Background and Terminology
1. It’s important to be clear about who we are talking about
2. Words matter!
3. Definitions of adolescence and young adulthood
   a. Child - defined by the Convention on the Rights of the Child (1989) as a person younger than 18 years, unless majority (i.e., the legal threshold of adulthood) is attained at a younger age
   b. Adolescence - historically defined by World Health Organization as the period between ages 10 and 19 years
   c. Youth – United Nations defines youth as people aged between 15 years and 24 years
   d. Teenager - term first used un the US in the 1920s and widely used in popular culture to refer to people aged 13-19
   e. Young people – a less formally defined term that generally refers to people aged 10–24 years
   f. Minor – legal term which is function of state law in the United States
4. Age Developmental Framework: The 10–24 year age range is increasingly divided into three categories: 10–14 years (early adolescence); 15–19 years (late adolescence); and 20–24 years (young adulthood)
   a. Physical, cognitive, and social and emotional development varies across these age groups
   b. Where you access young people varies across these age groups (school, bars, etc.)
5. National estimates from Youth Risk Behavior Survey
   a. Sexual identity among male high school students: 93.1% heterosexual, 2.0% gay, 2.4% bisexual, 2.6% unsure
   b. Sex of sexual contacts among male high school students: 53.5% females only, 1.3 males only, 1.9% both males and females, 43.6% never had sexual contact
   c. Gay or bisexual males report more sexual behavior than heterosexual counterparts
6. Centers for Disease Control and Prevention’s approach to school-based HIV/STD prevention

References
Case Studies

1. This is a changing field.
2. Since the first law journal article considering the implications of PrEP for minors and providing a comprehensive survey of minor consent statutes and their implication for confidential PrEP access (Burda 2016), multiple changes in law have occurred, including in Colorado and New York.
3. Major barriers to PrEP for adolescents and young adults: consent, confidentiality, and cost
4. Colorado (Consent)
   a. The Colorado state legislature voted to pass Senate Bill (SB) 146 on May 11, 2016, and the bill was signed into law by Governor John Hickenlooper on June 16, 2016.
      i. SB 146 repealed two HIV criminalization statutes, reformed another HIV criminalization statute, and standardized and modernized statutory language addressing sexually transmitted infections (STIs), including HIV.
      ii. The focus of the bill originally was to change the state’s HIV criminalization laws, but ended up modernizing HIV and STI laws, meaning minors could consent to HIV/STI services including prevention services (e.g., PrEP).
      iii. The bill was proposed by the Colorado Mod Squad (“mod” is short for “modernization”), a decriminalization taskforce led by the Positive Women’s Network-USA Colorado (co-chairs: Barb Cardell and Kari Hartel) and formerly known as the HIV Decriminalization Task Force.
   b. Prior to 2016, Colorado expressly allowed minors to consent to HIV testing and treatment, but not prevention services. HIV was dealt with separately from other STIs, at the time was defined to mean “means syphilis, gonorrhea, and any other type of sexually transmitted infection designated by the state board by rule as contagious, upon making a finding that the particular sexually transmitted infection is contagious; except that cases of AIDS, HIV-related illness, and HIV infections shall be governed solely by the requirements of part 14 of this article.” COLO. REV. STAT 25-4-401(1)(c) (2015),

