |
| 2.1 Background and aims of counselling and support | 9 |
| 2.2 Who should provide counselling and support? | 10 |
| 2.3 Content of counselling and support | 10 |
| 2.4 Quality characteristics of counselling and support | 11 |
| 3 Ethical considerations for decision-making | 12 |
| 3.1 Guidance for parents and the child's right to participate | 13 |
| 3.2 Guidance for the multidisciplinary team | 13 |
| 3.3 Limits to freedom of choice | 14 |
| 4 Interfaces with civil status administration | 14 |
| 5 Interfaces with social insurance | 15 |
| 6 Recommendations | 18 |
| Procedure adopted by the Commission in preparing the Opinion. | 21 |
| Literature | 22 |

Summary of mandate and definition of problem

In a letter dated 15 September 2011, the Director of the Federal Office of Public Health, Pascal Strupler, requested the Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE) to prepare an Opinion, for submission to the Federal Council, on ethical issues relating to “intersexuality”. This request to the Commission was issued on the basis of the Federal Council’s responses to two interpellations introduced in the National Council¹, in which the Federal Council was called upon to answer various questions concerning the management of differences of sex development and associated surgical procedures.

Under the Federal Council’s mandate to the Commission, the Opinion is to focus on questions of counselling and the provision of information for parents and the medical profession. In this connection, the Commission was also asked to consider to what extent the Swiss Academy of Medical Sciences could contribute to the clarification of unresolved questions. The Commission is also to identify any relevant interfaces with social insurance and with private law.

In the Commission’s view, differences of sex development raise a number of issues in the areas of legal and medical ethics. The following points would appear to be particularly pressing.

In Switzerland, an indication of sex is required for the official registration of births, with two sexes being recognized under the Swiss legal system. Underlying this requirement, firstly, is the assumption that sex is one of the essential features of a person’s identity; at the same time, it reflects the traditional view that all humans are either male or female. Individuals whose sex is not clearly identifiable as male or female are assigned to one of these two categories. A subsequent amendment of the recorded sex requires considerable effort and sometimes – without any adequate justification – entails significant disadvantages for the person concerned.

A consequence of this legal position and the underlying social attitudes regarding the need for unequivocal categorization is the employment of medical means for sex assignment. Thus, until quite recently, sex assignment surgery was carried out on “child welfare” grounds in essentially healthy infants and children. Such procedures are irreversible and may have serious effects on the life of the person concerned – for example, if it subsequently transpires that the medically assigned sex does not match the individual’s own sense of gender identity. As the children concerned are minors, lacking the capacity to consent, it falls to their legal representatives – i.e. usually the parents – to give the required consent for medical sex assignment procedures. While this proxy consent generally legitimizes such interventions, there is a risk that, from an ex post perspective, children’s fundamental human rights to physical and psychological integrity and self-determination may be violated. It therefore needs to be carefully examined whether, and in what circumstances, irreversible sex assignment procedures can be justified by invoking the child’s welfare.

¹ 11.3265 Interpellation Kiener Nellen. Management of differences of sex development (questions 3 and 4) and 11.3286 Interpellation Glanzmann. Cosmetic genital surgery in children with ambiguous physical sexual characteristics (questions 2 and 3).

Hereafter, the Commission uses the term “differences of sex development” or “sex variations” in order to avoid any negative or misleading connotations associated with the term “intersexuality”.

1 Introduction

Until just a few years ago, questions concerning social attitudes to – and the medical management of – individuals with ambiguous sexual characteristics were not widely debated. It is largely thanks to the efforts of self-help/advocacy groups that this situation has changed, and that increasing attention is now being paid to the topic of “intersexuality” in the media and in professional circles – including the fields of medical law and ethics – both nationally and internationally. The Swiss National Advisory Commission on Biomedical Ethics (NEK-CNE, hereafter “the Commission”) welcomes this development and hopes that, by issuing this Opinion, it can help to dispel any remaining taboos surrounding the topic and to ensure that, also in the Swiss context, due attention is paid to the ethical and legal questions arising in connection with differences of sex development. In the Opinion, the Commission addresses the questions highlighted by the Federal Council, as mentioned above.

1.1 Definition of terms

The term “intersexuality” (or “intersex”) refers to a condition in which an individual’s sex is biologically ambiguous – i.e. the development of chromosomal, gonadal or anatomical sex is atypical and, consequently, the sex-differentiating characteristics are not concordantly and unambiguously male or female. The genotype (genetic constitution) thus does not correspond to the phenotype (physical appearance), and the phenotype itself may not be categorizable as unequivocally male or female.

A biological condition of this kind may be diagnosed prenatally, at birth, during puberty, or only later in adulthood. Clinically, such cases are known as disorders of sex development (DSD). In medicine, DSD is used as an umbrella term, covering a wide range of conditions with varying causes, manifestations and courses. **In terms of insurance law, a diagnosis of DSD indicates a congenital condition, but this does not mean that the person concerned automatically requires medical treatment.** However, some forms of DSD may involve life-threatening disorders (e.g. adrenal insufficiency, salt wasting) or are associated with an elevated risk of cancer, necessitating medical interventions. Among the best-known forms of DSD are congenital adrenal hyperplasia (CAH), disorders of androgen synthesis, androgen insensitivity syndrome (AIS), gonadal dysgenesis, ovotesticular DSD and Leydig cell hypoplasia.² Owing to differences in definitions, the reported incidence (number of new cases) and prevalence (number of existing cases in a given population) varies between 1:3000 and 1:5000.³

For the clinical context, the Commission uses the standard abbreviation DSD. **The Commission wishes to emphasize that DSD does *not* refer to transsexuality.** Transsexuality is a condition in which an individual’s gender identity does not match their biologically *unambiguous* sex. Speaking of “intersexuality” as “non-true transsexualism” – a term used in the Federal

² For statistics and an account of the main groups of DSD, cf. Schweizer/Richter-Appelt 2012, pp. 52ff.

