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Unlocking Transformation and Healing: Confidentiality Policy Options for Accessible Youth and Young Adult Mental Health Care

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Policy solutions that work for low-income people

Unlocking Transformation and Healing: Background

The Center for Law and Social Policy's (CLASP) youth and young adult mental health framework calls for policy change that increases access to mental health supports that are healing and transformative for youth and young adults.[1] Through our Policy Advancing Transformation and Healing (PATH) initiative, CLASP has collaborated with partners over the last year to test this framework and advance systems and policy changes that support well-being for transition age youth and young adults (ages 16-25).

Today, too many young people can't get the mental health care they need

The challenges that nearly 1.1 million young people experience obtaining mental health services are the result of decades of failed policymaking that have created barriers, rather than clearing pathways, to care. Our work over the last year has led us to identify a set of policy options with broad applicability and strong potential to increase access to transformation and healing for economically marginalized youth and young adults. This brief examines barriers to confidentiality in young people's care and how state policymakers, insurance plans, youth health providers, and families can make improvements.

Confidentiality in mental health care is critical, as young people may forgo treatment without it. When young people are empowered to make informed health care decisions, they begin developing positive help-seeking habits, which has a beneficial, long-term impact on their health and wellbeing.[2] Leading U.S. medical associations agree on the importance of confidential care for adolescents.[3] When young people know care is confidential, they are more likely to seek health services, disclose risky behaviors, and return for follow-up care.

When their confidentiality isn't assured, youth and young adults are more likely to forgo care, especially those who are most at risk. Adolescents with higher-risk report engaging in health risk behaviors, experiencing psychological distress, and/or struggling to communicate with their parents.[4] Involving young people in health care decisions fosters autonomy, promotes good decision-making skills, and prepares them to take control of their health throughout their life. Further, when someone buys-in to their care, their treatment is more effective.[5]

A 2002 study found that almost **3 in 5 young women under 18 would stop using all or some sexual health care services if their parents were informed about it.**[6] In another study, **more than one in three adolescent respondents listed confidentiality concerns as the leading reason for forgoing care**.[7] Among both genders surveyed, young people who had experienced high depressive symptoms, suicidal ideation, and suicide attempts reported confidentiality concerns as a reason for forgoing health care at a significantly higher rate.

Young people should be educated on consent and confidentiality requirements, which are determined by a combination of federal and state laws, provider decisions, and insurance policies. The Health Insurance Portability and Accountability Act (HIPAA), a federal law, issues general guidance on the confidentiality of protected health information. State laws primarily determine when a minor can consent to their own care. Under HIPAA, in general, if a minor consents to their own care, that care is confidential. However, private insurance company policies can often breach that confidentiality when a young person is listed as a dependent. This brief discusses each of these issues in more detail.

Health Insurance Portability and Accountability Act

Our right to confidentiality in health care is primarily established by the Health Insurance Portability and Accountability Act (HIPAA).

This law establishes the confidentiality of medical information and how it can be shared. Signed into law in 1996, it mandates industry-wide standards for health care information and requires the protection and confidential handling of protected health information.[8]

The HIPAA Privacy Rule protects medical records and other health information by creating limits and conditions on how they can be disclosed without a patient's authorization. Each person has the right to examine and obtain their health records and to request corrections.[9] Health information can be shared with other health providers for treatment and care coordination. It can also be shared with family, relatives, and friends who are involved in a person's health care.[10] However, the person undergoing treatment can decide with whom their information can be shared.[11]

The State Policy Landscape on Minor Consent

Consent is primarily determined at the state level through minor consent laws.

These laws determine if/when a minor can consent to their own care. Generally, a parent or legal guardian must consent before a minor receives care.

