

PHELSI ISSUES IN GENETIC TESTING

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OBJECTIVES

- A Framework to consider ethical, legal & social issues
- What issues arise out of genetic testing?
- How should policies be developed to address the issues?

WHAT'S PHELSI?

- ELSI = Ethical, Legal and Social Implications
 - <http://www.genome.gov/10001618>
- PHELSI = ELSI in the Public Health Context
 - See www.sph.umich.edu/genomics
 - Focus Area: PHELSI

PHELSI PRINCIPLES

- Population vs. individual focus
- Prevention vs. treatment emphasis
- Public good vs. individual autonomy
- Distributive justice vs. the market
- Focus on elimination of health disparities and avoidance of discrimination

PHELSI AND GENOMICS

- Principals of the Ethical Practice of Public Health (PH Code of Ethics)
 - www.apha.org/codeofethics
 - (referenced here as "AJPH-#")
- PH Code of Ethics applied to genomics
 - See Thomas, et al, "Genomics and the Public Health Code of Ethics", Am J Public Health, Dec 2005, 2139-2143

NEWBORN SCREENING ISSUES

- How many tests should public health provide? Which should be included? (based upon science *and* values) (AJPH-1 & 3)
- Mandate, encourage, or make accessible? (AJPH-2, 6)
- Available for a price or accessible to all? (AJPH-4)

FOR WHAT PURPOSES SHOULD TESTS BE MADE AVAILABLE? ENCOURAGED? REGULATED? (APHA-1)

- Phenotypic vs Genotypic prevention
- Use of tests for paternity and ancestor tracing
- Use of test results for criminal justice purposes

BY WHOM AND HOW SHOULD TEST RESULTS BE USED?

- By employers? Insurers?
 - Adherence to privacy and confidentiality (AJPB-2, 10)
 - 27 states require consent for disclosure; most regulate use by insurers and/or employers (www.ncsl.org)
 - Pending Genetic Information Nondiscrimination Act (S.B. 306)

USE OF TEST RESULTS FOR PUBLIC HEALTH RESEARCH

- Accumulated blood spots, resulting from NBS, could become biobanks
 - Should they be available for research?
 - Should informed consent for research be required? How?
 - For whom should they be available?
 - (AJPH 10 & 12)
 - Duty to warn of conditions found?

GENETIC TESTS AND HEALTH DISPARITIES

- Is availability based on market or need? (AJPH-4)
- How can we prevent creation of a “genetic underclass”?
 - *Gattaca*
- Are we heading toward a new eugenics?
 - Duster, *Backdoor to Eugenics*

MARKETING ISSUES

- Direct-to-consumer marketing and Race-based Marketing
 - Gollust et al, "Direct to Consumer Advertising of Genetic Testing", *JAMA*, 2003; 289:46
- Is there harm if these lead to healthier behavior?

POLICY ISSUES

- Need for governmental (federal/state), institutional & professional policies
- Public health policy development combines science and societal values
 - IOM, *The Future of the Public's Health*, 1988
- Need to engage diverse communities; professionals as resources, not decision-makers (APHA-3, 6, 8)
 - Role of Public Health in Promoting Community Education and Engagement