³ Bosinski 2005.

Council's reply to the above-mentioned parliamentary questions – is incorrect and should therefore be avoided.

For non-technical usage, the Commission recommends the term “sex variation”, on the following grounds: not all cases of DSD involve a (pathological) “disorder”, i.e. a functional impairment associated with suffering. Not infrequently, a case of DSD may involve a variation from a norm of sex development which does not require medical treatment. From the perspective of those affected, the term “disorder” may thus appear stigmatizing, and accordingly the term “differences of sex development”⁴ (rendered in German as “Besonderheiten der Geschlechtsentwicklung”⁵) has been proposed as an alternative in the literature. The Commission endorses this proposal.

Of ethical importance, in the Commission's view, are all those cases of DSD where sex assignment represents a problem for parents, professionals, the state and ultimately also for the individual concerned. **Society's expectation that a child will be either a boy or a girl is called into question by DSD, without the child (while it lacks capacity) being able to express a view itself.** DSD poses particular challenges for ethics and law because the response to this unmet expectation may lead to crises, in which assistance will be required in many cases. The reaction to an exceptional situation of this kind needs to be acceptable from an ethical and legal viewpoint.

1.2 Current state of the debate

Until the end of the twentieth century, in line with the “optimal gender policy” advocated by John Money (1955), a child with a DSD was generally assigned a gender at an early age. The child's body was then surgically aligned with the assigned gender in the first months and years of its life. As it was easier for surgeons to create female than male genitalia, most of these children were surgically feminized. The child was then to be consistently reared in the surgically assigned gender role, without it (or the family) being informed about its differences or the reasons for the interventions. Secrecy was maintained even into adulthood. It was believed that this approach would enable the child to have a “normal” physical and psychosexual development. In fact, however, the treatment was often associated with severe physical complications, chronic pain, loss of fertility, psychological sequelae⁶ and impairment of sexual quality of life.⁷ In some cases, affected individuals also show high degrees of uncertainty of gender identity⁸, which may extend as far as a mismatch between assigned sex and gender identity in later life.⁹ In particular, the persistence of taboos, feelings of shame and perceived stigmatization in clinical management were reported by patients to be distressing or even traumatic.¹⁰

Growing criticism of the “optimal gender policy”, spreading from the US, led to a change of approach in medical practice. Since the 2005 International Consensus Conference, held in Chicago, where a “consensus statement on management of intersex disorders” was prepared by over 50

⁴ Wiesemann et al. 2010.

⁵ Arbeitsgruppe Ethik im Netzwerk Intersexualität «Besonderheiten der Geschlechtsentwicklung» 2008 (consensus paper).

⁶ Schützmann et al. 2009.

⁷ Schönbucher et al. 2010

⁸ Schweizer/Richter-Appelt 2009 und Schweizer et al. 2009.

⁹ Bosinski 2005.

¹⁰ Brinkmann et al. 2007; Kleinemeier et al. 2010; Ude-Koeller et al. 2006.

international experts from the Lawson Wilkins Pediatric Endocrine Society (LWPES) and the European Society for Paediatric Endocrinology (ESPE), new standards have been applicable for the classification, diagnosis and management of DSD.¹¹ These recommendations have been implemented at European DSD centres.¹² Under the new approach, decisions on irreversible genital surgery are to be guided by medical indications rather than cosmetic considerations. Interventions are to be appropriate to the individual's current needs (e.g. no vaginoplasty in childhood). All individuals are, however, still to receive a gender assignment. Acute, life-threatening conditions associated with DSD must always be treated.

In 2012, an Opinion dealing with "the situation of intersex people" was issued by the German Ethics Council. This recommends, among other things, the expansion of specialized interdisciplinary centres and of medical and psychological support services for affected individuals and their parents. It also opposes irreversible medical sex assignment measures and advocates the strengthening of the child's participatory rights. It calls for the establishment of a fund to provide recognition and assistance for individuals with DSD who have suffered as a result of earlier treatments. The Ethics Council proposes the introduction of an additional category "other" for the official registration of sex. It suggests that the individuals concerned should be able to enter into a registered civil partnership, or even to marry.

2 Professional counselling and support for affected parents and children

2.1 Background and aims of counselling and support

The birth of a child with a sex variation gives rise to uncertainties and anxieties and requires both the parents and the professionals involved to engage in processes of reflection and decision-making for which no "magic formulas" are available. In general, it is to be assumed that parents will always endeavour to promote their child's welfare.¹³ However, it is the mark of this particular exceptional situation that it is not immediately clear, and often a matter of dispute, what will actually promote the child's welfare. This emotionally challenging situation first needs to be coped with before any decisions are taken on (non-critical) therapeutic interventions which may have far-reaching consequences. Here, professional counselling and support for parents plays an important role.

