SAME AS IT EVER WAS

Presented by James M. Wood, Esq.

jasmwood@gmail.com

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the HIV Legal Services Fund of the American Bar Association HIV/AIDS Impact Project.

PROGRAM OVERVIEW

- Stigma of HIV/AIDS
- Privacy – Why It Matters
- Topics
  - Federal Laws
    - HIPAA
    - Privacy Act of 1974
  - State Laws
    - HIV & Criminilization Laws
    - Lab Reporting Laws
    - Minor's Autonomous Consent
    - Perinatal HIV Tests
    - Correctional Facilities
  - Cooper v. FAA – Privacy Act of 1974

DEFINITION OF PRIVACY

Privacy is the right to be let alone or to be free from misuse or abuse of one's personality. The right of privacy is the right to be free from unwarranted publicity, to live a life of seclusion, and to live without unwarranted interference by the public in matters with which the public is not necessarily concerned.

STIGMA AND FEAR

STIGMA TODAY

Billy Porter

CONSTITUTIONAL RIGHT TO PRIVACY

UNITED STATES CONSTITUTION

No express right to privacy

Origins of implied right:

First, Fourth, Fifth, Ninth and 14th Amendments

STATE CONSTITUTIONAL RIGHTS TO PRIVACY

BROAD

- California – Article 1, sec 1
- Alaska, Amendment 3

SEARCH AND SEIZURE

- Florida, Article 1, sec. 23
- Hawaii, art. 1,
- Illinois art. I, § 6.
- Louisiana art. I, § 5
- Montana art. II, § 10
- New Hampshire art. 2-b
- South Carolina art. I, § 10
- Washington, art. 1, sec. 7

CALIFORNIA CONSTITUTION ARTICLE 1, SECTION 1

All people are by nature free and independent and have inalienable rights.

Among these are enjoying and defending life and liberty, acquiring, possessing, and protecting property, and pursuing and obtaining safety, happiness, and privacy.

STORM WARNINGS

- “Nothing in the text or original understanding of the Constitution establishes a right to an abortion.”

- Judge James C. Ho in *JACKSON WOMEN'S HEALTH ORGANIZATION v. THOMAS E. DOBBS, M.D., M.P.H.,*

FEDERAL STATUTES

TWO FEDERAL LAWS

HIPAA

- The Privacy Rule standards address the use and disclosure of individuals' health information
- Has standards for individuals' rights to understand and control how their health information is used.
- Goal: to ensure that individuals' health information is properly protected while allowing the flow of health information needed to provide . . .high quality health care and to protect the public's health and well-being.
- No personal cause of action.

- https://www.cdc.gov/phlp/publications/topic/hipaa.html

PRIVACY ACT - 5 U.S.C. § 552a

- Establishes Code of Fair Information that governs the collection, maintenance, use, and dissemination of personally identifiable information in federal records about individuals
- Act requires that agencies give the public notice of their systems of records by publication in the Federal Register.
- Act prohibits the disclosure of information from a system of records absent of the written consent of the subject individual, unless the disclosure is pursuant to one of twelve statutory exceptions.
- Provides for recovery of "actual damages"

STATE LAWS

CRIMINALIZATION OF HIV

CRIMINALIZATION OF HIV

1.HIV-specific laws that criminalize or control behaviors that potentially exposes to HIV.

- Oregon, California, New York and others

2.Sexually transmitted disease (STD), communicable, contagious, infectious disease laws that criminalize or control behaviors that can potentially expose another to STDs/communicable/infectious disease. This might include HIV.

