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Goal: End disparities between medical and legal accuracy in local government resources about HIV.

Modernizing HIV Education and Labor Law in New York City — Concept Paper
Spring 2022

Introduction

Over the last thirty years, prevention and treatment of HIV have improved enormously. HIV, which first became a public health epidemic in the 1980s, went from being a mysterious ailment about which practically nothing was known to one of the most-researched and best-understood chronic health conditions in human history. With these gains in knowledge have come gains in life expectancy, reductions in new cases, and changes to many branches of medical science. HIV/AIDS advocates in all fields have worked hard for these gains, and it is time our hard-won knowledge be incorporated into laws and policies.

ACT UP proposes a direct, nonpartisan strategy to improve the public's understanding of how to prevent and treat HIV through carefully-tailored laws, resolutions, and policy changes in the areas of Education and Labor. By keeping these legal changes specific, and prioritizing the most broadly-supported, it is possible to minimize the controversy that so often surrounds — and delays — policy changes related to HIV, resulting in more accurate information reaching the public sooner. These changes would improve the average New Yorker's knowledge of HIV and public health, which would reduce transmissions and social stigma, thus contributing to finally ending the HIV epidemic.

Background

In the 1990s, at the height of the HIV epidemic in the United States, many jurisdictions understandably passed laws to address the public health crisis they faced. These laws were often intended to inform the public about HIV through school and workplace requirements, such as mandatory HIV lessons for children, changes to workplace safety procedures, and guidelines about preventing and treating accidental exposure. Such policies were based on the information available at the time, and many of them were considered important public health victories. Unfortunately, these laws and policies have only rarely been revisited as our understanding of HIV has improved, resulting in a dangerous, and sometimes costly, divergence between legal accuracy and medical accuracy over the last three decades.

ACT UP, through our own work and the work of many of our fellow HIV/AIDS advocates in New York City, has devised a list of high-priority, relatively uncontroversial changes that, implemented well, would have an outsized impact on correcting this troublesome divergence. Inconsistent information causes confusion and mistrust – a fact the COVID epidemic is currently demonstrating all too well.

Overview and Proposed Changes

Local Education Law **Note:** HIV Education, Sexual Health Education, general Health Education, and Science Education are partly-overlapping disciplines covered by different regulations.	
Overview of Current Situation	**Proposed Change and Rationale**
HIV Curriculum NYC Health requirement overview • New York State (NYS) currently requires K-12 Health and HIV lessons. NYS does not have a	**Proposed change:** A legal requirement that the already-mandatory NYC HIV curriculum, and/or resources provided to teachers by the NYCDOE, be regularly updated for

medical accuracy requirement for HIV education. ● New York City additionally requires medically accurate, age-appropriate Sexual Health education in grades 6-12. ● NYC does not specifically require HIV education to be medically accurate. The current New York City HIV Curriculum is out of date — last overhauled in 2012, with minor updates in 2015. It contains: ● Only early information about PrEP, which was new at the time. ● No information about Treatment as Prevention or viral suppression (U=U). ● Contradictory information about prevention methods, as well as about stigma. ● Inconsistent messages about relative risk of different transmission methods. ● Insufficient information on managing HIV as a chronic illness, rather than an STI.	medical accuracy, in accordance with CDC recommendations. Ideally an update would be required every 5 years, and no more than every 10. **Rationale:** Nearly twenty states, including New Jersey, have long had medical accuracy mandates, and jurisdictions in NYS are given wide latitude to make decisions about local Health curricula. A local law requiring that the NYC curriculum be updated for medical accuracy at regular intervals would ensure that students are taught more up-to-date information than most currently are, and preemptively ensure that future medical developments will be incorporated into the curricula. Additionally, well-meaning parents and teachers who trust the DOE to provide reputable resources for their students will be directed to more current information.
HIV Education Compliance NYC Local Law 14 requires tracking how many students receive at least one semester of health education. ● The data for 2019-2020, as well as previous years, shows nearly 100% compliance. ● Teachers, however, anonymously report being pressured to tick boxes (e.g.) stating that the HIV education requirement has been fulfilled, regardless of truth. NYC Local Law 15 requires tracking the presence of Health Instructors in public schools. ● The data for 2019-2020 shows most schools do not have a certified, full-time Health teacher. ● HIV instruction is generally done by other school faculty or staff, e.g. gym teachers, science teachers, nurses, guidance counselors, etc., or by nonprofits who visit the students at school. HIV Education is therefore taught inconsistently, by a patchwork of well-meaning community members, with varying degrees of knowledge, who do not all teach the same information.	**Proposed change:** A meaningful, verifiable compliance mechanism that ensures equivalent HIV information has been shared with all public school students at certain grade levels. **Discussion and Rationale:** A bill might simply order the NYCDOE to develop a new mechanism, or it might mandate a specific point of compliance. There are various forms the latter could take; compliance might be assessed by either student data collection, or during regular physical inspections already performed by officials. From consulting teachers and students, two likely mechanisms are: ● Schools might be required to display HIV educational materials, such as posters, created by a reputable public health body, that clearly present information about HIV prevention and treatment options, as well as resources for further information. ● For ensuring that HIV education is actually taught to individual students, the DOE might require all students in a particular grade or grades to take an automated online HIV module, like those already used for on-the-job trainings or college courses. Further discussion of these suggestions may be found in the Supplement on page 6.

