Beyond AIDS and HIV Legislation in California, 1998-2013

From good epidemiological ideas to policy and legislation: The case of Beyond AIDS

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“We don’t just do any darned thing just because it happens to be a good idea”

- The world will not easily adopt anything that involves the need to change
- Machiavelli:
  - *“It must be considered that there is nothing more difficult to carry out, nor more doubtful of success, nor more dangerous to handle, than to initiate a new order of things. For the reformer has enemies in all those who profit by the old order, and only lukewarm defenders in all those who would profit by the new order, this lukewarmness arising partly from fear of their adversaries, who have the laws in their favour; and partly from the incredulity of mankind, who do not truly believe in anything new until they have had actual experience of it. Thus it arises that on every opportunity for attacking the reformer, his opponents do so with the zeal of partisans, the others only defend him half-heartedly, so that between them he runs great danger."*

The Case of Beyond AIDS

- The idea: Why not apply public health control measures used for some other diseases (TB, syphilis) for HIV?
- The situation (1998, when organization founded):
  - Only AIDS (late stage reached after 10+ years) was reportable to public health (not all stages as for other diseases)
  - Little effort was made to find people exposed to HIV
  - Testing for HIV required special written consent (not required for other diseases)
  - Prevention strategy was directed at community education (not using control at the source as with other diseases)

Reasons HIV was an exception

- When HIV test was developed (1985), only 5% of men who tested positive had AIDS
  - Staff at Centers for Disease Control (CDC) assumed that most people testing positive would not become ill
  - Stigma and discrimination triggered confidentiality laws protecting HIV results
  - It was not known that at all stages of HIV infection, virus is present and disease is contagious, and that almost everyone would get AIDS eventually
- There was no treatment
  - First drug, AZT, approved 1987; effective drug combinations 1996

Sources of opposition to change

- Gay rights advocates
  - Fearful of stigma, discrimination, and potential quarantine
  - Struggling to preserve sexual freedom and anonymity
  - Developed strong lobby, and organizations like “Act Up” that demonstrated
- Funded agencies
  - Determined to continue programs (and budgets) as usual
- Civil rights advocates (e.g., ACLU)
  - Privacy concerns

What motivates political action?

- Defending interests (income, power, etc.)
  - Established AIDS organizations opposed change
- Defending or fighting for rights
  - Gay activists sought equality, sexual freedom, treatment
  - ACLU fights for privacy
- Solidarity with one's group
  - Patriotic instinct can be invoked by sexual orientation, religion, etc.
- Moral indignation
  - Beyond AIDS founders outraged that people not informed they were infected or exposed, and that public health couldn't know who was infected
  - Conservatives opposed recognition of gays, sexual "deviance"
- Altruistic principles
  - Beyond AIDS leaders wanted to save lives

Timeline in a long struggle

- 1987: Future founders of Beyond AIDS met
  - Congressional hearing, book promotion, friends of friends
- 1998: Beyond AIDS founded
- 1998: First project to kill California bill reporting HIV by secret codes (AB 1663): Gov. Wilson vetoed
- 1999: New similar bill passes (AB 103) and veto sought from new Governor: Gov. Davis vetoed
- 1999: First Beyond AIDS bill for name reporting (SB 1029), failed
- 2000: Reporting by secret codes passed in obscure part of state budget, signed by Gov. Davis
- 2000: First Beyond AIDS bill passed to promote prenatal testing, but vetoed by Gov. Davis

Timeline in a long struggle, contd.

- 2001: Beyond AIDS attempt to change regulations to implement "unique identifier" reporting codes, failed
- 2002: Three Beyond AIDS bills introduced, all passed but 2 vetoed (HIV testing in prisons, prenatal testing); bill signed would re-examine coded reporting if not working (AB 2994)
- 2002: Rep. Tom Coburn, physician and friend of Beyond AIDS, got language into Ryan White CARE Act requiring effective HIV reporting by 2006 (not mentioning names)
  - If reporting failed, funding would be based only on AIDS cases
  - By 2006, this provided financial incentive to holdout states to switch to name reporting
- 2003: On 3rd try, Beyond AIDS gets prenatal testing bill passed and signed as one of last acts of Gov. Davis (AB 1676)
- 2005: Supported second attempt to get name reporting of HIV (failed)

Timeline in a long struggle, contd.

- 2006: Third attempt to get name reporting of HIV passes (SB 699), signed by Gov. Schwarzenegger
- 2007: Testing without written consent approved and signed (AB 682), but with complicated requirements due to ACLU concerns
- 2011: Referral of partner services to public health may be done with patient's consent (SB 422); took effect 2012
  - Other desired changes deleted due to ACLU opposition
- 2013: Primary care physicians mandated to offer HIV testing; oral consent permitted for testing in non-medical settings (AB 446); takes effect 2014

Can public health be science-driven?

- Nothing can be done in public health without public authority, both for funding and for police power
- This guarantees a political component to the design and maintenance of public health programs
- What is scientifically true is usually controversial
  - Examples: global warming, abstinence education, born gay
- Public health officials must steer a course between science and political reality, pushing to maximize the science while maintaining enough political support
- Prevention does not have the same constituency as disease-driven programs (those who are well and would have become sick don't know it and don't lobby)

What is the scientific basis for HIV control?

- Efforts targeting entire demographic groups
  - Screening directed at high-risk groups detects many infections
    - People who know they have HIV tend to reduce risk behavior
  - Uganda's "A-B-C" program drove down incidence and prevalence
    - Abstinence
    - "Be faithful"
    - Condoms
    - First two achieved most of the change
    - Populations have changed behavior only when people see illness and deaths around them

What is the scientific basis for HIV control (contd.)?

- Efforts to control transmission at the source
  - Had little emphasis for first 30 years of epidemic
    - What is proper balance?
  - Testing exposed partners is high-yield, should be cost-effective
  - Intercepting exposed persons can avert infection before it happens
  - Infected persons can be helped and persuaded to reduce behavior that will expose others

What is the scientific basis for HIV control (contd.)?

- Infected persons can be treated to reduce infectiousness
  - Idea postulated by Hattis and Jason in 1996, endorsed by California Medical Association
  - Finally proven effective by 2011; Science Magazine "Science Breakthrough of the Year"
  - Biggest thing at 2012 International AIDS Conference
  - July 2013: President Obama issues "HIV Continuum of Care Initiative
    - Increase screening to find about 20% of cases still undetected
    - Link cases to care
    - Initiate antiviral medication
    - Achieve undetectable viral level ("load"), to benefit patient and to prevent further transmission