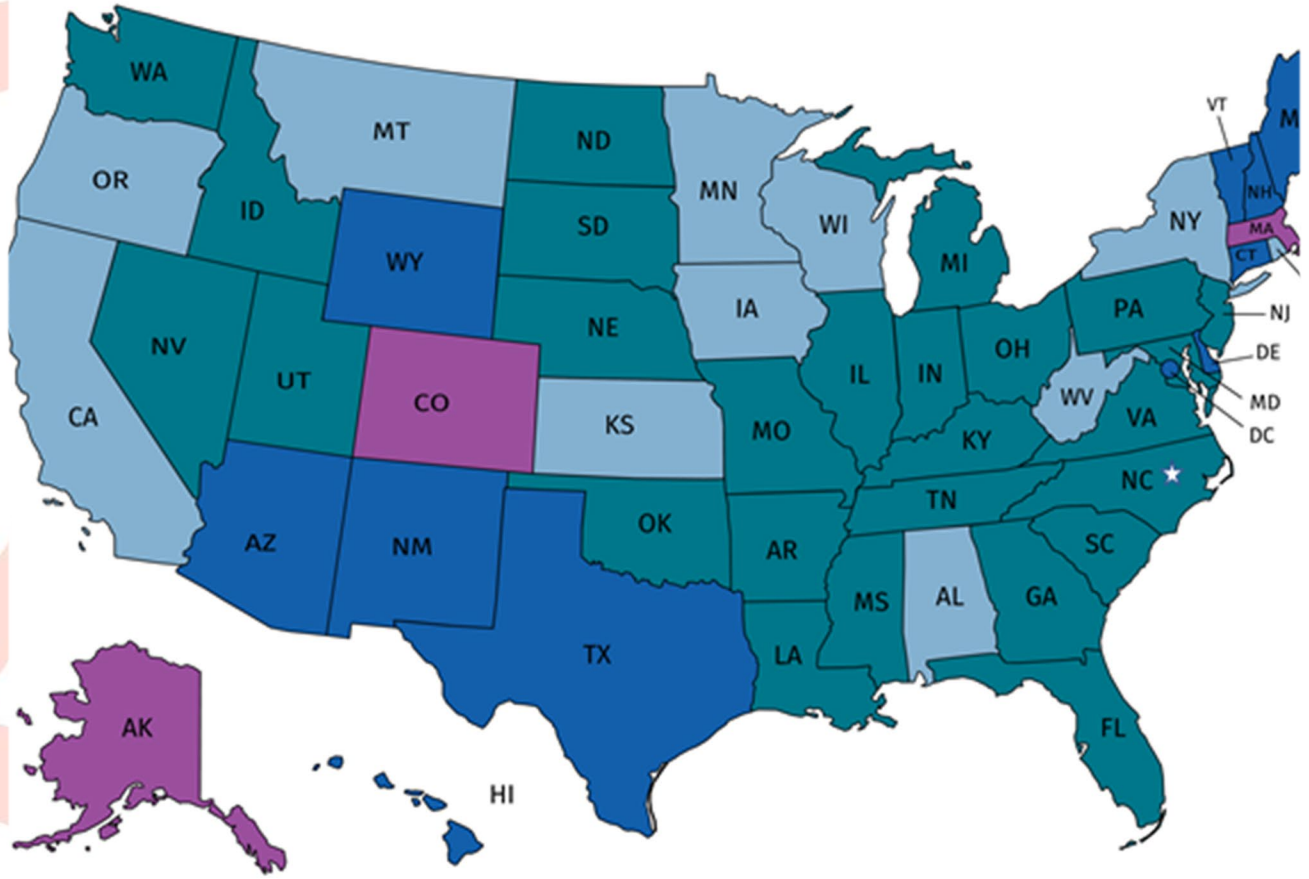
- Washington, Dakotas, Pennsylvania and others

3.Sentence enhancement laws specific to HIV, or STD that do not criminalize a behavior but increase the sentence length when a person with HIV commits certain crimes.

- Alaska, Massachusetts and Colorado

4.No specific criminalization laws

- Arizona, New Mexico, Hawaii and others



CRIMINALIZED OR CONTROLLED BEHAVIORS

- Donation of Blood or Tissues (19)
- Vaginal Sex (16)
- Anal Sex (15)
- Oral Sex (12)
- Prostitution and Solicitation (11)
- Biting, Spitting, Throwing and Placing (10)
- Sharing Sex Objects (5)
- Sharing Needles

EXAMPLES OF CRIMINILIZATION

ILLINOIS

- People living with HIV/AIDS may be prosecuted for engaging in condomless intercourse without disclosing HIV status to partner.
    - 2 felony, punishable by 3 - 7 years in prison and a $25,000 fine
    - The accused must prove that their sexual partner knew of their HIV status, that the activity could result in HIV transmission, and consented to the activity with that knowledge.
    - Illinois law states that a person may be prosecuted for selling, exchanging or transferring non-sterile injection equipment, even if the recipient does not use it.

