**Privacy and autonomy in the health sphere: youth friendly health services**

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## **Preface**

Youth are often minimally discussed in traditional UN spaces. There is more to be done to recognize age as an intersecting form of discrimination throughout the UN Special Procedures mechanism. In 2019, only 33% of Special Procedures reports addressed youth in more than one sentence[[1]](#footnote-2). Youth face unique challenges that are therefore often overlooked or not adequately addressed in Special Procedures Reports. We aim to contribute to the meaningful inclusion of youth, as well to stress their needs, by submitting youth-led contributions such as this report.

We applaud the Rapporteur for focusing this call for submission specifically on young people under the age of 18, although we believe structural attention to the different needs and realities of young people is required to achieve a meaningful participation and integration of young people, and adequate change and justice for all.

## **About CHOICE**

CHOICE for Youth and Sexuality (CHOICE) is a professional youth-led organization that advocates for the Sexual and Reproductive Health and Rights (SRHR) of young people worldwide and for their meaningful participation in the decisions made about their lives. We strengthen the capacity of young people and youth-led organizations on SRHR, meaningful youth participation (MYP), youth leadership and advocacy skills and support them to become leaders and change-makers in their communities, and at national and international level. CHOICE strives to see a world in which all young people have the power to make decisions about their sexual, reproductive, and love-lives, and pays particular attention to youth facing multiple and intersecting forms of discrimination based on race, sex, sexual orientation, gender identity and expression, and ability. CHOICE works with young activists across Africa, Asia and the Americas to execute this vision.

## **What is this submission about?**

Article 16 of the Convention on the Rights of the Child (1989) states:

*a.*     *No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.*

*b.*     *The child has the right to the protection of the law against such interference or attacks.*

In 2016, the inaugural Special Rapporteur on the right to privacy established five thematic areas of work for his mandate, being:

1. Big data – open data
2. Health related data
3. Security and surveillance
4. Corporations’ use of personal data
5. **A better understanding of privacy**

The thematic strand ‘A better understanding of privacy’ is the focus of this call for submissions, and examines the right to privacy in the broader sense of the dignity of the individual. The focus is on how privacy affects the evolving capacity of the child and the growth of the autonomy, and what factors enhance or constrain this development.   
CHOICE will take a closer look at the privacy and autonomy of the child in the health sphere, and what a youth-friendly health service environment with respect to youth’s privacy, entails. This relates to the following point from the questionnaire:

* Online and offline in the social, recreational, educational, justice and health spheres

## **Privacy in (youth-friendly) health services**

Privacy and confidentiality are one of the main concerns for young people when seeking sexual and reproductive health services. They fear confidentiality will be compromised when it’s not clearly stated this will be upheld, and worry about their parents’ or communities response when it’s known they sought SRH services[[2]](#footnote-3). Unfortunately, this concern is often valid. Next to this, young people seeking services are disproportionately subjected to discrimination from health staff. Studies in Kenya, Laos and Zambia documented half to two-thirds of professionals were not willing to provide contraceptives to adolescents[[3]](#footnote-4). In an extensive research where it was examined what factors determined a health service to be perceived as ‘youth-friendly’ by youth themselves, one of the main domains was ‘staff attitude’. The main feeling accompanied with this was **trust**. Young people for example prefer continuity of care with the same provider, building on both feelings of trust and privacy.[[4]](#footnote-5)

**The WHO defines adolescent-friendly health service as one that is accessible, acceptable, equitable, appropriate, and effective. Lack of privacy and confidentiality are one of the most important factors impacting young people’s (perceived) access to services.**

**For a clinic to be youth-friendly, it is important all staff endorses, and is open about their confidentiality policy.** Young people may want to discuss their health issues with their parents or others, but must remain in control of their private information and professionals must thus ensure young people are provided with confidential care at all times. When the young person is a minor, their confidentiality might be challenged.