Local Labor Law	
Overview of Current Situation	**Proposed Change and Rationale**
Bloodborne Pathogen Informational Materials OSHA and PESH BBP policies nearly always discuss HIV and Hepatitis (and sometimes other viruses) together because they are bloodborne pathogens (BBP). ● However, HIV and Hepatitis are different viruses, with important differences in how they are treated and transmitted. Grouping them together in Labor law results in confusion about prevention options and risk of exposure. ● Hepatitis-B (HBV), the virus most frequently grouped with HIV in Labor law, can live outside the body, and in dried blood, for at least 7 days (CDC). Neither of these is true of HIV (CDC). This distinction is not made in many materials used for workplace safety. ● Additionally, a vaccine is available for HBV, and a cure is available for Hepatitis-C (HCV), while HIV infections can be prevented both before and after exposure with pre- and post-exposure prophylaxis. This information is also not presented in many materials used for workplace safety. New York City agencies base their policies on OSHA/PESH, with some supplemental local regulations and laws. ● Consequently, information that is missing from OSHA/PESH regulations is often missing from local DOL/agency policies. ● For example, here is the NYCDOE's 2019 BBP packet for school administrators. Information is included about the HBV vaccine, but not about PrEP/PEP for HIV.	**Proposed Change:** A legal requirement that all OSHA/PESH materials disseminated in NYC that cover bloodborne pathogens (BBP), and already contain information about Hepatitis prevention, be supplemented to: (A) include information about pre- and post-exposure prophylaxis for HIV, and (B) make clear that some workplace activities, though they may carry a risk of exposure to one specific BBP, carry no risk of exposure to others. **Rationale:** OSHA/PESH materials have enormous influence on public health knowledge because of trainings, posters, union contracts, and so on. It is crucial that they are all medically accurate so that employees do not believe that they are at risk of HIV when they are not. It is likewise crucial that employees know about their HIV prevention and treatment options, as distinct from their HBV and HCV options, in case they are exposed to HIV. Secondly, people living with HIV may experience stigma in the workplace due in part to the prevalence of training materials that incorrectly imply that HIV is transmissible in spit, e.g., when it never has been. Finally, lawsuits and investigations related to BBP exposures can be costly, and it is likely that some of them would be prevented if clearer, more accurate information were consistently shared with employees.
Public Employee HIV Training Most public employee HIV training has, for legal compliance reasons, been constructed around the current OSHA/PESH guidelines or HIV Education curriculum discussed above. (See previous sections for links.) To summarize: ● Most Labor safety materials do not include sufficient information about the differences between prevention and treatment of HIV and other bloodborne pathogens. ● The HIV Education curriculum does not include sufficient or consistent information about prevention and treatment of HIV, or about living with HIV as a chronic illness.	**Proposed Change:** A legal requirement that public-facing NYC public employees (such as teachers and police) undergo medically-accurate HIV training, and that those training materials be updated for medical accuracy at regular intervals, ideally every 5 years. **Rationale:** Public employees deserve accurate workplace safety info. Most public employees have been trained using incomplete or outdated HIV materials. Public employees who work directly with the public, such as educators and first responders, are trusted sources of information in their communities, and are in key positions to address misinformation and stigma.