TEXAS

- No criminal statutes explicitly addressing HIV exposure, but prosecutions have arisen under general criminal laws.
- People living with HIV (PLHIV) have been prosecuted for HIV exposure for attempted murder and aggravated assault.
- Aggravated assault statute makes it a second degree felony to cause serious bodily injury to another or to use or exhibit a deadly weapon in the commission of an assault.
- A felony of the second degree carries a punishment of two to 20 years in jail and a possible fine of $10,000.4
- Texas courts have found that the seminal fluid of a PLHIV may constitute a deadly weapon

CALIFORNIA

BEFORE 2017

- 3 – 8 years for not disclosing status
- 3 years for soliciting or engaging in sex work
- Test results could be used to prove knowledge
- 2 – 6 years for giving blood or tissue
- Transmission not required

SENATE BILL 2017

- **Intentional** transmission of infectious or communicable disease a misdemeanor
- A defense it took measures
- Sex workers living with HIV not subject to felony
- Prostitution convictions do not trigger mandatory testing
- Not a felony to donate blood, tissue or milk

RESPONSES

ASSOCIATIONS

- September 2010 – Center for HIV Law and Policy – Positive Justice Project
- October 2012 – HIV Medicine Association

GOVERNMENT

- July 2010 – White House
- March 15, 2014 – United States Department of Justice and CDC study
- July 15, 2014 – DOJ – “Best Practices Guide . . . “

GILEAD'S 2020-2022 HIV Anti-Criminilization Initiatives

- Grantees:
  - Health Not Prisons Collective
  - Elizabeth Taylor AIDS Foundation
  - Center for HIV Law & Policy
  - Williams Institute

HIV IS NOT A CRIME

RESOURCES

1. The Center for HIV Law and Policy: HIV Criminalization in the United States
2. The Center for HIV Law and Policy: Criminal Law web page and resource bank
3. The Center for HIV Law and Policy: The Science of HIV for Lawyers and Advocates

- https://www.hivlawandpolicy.org/

STATE LAW

DISCLOSURE OF HIV TEST RESULTS

TESTING ISSUES

- Is written informed consent required?
- Can results be issued in response to a subpoena?
- Must a sexual partner be notified of results?
- Must positive test results be reported to local health department?
- Must the patient's name be included?
- Can a test be mandatory?

HIV LAW & POLICY

DONATE

FULL SITE SEARCH

Search

FIND LAWS IN YOUR STATE

HIV POLICY RESOURCE BANK

FEATURED ISSUES

Confidentiality and Disclosure

Criminal Law

Employment

HIV as a Disability Under Antidiscrimination Law

Immigration

Click a state for details on HIV-related laws, guidelines for healthcare workers, and testing and treatment information.

Alabama
Alaska
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
District of Columbia
Florida
Georgia
Hawaii
Idaho
Illinois
Indiana
Iowa
Kansas
Kentucky
Louisiana
Maine
Maryland
Montana
Nebraska
Nevada
New Hampshire
New Jersey
New Mexico
New York
North Carolina
North Dakota
Ohio
Oklahoma
Oregon
Pennsylvania
Puerto Rico
Rhode Island
South Carolina
South Dakota
Tennessee
Texas
Utah
Vermont

Featured Resources

Map: HIV Criminalization in the United States, CHLP (updated July 2020)

Map: An Overview of States Criminalizing Viral Hepatitis, CHLP (updated July 2020)