¹ “Any county, district, or municipal public health agency, state institution or facility, medical practitioner, or public or private hospital or clinic may examine and provide treatment for HIV infection for any minor if such physician or facility is qualified to provide such examination and treatment. The consent of the parent or guardian of such minor shall not be a prerequisite to such examination and treatment. The physician in charge or other appropriate authority of the facility or the licensed physician concerned shall prescribe an appropriate course of treatment for such minor. The fact of consultation, examination, and treatment of such a minor under the provisions of this section shall be absolutely confidential and shall not be divulged by the facility or physician to any person other than the minor except for purposes of a report required under sections 25-4-1402 and 25-4-1403 and subsection (8) of this section and a report containing the name and medical information of the minor made to the appropriate authorities if required by the "Child Protection Act of 1987", part 3 of article 3 of title 19, C.R.S. If the minor is less than sixteen years of age or not emancipated, the minor's parents or legal guardian may be informed by the facility or physician of the consultation, examination, and treatment. The physician or other health care provider shall counsel the minor
c. Effective July 1, 2016, minors could consent to HIV/STI services including prevention services.
   i. COLO. REV. STAT. § 25-4-402(10) (2017): "Sexually transmitted infection" refers to chlamydia, syphilis, gonorrhea, HIV, and relevant types of hepatitis, as well as any other sexually transmitted infection, regardless of mode of transmission, as designated by the state board by rule upon making a finding that the particular sexually transmitted infection is contagious.
   ii. COLO. REV. STAT. § 25-4-409 (2017):
      (1) (a) A health care provider or facility, if consulted by a patient who is a minor, shall perform, at the minor's request, a diagnostic examination for a sexually transmitted infection. The health care provider or facility shall treat the minor for a sexually transmitted infection, if necessary; discuss prevention measures, where applicable; and include appropriate therapies and prescriptions.
      (b) If a minor requests a diagnostic examination, care, prevention services, or treatment for a sexually transmitted infection, the health care provider who provides such services is not civilly or criminally liable for performing the service, but the immunity from liability does not apply to any negligent act or omission by the health care provider.
      (2) The consent of a parent or legal guardian is not a prerequisite for a minor to receive a consultation, examination, or treatment for sexually transmitted infections. For the purposes of this section, health care provided to a minor is confidential, and information related to that care must not be divulged to any person other than the minor; except that the reporting required pursuant to the "Child Protection Act of 1987", part 3 of article 3 of title 19, C.R.S., still applies. If the minor is thirteen years of age or younger, the health care provider may involve the minor's parent or legal guardian. A health care provider shall counsel the minor on the importance of bringing his or her parent or legal guardian into the minor's confidence regarding the consultation, exam, or treatment.

d. Lessons Learned
   i. Framing in terms of public health modernization as opposed to HIV minor consent or HIV criminalization only
   ii. Bridging the divide between HIV and other STIs
   iii. Bipartisanship (purple state with a Republican control of the Senate at the time)

---

2 "Any physician . . . with the consent of the minor patient, may make a diagnostic examination for sexually transmitted infection and may prescribe for and treat the minor patient for sexually transmitted infection without the consent of or notification to the parent or guardian . . . ."
iv. Meaningful involvement of people living with HIV in a coalition of grassroots activists, community leaders, lobbyists, medical experts, and others
v. Building support (modernization supported by the Colorado Organizations Responding to AIRS (CORA) and the Colorado Department of Public Health
vi. Navigating contentious issues
vii. Reform efforts are tricky, take time, do not come in “one-size-fits-all”

5. Colorado (Confidentiality)
   a. Unlike consent issues, which pertain only to minors, confidentiality issues relate to both minors and young adults (Note: The Affordable Care Act (ACA) permits young people up to age 26 to remain as dependents on their parents’ insurance plans, and there are confidentiality breaches that can result because of this)
      i. Federal mechanisms for protecting confidentiality: HIPAA and Title X
         1. For example, HIPAA has an abuse, neglect, engagement exception that allows covered entities like providers and insurers to without communications where a minor could be subjected to violence, abuse or neglect
         2. Pursuant to HIPAA, individuals can request that providers and insurers place certain restrictions on disclosure of the minor’s personal health information; although providers and insurers need not honor the requests, if they do honor the requests, providers and insurers must heed them if care has been fully paid for by the minor or “anyone other than the health plan.” A patient is also allowed to request that communications concerning PHIs are sent “by alternative means or at alternative locations”. Providers and insurers must accommodate reasonable requests, but an insurer may require a statement of endangerment to honor the request
      ii. State mechanisms for protecting confidentiality: health/insurance privacy statutes and regulations
      iii. Limitations to protecting confidentiality: caregiver notification provisions and explanations of benefits (EOBs) sent by insurers to insured individuals that often disclose the specific care furnished to dependents on parent’s health plans
   b. Confidentiality and Colorado Medicaid
      i. Federal law does not specifically require state Medicaid agencies or Medicaid managed care organizations to send EOBs for the general provision of services
      ii. Federal law simply requires state Medicaid agencies must have a method for verifying with beneficiaries that they received the services which the provider billed. 42 CFR § 455.20(a). In addition, federal law requires Medicaid MCOs to notify enrollees in writing whenever a decision is made to deny a service authorization request or to authorize a service in amount, duration, or scope that is less than requested. 42 CFR § 438.210(c).
iii. Health First Colorado, Colorado’s Medicaid Program, does not send EOBs.