Crucial to the child's welfare from a medical/psychological viewpoint is that, after the birth, the parents should accept the child as it is, and that a normal emotional attachment should be established between them. To develop self-confidence, the child must have a sense of security. **The initial aim of counselling and support is therefore to create a protected space for parents and the newborn, so as to facilitate a close bond. In addition, the parents need to be enabled to take the necessary decisions on the child's behalf calmly and after due reflection. In this process, they should not be subjected**

¹¹ Lee et al. 2006, Hughes et al. 2006.

¹² Pasterski et al. 2010.

¹³ Cf. NEK-CNE Opinion no. 16/2009 "Research involving children".

to time or social pressures. Parents' rapid requests for medical advice or for corrective surgery are often a result of initial feelings of helplessness, which need to be overcome so as to permit carefully considered decision-making.

The child, likewise, in accordance with its level of mental development, requires psychosocial support so that it can be involved in treatment decisions at an early stage or take such decisions, when it becomes competent to do so. The importance of psychosocial support increases with the child's age and growing self-awareness and decision-making capacity.

2.2 Who should provide counselling and support?

Various stages of counselling and support for parents and individuals affected by DSD are to be distinguished, each involving different professionals.

If a sex variation is suspected in an unborn child during pregnancy, e.g. on the basis of a chromosome analysis, the expectant mother or couple should be offered psychosocial counselling.

All professionals who work with parents and the newborn before, during and after birth are to be specially trained for care provision in the initial phase, so that they can undertake early crisis intervention measures with a motivating, supportive approach.

As soon as possible, the parents and their child should be referred to a specialized centre where responsibility for counselling and care is assumed by a multidisciplinary team with the necessary medical, psychological, legal, educational, social, ethical and other expertise. As the multidisciplinary team will ideally provide care over the long term, its composition may change as required over the years.

2.3 Content of counselling and support

The Commission suggests that the following items should form part of the counselling and support to be provided at least throughout the period of medical care:

- a diagnosis which is as precise as possible, based on genetic analysis, and also including the healthy aspects of the child;
- information on the need for treatment, therapeutic options and risks;
- information on possible health risks and symptoms associated with DSD;
- information on legal matters, specifically concerning the official registration of sex and the possibility of amending the recorded sex at a later date;
- assistance with insurance questions: coverage of the costs of treatment and psychosocial support by the Disability Insurance (IV) and, after the age of 20, the mandatory health insurance scheme;

- information on challenges relating to the physical and psychological development of children with DSD in puberty and adulthood, and on dealing with social expectations concerning unambiguous sex, the social environment and questions of upbringing;
- information on risks for subsequent pregnancies;
- details of self-help groups and online resources offering additional support;
- information meeting the family's specific requirements.

2.4 Quality characteristics of counselling and support

When providing counselling and support, it should be remembered that, depending on the particular diagnosis and family situation, the concerns and needs of the affected child – and hence also of its parents – may vary widely. Careful diagnostic investigations are therefore the essential first step. **It is important to bear in mind and also to point out to the parents that a diagnosis does not in itself entail any treatment or other medical measures, but serves initially to provide an overview of the situation and a basis for subsequent decisions, which may also take the form of watchful waiting.**

To prepare the parents for the coming challenges, they should be offered expert, sensitive and individually tailored support, possibly beginning before the birth and continuing from birth into adulthood. If requested, and if resources permit, a member of the multidisciplinary team may visit the family's home to provide personal advice. The information flow is to be coordinated by an expert within the multidisciplinary team, with the aim of avoiding contradictory information being given to the parents or the individual concerned.

The information about the complex situation communicated to the parents and later also – in an age-appropriate manner – to the individual him/herself should be comprehensive, intelligible and essentially unbiased. For this purpose, use should be made of evidence-based assessment instruments and guidelines, which can help to determine in a systematic way parents' and children's needs for information on disease/health. In the counselling process, attention is to be drawn to alternative viewpoints and conceptions. **As the nature of the counselling has a decisive influence on decision-making, a balance needs to be struck between medical information and non-medical counselling.** It should also be ensured that information has been properly understood. To avoid common misconceptions, it should be made clear that genital (sex assignment) surgery does not determine either the patient's subjective gender identity or his/her sexual orientation in later life.

3 Ethical considerations for decision-making

3.1 Guidance for parents and the child's right to participate

In the case of DSD, a small number of decisions on medical treatment need to be taken in infancy and early childhood. In general, parents make such decisions on behalf of and in the best interests of their child.¹⁴ In doing so, they have the task of supporting the child in developing its gender identity, while respecting its physical and psychological integrity. Parents should also be aware that they are intervening in a highly sensitive sphere, which concerns the core of the child's personality. Such interventions have lasting effects on the development of identity, fertility, sexual functioning and the parent-child relationship. **The parents' decisions should therefore be marked by authenticity, clarity and full awareness, and based on love for the child, so that they can subsequently be openly justified vis-à-vis the child or young adult.**

Ethically and legally, parents' responsibility and decision-making authority is constrained by the child's welfare and competence. Determination of the child's welfare is a normative process; depending on how it is interpreted, conflicts of interests may arise: the child's welfare may be defined on the basis of (a) the child's current interests or (b) the future adult's anticipated interests. Here, depending on the goal, conflicting options may present themselves. There is no guarantee that a decision which is good for the child in its current state will also be best for this person in puberty or adulthood. **The Commission recommends that the determination of the child's welfare should be based as far as possible both on the current interests of the child and on the anticipated interests of the future adult.** In cases of conflict, the multidisciplinary team – together with the parents and if possible with the involvement of the child – should seek to weight the two goals for the individual case.

