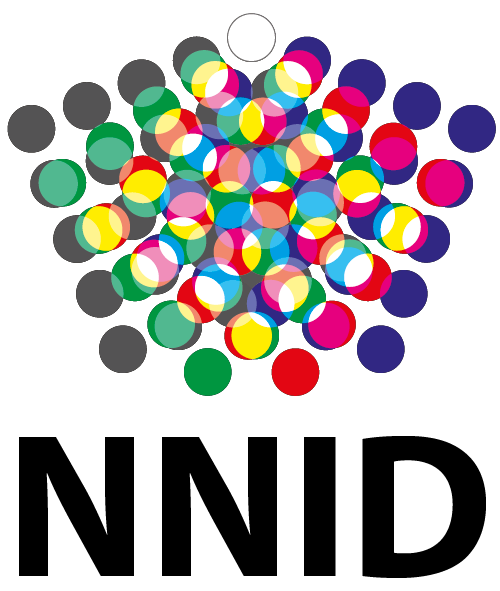
**Intersex Children**

**and the Right to Privacy**



NGO Submission – Privacy and the Child for Special Rapporteur on the Right to Privacy

Joseph A. Cannataci

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**Summary**

Intersex children face substantial violations of their right to privacy, especially as it relates to their independence, autonomy and ability to develop a personal identity. Around the world intersex children are exposed to non-consensual unnecessary medical treatment. These interventions include surgical and hormonal treatment to adjust external and internal sex characteristics in accordance with societal norms of male or female, and psychological treatment to enforce and strengthen the assigned gender. Medical examinations of sex characteristics of intersex children often have an unnecessarily repetitive character and include more attendees than required for the health of the child. Information about intersex children is regularly spread beyond the scope of ensuring health care for the child. This practice is especially common with medical photography and videography of intersex children’s genitalia. A shocking amount of this material can be found online, without any restrictions. Finally, some intersex persons experience difficulty in gaining access to identity documents. We request the inclusion of these issues in the Report of the Special Rapporteur on the right to privacy made to the Human Rights Council.

**Background and Methodology**

Stichting NNID is and intersex-led human rights organization working on the rights, visibility and equality for intersex people. Information in this report is based on peer-reviewed scientific sources, evidence gathered and documented at events and online, and reports made by intersex people to Stichting NNID and other intersex organizations in NNID’s network who reported it to NNID.

**Non-consensual unnecessary medical treatment**

Throughout the world, intersex children are exposed to non-consensual, unnecessary medical treatment to bring their sex characteristics, both externally and internally in line with society’s normative definition of male or female.[[1]](#footnote-1) These treatments include surgical interventions, hormone treatments, and psychological treatments to enforce and strengthen the assigned sex and gender. Several reasons are mentioned by doctors for these treatments, which are not medically necessary, do not follow from any scientific research or can at least be postponed until free and fully informed consent can be given. For example the following arguments have been given to perform such interventions: to follow the parents’ wishes, preventing stigma, reinforcing individual and social identities, preventing the development of sex characteristics not in line with the assigned sex and gender during puberty, facilitating future procreation, and making penetrative sexual intercourse between a man and a woman a possibility.[[2]](#footnote-2) These interventions impede the sexual development of the child and can lead to issues with sexual function and diminished sensation. Additionally, it impedes the development of personal identity, including in terms of gender identity and expression.

Nationals laws that should insure intersex children’s independence and autonomy in unnecessary medical treatment either do not exist or are not enforced. Decisions regarding these interventions are, in most cases, officially made by the parents as they are performed when the children are still too young to provide consent. However, it should be noted that the parents are almost entirely dependent on medical personnel for the information they receive. Parents may not realize that they are de facto opting for experimental treatment on their children[[3]](#footnote-3).

Health professionals often believe that the sex assignment of intersex children is not an issue[[4]](#footnote-4). However, recent research has shown that five percent of *all* intersex children, including those with forms of sex diversity that are usually not recognized at birth, change sex before puberty[[5]](#footnote-5). It is impossible to predict which of the children will belong to the group that will reject the assigned sex.

The main structural problem in the treatment of intersex children is connected to the desire of health professionals and parents to predict the future gender identity of the child and to control the outcome of this prediction (“predict & control”). However, a system is needed in which health professionals gather the information that is required for the child to make decisions regarding intersex when the child is old enough to provide free and fully informed consent (“measure & react”).

The consequences can be severe: unnecessary surgery at young age often leads to lifelong physical and mental health issues due to the irreversible character. When children grow older and their gender identity becomes clear they can be confronted with a body that goes contrary to their identity as a consequence of the medical interventions they received as a child. They will never be able to alter this. It is therefore not surprising that a recent intersex study showed that the number of participants with psychological problems is 4.3 times higher than in the control group and that the number of participants who attempted suicide is 3.5 times higher than in the control group[[6]](#footnote-6). The researchers say that in reality, the percentage of suicide attempts might be higher because a significant number of respondents refused to answer the question about suicide.