However, there are exceptions that allow minors to consent to their own care.[12] These allowances are generally made by state statute, and they fall primarily into two categories:

1) exceptions based on the status of the minor
2) exceptions based on the kind of care provided

Status: Which young people can consent to their own care?[13]

- Emancipated Minors
- Married Minors
- Minors in the Military
- Minors living apart from their parents, including minors who are experiencing homelessness
- Minors who are pregnant
- Minors who are incarcerated

Care: What kind of care can a minor consent to?[14]

- Family planning services
- Abortion services
- Care related to STDs
- Drug/Alcohol Treatment
- Mental Health care
- Emergency Care
- General Medical Care

Red = Every state | **Yellow** = Almost every state | **Blue** = some states

A closer look at state laws governing young people's consent

Family Planning Services, Contraceptive Care, and Abortion Services[15]:

Even in states without a specific statute, there is a basis for minors to consent to family planning services, contraceptive care, and abortion. Based on federal law, minors can consent to family planning care at any site that receives federal Title X Family Planning Program funding. They can also consent to such services if they are using Medicaid to pay for their care. Further, they can consent to reproductive health care if there is no valid statute prohibiting them from doing so. For abortion services, a series of Supreme Court rulings beginning in 1976 determined that parents do not have an arbitrary right to veto abortion decisions made by their minor children. Based on this, states that require parental consent must also create alternative mechanisms for a minor to obtain an abortion without this consent.

Drug and Alcohol Treatment and Mental Health Care:

State laws vary when it comes to allowing minors to consent to treatment for drug and alcohol use and other mental health services. Some states allow consent by minors only; others require both a minor's and their parent's consent; and still others accept consent from either the young person or their parents. By the numbers[16]:

- **In 49 states**, minors can consent to some kind of care related to drug/alcohol use. Utah is the only state with a specific statute explicitly stating minors cannot consent to drug/alcohol treatment.
- **In 34 states**, they can consent to outpatient mental health services without needing parental consent.
- **In 24 states**, minors alone can consent to some kind of mental health or substance abuse care, but there is no consensus among states regarding the type of care (whether it is mental health or substance abuse care) or the modality of care (whether it is inpatient or outpatient).

Only **14 states** are consistent across treatment type and modality[17]:

- **9 states** allow minors-only consent regardless of the type or modality of care.
- **5 states** allow consent by either minors or parents regardless of the treatment type and modality.
- In every other state, the requirements for inpatient treatment may differ from the requirements for outpatient treatment, and the requirements for mental health care may differ from the requirements for substance abuse care.

General Medical Care: The Mature Minor Doctrine[18]

The "Mature Minor" doctrine establishes the right of health care providers to treat older adolescents without seeking parental consent, so long as the young person can and does give informed consent. While only a few states have formally incorporated this doctrine, the Supreme Court has acknowledged it without specifying a precise definition. State statutes and judicial decisions formalizing the doctrine differ in their definition of "mature minor" and in the scope of care to which they can consent.

Minor Confidentiality: HIPAA, State Laws, and Private Insurance

> **Confidentiality for youth who are minors is determined by a combination of both minor consent laws and the HIPAA privacy rule. However, private insurance companies can breach confidentiality, notably by sending an Explanation of Benefits (EOB) to the primary policy holder.**

If a state has not passed a specific statute regarding minor confidentiality and consent, they defer to the HIPAA privacy rule. Generally, a parent does not have the right to access a minor's health information if:

- a young person consents to their own health care;
- a young person receives health care without parental consent;
- a parent has agreed to confidentiality between the young person and their health care provider;[19] or
- a provider believes granting parental access will cause harm to the young person or to someone else. However, this provision primarily relates to situations of domestic violence, abuse, or neglect.[20]

Parents and guardians can also proactively ensure their minor child's confidentiality by:

- signing a release form granting their child the right to consent to medical care;
- providing advance consent for their child to access a broad array of care; and agreeing for their child to have a confidential relationship with a health care provider.[21]

Confidentiality based on care:

Reproductive Health Care

- Sites that receive Title X Family Planning funding are confidential.
- Medicaid requires confidential family planning services be available to adolescents with Medicaid.[22]

Drug/Alcohol Treatment

- In forty-eight states, minors can obtain confidential treatment for substance abuse.[23]

Mental Health

- Forty-eight states have laws expressly allowing minors to receive confidential treatment for mental illness, including addiction.[24] Utah and Wyoming are the only two states without a specific statute expressly allowing minors to receive confidential treatment.