Related Resolutions	
Overview of Current Situation	**Proposed Change and Rationale**
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Article 10 Article 10 is a NYS Mental Hygiene law pertaining to sex offenders who require civil commitment or supervision. Currently, NYS is using Article 10 to justify holding at least one person with HIV after he's served his full prison sentence. ● Williams's HIV status at the time of his crime has been a key part of the State's decision to continue to confine him. ● This is true despite dramatic advances in HIV prevention and treatment over the last twenty years. ● He has, so far, been incarcerated for eleven years beyond the end of his original sentence.	**Proposed Change:** A resolution calling for clarification of Article 10 of New York State's Mental Hygiene Law so that it cannot be used prejudicially against people with HIV. **Rationale:** People with HIV should not be punished more harshly than people who do not know their HIV status who commit equivalent crimes. People who know they have HIV are less likely to transmit HIV than people who do not regularly get tested for HIV. Additionally, people with HIV who have served a full sentence should be released according to the same standards as others.

Conclusion

The lack of clear, modern, medically accurate HIV information in communications between government agencies and the public undermines both individual and community health. The proposed changes help rectify the divergence between legal and medical accuracy, while providing opportunities for the development of durable, replicable models that will reduce stigma and transmissions, helping to end the epidemic once and for all.

About

The AIDS Coalition to Unleash Power (ACT UP) was founded in 1987 in New York City. Our mission statement says ACT UP is "a diverse, nonpartisan group of individuals, united in anger, and committed to direct action to end the AIDS crisis." We have always been a 100% volunteer-run organization, with a flat democratic structure, and no employees or barriers to membership. ACT UP has no shareholders or sponsors, and is therefore completely free to choose which goals to pursue.

Many current and former members of ACT UP are involved in HIV/AIDS work in the larger community, and we collaborate closely with a network of local groups, nonprofits, and coalition partners to achieve specific goals, as needed.

The City Council Working Group was formed in the Winter of 2021 to survey City Elections candidates on common-sense HIV policy positions, and to advocate for changes to local law that will more quickly end the HIV epidemic in New York. We aim to do this by correcting the divergence between medical and legal accuracy that has been allowed to occur over the last three decades, and by prioritizing legal asks that data suggest are relatively common-sense, uncontroversial, and bipartisan. Data we consider comes from various organizations, including, but not limited to, the New York State AIDS Advisory Council, the U.S. government, the Guttmacher Institute, SIECUS, the Kaiser Family Foundation, and the Center for HIV Law and Policy. We also consider information we receive from public employees, such as teachers, and from people who receive services, such as HASA clients. The results of our 2021 Primary Candidate Survey may be found here.

Email education@actupny.com for more information.

Supplement: HIV Education Compliance Mechanism Suggestions

Background Information and Teachers' Concerns

One of the main difficulties with compliance is that so much of it is done indirectly, with employees being asked to simply tick a box (or similar) stating that they have done a task. Due to time constraints and limited resources in schools, well-meaning teachers often become overwhelmed by all they are expected to do, and find themselves choosing which tasks to prioritize. Many of the non-health teachers responsible for HIV Education, especially in younger grades, choose to prioritize subjects that seem more immediately relevant or important for their students. This is not a condemnation of teachers who make such choices; we recognize that these decisions are almost always the result of inadequate funding and resources, not of malevolence.

The non-Health teachers we spoke to as we developed these HIV compliance suggestions expressed guilt that the current logistics of their jobs require them to pick and choose which information to teach; at the same time, they were realistic about the fact that they would be more likely to teach HIV Education if the resources were pre-packaged and consistent, and if the compliance checks were more scrutinized. Simultaneously, the more burdensome the compliance checks become, the more resistance they will encounter during implementation.