c. Confidentiality and Colorado Private Insurance
   i. Federal law does not require EOBs to be sent home as a general matter, but it does require certain plans notices of adverse benefit determinations.
   ii. Sending EOBs is a common practice among private insurers, often as a way to verify services to curb health care fraud, and health insurance companies often provide an EOB to the policyholder instead of the member seeking care.
   iii. To allow members control over access to confidential information, the Colorado Division of Insurance issued regulations requiring health plans in the state to ensure confidential communication between the insurer and a covered adult child; information may not be sent to the policyholder without prior consent of the covered adult child. 3 CCR 702-4 Amended Regulation 4-2-35. (“Carriers must take reasonable steps to ensure that the protected health information (PHI) of any adult child or adult dependent who is covered under the policy is protected. This protection includes ensuring that any communications between the carrier and covered adult child remain confidential and private, as required under the Health Insurance Portability and Accountability Act (HIPAA). This protection of personal health information would include, but is not limited to, developing a means of communicating exclusively with the covered adult child or adult dependent such that PHI would not be sent to the policyholder without prior consent of the covered adult child or adult dependent.”)
   iv. Problems and Potential Solutions: (1) This regulation only applies adult children. Extend confidentiality protections for non-adult children. (2) Even for covered adult children, their address may be the same as the policyholder, such there is the possibility of confidentiality breaches. Require/support insurers to allow electronic communications or make technical changes to redirect communications. (3) Insurer implementation and the need for strategic litigation. Where the insurer sends to policyholder, ripe for negligence per se lawsuit. Even in jurisdictions without a regulation like in Colorado, insurers often have their confidentiality policies and forms, which could be the basis for litigation. Some type of enforcement mechanism is critical.

6. New York (Consent)
   a. On December 14, 2016, the New York State Department of Health published proposed amendments to regulations to allow minors to consent to treatment and prevention of HIV infection (Amendment of Sections 23.1 and 23.2 of Title 10 NYCRR (Expansion of Minor Consent for HIV Treatment Access and

---

3 Under the Employee Retirement Income Security Act (ERISA), covered health plans must send notice to the participant or beneficiary of any adverse benefit determination. See 29 CFR § 2560.503-1(g). Federal law also requires insurers of non-grandfathered group and individual health insurance plans to issue notices of adverse benefit determination.
Prevention). These amendments were in furtherance of Governor Andrew Cuomo’s plan to end HIV/AIDS in New York State by 2020, and followed a series of activities, including a statewide forum hosted by the New York State Department of Health AIDS Institute on November 18, 2015, entitled “PrEP for Adolescents: Successes, Challenges, & Opportunities.” The amendment went into effect on April 12, 2017.

i. One amendment changed the regulations to include HIV on the Group B list of sexually transmitted diseases along with Human Papilloma Virus (HPV) and Genital Herpes Simplex, and the regulations were amended to including prevention services as a part of treatment for persons who are infected or are suspected at risk of being infected with an STD.

ii. Impact of amendment to regulations on minors:

1. With respect to minor access to PrEP, the most significant impact of including HIV under Group B STDs is that, under Section 23.4, minors under the age of 18 are able to consent to diagnostic, treatment and prevention services for a number of diseases including Group B STDs. This means that minors can obtain PrEP as well as antiretroviral treatment without needing their parents’ knowledge or consent. This access is limited to minors who are infected with or been exposed to an STD.