In some countries, the law namely requires parental consent for minors to access certain sexual and reproductive health services. The law might also state an obligation for a professional to report a girl to the police who may have had an illegal abortion or if she’s in a same-sex relationship. This shows how related laws criminalizing sexual behavior or abortions impact the autonomy and privacy, and thus health and safety of young people. For young LGBTI, the most notable concern is the criminalization of same-sex relationships. Irrespective of consent, homosexual acts committed in respect of minors are subject to increased penalties. Fearing penalties for being in a same-sex relationship creates another barrier for accessing health information and services (UNFPA, 2017).

Another set of laws that gravely infringes upon the privacy of young people is the criminalization of HIV transmission. Besides fueling stigma against people living with HIV, this can drive people further away from prevention and treatment. The UNFPA report ‘Harmonizing the Legal Environment for Adolescent Sexual and Reproductive Health and Rights’ (2017) states: ‘*Countries such as South Africa have also show that criminalizing HIV transmission can infringe on the right to privacy to an extent that is not justified, as it requires inquiry into intimate medical histories and sexual affairs*.’[[5]](#footnote-6)

Echoing the recommendations mentioned in the UNFPA report, CHOICE therefore also recommends to:

* Push for the decriminalization of same-sex relationships;
* Decriminalize transmission with no exceptions and monitor application of the general criminal law focused on the intentional transmission of HIV to ensure it is not used inappropriately.

Research showed an increase in teen pregnancies after parental consent was set as a requirement for young people (under 18) to access contraceptives.[[6]](#footnote-7) Not only a rise in teen pregnancies seems to be an effect of enforcing parental consent: a study among minors at 33 Planned Parenthood clinics in the United States found that 47% of minors indicated they would stop using all family planning related services if their parents were notified they sought birth control. Another 12% indicated that in the case of parental involvement, they would delay testing and treatment for sexually transmitted infections including HIV or pregnancy testing and care.[[7]](#footnote-8)

**Mandatory parental notification or consent for prescribed contraceptives clearly impedes young people’s use of sexual and reproductive health services, risking an increase in teen pregnancies and the spread of STIs including HIV.**

The research also addresses proponents of this measure: ‘*Proponents argue that requiring parental notification would strengthen parents’ ability to educate their children and safeguard them form the medical risks associated with prescribed contraceptives. Some proponents also believe that mandating parental notification would encourage adolescents to use condoms rather than prescribed contraceptives, reducing rates of sexually transmitted infections.’*

Both arguments can be debunked. A health professional is capable, and arguably more so than the average parent without medical training, to inform the minor of the health risks associated with prescribed contraceptives, and providing (parents’) space for (comprehensive) sexuality education should not hamper access to services in any way. The research also proves mandating parental notification does not reduce, but increases the rate of STIs.

**Information about any legal obligation to involve the parents, guardian or authorities must therefore be clear at the beginning of a consultation, as this poses a grave threat to the privacy, safety and wellbeing of the minor in question.**

The breach of confidentiality described here might be lawful, but is not necessarily in line with (medical) ethics, or with the best interest of the minor in mind. Agreements should also be made for follow-up of consultations. In messaging from health professional to patient, chances of exposure of private information to family members or friends must be minimized. There are exceptions: a breach of privacy might be necessary in case the professional suspects (sexual) abuse of the minor.

When parental notification or consent is enforced or not, is a rather controversial issue. CHOICE recommends the privacy of the child prevails when their wellbeing and safety could be compromised by enforcing parental notification or consent. **Respect to bodily autonomy and thus related privacy rights must be protected for everyone, including persons under the age of 18.**

## **Zooming in: in the Netherlands**

### **Rights of minors in Dutch health care**

In the healthcare sector (including mental health care), clients and patients have specific rights, which are summarized under the WGBO. This law consists of three age groups, with each of them having specific conditions:

* + Children under 12 years’ old
  + Youth from 12 till 16 years’ old
  + Youth above 16 years’ old

Children under 12 years old are not allowed to decide on any medical procedure and need consent from both guardians or parents for any procedure or treatment. Both of the parents/guardians need to be fully informed about the decisions they make for their child. Parents also have the right to access the medical record of the child. The physician is not allowed to give insight in the record to the child themselves, but parents are allowed to share the information with the child.