An additional problem, of course, is that many schools that are faithfully teaching HIV Education are using incorrect or outdated information, which is why a separate Local Law requiring regular medical accuracy updates to the NYCDOE HIV curriculum and resources is so important.

Compliance Suggestions from Students and Teachers

It is not necessary for the City Council to specify a compliance mechanism, but if there is interest in doing so, we suggest the following based on advice from teachers and students. These mechanisms:

- Will not place further instructional burden on classroom teachers, or take longer than already mandated
- Ensure accurate, consistent information across schools, regardless of variations in direct instruction
- Can be designed so they are multilingual, thus improving access for English Language Learners
- Should be done alongside direct instruction, but will serve as a failsafe in case that does not occur
- Are durable and replicable

Requiring that HIV Information Be Displayed During School Inspections

Regular physical inspections of schools are already performed by superintendents and other officials, who ensure that health and safety information is adequately displayed. Schools should be required to display HIV educational materials, such as posters, created by a reputable public health body, that clearly present information about HIV prevention and treatment options, as well as resources for further information. Materials should be placed in a consistent location from school to school, such as a nurse's office, for ease of compliance and inspection, and could be multilingual. This would be a cost-effective way to ensure that, even if HIV Education is not properly taught, quality information is being posted in common areas for all to read.

Individual Student Assessment via Automated Module

For ensuring that HIV education is actually taught to individual students, the DOE might require all students in a particular grade or grades to take an automated online HIV module, like those used for on-the-job trainings or college courses. These modules already exist, but would need to be checked regularly for accuracy and clarity. Alternatively, if the City designed its own automated modules, it would be possible to update them at the same intervals as, and make sure they were consistent with, the NYC HIV curriculum. After initial setup cost, the City could then license its modules for use in other jurisdictions. This would likely be more cost-effective and durable than buying into pre-existing modules. An automated module would alleviate some of the burden on the non-Health teachers currently handling the bulk of HIV Education in NYC, while building in individual assessment and quality control. Such modules should be taken in conjunction with in-person instruction, but would serve as a failsafe if in-person instruction does not occur. Automated modules could also be offered in other languages with relative ease to improve HIV Education access.

Supplement: Frequently Asked Questions (Last updated March 2022)

1) Some of these asks are logistically complicated! I thought you said this would be easy.

A) All legal changes are logistically complicated for the involved agencies to implement. What these asks are is *legislatively* simple, as well as popular: The public wants accurate, consistent health information from government agencies, especially in the era of COVID-19. If these changes are written narrowly, it will be easy to find support for them. Implementation by the Depts. of Education and Labor may be more challenging, but opposing the dissemination of accurate public health information due to bureaucratic inconvenience is not an easily defensible position — especially if a law has been passed requiring the Departments to make changes, and many of the agencies' own employees support those changes. In some cases, compliance could be as simple and cost-effective as requiring posters to be hung in schools and workplaces so that people in need know where to look for reliable information.

2) Why is HIV Education separate from Sex Education? Why can it be risky to bundle them together in legislation? Don't they go together?

A) Sex Ed and HIV Ed are *already* regulated separately and considered separate health topics. They are controversial for different reasons, and it is common for communities to support one but not the other. By regulating them separately, there is a protective effect on HIV Ed when Sex Ed is under attack (and vice-versa). Though not ideal, it is possible to teach about HIV without teaching about sex (and vice-versa). Oftentimes, HIV is covered only briefly in comprehensive Sex Ed classes, as there are many other topics to cover.

B) Secondly, and more importantly, Sex Ed and HIV Ed are regulated separately because HIV is first and foremost a *chronic illness* that is transmitted several different ways, not just sexually. By only teaching about HIV in Sex Ed, we forget that it is a common, lifelong *chronic illness* with a risk rate of approximately 1 in 70 here in New York State — this is one of the reasons HIV Education begins in Kindergarten, while Sex Ed typically begins in middle school. We must teach students how to manage and live healthfully with HIV, not just how to avoid it. Focussing on HIV as a preventable and treatable chronic illness has become easier with the advent of medicinal prevention (pills) in the forms of PrEP and TasP, which work for all transmission methods (including non-sexual ones). By giving HIV lessons their own dedicated instructional time and materials, including for young children, we ensure that it is covered thoroughly for the many students who already live with HIV in their families or communities.

