



# Private Matters:

## Supporting the Sexual Health of New York's Youth by Protecting Sexual Privacy

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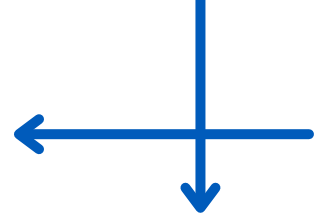
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For additional details about this project and our findings, see: Bay-Cheng, L. Y., Mencia, J. J., Ginn, H. G., & Odigie, H. E. (2021). Between rights on paper and capabilities on the ground: Policy-based barriers to marginalized women's sexual rights. *Sexuality Research & Social Policy*.

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# INTRODUCTION



In New York State (NYS), a minor is defined as anyone 17 years of age or younger [1]. Even though they are not considered adults, NYS grants minors the right to complete and confidential sexual health care if they are deemed as having the capacity to consent [1].

## What is Capacity to Consent?

Capacity to consent is defined as an individual's ability to understand information relevant to a decision and the potential consequences of a decision [1]. Providers assess someone's capacity to consent based on that person's ability to answer questions and communicate clearly. As examples, intoxication and some health conditions or disabilities may be seen as interfering with someone's capacity to consent [1].

***Even with laws asserting their right to complete and confidential sexual health care, NYS youth still face barriers to actually utilizing that right.***

The UB Capable Girls Research Team interviewed 39 service providers from various agencies in Buffalo, New York. Additionally, we consulted girls living in Buffalo about their sexual health rights and access to resources. Both providers and young women pointed out two major barriers to allowing youth to exercise their right to sexual health services:

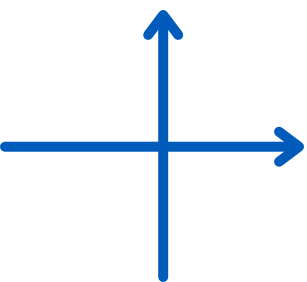


**Uncertainty among youth and providers about youths' right to privacy.**

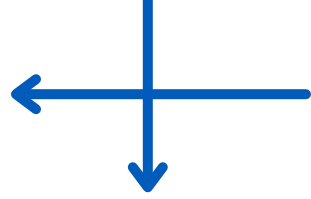


**Insurance Practices (e.g., EOBs) that threaten youths' right to privacy.**

In the next sections, we summarize how **privacy** affects youth sexual health and recommend ways to reduce these two privacy threats [5].



# WHY PRIVACY MATTERS



As mentioned, the UB Capable Girls study found two major barriers to minors' privacy when accessing sexual health services:

## 1 **Uncertainty about minors' rights among both young people and service providers**

Despite young people having the right to sexual health services, this is not always understood by the patient or provider [5]. While many providers support confidentiality and generally feel comfortable discussing sexual health with minors, they also admit to needing additional training regarding confidentiality and minors' rights [2].

In the UB Capable Girls project providers explained:

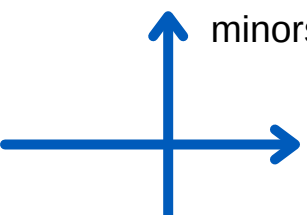
- The challenges of knowing what information to share with whom, including mandatory reporting laws or ideas regarding parent/guardian rights
- How providers' personal values regarding sex, sexuality, and parent/guardian rights influenced their work with youth
- The uneasiness that accompanies working with youth regarding sexual issues and doing something "wrong" (e.g., going against a parent's wishes)

We also found that girls in Buffalo were uncertain of their rights and did not trust that healthcare providers would honor them [5].

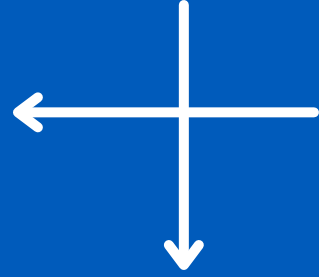
## 2 **Insurance practices that expose confidential information about services received by minors**

Explanation of Benefits (EOBs) are another threat to maintaining youths' privacy [5]. EOBs are documents associated with health insurance that report any received treatments to the policyholder [3]. EOBs are sent to the primary policyholder after they or someone on their insurance plan has seen a healthcare provider. EOBs show the service received, the cost, and how the fee was covered [3].

In NYS, EOBs are mandated by state law and must include information on the services provided [3]. Few protections exist in NYS to address confidentiality breaches caused by EOBs [3]. While these options are important, protections to minors are scarce and do not prevent lapses in confidentiality from occurring [1,3].