As soon as the child attains capacity, it must consent to medical treatment itself, since such cases involve the exercise of highly personal rights.¹⁵ Parents do not have a right to veto a decision made by a child which has already attained capacity. People have capacity if they can understand the purpose, appropriateness and effects of a given course of action and are also in a position to act of their own free will in accordance with rational judgement and to withstand pressure exerted by third parties within normal limits. In Switzerland, as regards the right to veto physical interventions, it is assumed that a child attains capacity between the ages of 10 and 14 years, although capacity is acquired by degrees and is also influenced by the severity and implications of the intervention. Empirical studies indicate that, on the basis of experience with their own body and with illnesses, children can already make rational decisions on treatment before the age of 10 years. However, it should be recalled that, with regard to sexual self-determination, the age of consent specified in Art. 187 of the Swiss Criminal Code (StGB) is 16 years.

¹⁴ On parents' role as proxies cf. NEK-CNE Opinion no. 16/2009 "Research involving children".

¹⁵ Art. 19, para. 2, Swiss Civil Code (ZGB). Federal Supreme Court Decision BGE 114 Ia 350, 360; BGE 134 II 235 ff.; Michel 2009, 80 ff.

The Commission strongly supports the idea that, even before they attain capacity, children should participate in medical treatment decisions in an age-appropriate manner, and that their views should be taken into account as far as possible. Here, the requirements to be applied for capacity in the case of *consent* to treatment are more stringent than for *refusal* of treatment. As children are susceptible to influence and frequently wish to satisfy family or parental expectations, it should also be ensured that, in order to boost their confidence, they receive independent, professional psychosocial support. It must be ensured that the wishes they express are authentic, and that they are able to cope with the demands of the decision-making situation.

3.2 Guidance for the multidisciplinary team

The interdisciplinarity of the treatment and care team should lie not merely in the representation of various disciplines, but in a genuine commitment to equal status for all parties involved. While diagnosis is a matter for medical experts, proposals for treatment are to be discussed within the multidisciplinary team. The multidisciplinary team has the key task of providing parents, or the (competent) individual, with information on medically indicated and appropriate treatment options, which may vary widely in terms of the associated opportunities and risks. Decisions on the next steps are to be taken on an individual basis, in partnership with the parents and if possible the child. Here, it should be borne in mind that in most cases an intervention is not a matter of medical urgency. **Decisions on sex assignment interventions are to be guided by the questions of what genitalia a child actually requires at a given age (apart from a functional urinary system) and how these interventions will affect the physical and mental health of the child and the future adult.** Treatment needs to be carefully justified, especially since – in functional, aesthetic and psychological respects – surgically altered genitalia in DSD are not comparable to natural male or female genitalia.

Decisions are to be guided, above all, by the child's welfare. Attention needs to be paid to the child's individual circumstances, including its family, social and cultural environment; however, the team's reflections should not be influenced by prejudices vis-à-vis other cultures or religions. The limiting factor in the consideration of family/cultural circumstances will be the physical and psychological integrity of the child. An irreversible sex assignment intervention involving harmful physical and psychological consequences cannot be justified on the grounds that the family, school or social environment has difficulty in accepting the child's natural physical characteristics. The harmful consequences may include, for example, loss of fertility and sexual sensitivity, chronic pain, or pain associated with dilation (bougienage) of a surgically created vagina, with traumatizing effects for the child. **If such interventions are performed solely with a view to integration of the child into its family and social environment, then they run counter to the child's welfare.** In addition, there is no guarantee that the intended purpose (integration) will be achieved. In order to avoid parents of a child who

lacks capacity seeking sex assignment surgery abroad if they are denied this option in Switzerland, it may be pointed out that the intervention can also be performed in later life, should the individual concerned so desire.

3.3 Limits to freedom of choice

As part of the state's duty of care, it is obliged to protect children whose parents request interventions which clearly violate the child's welfare or participatory rights. **The following basic principle should therefore apply to the management of DSD: on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself.** This includes genital surgery and the removal of gonads, unless there is an urgent medical indication for these interventions (e.g. increased risk of cancer). Exceptions to the general rule would be cases where a medical intervention is urgently required to prevent severe damage to the patient's body or health.

Finally, in the interests of child protection, there should be a legal review of the liability implications of unlawful sex assignment interventions in childhood, and of the associated limitation periods. Questions of criminal law, such as the applicability of offences of assault (Art. 122 and 123, StGB) and the prohibition on genital mutilation (Art. 124, StGB), should also be investigated.

4 Interfaces with civil status administration

In Switzerland, an indication of sex is required for the official registration of births (Art. 8, lett. d, Civil Status Ordinance/ZStV), with only two sexes being recognized under the Swiss legal system. Underlying this requirement, firstly, is the assumption that sex is one of the essential features of a person's identity; at the same time, it reflects the traditional view that all humans are either male or female. Individuals whose sex is not clearly identifiable as male or female are thus assigned to a category which may possibly not match their subjective gender identity in later life. **A subsequent amendment of the recorded sex requires considerable effort and sometimes entails significant disadvantages for the person concerned. This procedure should be reviewed from the viewpoint of possible discrimination.** To address this situation and improve the position of the individuals concerned, the following three options were discussed by the Commission:

- The restriction to two categories of sex is based on custom; no specific legal regulations exist on this question. It would in principle be possible to introduce additional categories and adapt the federal authorities' computerized civil status register (Infostar) accordingly. Conceivably, a third category such as "other"¹⁶ could be adopted. Alternatively, two fur-

¹⁶ Australia was the first country to introduce a third category of this kind in passports for its citizens.

ther categories could be introduced, based on the binary classification, but indicating the uncertainty of the sex assignment (e.g. "female *" or "male *").