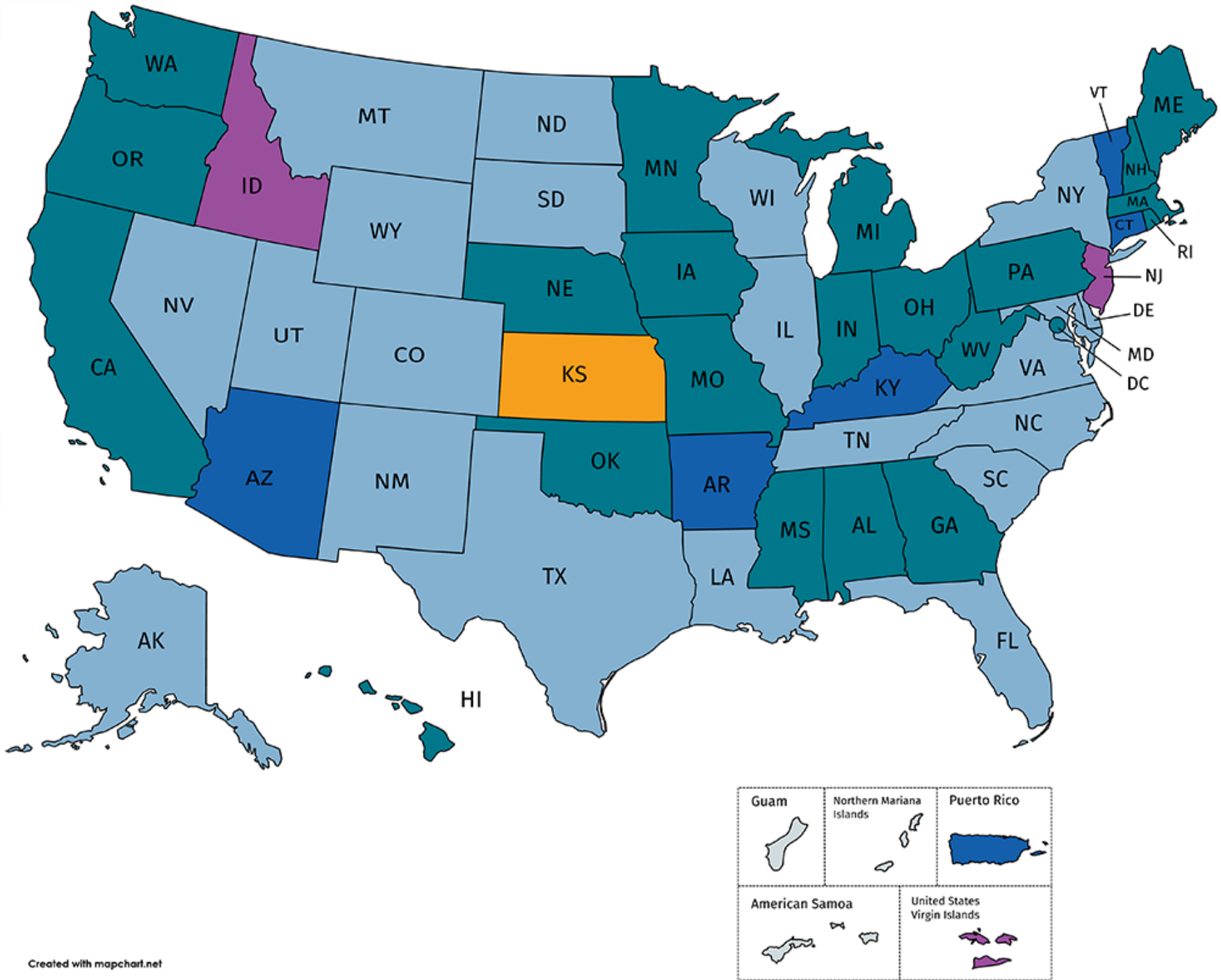
Chart: U.S. HIV Laws and Prosecutorial Tools, CHLP (updated June 2020)

HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice, CHLP (updated May 2020)

Fact Sheet: Punishment is Not a Public Health Strategy: The Criminalization of Viral Hepatitis, CHLP (2018)

HIV Criminalization Beyond Non-Disclosure: Advocacy Toolkits on Intersections with Sex Work and Syringe Use, CHLP and National LGBTQ Task Force (2017)

Guiding Principles for Eliminating Disease-Specific Criminal Laws, Positive Justice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RI
NJ
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MD
DC
AK
HI
Guam
Northern Mariana Islands
Puerto Rico
American Samoa
United States Virgin Islands
Created with mapchart.net