# THREATS TO SEXUAL PRIVACY



*They're [other providers] either so cautious that everything is reported because they don't really know what to keep confidential, or they're afraid of it falling back onto their shoulders. They just don't know that they have to report or they don't really recognize where a report should be based.*

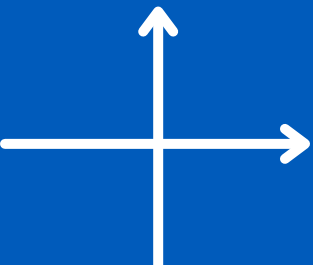
**- sexual health care provider**

*I agree that privacy is a big barrier. I'm always worried that if I talk to a doctor about something, or someone about anything, that my mother will find out.*

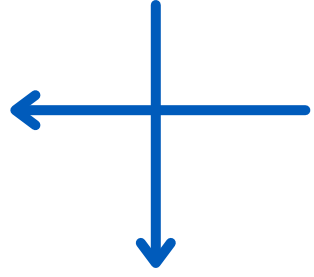
**- youth consultant**

*I get nervous when talking to healthcare providers because I feel like they are going to judge me or are going to tell everything I say to my parents, which I wouldn't want from a healthcare provider.*

**- youth consultant**



# IMPORTANCE OF SEXUAL PRIVACY



Confidentiality threats can have many negative impacts on young people, especially those who forgo healthcare due to privacy concerns [4]. This is troubling, as young people who are concerned about confidentiality also report stress and poor communication with parents and guardians, meaning they may have less social support than others [4].

Girls who raise concerns about privacy also experience other sexual health disparities, including: lower contraceptive use; prior diagnosis of Sexually Transmitted Infections (STIs); unwanted pregnancies; substance abuse; suicidal thoughts; and suicide attempts [4]. Other young people mention delaying necessary sexual health services, substance abuse treatment; mental health treatment and interpersonal violence care due to privacy concerns [4].

Confidentiality concerns are based in real fears about serious consequences, including: violence, abandonment, or ostracism - by parents, partners, or peers - for being sexually active at all, for possible outcomes such as pregnancy, or if their sexual orientation is exposed [6].

17.6%

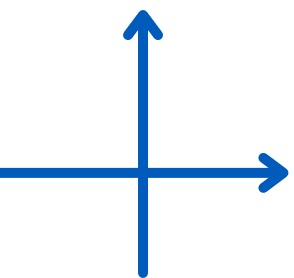
Of young people ages 15-17 stated that they would not seek health care due to confidentiality concerns [9].

34%

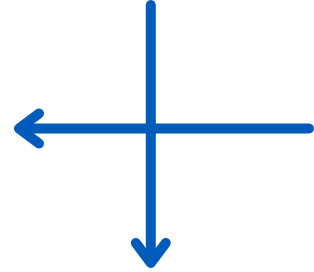
Of young people ages 15-17 those who had confidentiality concerns were less likely to receive sexual health services [9].

36.8%

Of young people ages 15-17 were able to spend time alone with their health care provider during a visit without the presence of another adult [9].



# PROTECT YOUTH SEXUAL PRIVACY:



## Adopt a Youth Sexual Rights Statement

To reduce the uncertainty of both youth and providers, we recommend that all agencies and providers working with youth start using a Youth Sexual Rights Statement. Below, we offer an example of what this could look like.

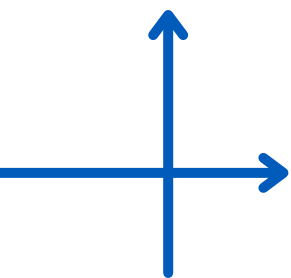
Anyone consulting youth regarding sexual matters would recite verbatim the identical brief, plainly-phrased description of their right to privacy. The uniform repetition of this statement by providers across fields and settings - in health clinics, in schools, community programs, and on - would deliver a clear, consistent message about confidentiality and providers' commitment to honor it.

*As a minor in New York State, you have the right to comprehensive and confidential sexual health care. This means that no one, including parents or guardians, gets to know what happens during this appointment unless you tell them. This includes what we talk about, any tests or treatment you get, or whatever next steps you take.*

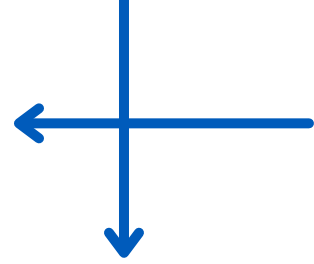
*Three important details:*

- 1. If I think you or someone else is in danger, I have to contact authorities who are able to help.*
- 2. If someone tests positive for a sexually transmitted infection, I have to report this to the Department of Health, but no one else.*
- 3. Depending on what kind of health insurance you have, there may be extra steps we need to take to protect your privacy.*