Private Insurers' Explanation of Benefits (EOB) can Breach Confidentiality

The Affordable Care Act (ACA) allows young adults up to age 26 to remain on their parent's insurance. While this helps to expand coverage to 18-25-year-olds, it has the unintended consequence of increasing violations of their confidentiality. Many insurance companies communicate mainly with the primary policyholder, risking the confidentiality of young people who are listed as dependents and receive services through the plan. One major way this happens is when the health insurer sends the policyholder an Explanation of Benefits (EOB).[25]

Private insurance companies send policyholders an EOB to inform them of insurance claims and actions taken on their account by anyone covered under their policy, including dependents on the plan. Young people could be listed as dependents on their parents plan or on their spouse's plan. Generally, the primary insurance holder receives the EOB—not the individual who received services. While these documents help to hold insurance companies accountable and reduce fraud, they also pose a challenge to confidential service delivery.[26] EOBs can contain protected health information and list the services provided.[27]

The fear of a confidentiality breach through an EOB could prevent young people from accessing certain services, such as reproductive health and mental health care. Additionally, to ensure confidentiality, young people with private insurance may seek services at already overburdened safety net providers, or providers may opt to not bill private insurance to protect confidentiality, forcing young people to pay a higher out-of-pocket cost for services their insurance covers.[28]

Whose confidentiality is at risk when it comes to EOBs?

The Affordable Care Act (ACA) gave many young people access to health insurance, notably through allowing young people to remain on their parent's insurance up to age 26. In 2013, 15 million young adults (19-25) were on their parents' health plans. 7.8 million would not have been able to enroll prior to the ACA .[29] While this advanced young people's access to needed mental health services, it increased the likelihood of EOBs breaching confidentiality, especially considering 42% of insurance claims for young adults are related to mental health and substance abuse services.[30] According to 2018 data:

18-25 Y.O.

40% living in poverty have private health insurance

47% between 100% and 200% FPL have private insurance

16 Y.O.

18% living in poverty have private health insurance

36.1% between 100% and 200% FPL have private insurance

17 Y.O.

16.1% living in poverty have private health insurance

35.1% between 100% and 200% FPL have private insurance

Both policymakers and insurance companies can help avoid harmful violations of young people's confidentiality by closing gaps in EOB policy.

There is no federal guidance governing EOB issuance or suppression. In about half the states, the law either requires or presumes an EOB be sent to policyholders. At least eight states have adopted statutes or regulations that protect the confidentiality of dependents. However, many EOB procedures are determined by health plan contracts and insurance policies, not state regulations. Therefore, individuals can sometimes negotiate directly with their private insurance company to address potential confidentiality breaches.

Policymakers, insurance companies, and providers can pursue a number of strategies to prevent EOBs from breaching confidentiality. They can enact policies that change the recipient of an EOB, enact policies that prevent an EOB from being sent in limited circumstances, or enact policies that edit the content of an EOB. Current Procedural Terminology (CPT) codes could be used in the latter two strategies. Operated by the American Medical Association (AMA), CPT codes describe medical services and procedures. They are used in health insurance billing to notate what services were provided. Each of these strategies, described

below, have strengths and drawbacks. Therefore, to be most effective, more than one strategy should be adopted.

Changing the Recipient of an EOB[31]

One promising strategy is allowing young people who get care to request an EOB be sent to their preferred address, not to the policyholder. In some states and with some insurance companies, individuals can call their insurance companies to make the request. However, this solution places the burden on young people; dependents would need to be aware of this option and take the initiative to call their insurance company. Further, if a physical EOB must be sent, dependents who live with the primary policyholder may be unable to provide an alternate address.