- The Civil Status Ordinance could be revised so that in the future no indication of sex would be required when births are officially registered.
- The two existing categories of sex would be maintained, but to meet the needs of people of ambiguous sex more effectively and flexibly, a facilitated system could be introduced for amending the sex recorded in the civil status register.
- The Commission's conclusions were as follows: the Commission supports the idea that sex variations should be placed on an equal footing with the traditional categories of "male" and "female", as no-one should be subjected to discrimination on the grounds of sex. **Categorization as male or female which is driven by social factors or a desire for legal certainty, rather than being based on medical considerations or the sincere wishes of the individual concerned, represents an unacceptable violation of personal liberty.** It also leads to unjustifiable discrimination.

The Commission takes the view that at present the binary classification system should be maintained, as it is deeply embedded socioculturally and people with DSD often also wish to find their place in society as a man or woman. Accordingly, the introduction of additional categories of sex, as envisaged in option 1, could lead to renewed stigmatization. **Option 3 – calling for a facilitated system for amendment of the recorded sex – appears to the Commission to be an appropriate compromise at this time.** Here, simplified amendment of the recorded sex by the cantonal supervisory authority could be considered. This would offer the advantage of sparing (already overstrained) parents, or the person of ambiguous sex, the need for court proceedings. In the assessment of sex, considerable weight should be attached to the individual's self-identified gender, supported by objective grounds, with physical sexual characteristics only being considered secondarily.¹⁷ In view of the significant and unpredictable changes associated with the course of DSD in childhood and adolescence, amendments should be possible within an unbureaucratic, low-threshold framework.

5 Interfaces with social insurance

DSD is one of the so-called congenital conditions for which comprehensive treatment up to the age of 20 years is covered by the Disability Insurance (IV) scheme (Art. 13, para. 1, Disability Insurance Act/IVG). A congenital condition is one which is already present at the end of the birth process. A predisposition to a disease is not sufficient to qualify as a congenital condition.

¹⁷ Cf. Obergericht (Court of Appeals) of Canton Zurich, Civil Chamber II, decision of 1 February 2011 – NC090012/U; FamPra. ch 04/2011, 932 ff. (comments by Andrea Büchler and Michelle Cottier).

Treatments covered by the IV encompass:

1. the congenital condition itself; and, if applicable,
2. all health impairments which medical experience has shown to be part of the symptomatology of the congenital condition; and, if applicable,
3. all health impairments which, according to medical experience, are not part of the symptomatology of the congenital condition, but which frequently occur as a consequence of, and are specifically linked to, the congenital condition (with an “established sufficient causal relationship” between the congenital condition and the secondary disorder).

Given the special nature of DSD as a congenital condition, a number of points arise which need to be taken into account in the application of the IV regulations and may also require adjustments to legal practice and legislation. These points are discussed below.

In DSD, careful diagnosis involves a genetic analysis, which however only provides diagnostic clarification in 50% of cases and which for technical reasons cannot be completed by the end of the birth process. In some individuals, DSD only becomes apparent in puberty, when secondary sexual characteristics fail to develop or characteristics of the opposite sex develop. Cases have also been reported in which DSD was only diagnosed in adulthood. But this does not alter the fact that DSD is a congenital – not an acquired – condition.

Specifying the health impairments which are part of the symptomatology of the congenital condition, or are among the established secondary disorders, is a matter for medical experts. Here, legal practice and the approval of IV reimbursement are based on medical assessments. Such assessments need to be carefully formulated, in particular with regard to possible psychosocial consequences (e.g. disorders of personality development and of behaviour in the family/school setting, psychiatric illnesses). **Especially delicate are those cases where a psychosocial indication is used to justify the medical urgency of surgical sex assignment in children who lack capacity. Here, there is a particularly great risk of insufficient respect being accorded to the child’s (future) self-determination and its physical integrity.** For the establishment of a psychosocial indication involves numerous uncertainties and imponderables.¹⁸ In addition, there is a lack of representative studies with sufficient numbers of cases and control groups comprising untreated or non-invasively treated DSD subjects; also lacking are data on patient satisfaction and on the effectiveness of various surgical sex assignment procedures carried out at different times (from infancy to adulthood).¹⁹ Available studies on psychological state, impairment of body experience and sexual quality of life in people with DSD paint a mixed picture.²⁰

Since IV coverage only applies up to the age of 20, pressure could arise from a medical standpoint to carry out treatments at an early stage. **In or-**

¹⁸ For example, the establishment of a psychosocial indication is based on a subjective assessment, shaped by the clinician’s own values and often involving prognostic statements about expected psychosocial development, despite the inadequate availability of data for an evidence-based approach.

¹⁹ Schweizer/Richter-Appelt 2012, pp. 188ff.

