

## **A good first step: Germany adopts law banning IGM. But there is still room for improvement**

On March 25, 2021, the German Bundestag adopted a draft law from the federal government “for the protection of children with variants of sex development” (19/24686). The law provides a first, yet non-comprehensive, framework to protect intersex children from non-vital, non-emergency medical interventions.

“This law is the result of more than 25+ years of intersex activism in Germany and we are very glad to see the years of work of national intersex activists have finally come into fruition”, says Dan Christian Ghattas, Executive Director of OII Europe: “We congratulate the German Bundestag for taking this first step towards protecting intersex children from non-vital medical interventions. However, while the law sets a good frame only time will show whether this frame allows for a comprehensive protection of all children with variations of sex characteristics. We therefore especially applaud the German parliament for acknowledging the work in progress character of this law for including in the law a provision and a set of questions that will, in 5 years time, guide the evaluation of the law. This measure shows that the German Bundestag is aware and acknowledges some of the risks and possible legal gaps of the current version law and is committed to extent the protection in the future. We also sincerely congratulate all MPs who voted against a tabled proposal to explicitly exclude intersex children with a CAH diagnoses from the protection offered by the law. These children are one of the biggest group suffering from non-vital medical interventions.”

“We see a lot of the positive points in the adopted law,”, continues Miriam van der Have, Co-Chair of OII Europe, “But we also see risks and gaps that need to be monitored closely. The law, for instance, limit its protection to those children who are diagnosed along the current medical definition of so-called DSDs (disorders of sex development). Once these definitions and diagnoses change the affected children are not covered under the law anymore and left without protection. The law itself establishes these limits. By doing so it yet again defers its political responsibility to protect all intersex children to the medical profession”.

“Taking human rights of intersex children serious and protecting these most vulnerable members of society is an ongoing learning process”, concludes Kitty Anderson, Co-Chair of OII Europe. “We will support our German member organisation in monitoring the implementation of the law and its future evaluation.”

The law envisions three possible situations:

1. **Interventions which *solely* aim to “adjust”, i.e., alter the child’s physical appearance → intervention unlawful, parental consent not possible**  
In this situation parental consent is not possible as the law prohibits parents or legal guardians to “consent to treatment of a child who is incapable of giving consent and who has a ‘variants of sex development’ which, without any other reason for the treatment being added, is carried out solely with the intention of making the child's physical appearance similar to that of the male or female sex”. (§ 1631e (1.1))
2. **Interventions which are not deferrable but vital → intervention lawful, parental consent possible**

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<sup>i</sup> The German law creates a new legal term, "Variante der Geschlechtsentwicklung" (“variant of sex development”). This terminology should not be confused with the human rights compliant term “variation of sex characteristics”. Instead it is equivalent with the diagnostic and pathologising term "disorder/difference of sex development" and used this way throughout the act.

In this case parental consent is possible without any additional procedure, as the justification of the law details: “If there is a danger to life or health and an operation must be performed quickly, it must be assumed that the child would give priority to averting this danger if he or she had full capacity of understanding and judgement; such an operation is therefore permitted without authorisation under the narrow condition mentioned. [...] Subsequent authorisation by the family court is not provided for in such cases. However, the possibility of a later review under criminal or civil law remains open.” (p. 28)

**3. Interventions which include the elimination or aim to eliminate a perceived functional disorder, whether or not there is actually a concrete health risk at the present time → intervention lawful, provided approval by the family court; however with the exception of interventions that become a matter of urgency**

Article 1631e (2) specifies that parents may “consent to surgical interventions on the internal or external sex characteristics of a child who is incapable of giving consent and has a difference of sex development, which could result in an approximation of the child's physical appearance to that of the male or female sex” with the exception of interventions that have the sole purpose of aligning the child’s appearance, as the latter is prohibited by § 1631e (1), and “if the intervention cannot be postponed until the child has made a self-determined decision”.

For all interventions which fall under § 1631e (1.2) parents or legal guardians need to seek the “approval of the family court unless the surgical intervention is necessary to avert a danger to the child's life or health and cannot be postponed until approval has been granted”. The family court may grant the permission on application by the parents if “the planned intervention is in the best interests of the child”. (§ 1631e (1.3))

In order to prove that the planned procedure is in the best interest of the child the parents need to submit to the family court an opinion of an interdisciplinary commission, which consists of the person treating the child, at least one other medical person, one person with a professional qualification in psychology, child and youth psychotherapy or child and youth psychiatry, and one person trained in ethics. At the request of the parents, the commission should involve a counselor with a variant of sex development, however this is not a requirement (§ 1631e (1.4))

If the commission is in favour of the intervention, it shall be presumed that the planned intervention is in the best interests of the child (§ 1631e (1.3)). In addition, in case of a sudden emergence of urgency the intervention can be carried out without the approval of the family court and without seeking any subsequent confirmation from the court after the intervention has taken place.