TESTING ISSUES

- INFORMED CONSENT
- ANONYMOUS TESTING
- TESTING FOR MINORS
- PARTNER NOTIFICATION REQUIRED
- POST-TEST COUNSELING

SUMMARY OF CALIFORNIA TESTING LAW

Perinatal HIV testing	West's Ann. Cal. Health & Safety Code §125085external icon West's Ann. Cal. Health & Safety Code §125090external icon West's Ann.Cal.Health & Safety Code § 125107external icon
HIV testing in the general population	CAL. HEALTH & SAFETY CODE § 120990external icon Cal. Health & Safety Code § 120895external icon
Laboratory reporting laws	West's Ann. Cal. Health & Safety Code § 121023external icon 17 CCR § 2643.5external icon

CALIFORNIA TESTING

- **Informed Consent Required:**
  - No
- **Pre-Test Counseling:**
  - No
- **Post-Test Counseling (Only for HIV Diagnosis):**
  - Yes
  - Counseling must be offered to a patient with a confirmed HIV positive test. Counseling must be offered to notified partners and contacts.
- **Anonymous Testing Available:**
  - Yes
  - Testing must be made available anonymously. Free anonymous testing is available at designated anonymous testing sites.
- **Partner Notification Required:**
  - Yes
  - Notification to sexual and needle sharing partners of possible exposure to HIV is required.

CALIFORNIA – WHEN TESTS MAY BE DISCLOSED

- (a) **To the subject** of the test or the subject's **legal representative**, **conservator**, or to any **person authorized** to consent to the test
- (b) To a test subject's **provider of health care**
- (c) To an **agent or employee of the test subject's provider of health** care who provides direct patient care and treatment.
- (d) To a provider of health care who procures, processes, distributes, or uses a **human body part**
- (e) (1) To the designated officer of an **emergency response employee**, and from that designated officer to an emergency response employee regarding possible exposure to HIV or AIDS. . .

CALIFORNIA PENALTIES FOR DISCLOSURE

CMIA - California Civil Code §§ 56-56.37.

- Prohibits disclosure without consent
- Governs how information is stored
- Damages
  - Nominal and actual damages
  - Administrative fine

H&S 120975, 12080

- Prohibits disclosure of HIV test results
  - What does that mean?
- Penalties
- Negligence per se

Minor's Autonomous Consent

CDC TABLE

- As of 2020, all jurisdictions have laws that explicitly allow a minor of a particular age (as defined by each state) to give informed consent to receive STD diagnosis and treatment services.
- In some jurisdictions, a minor might be legally allowed to give informed consent to receive specific STD or HIV services, including PrEP, even if the law is silent on those disease-related services.

HIV TESTING IN PRISONS

- Types of prison HIV testing policies:
  - Conducted on all prisoners upon admission, conviction, and/or prior to release, without informed consent.
  - Considered a standard part of a medical examination on admission, conviction, or prior to release. Recommended to all prisoners.
  - offered and recommended to all prisoners on admission, conviction, or prior to release, but is only undertaken if prisoners specifically agree to the test (“opt-in” to testing).
  - HIV testing is offered to prisoners on admission, conviction, or prior to release, but it is not recommended
  - Prisoners can receive a test—at any time or only under certain circumstances—if they actively request it, but it is not offered to them.
  - Prisoners have no access to HIV testing and counselling.

MANDATORY TESTING IN UNITED STATES

- HIV testing is **mandatory** in the U.S.:
  - blood and organ donors;
  - military applicants and active duty personnel;
  - federal and state prison inmates under certain circumstances;
  - and newborns in some states.
- As of January 2010, HIV testing is no longer mandatory for those wishing to emigrate to the United States or for refugees.

EXCEPTIONS TO RIGHT TO PRIVACY

WHEN THERE IS NO RIGHT TO PRIVACY

- Disclosures with consent or voluntarily
- Disclosures required by law
- Disclosures in the public interest

DISCLOSURES WITH CONSENT – EXPRESS OR IMPLIED

- Written authorization
  - Applies only to what is waived
- Voluntary disclosure
- Litigation
  - Waiver applies only to relevant injury

DISCLOSURES REQUIRED BY LAW

- Reporting of cases
- Judicial or administrative proceedings by subpoena
- Law enforcement requesting subpoena or by court order
- Litigation
- Inmates non-prison health information
  - Consider protective orders