²⁰ Karakazis 2006; Lee et al. 2006, pp. 493f.

der to avoid possibly unnecessary or premature treatments, the Commission recommends that, in consultation with medical experts, the existing age limit specified in Art. 13, para. 1, IVG should be reviewed and revised upwards for somatic and psychological/psychiatric treatments of DSD. Alternatively, the list of items reimbursable under the Health Insurance Act for DSD-related congenital conditions could be brought into line with the IV standard.

Because parents generally take decisions on behalf of their child which impinge on intimate areas of the child's life and its identity, and which can also have fundamental effects on fertility and sexual sensitivity, everything possible must be done to ensure the high quality and authenticity of such decisions. Here, professional counselling and psychosocial support for parents is crucial. From a functional viewpoint, the support provided for parents can be seen as a component of the treatment for the congenital condition, i.e. as an element in the overall therapeutic plan. However, from the perspective of the IV, parents are not currently entitled to receive reimbursable services in connection with a child's DSD-related congenital condition. **The Commission therefore recommends that a legal basis should be established which would provide for a special obligation to cover counselling and support for parents.** It would also be desirable for the costs of counselling and support provided for parents and individuals with DSD to be reimbursed by the IV beyond the age of 20, or alternatively for the list of items reimbursable under mandatory health insurance to be brought into line with the IV standard.

In the area of mandatory insurance coverage, to the Commission's knowledge, people with DSD are not subject to discrimination, although the services covered by the IV are more comprehensive than under mandatory health insurance. However, in voluntary supplementary health insurance – as is generally the case in the private insurance sector – provisos and exclusions are permissible if a medically certified condition exists, which essentially disadvantages people with congenital conditions.

Finally, the Commission notes that the terminology used in legislation (e.g. "true hermaphroditism and pseudohermaphroditism", Ordinance on Congenital Conditions/GgV, no. 359) should be revised, and the standard specialized terminology should be adopted.

6 Recommendations

1. The suffering experienced by some people with DSD as a result of past practice should be acknowledged by society. The medical practice of the time was guided by sociocultural values which, from today's ethical viewpoint, are not compatible with fundamental human rights, specifically respect for physical and psychological integrity and the right to self-determination.

The Commission's other recommendations come under two separate headings – *medical ethics* and *legal ethics*:

Medical ethical recommendations

2. Decisions on medical treatments of a pharmacotherapeutic or surgical nature are to be taken jointly in a multidisciplinary team with the involvement of the parents and, as far as possible, the affected child. As soon as capacity is attained, the affected individual decides for him/herself. The family and cultural context may only be taken into account if the welfare of the child is not jeopardized as a result.
3. The following basic principle should apply to the management of DSD: on ethical and legal grounds, all (non-trivial) sex assignment treatment decisions which have irreversible consequences but can be deferred should not be taken until the person to be treated can decide for him/herself. This includes genital surgery and the removal of gonads, unless there is an urgent medical indication for these interventions (e.g. increased risk of cancer). Exceptions to the general rule would be cases where a medical intervention is urgently required to prevent severe damage to the patient's body or health.
4. Protection of the child's integrity is essential. Given the uncertainties and imponderables involved, a psychosocial indication cannot in itself justify irreversible genital sex assignment surgery in a child who lacks capacity.
5. Professional psychosocial counselling and support should be offered free of charge to all affected children and parents. This support should be expert, sensitive and individually tailored and should extend from the time when DSD is first suspected into adulthood.
6. To guarantee the requisite professional level of counselling, support and treatment services, this function should be concentrated at a small number of specialized centres in Switzerland.
7. Given the sensitivity and complexity of the issues, and the need for interdisciplinary decision-making, the Commission suggests that guidelines on education and training for the professionals involved should be

prepared by the Swiss Academy of Medical Sciences (SAMS) and other competent professional bodies.

8. Clinical treatment guidelines in Switzerland should be based on international standards and, if necessary, should be improved through co-operation at the international level. Accordingly, standard international terminology should be adopted.
9. There is a need for representative studies with sufficient numbers of cases and control groups comprising untreated or non-invasively treated DSD subjects. Data should also be collected on patient satisfaction and on the effectiveness of various treatment methods and surgical sex assignment procedures. To facilitate the practice of evidence-based medicine and to optimize treatment paths, research should increasingly be conducted in cooperation with international partners in these areas.
10. The long-established constitutional principle that no-one is to be subjected to discrimination on grounds of sex also applies to people whose sex cannot be unequivocally determined. Any discrimination resulting from existing regulations must be eliminated.
11. In a case of DSD, it must be possible for the sex recorded in the official registration of births to be unbureaucratically amended. It should be permissible for the cantonal supervisory authority to make such an amendment. The assessment of sex should be guided, as far as possible, by the (verifiable) self-identified gender of the individual concerned, with physical sexual characteristics playing a subordinate role. In view of the unpredictable course of DSD in childhood and adolescence, amendments should be possible without undue bureaucracy.
12. There should be a legal review of the liability implications of unlawful interventions in childhood, and of the associated limitation periods. Questions of criminal law, such as the applicability of offences of assault (Art. 122 and 123, StGB) and the prohibition on genital mutilation (Art. 124, StGB), should also be investigated.
13. The Commission recommends that the age limit ("up to the age of 20 years") specified in Art. 13 para. 1, IVG for IV coverage of somatic and psychological/psychiatric treatments for people with DSD should be raised; alternatively, the list of items reimbursable under mandatory health insurance should be brought into line with the IV standard. The aim would be to make allowance for the special nature of this congenital condition and to avoid any pressure arising for premature surgical sex assignment procedures. Any amended age limit for IV coverage in cases of DSD would be set in consultation with medical experts. If an age li-

***Legal ethical
recommendations***

mit is specified, provision should be made for justified exceptions to the rule.