While these articles, at first glance, seem to ensure a protection of intersex infants and children from non-vital medical interventions, the details show a much more complex picture, which includes clear pros but also, as a con, loopholes and a risk of possible circumvention of its essential aim.

On the positive side the law

- provides a first, yet non-comprehensive, framework towards protecting intersex children from non-vital, non-emergency medical interventions
- makes surgeries that are solely performed for the reason of altering the child’s body to a more normative appearance and without fully informed consent of the intersex child unlawful
- provides for a family court approval procedures for interventions that are to be carried out with the aim to eliminate a perceived functional disorder at the present date or in the future

- provides for an interdisciplinary commission to determine whether such a planned intervention, is to be considered to be in the best interest of the child; the law also includes a set of questions that the opinion needs to address (§ 1631e (1.5))
- does not follow the proposal tabled by one party to explicitly exclude children with a CAH diagnoses from the legal protection; this is especially important as these children make up one of the biggest groups suffering from non-vital interventions
- extends the retention period for medical records for treatment of children with variants of sex development until the age of 48 (§ 1631e (1.6))
- provides for an evaluation of the law after 5 years (§ 1631e (6)) and an obligatory examination by the Federal Government about whether an extension of the provisions is appropriate in the following respects:
  - “1. extending the family court approval procedure to additional types of treatment or to additional groups of children,
  - 2. introduction of a procedure for verifying the capacity of a child to give consent,
  - 3. introduction of requirements for the treatment of children with differences of sex development who are capable of giving consent,
  - 4. introduction of an obligation to seek independent advice on dealing with variants of sex development, and
  - 5. inclusion of a provision on the costs of the opinion of the interdisciplinary commission.”
- the justification of the law mentions some of the most common non-vital interventions and uses them as an example of interventions family courts should consider to be falling under § 1631e (1.1) and hence as prohibited; while having not binding force this addition can give some guidance in family court procedures

Central obstacles that the law places in the way of comprehensive protection of intersex children are:

- lack of universality:
  - the law only protects children with a so-called ‘difference of sex development’ the law fails to protect all intersex children equally,
  - as detailed in the justification of the act, § 1631e (1.2) allows for interventions that are “necessary to cure or eliminate a functional disorder or to maintain reproductive capacity without there being a concrete health risk at the present time”, even if “they result in the physical appearance being adjusted” (p. 27); reports of intersex adults have shown that some of these interventions have a high risk of creating psychological trauma as well as physical health issues if they are performed at an early age and without the intersex individuals personal and fully informed consent (e.g. hypospadias repair, creation of a neo-vagina)
- lack of a clear definition of “urgency”:
  - the law does not specify when an intervention is to be considered too urgent for a proceeding at the family court as laid down in §1631e (1.2); this is even more problematic considering that family courts are used to process urgent applications within weeks and even days and that the law does not provide for the obligation to seek the court’s consent at least a posteriori;
- lack of full protection against possible conflict of interest:
  - the medical professional who treats the child is part of the commission
  - the law stipulates that one of the at least two medial professionals in the commission shall not be employed in the healthcare facility where the surgical procedure is to be performed (§ 1631e (1.4)); while this stipulation aims to limit the risk, the rest of the

commission can still consist of staff of this facility; there is a clear risk of possible bias, in particular considering the still prevailing medicalisation and pathologisation of intersex bodies in medical settings and healthcare facilities specialising in DSD related interventions

- lack of guarantee of comprehensive information
  - while the law stipulates that the commission statement needs to clarify if peer counseling of the parents and the intersex child has taken place, and, if yes, whether the peer counselor supports the planned intervention, it abstains from making this peer counseling a mandatory part of such a process; hence, full information, including non-medicalized information, of the parents and the child is not ensured
- lack of monitoring mechanism:
  - while the law provides for a set of guiding questions for possible future amendments in the context of its evaluation, it does not provide for an ongoing, accompanying monitoring mechanism
- lack of low-threshold access to justice for future intersex adults in case the law is breached:
  - a federal central register for the storage of patient files was not introduced due to time constraints; this makes not only the monitoring difficult but will also likely have a negative impact on the accessibility of medical records for future intersex adults
  - possible penalties via the criminal and civil code but no specific provision that take into account the specific circumstances of the vulnerability of the possible victim of such a breach; in addition, as legal experts have pointed out, the presented law may be at risk to causing challenges in applying the criminal and civil code
- lack of regulation of foreign evasion:
  - prohibited interventions on intersex children, who live in Germany, may still be performed in another country without any repercussions

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