PUBLIC INTEREST DISCLOSURES

- California – may not be disclosed without written consent
- HIV-related research
  - HIV Test results are required to be reported to CDPH
- Medical emergency
- Investigation by CDPH

ONE STATUTORY MESS

COOPER V. FAA

DRAMATIS PERSONAE

Hon. Vaughn Walker

N. D. CA.

Hon. Milan Smith

9th Circuit

Hon. Samuel Alito

United States Supreme Court

STANMORE CAWTHON COOPER

THE PRIVACY ACT – 5 U.S.C. 552a (1974)

b) CONDITIONS OF DISCLOSURE.—No agency shall disclose any record which is contained in a system of records by any means of communication . . . to another agency, except pursuant to a written request by, or with **the prior written consent** of, the individual to whom the record pertains, **unless** disclosure of the record would be—

. . . .

(3) for a **routine use** as defined . . . ; or

. . . . .

(7) to another agency . . .for a civil or criminal law enforcement activity if the activity is authorized by law, and if the head of the agency or instrumentality has made a written request to the agency which maintains the record specifying the particular portion desired and the law enforcement activity for which the record is sought;

THE PRIVACY ACT - REMEDIES

(g)(1) CIVIL REMEDIES.—Whenever any agency

. . .

(D) fails to comply with any other provision of this section . . .in such a way as to have an **adverse effect** on an individual, the individual may bring a civil action against the agency . . .

. . .

(4) In any suit brought under the provisions . . . of this section in which the court determines that the agency acted in a manner which was **intentional or willful**, the United States shall be liable to the individual in an amount equal to the sum of—

(A) actual damages sustained by the individual as a result of the refusal or failure, but in no case shall a person entitled to recovery receive less than the sum of $1,000;

OPERATION SAFE PILOT

National security or violation of Privacy Act

OPERATION SAFE PILOT

OSP – December 2005

". . . The purpose of the review . . . was intended to ensure that pilots with FAA licenses were who they claimed to be."

- Declaration of Jonatan L Lasher

OSP – August 6, 2002

"Identifies and targets active pilots who have falsified FAA required medical records claiming they are in good health in order to receive a pilot's medical certificate and at the same time claiming they have a disabling medical condition to the Social Security Administration."

OSP AND MR. COOPER

- October 25, 2014 – DOT-OIG and SSA-OIG get Cooper's 38 page FAA file and 230 pages in Social Security file
- January 19, 2005 – Cooper's records reviewed by FAA surgeon
  - No knowledge or training about HIV/AIDS
  - Recommends emergency revocation
- March 22, 2005 - Special Agents interview Mr. Cooper in Starbucks, show him his records, give him revocation order, and take his pilot certificate and log book
- April 1, 2005 – DOT-OIG opens case against Cooper
- August 15, 2005 – DOT-OIG opens an investigative file against Cooper

COOPER INDICTED AND PLEA BARGAINS

- August 30, 2005 – Cooper indicted for four felonies – making false statements to FAA
- US Attorney issues press release
- KGO-TV – Cooper learns he has been indicted - “Lying Pilot with HIV”
- March 7, 2006 – pleads guilty to single misdemeanor before Judge Vaughn Walker
  - $1000 fine and two years unsupervised probation

THE IMPACT OF VIOLATION OF COOPER'S PRIVACY RIGHTS

Mr. Cooper

- Because of ostracism in the South told very few about orientation and HIV status
- As employee of SSA, felt betrayed
- Anxious about who knew
- Learned about indictment from KGO-TV
  - "Lying Pilot" news segment
  - Pilots indicted for lying about schizophrenia, drug addiction and disease
- Mortification and extreme embarrassment

Psychiatrist

- Anxiety Disorder NOS – Experienced:
  - Event threatened his integrity and future
  - Reduction in awareness of surroundings
  - Symptoms of emotional avoidance
  - Increased symptoms of sleeplessness, irritability and restlessness
  - Feelings of humiliation, sexual withdrawal and ostracism

OSP IN THE COURTS

RICH IN IRONY

COOPER V. FEDERAL AVIATION ADMINISTRATION, et al.