Youth between 12 and 16 years old need to give additive consent (besides their parents/guardians) to the (medical) procedure/treatment and all parties need to be fully informed. Both youth and parents can access the medical record and the young person can also object to the right to insight of (one of the) parents, which the physician has to record.

From 16 years onwards, youth can decide on their own about any medical procedure. They have to be fully informed and can (independently from their parents/guardians) give agreement on a certain treatment or procedure, unless they are deemed incompetent (in this case they need a legal guardian/parent).

### **Abortion**

In line with the rules stated above, between the age of 12 and 16 years old, both the consent of the legal guardians and the child is needed to perform an abortion. In the case of abortion, there are several exceptions where a medical doctor is allowed to carry out abortions without the consent of the parents:

* The abortion is needed to avoid serious harm to the child; or
* The child deliberately continues to wish for abortion, even if the parent(s) with authority has refused to consent

In the ideal situation, the parents will be informed about the procedure, to help the child with any emotional or other distress, but if this is not possible (for any reason), then the medical doctor is tasked with giving the right supportive guidance for the child and record this in an appropriate way in the medical record (to avoid the parents receiving information or bills of the abortion).[[8]](#footnote-9)

**CHOICE supports this Dutch best practice of the principle of engaging or informing parents or guardians when possible and useful, unless this compromises the wellbeing and safety of the young person.**

## **Recommendations**

Recommendations have been taken up throughout the text. They are repeated below:

* + Clinics offering services to young people ensure their staff endorses, and are open about their confidentiality policy.
  + Information about any legal obligation to involve the parents, guardian or authorities is made clear to the young person at the beginning of a consultation, as this could pose a grave threat to the privacy, safety and wellbeing of the minor in question.
  + When the health, overall wellbeing or safety of the young person could be compromised, health professionals refrain from notifying parents or guardians.

Recommendations on related laws that endanger the right to privacy and bodily autonomy of young people:

* + Push for the decriminalization of same-sex relationships
  + Decriminalize transmission with no exceptions and monitor application of the general criminal law focused on the intentional transmission of HIV to ensure it is not used inappropriately.

1. CHOICE keeps track of this through internal research using an index. [↑](#footnote-ref-2)
2. Kennedy, E. C., Bulu, S., Harris, J., Humphreys, D., Malverus, J., & Gray, N. J. (2013). “Be kind to young people so they feel at home”: a qualitative study of adolescents’ and service providers’ perceptions of youth-friendly sexual and reproductive health services in Vanuatu. *BMC health services research*, *13*(1), 455. [↑](#footnote-ref-3)
3. Braeken, D., & Rondinelli, I. (2012). Sexual and reproductive health needs of young people: matching needs with systems. International Journal of Gynecology & Obstetrics, 119, S60-S63. [↑](#footnote-ref-4)
4. Ambresin, A. E., Bennett, K., Patton, G. C., Sanci, L. A., & Sawyer, S. M. (2013). Assessment of youth-friendly health care: a systematic review of indicators drawn from young people's perspectives. *Journal of Adolescent Health*, *52*(6), 670-681. [↑](#footnote-ref-5)
5. UNFPA: Harmonizing the Legal Environment for Adolescent Sexual and Reproductive Health and Rights (2017). Via: <https://esaro.unfpa.org/sites/default/files/pub-pdf/2017-08-Laws%20and%20Policies-Digital_0.pdf> [↑](#footnote-ref-6)
6. Zavodny, M. (2004). Fertility and parental consent for minors to receive contraceptives. *American Journal of Public Health*, *94*(8), 1347-1351. [↑](#footnote-ref-7)
7. Reddy DM, Fleming R, Swain C. Effect of mandatory parental notification on adolescent girls’ use of

   sexual health care services. JAMA. 2002;288:

   710–714. [↑](#footnote-ref-8)
8. https://www.knmg.nl/advies-richtlijnen/artseninfolijn/praktijkdilemmas-1/praktijkdilemma/wanneer-mag-abortus-bij-minderjarige-zonder-medeweten-ouders.htm [↑](#footnote-ref-9)