Some medical treatments and studies (including a test described as 'clitoral sensory testing and vibratory sensory testing'[[7]](#footnote-7)) for intersex children can be classified as sexual abuse[[8]](#footnote-8). Several scientists and agencies consider the medical treatment undergone by a group of intersex children to be comparable to Female Genital Mutilation (FGM)[[9]](#footnote-9). Additionally, a growing number of intersex people claim to have experienced medical attention as (sexual) abuse[[10]](#footnote-10). All these issues suggest that medical attention is the cause of the issues intersex children and people face and not a result of physical diagnosis.

**Medical examinations and sharing patient information**

While growing up, intersex children in all countries are subjected to regular genital exams. These exams often involve multiple attendees and are often repeated by multiple health workers[[11]](#footnote-11). A Dutch Urologist described at a conference that she starts performing these examinations at a pre-pubescent age because the children are more cooperative at that time[[12]](#footnote-12). A British intersex person explained in an interview that he had stopped counting how many doctors and nurses had seen him naked. Over the past few years it was at least a hundred people.[[13]](#footnote-13) While some examination may be medically necessary, it is highly unlikely that the repeated nature and inclusion of multiple attendees are in the best interest of the child’s medical care. These exams can be damaging to the children’s development and violate their autonomy.

Furthermore, information regarding a child’s sex characteristics can be spread to more people than is necessary for medical care, violating the child’s right to privacy. For example, the mother of an intersex child in India described that gossip among medical attendants resulted in the child’s genitals becoming a matter of curiosity for hospital staff. Some of the hospital’s employees stopped by specifically to look at the child’s genitals and laugh[[14]](#footnote-14).

The report from the taskforce on policy, legal, institutional and administrative reforms regarding intersex persons in Kenya described that many intersex people felt that they were used as ‘specimens’ of curiosity. This was a result of “too much exposure to the doctors, nurses, student interns, who often posed many unnecessary, intrusive and embarrassing questions”[[15]](#footnote-15).

**Medical photography and videography of genitals**

Furthermore, photographs and videos are often taken of intersex children’s genitals, either during examinations or during surgical interventions aimed at adjusting their sex characteristics. These images are regularly shown in medical publications, online and when health workers discuss intersex at conferences. This practice goes far beyond the scope of ensuring health care for the individual child and beyond ensuring that there is teaching material. There is a shocking amount of unrestricted material available online. In some rare cases the faces of the children are shown in the publications, violating their privacy.[[16]](#footnote-16)

This practice persists, despite research that showed that medical photography of intersex children’s genitals is damaging to their development.[[17]](#footnote-17) Parents of several intersex children in Poland even reported to a Polish intersex organization that at one specialized clinic, the photographs of their child’s genitalia were displayed on top of the child’s files. This clinic hereby exposes images of these children’s genitalia to a large number of people. Parents from a conservative Muslim background in India described how their daughter at age 13 was made to remove her clothes by medical staff. Subsequently, a group of doctors took photographs of her genitals on their mobile phones, while she objected.[[18]](#footnote-18) It goes against children’s autonomy when images of their genitals are shared without their consent or even the opportunity to object.

**Identity documents**

It can be challenging for intersex people to gain access to identity documents. Intersex organizations from India, Zimbabwe and Kenya have received reports from members experiencing issues. These problems occur mostly when intersex people’s sex has been registered in a way that did not match the sex characteristics they developed in puberty, or if the assigned gender identity does not match with who they are.

**Conclusion**

Intersex children face serious violations of their right to privacy. The treatment they receive is forced, unnecessary, and without their prior free and fully informed consent. Especially the repetitive nature of physical and mental examinations and in some cases surgical procedures is damaging to intersex children’s independence, autonomy and ability to develop a personal identity. The sharing of photographs and video of intersex children’s genitalia is prolific, while these intersex children have not given consent to this invasion of their privacy. Therefore, we request the inclusion of these issues in the Report of the Special Rapporteur on the right to privacy made to the Human Rights Council.

**Contact information**

Annelies Tukker

Policy Officer

Stichting NNID

Staddijk 91

6537TW Nijmegen, The Netherlands

0031 - 62 87 43 118

annelies.tukker@nnid.nl

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    Geslachtsvariatie en Seksualiteit: 'Voorbij het binaire denken', 29 November 2019, Ede, The Netherlands.

    “I tell them that before they come into puberty, that's when they are often still very open to information and they're not seated across me being irritable. Yes, that is really the time to explain it to them. And to do a physical examination together, because in puberty they find it embarrassing. And if I have seen it before puberty, and I know more or less what it looked like, then I can just talk with them. That physical examination is not nice at all for a lot of people. [They will say:]"Oh then I have to go to that doctor, then I have to take off my underpants again". So, I try to minimize that.” (translated from Dutch to English). Audio recording and transcription available through contact information below. [↑](#footnote-ref-12)
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