*Do you have any questions about your sexual rights?*



# PROTECT YOUTH SEXUAL PRIVACY:



## Pursue Legislation to Change Insurance Practices

The privacy threat posed by EOBs affects youth across the U.S., and some states have passed legislation to change this. States such as California and Massachusetts offer New York two models to follow:

### California's Confidential Health Act (CCHA)



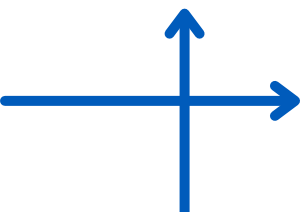
CCHA provides a Confidential Communications Request (CCR), which notifies insurance companies to stop sharing confidential information with the policyholder of the insurance. Prior to seeing a healthcare provider, a patient would submit a CCR to their insurance plan if they would like information about their services to be kept from the policyholder. Insurance companies are automatically mandated to accept CCRs if the services are related to sexual health services, sexual assault services, and substance abuse treatment. A CCR prevents a policy holder from receiving any information related to the confidential care, such as an EOB or other forms of communication [7].

### Protect Access to Confidential Healthcare (PATCH)

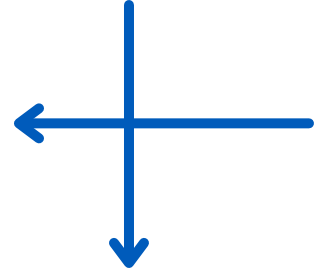


PATCH is legislation in Massachusetts that guarantees confidential information is not shared with any other member on the insurance plan. Under the PATCH Act, EOBs can be sent directly to the patient, to a different address, not be sent for certain services, require insurance companies to use generalizable terms when describing sensitive services, and avoid describing services altogether. Additionally, the PATCH Act mandates that insurers inform subscribers of options to have their confidentiality maintained [8].

NYS laws regarding confidentiality provide little direction to insurance companies for navigating billing and claims, which creates ambiguity about how to protect minors' privacy [11]. Billing procedures also vary by company, making it difficult to prevent confidentiality breaches [11]. Greater collaboration between health insurance companies and health care providers is necessary to develop confidential billing practices [10].



# PROTECT YOUTH SEXUAL PRIVACY:



## Navigate Around Privacy Threats

While legislative adaptations are ideal, this process is timely and involves agreement from multiple stakeholders. In the meantime, it is essential that healthcare providers understand and implement alternative solutions to provide confidential care despite the current lack of protections.

In our conversations with service providers, they offered tips to protect youths' rights to privacy:

### When Meeting:



- Talk openly and explain clearly any potential confidentiality issues
- Help youth call insurance companies with questions and concerns and assist them in finding alternative insurance options if needed (e.g., NYS's Family Planning Benefit Program)

### When Recordkeeping:



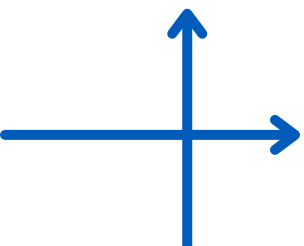
- Require patients' consent before sharing information with a third-party (e.g., anyone the patient may designate to pick up medication, schedule appointments on their behalf, discuss medical information)
- Adjust recordkeeping to indicate when confidentiality is needed by a patient (e.g., "Confidentiality needed!" alert or option in bookkeeping and online records/charts )

### When Communicating:

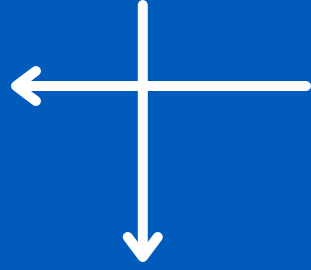


- If contacting youth, use the mode of communication (text, email, phone, etc.) that youth prefer
- If sending or leaving a message, use only generic names and terms (e.g., do not use your agency's full name)

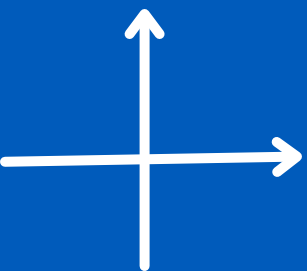
Although some of these steps are specific to health care, others are relevant to all youth services. This is especially important since sexuality-related issues may come up in many different settings. **Anyone working with youth should be prepared to honor their rights.**

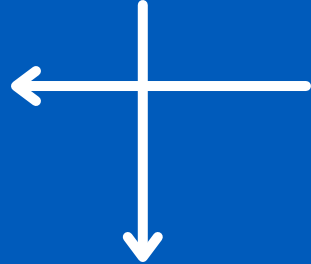


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