

The use of pathologizing language, omission of information, and how it affects the ability to give full free and informed consent.

During the 3rd cycle, Denmark received recommendations from the Kingdom of The Netherlands, to in consultation with rights holders, develop national guidelines, for responding to people with variations in sex characteristics, including the possibility to postpone non-emergency, invasive and irreversible surgery and hormone treatment on infants and children until they in a meaningful manner, can participate in the decision-making and give their informed consent.

The individuals' right to informed consent is one of the cornerstones in the work for intersex rights. But to be able to properly give consent, you need to be fully informed. The use of pathologizing language, and omission of information, effects the individuals ability to understand what they do consent to - And thereby their ability to consent.

Intersex people should be the only ones to decide whether they wish to modify the appearance of their own bodies, and except in cases with immediate danger to life, procedures should be postponed till the individual is old or mature enough to, in a meaningful manner, participate in the decision making, and give their full free and informed consent.

But medical staff in Denmark, rely heavily on the parents' ability to consent to surgeries and treatments, and are claiming to obtain full, free and informed consent, however the consents given, are often based on pathologizing and extremely inadequate information.

Key rights challenges and their impact:

Despite legal provisions guaranteeing informed consent at the national level, it continues to be undermined in the healthcare settings as a result of the power and knowledge imbalance in doctor-legal guardian relationship.

While powerlessness, exacerbated by pathologization and stigma, result in intersex children being disproportionately vulnerable to the deprivation of legal capacity.

Highly pathologizing or medicalized, poor, inadequate or partial information which lack information about treatment alternatives, the lack of quality evidence to the necessity and benefits for the child of said procedures, and the potential irreversible damage caused by these irreversible, unnecessary surgeries and treatments, is distributed to parents of intersex children prior to asking them to consent to treatments and surgeries.

The questionable nature of the information, and omission of relevant facts, constitutes a barrier, to the individual's full understanding, of what they are actually consenting to.

Recommendations:

1. Ensure that the information material distributed to intersex people, and their parents or legal guardians, inform about treatment alternatives, about the lack of quality evidence to the necessity, and benefits of said procedures, and about the potential irreversible physical and psychological damage, unnecessary surgeries and treatments may cause.
2. Develop and implement a human rights-based legislation that prohibits all forms of treatment and surgery, that affect and/or alter the sexual anatomy of intersex children, until they are mature enough to understand the consequences, participate in decision-making and give full, free and informed consent; except in cases where treatments or surgeries are exclusively aimed at alleviating immediate danger to life, or immediate risk of serious and irreversible physical harm.
3. Educate and train medical and psychological professionals on the range of sexual and related biological and physical diversity, and on human rights of intersex persons, including their right to bodily autonomy, physical integrity and self-determination.