Using CPT codes to suppress an EOB or to edit its content[32]

CPT codes could be used in two innovative ways to prevent confidentiality breaches in EOBs. One strategy is to create a CPT code for confidential services. For any service coded this way, an EOB would be suppressed. This strategy doesn't require work on the part of the person receiving care, but instead, it places the onus on practitioners familiar with insurance protocols. However, in states that require EOBs be sent without exception, there may be legal and logistical issues that are difficult to overcome. Further, all CPT codes would need to be approved by the AMA.

A second policy strategy would be using CPT codes to edit the content of an EOB. A generic CPT code could be applied for sensitive services, changing the specificity of care shown on the EOB. Instead of listing the specific health services provided, the EOB would list the general kind of care given. Yet this option also has its challenges: the policyholder would still receive an EOB, which could include the location where health services were provided. This means that policyholders could infer information even from limited details, and/or pressure dependents into divulging information.

Examples of States Currently Working to Protect Young People's Confidentiality in Health Care

Policymakers can look to existing policy approaches that prioritize youth access to confidential health care. A number of states have taken measures to prevent confidentiality breaches:

- **In Washington,** when a minor or adult consent to their own care, insurers cannot disclose any protected health information (PHI) including through mailing an EOB. Without the consent of the patient, insurers and health care providers are also prohibited from mailing appointment notices or calling the home to confirm appointments. Further, insurers cannot require minors to obtain permission from the policyholder prior to receiving care.[33]
- **In Connecticut, Delaware, and Florida,** laws establishing minor consent for STI treatment further stipulate that care must be confidential, including in relation to sending a bill.[34]
- **In Colorado,** health plans must develop a way to communicate directly with a dependent.[35]
- **In Maine,** a young person can withhold consent when the policyholder requests an EOB. Without their consent, the insurance company cannot disclose the EOB to the policyholder. While this protects confidentiality, the primary policyholder will still know the dependent accessed care and may pressure them into revealing information about it.[36]

Policy Recommendations to Advance Confidentiality for Young People's Mental Health Care

State policymakers have the authority to promote and protect confidential care for youth and young adults. Changes to minor consent laws typically require legislative action, while some efforts to suppress EOBs can be handled administratively. Together, exercising these policy options can help to ensure that young people don't forgo necessary care because of confidentiality concerns. We recommend the following policy solutions:

- Codify the mature minor doctrine, which allows young people to consent to a broad range of care.
- Develop a set of comprehensive release forms for broad parental consent and confidential minor-provider relationships. Ensure these forms are distributed to providers who serve adolescents.
- Encourage providers to discuss the benefits of confidential care with parents and minors.
- Ensure minors receiving care are aware of and understand what information will remain confidential and what services they can receive without parental consent.
- Pass statutes allowing minors to consent to inpatient and outpatient mental health services, and care related to drug/alcohol use without needing parental consent.
- Ensure state law allows minors to provide consent for care related to mental illness, including addiction.
- Adopt one or more strategies to prevent insurance companies from using EOBs in ways that breach young adults' confidentiality. States should aim to create systems that don't require young people to know the ins and outs of insurance claims to guarantee their confidentiality. Confidentiality should be assured without a young person requesting it.

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Conclusion

State and local policy makers can reshape the mental health policy landscape to one that advances transformation and healing for youth and young adults. The goal in such a system is to change young people's lives by acknowledging and taking steps to reduce the threats that they experience. ***Policy choices must facilitate access to life-changing supports, or risk perpetuating further harm.*** Confidentiality represents a key policy area where changes can make a meaningful difference for youth and young adults. Ensuring confidentiality and allowing for minor consent empower young people to take control over their health care, increasing the likelihood that they seek services.

As documented throughout this brief, some states have exercised each of these options, but none are universal. State and local leaders can immediately review existing policies in confidentiality and minor consent and look for opportunities to increase equitable access to care for youth and young adults. Adopting the recommendations on confidential care outlined in this brief will help to ensure that state and local mental health policies create pathways to transformative, healing experiences for young people who need them most. In doing so, we can advance a future that prioritizes youth and young adult mental health, well-being, and healing on a national scale.

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