3) Won't separating HIV and hepatitis information in bloodborne pathogen (BBP) informational materials make it harder to get information about hepatitis? Won't this stigmatize hepatitis?

A) No. BBP materials should provide accurate information on transmission methods, prevention, and treatment options for *both* HIV and applicable strains of hepatitis, making the differences between them clear. Right now, many BBP documents are written such that anything that is true for *one* BBP appears to be true for *all* of them, even if this is false. Breaking down the differences between HIV and hepatitis transmission, prevention, and treatment will reduce stigma and improve outcomes for all BBPs.

4) OSHA and PESH are not locally regulated. Can the City Council actually do anything about them?

A) New York City has passed supplemental labor laws in the past, to, e.g., regulate the construction industry or ensure protections for hourly workers. Requiring workplaces in New York City to post health and safety information that is *more* detailed than what is required by the State fits within the requirements of OSHA/PESH, and may result in statewide changes due to NYC's influence on NYS law. The related resolutions (page 4) demanding reviews of federal and state OSHA/PESH BBP regulations should encourage similar changes at other levels of government, which could be duplicated from NYC's, if our supplemental law is written and implemented well.

5) What makes this cost-effective?

A) By setting durable, high standards, all City resources become more consistent and medically-accurate over time without increasing spending. Rather than update everything at once, changes to each set of

materials should be made each time they are reviewed during future scheduled updates, ensuring there will be few additional costs beyond what was *already* going to be spent on those updates. In the majority of cases, it will be possible to modify existing HIV resources using information from trusted City agencies, like the DOHMH, as regular updates occur. There is no need to reinvent the wheel.

B) HIV information resources reach about 20% of New Yorkers during our *already-required* work and school HIV lessons, including high numbers of people from the most at-risk demographics. By improving information quality for the general public, we improve information quality for the demographics the general public is composed of, and reduce doubts about inconsistencies.

C) Ensuring City resources – especially DOE and workplace resources – are consistent and regularly checked for medical accuracy will reduce HIV exposures, transmissions, and associated costs over time by improving both public knowledge and trust in local government. Even requiring just one consistent, well-placed safety poster can make a huge difference – Heimlich maneuver posters are a perfect example.

D) The City may be able to sell or license any HIV resources it chooses to develop – such as an educational module for students, trainings, or printables – to other jurisdictions, which are likely to be interested in copying our regular medical accuracy updates if they are written and implemented well. There is also precedent for Departments charging workplaces fees for printed materials in order to recoup costs.

6) Who supports these efforts? Where's your sign-on letter?

A) Virtually all HIV/AIDS advocates, and advocates in related areas, are in favor of the changes we're proposing, and data indicates the public is as well. In fact, the public — and many AIDS advocates! — think the HIV information shared with students and employees is medically accurate already, and are surprised to learn it isn't. We have behind-the-scenes support for these asks, but would like to have a bill number for at least one of the proposed changes before publicly circulating a formal sign-on. This will ensure the sign-on is meaningful and actionable.

7) Who opposes these efforts?

A) Requiring government agencies to share medically-accurate information is common-sense and bipartisan. The only opposition we've identified is from:

a) People responsible for implementing the changes, who are concerned that they will be burdensome. We respond to this by saying that the Depts. of Education and Labor are *already* required to share HIV information with the public, and what we are proposing is that the information government agencies are *already* legally required to share be updated for medical accuracy whenever they are next updated..

b) People who mistakenly believe that HIV advocates are calling for biased or political information to be taught. We respond to this by saying we are asking only that the HIV information shared by the Depts. of Education and Labor be consistent with the medically-accurate information already shared by other trusted, nonpartisan government agencies like the DOHMH, CDC, and NIH.