2. 10 CRR-NY 23.4 (2017): When a health care provider diagnoses, treats or prescribes for a minor, without the consent or knowledge of a parent or guardian as permitted by section 2305 of the Public Health Law, neither medical nor billing records shall be released or in any manner be made available to the parent or guardian of such minor without the minor patient’s permission. In addition to being authorized in accordance with section 2305 of the Public Health Law to diagnose, treat or prescribe for a person under the age of 18 years without the consent or knowledge of the parent or guardian of such person where the individual is infected with a sexually transmitted disease, or has been exposed to infection with a sexually transmitted disease, health care practitioners may (as authorized by their scope of practice) render medical care related to other sexually transmitted diseases without the consent or knowledge of the parent or guardian.

b. The New York State Department of Health (NYSDOH) received a total of 38 comments, which all expressed support for the proposed amendments to Sections 23.1 and 23.2 of the Official Compilation of Codes, Rules and Regulations of the State of New York. Comments were received from health care providers that provide treatment to patients who are HIV-positive, community-based organizations and government agencies.
New York Amendments (*Underline = changes*)

Group B of Section 23.1 is amended to read as follows:

**Group B**

Facilities referred to in section 23.2 of this Part must provide diagnosis and treatment, including prevention services, as provided in section 23.2(d) of this Part for the following STDs:

- Human Papilloma Virus (HPV)
- Genital Herpes Simplex
- Human Immunodeficiency Virus (HIV)

Section 23.2 is amended to read as follows:

Each health district shall provide adequate facilities either directly or through contract for the diagnosis and treatment, including prevention services, of persons living within its jurisdiction who are infected or [are suspected] at risk of being infected with an STD as specified in section 23.1 of this Part.

7. California (Consent and Confidentiality)
   a. California Family Code §6926
      i. “A minor who is 12 years of age or older may consent to medical care related to the prevention of a sexually transmitted disease.”
      ii. Cannot disclose to parents/guardians without minor’s signed consent
   b. California Health Information Act (CHIA), SB 138, Confidentiality of Medical Information (2013-2014 Session)
      i. Passed and signed into law in 2013 and took effect on January 1, 2015
      ii. Requires that health plans allow enrollees who are legally authorized to consent to care to request an alternative method to receive EOBs (e.g., that EOBs be sent to an alternative mailing address or be made electronically available only to the enrollee).
      iii. To the extent permitted by federal law, requires health plans to allow individuals or clinicians to request EOBs not be sent to policyholders for sensitive services when disclosure of this information could lead to patient endangerment
         1. Sensitive services include STD services (including PrEP), contraceptive services, sexual assault services, mental health and addiction services.
      iv. How does it work?
         1. Individual submits confidential communication request (CCR) to insurer verbally or in writing
         2. Individual must provide the insurer with a way to communicate information directly to the patient (i.e., physical or electronic address)
         3. Insurer has 7-14 days to implement
4. CCR lasts until the person sends in another one or tells the insurer that he/she wants to cancel it
5. CCR does not limit provider from talking to patient or patient’s insurer
   v. Can use myhealthmyinfo.org to generate a script for adolescents and young adults communicating with policyholders

8. San Francisco (Cost)
   a. Created an “Emergency Youth Truvada Fund” to help overcome cost barriers
   b. Even with minor consent, in the absence of confidential insurance access, many young people case barriers to paying for PrEP
   c. Gilead’s patient assistance program for PrEP are not currently available to people under 18 because Gilead bases its program on FDA approval of PrEP for adult use only
   d. The Emergency Youth Truvada Fund is available to youth ages 15-24 (younger on case by case basis) in San Francisco when otherwise unable to access PrEP

9. Other Issues and Jurisdictions
   a. Clinic locations, clinic hours, and the length of medical visits (20 minutes) present challenges to reaching youth with PrEP services
   b. Working groups have been formed in various jurisdictions (Washington State, Colorado) to address PrEP access for minors
   c. Outside of San Francisco, hospitals, especially Children’s Hospitals, absorb the cost of providing PrEP to minors, and can generally only do so with state funding, which is often limited or temporary option. Long-term solutions are needed.

References