14. The Commission recommends that, in non-specialist language, DSD should only be referred to as “differences of sex development” or “sex variations”, and that other terms, including “intersexuality”, should be avoided. The terminology used in legislation (e.g. “true hermaphroditism and pseudohermaphroditism”, Ordinance on Congenital Conditions/ GgV, no. 359) should be revised, and the standard specialized terminology should be adopted.

Procedure adopted by the Commission in preparing the Opinion

In order to gain an overview of the various positions, the Commission (plenary session and working group) conducted a total of three hearings with people directly affected and experts:

- Mme A., mother of a child with DSD
- Michelle Cottier, Assistant Professor at Basel University, in cooperation with Professor Andrea Büchler, Zurich University
- Professor Christa Flück, Paediatric Endocrinology, Inselspital Bern
- Professor Ulrich Meyer, President of the Second Social Law Division of the Federal Supreme Court
- Dr Blaise-Julien Meyrat, Department of Paediatric Surgery, CHUV Lausanne
- Dr Francesca Navratil, paediatric and adolescent gynaecologist, Zurich
- Karin Plattner, self-help group “Verein SI Selbsthilfe Intersexualität” and mother of a child with DSD
- Knut Werner-Rosen, psychologist/psychotherapist, Berlin
- Dr Jürg Streuli, Institute of Biomedical Ethics, Zurich University
- Daniela Truffer & Markus Bauer, human rights advocacy group “Zwischengeschlecht.org”

The Commission also took note of written input from the following experts:

- Michael Groneberg, PD, Fribourg University
- Mirjam Werlen, lic.iur./ LL.M., Bern

Literature

References

- Arbeitsgruppe Ethik im Netzwerk Intersexualität «Besonderheiten der Geschlechtsentwicklung» (2008): «Ethische Grundsätze und Empfehlungen bei DSD: Therapeutischer Umgang mit Besonderheiten der Geschlechtsentwicklung/Intersexualität bei Kindern und Jugendlichen», in: *Monatsschrift Kinderheilkunde* 3 (156), 241-245.
- Bosinski H.A.G. (2005): «Psychosexuelle Probleme bei Intersex-Syndrom», in: *Sexuologie* 12 (1/2), 31-59.
- Brinkmann L. et al. (2007): «Gender Assignment and Medical History of Individuals with Different Forms of Intersexuality: Evaluation of Medical Records and the Patient's Perspective», in: *Journal of Sexual Medicine* 4, 964-980.
- Hughes, I.A. et al. (2006): «Consensus statement on management of intersex disorder», in: *Journal of Pediatric Urology* 2, 148-162.
- Karkazis, K. (2006): «Early Genital Surgery to Remain Controversial», in: *Pediatrics* 118, 814-815.
- Kleinemeier, E. et al. (2010): «Jugendliche mit Störungen der Geschlechtsentwicklung», in: *Monatsschrift Kinderheilkunde* 10, 965-971.
- Lee P.A. et al (2006): «Consensus statement on management of intersex disorders. International Consensus Conference on Intersex», in: *Pediatrics* 118 (2), e488-e500.
- Michel, M. (2009): *Rechte von Kindern in der medizinischen Heilbehandlung*, Basel: Helbing Lichtenhahn Verlag.
- Money, J. et al. (1955): «Hermaphroditism: recommendations concerning assignment of sex, change of sex, and psychologic management», in: *Bulletin of the Johns Hopkins Hospital*, 97 (4), 284-300.
- Pasterski V. et al. (2010): «Consequences of the Chicago consensus on disorders of sex development (DSD): current practices in Europe», in: *Archives of Disease in Childhood* 95 (8), 618-U65.
- Schönbucher, V. et al. (2010): «Sexual quality of life of individuals with 46,XY Disorders of Sex Development», in: *Journal of Sexual Medicine*, DOI: 10.1111/j.1743-6109.2009.01639.x.
- Schützmann, K. et al. (2009): «Psychological Distress, Self-Harming Behavior, and Suicidal Tendencies in Adults with Disorders of Sex Development», in: *Arch Sex Behav* 38, 16-33.

- Schweizer, K./Richter-Appelt, H. (2009): «Leben mit Intersexualität: Behandlungserfahrungen, Geschlechtsidentität und Lebensqualität», in: *PID* 1, 19-24.
- Schweizer, K./Brunner, F./Schützmann, K./Schönbucher, V./Richter-Appelt, H. (2009): «Gender Identity and Coping in Female 46, XY Adults With Androgen Biosynthesis Deficiency (Intersexuality/DSD)», in: *Journal of Counseling Psychology* 56 (1), 189-201.
- Schweizer, K./Richter-Appelt, H. (Hg.) (2012): *Intersexualität kontrovers: Grundlagen, Erfahrungen, Positionen*, Giessen: Psychosozial-Verlag.
- Ude-Koeller, S. et al. (2006): «Junge oder Mädchen? Elternwunsch, Geschlechtswahl und geschlechtskorrigierende Operationen bei Kindern mit Störungen der Geschlechtsentwicklung», in: *Ethik in der Medizin* 18, 63-70.
- Wiesemann, C. et al. (2010): «Ethical principle and recommendations for the medical management of differences of sex development (DSD)/ intersex in children and adolescents», in: *Eur J Pediatr* 169, 671-679.