AGES FOR VIOLA

THE LITIGATION

- March 8, 2007 – Complaint filed based on Privacy Act and Violation of Article 1, Section 1 of the California Constitution

- March 2007 – April 28, 2008 – discovery
  - Cooper's damages were limited to emotional distress of being outed
  - Admissions – None of the routine uses apply
  - Government failed to comply with its own guidelines
  - July 2007 - FAA admits to Congress that failed to give proper notice

MOTIONS FOR SUMMARY JUDGMENT – COMPLAINT DISMISSED

- " . . .the court finds that the SSA-OIG's transmission of Cooper's records to another agency without his prior consent was unlawful under 5 USC 552a(b)"

- Triable issue as to whether the Privacy Act violations were willful

- **". . . While allegations of mental distress are sufficient to establish that Cooper meets the 'adverse effect' standing requirement, they are insufficient to meet the requirement of actual damages"**

THE ACTUAL DAMAGES CONUNDRUM

The Statute

- If the Privacy Act is violated, the United States is liable in an amount equal to the sum of –
  - (A) **actual damages** sustained by the individual . . .

The Trial Court

- "Actual damages" is **facially ambiguous**
- "[w]hen 'analyzing whether Congress has waived the immunity of the United States, [courts] must **construe waivers strictly in favor of the sovereign** * * * and not enlarge the waiver beyond what the language requires.'"
- " . . . Ambiguity as to whether [the Act's] provision for actual damages includes mental distress without evidence of pecuniary damages must be resolved in favor of the government defendants."

THE NINTH CIRCUIT

THE CLARITY OF ACTUAL DAMAGES

UNANIMOUSLY REVERSED AND REMANDED

- Held: “ . . . Actual damages . . . encompasses both pecuniary and nonpecuniary damages”

UNANIMOUSLY REVERSED AND REMANDED

- Extrinsic Sources
  - Legislative history is "murky, ambiguous and contradictory"
  - Fair Credit Reporting Act – 15 USC 1681 *et seq – 1970*
    - Private right of action for *actual damages*
    - *Actual damages include emotional distress – 2nd, 4th, 5th and 9th Circuits*
- *Sovereign Immunity*
  - *The waiver is unequivocally expressed*
  - *Clear intent is found "in the statute itself – its purpose, structure, and language – and external support in the language and construction of FCRA"*
- *Trial court's error: " . . . relied on the sovereign immunity canon alone, to the exclusion of traditional tools of statutory construction"*

FED. AVIATION ADMIN. V. COOPER IN UNITED STATES SUPREME COURT

THE OPINION

Majority

- J Alito (delivered opinion)
- C J Roberts
- J Scalia
- J Kennedy
- J Thomas

Dissent

- J Sotomayor (filed dissent)
- J Ginsburg
- J Breyer

THE MAJORITY

- Holding: “Actual Damages” does not include damages for mental or emotional distress
  - Waiver of sovereign immunity in Privacy Act is not unequivocal

THE DISSENT

“After today, no matter how debilitating and substantial the resulting mental anguish, an individual harmed by a federal agency’s intentional or willful violation of the Privacy Act will be left without a remedy unless he or she is able to prove pecuniary harm.

“That is not the result Congress intended when it enacted an Act with the express purpose of safeguarding individual privacy against Government invasion. And it is not a result remotely suggested by anything in the text, structure, or history of the Act.”


WHAT CAN WE DO ABOUT STIGMA ?
An effective response to the HIV epidemic must tackle the root causes of stigma and ensure services are inclusive and accessible.
HUMAN RIGHTS FOR ALL
PROTECT
• Anti-discrimination laws
• Decriminalisation
• Challenging violence
INCLUDE
NOTHING ABOUT US WITHOUT US
• Key populations in healthcare service design and implementation
• Stigma and discrimination reduction as a goal in national strategies
MY BODY MY BUSINESS
EMPOWER
• To understand rights
• To act on violations
EDUCATE
HIV STIGMA IS THE REAL KILLER
• To address fears
• To change attitudes
ADVOCATE FOR ACTION!
AVERT.ORG

CALL NOW

Call (202) 224-3121 and a switchboard operator will connect you directly with the Senate office you request.

CONCLUSION