Further reading

- «Intersexualität», in: *Thema im Fokus: Die e-Zeitschrift von Dialog Ethik* (2011) 97.
- Bize R. et al. (2011): «Vers un accès à des soins de qualité pour les personnes lesbiennes, gays, bisexuelles et transgenres», in: *Revue Médicale Suisse* 7, 1712-1717.
- Büchler, A./Cottier, M. (2005): «Intersexualität, Transsexualität und das Recht: Geschlechtsfreiheit und körperliche Integrität als Eckfeiler einer neuen Konzeption», in: *Freiburger FrauenStudien* 17, 115-140.
- Cottier, M. (2011): «Geschlechterleben: Eingriffe in den Geschlechtskörper und das Prinzip der Selbstbestimmung», in: Krebs, A./Pfeiderer, G./Seelmann, K. (Hg.): *Ethik des Lebens: Basler Beiträge zu einer Ethik der Lebensführung*, Zürich: Pano Verlag, 87-109.
- Duttge, G./Engel, W./Zoll, B. (Hg.) (2010): *Sexuelle Identität und gesellschaftliche Norm*, Göttingen: Universitätsverlag.
- Forscherguppe Intersexualität des Universitätsklinikum Hamburg-Eppendorf, Zentrum für Psychosoziale Medizin, Institut für Sexualforschung und Forensische Psychiatrie, Richter-Appelt, H. et al.: *Forschungsbericht 207/208: Katamnestische Untersuchung von erwachsenen Personen mit verschiedenen Formen der Intersexualität und Transsexualität*.
- Fröhlich, U. (2003): *Leben zwischen den Geschlechtern: Intersexualität – Erfahrungen in einem Tabubereich*, Berlin: Ch. Links Verlag.

- Groneberg, M./Zehnder, K. (Hg.) (2008): *«Intersex»: Geschlechtsanpassung zum Wohl des Kindes? Erfahrungen und Analysen*, Fribourg: Academic Press Fribourg.
- Hester, D. (2004): «Intersex(e) und alternative Heilungsstrategien. Medizin, soziale Imperative und identitätsstiftende Gegengemeinschaften», in: *Ethik in der Medizin* 16, 48-67.
- Höhne, S./Finke, R. (2006): Intersexualität bei Kindern, Uni-Med Bremen.
- Intersex Society of North America (2006): *Clinical Guidelines for the Management of Disorders of sex development in Childhood: Consortium on the Management of Disorders of Sex Development*, <http://www.ac-cordalliance.org/dsdguidelines/clinical.pdf> (letzter Zugriff 11.9.2012).
- Intersexuelle Menschen e.V./XY-Frauen (2008): *Schattenbericht zum 6. Staatenbericht der Bundesrepublik Deutschland zum Übereinkommen der Vereinten Nationen zu Beseitigung jeder Form der Diskriminierung der Frau (CEDAW)*. http://intersex.schattenbericht.org/public/Schattenbericht_CEDAW_2008-Intersexuelle_Menschen_e_V.pdf (letzter Zugriff 11.9.2012).
- Karkazis, K./Tamar-Mattis, A./Kon, A.A. (2010): «Genital Surgery for Disorders of Sex Development: Implementing a Shared Decision-Making Approach», in: *Journal of Pediatric Endocrinology & Metabolism* 23, 789-806.
- Klöppel, U. (2010): *XXOXY ungelöst: Hermaphroditismus, Sex und Gender in der deutschen Medizin. Eine historische Studie zur Intersexualität*, Bielefeld: transcript.
- Lang, C. (2006): *Intersexualität: Menschen zwischen den Geschlechtern*, Frankfurt/New York: Campus Verlag.
- Meyer, U. (2009): «Krankheit als leistungsauslösender Begriff im Sozialversicherungsrecht», in: *Schweizerische Ärztezeitung* 90 (14), 585-588.
- Die Philosophin. Forum für feministische Theorie und Philosophie (2003): *Intersex und Geschlechterstudie*, Berlin.
- Richter-Appelt, H./Schweizer, K. (2010): «Intersexualität oder Störungen der Geschlechtsentwicklung: Behandlungen von Personen mit nichteindeutigem körperlichen Geschlecht», in: *Psychotherapeut* 55, 36-42.
- Rothärmel, S. (2006): «Rechtsfragen der medizinischen Intervention bei Intersexualität», in: *MedR* Heft 5, 274-284.
- Streuli, J.C. (2010): «Intersex – eine Problemanalyse im Grenzbereich der Medizin», in: *SGBE Bulletin* 60, 8-10.
- Völling, C. (2010): *Ich war Mann und Frau: Mein Leben als Intersexuelle*, Köln: Fackelverlag.

Westerfelder, M. (2011): «Medizinische und juristische Aspekte zur Behandlung intersexueller Differenzierungsstörungen», in: *Urologe* 50, 593-599.

Zehnder, K. (2010): *Zwitter beim Namen nennen: Intersexualität zwischen Pathologie, Selbstbestimmung und leiblicher Erfahrung*, Bielefeld: transcript.

