

GENETIC SECRETS (ROTHSTEIN, 1997)

3 HUMAN GENOME PROJECT: 1990

7 ORDER ≠ MEANING

- C.S., SIMULATION, DATABASE, COMPLEXITY

INTERP.
Likelihood = high

13 FUNCTIONING OF 100K HUMAN GENES: COMPUTATIONAL APPROACH

- 'PRESUMPTIVE' DETERM. OF FUNCTION (VIA COMP.)

18 COMPLEX SYSTEMS + NETWORKS

*→ 22 MUST BE ACQUIRED, STORED, ANALYZED, DISTRIBUTED BY COMPUTERS

CS = INTRINSIC

LEGAL / ETHICAL: ANALOGICAL VALUES (PROBLEMATIC)

24 : INCOMPLETE INFO.

: COSTS TO LIBERTY, ECON., PUBLIC BURDENS

SHAPING OF EVOLUTION

Free Will v. DETERMINISM

2. ALLEN: PRIVACY

32 ~ risk violent crime EXCEEDS GENETIC ILLNESS

PRIVACY: ACCESS TO INFO - ACCESS TO PERSON - DECISIONAL - PROPRIETARIAN

42 CONFIDENTIALITY - SECRECY - ANONYMITY

*→ 46 PRIVACY - AS - PHYSICAL INTEGRITY:

- PHYSICAL CONTACT - AS - CONSENSUAL / MANDATING CONSENT
- MEDICINE - AS - PROF. - REQUIRES INFORMED CONSENT
- PHYSICAL ASPECTS - ~ GIVEN ↓ EMPHASIS IN LITERATURE

GENE - AS - INFO
REMOVES FROM PHYS.
INFO. - PROFESSIONALS
REMOVE ETHICS48 DECISIONAL:

- CONTROVERSIAL (GAVISON)
- ABORTION DECISION ~ RECOGNIZED

PROPRIETARY:

*→ • NAME / LIKENESS APPROPRIATION = INVASION

EFFECT OF
DNA Rhetoric3. MURRAY: EXCEPTIONALISM:62 breadth, STABILITY, ABUSE potential, UNLOCKING SECRETS
MATCH ability

64 CONS: • DIFFICULT to MATCH

- ≠ prophetic
- ≠ UNIQUE

ARGUMENT
FROM TECH.

69 REDUCTIONISM / DETERMINISM - ENCOURAGE SPECIAL treatment

*→ 71 • VICIOUS CIRCULARITY IN GIVING SPECIAL TX

4. PT-DR Relationship:

- 79 (ASSUMES) GENETICS = HEART OF PERSONALITY
 81 EXPLOITATION
 84 DUAL AGENCY

5. Clinical Perspective:

- 92 INFO. + TRUST
 95 health + SAFETY EXCEPTION TO DISCLOSURE
 97 MED. GENETICS: specially only in 1995
 100 +50 yrs: GENETIC CHARTS KEPT SEPARATE
 102 ARRANGEMENT ≠ CELLULAR FUNCTION
 * > 106 CORPORATE MED. - LOSS OF DR-PT RELATION: INABILITY OF LAW TO PROTECT

6. COUNSELING:

- 108 4 relationship ∴ CONFIDENTIALITY
 124 "CLIENTS" = CONTROL

BUT = beyond
DR-PT

NAIVE

7. INFORMED CONSENT:

- 126 SPECIFIC / STORED TISSUE
 131 shadow PT. CHARTS
 133 ANONYMOUS TESTING + RISKS
 IRB BYPASS + STORED SAMPLES

8. SCREENING:

- * > 138 Medical Commodity - CARE MENTION
 Public Health BENEFITS = UNKNOWN
 Govn't ABUSE POTENTIAL

NO I.P.
TREATMENT

9. CONFIDENTIALITY / Commercial:

- 161 H.G.P. - COMMERCIAL
 169 ZERO-SUM PATENT v. COLLABORATION
 INFO. FLOW - Related to perceived VALUE
 173 MOORE (1990)
 175 INCENTIVE

- Property v. RESOURCE
 * > • PRIVATE ACTIONS w/ public guidance / goals
 • NATURAL RESOURCE LAW
 178 FAIRNESS v. EFFICIENCY

10. BIOMARKERS:

190 Risk: detection ability > ability to INTERPRET

11. ENVIRON. SCREENING:

208 COURT-ORDERED RESEARCH DISCLOSURE: VIA DISCOVERY
 INCLUDING NON-PARTY RESEARCH

12. FORENSIC:

* 213 DNA ANALYSIS: ANOTHER VARIATION OF INFO. AGE
 COLD (NO PIC) SEARCHES % WARM (PIC OF SUSPECT)
 223 NDIS - PRIVACY ACT (1994) (CODIS)

13. DNA DATA BANKS:

234 ARRESTEE-ONLY INCLUSION
 4th Am. challenges: REJECTED
 FINGERPRINTING / SAMPLE - INCREASE
 236 UK: RECORDABLE OFFENSE: ARREST / CONVICTION
 : 'VOLUNTARY' SAMPLES - MASS COLLECTION
 240 COMMERCIAL DIAGNOSTIC LABS: 90% STORAGE
 . MOORE
 244 INCLUDE DNA BANKS

15. WORKPLACE:

283 AT WILL DOCTRINE -
 . LONG TRAD. OF EMPLOYER INQUIRY
 CONST. (GOV'T / SOME STATE PRIVATE) + TORT PROTECTS.
 286 CONSENT DEFENSE
 ADA: BEST PROTECT: NON-ESSENTIAL TO EMPLOYMENT - PRIVATE
 290 STATE LAW - GENETICS
 295 H.I.P.A. 1996: NO PREEXISTING CONDITION
 BUSINESS INTERESTS - OVERRIDE

16. INSURANCE:

301 M.I.B.
 . APPLICANTS
 INS. REG. = STATE
 311 HIPA: PORTABILITY % NEW COVERAGE
 313 E.U.: NO TESTING - LIFE INS.

17. Schools:

325 IDEA: least RESTRICTIVE ENVIRON.

A.D.A. / Rehab. Act

327 FERPA

HHS. MUMM SUBJECTS

TORT ACTIONS

18. COURTS:

* > 332 JUDGES UNDERSTANDING OF GENETICS = CRITICAL TO ADJUDICATION

344 COURTS - PROBLEMATIC METAPOLICY ENVIRONMENT

· FORMATIVE TIME

· LEGISLATIVE POLICY-MAKING ZONE

* > 348 JUDICIAL CONF. ON GENETICS

19. JUSTICE:

366 policy + distrib. JUSTICE

20. LAWS:

371 NEWBORN SCREENING + ↓ CONFIDENTIALITY PROVISIONS

SICKLE CELL - MANDATORY V. VOLUNTARY

· 1ST STATE CONFIDEN. LAWS

H.G.R.A. - 1980 & PASS

373 NO COMPREHENSIVE STATE LAW (90-92) → Cal / CAL ('94)

375 G.P.A.: CONTROL

381 GENETIC PRIVACY + NON-DISCRIM. ACT (1995) +

· COMPREHENSIVENESS PROBLEMS

21. E.U. DATA:

293 Specific Targeting 1x % U.S. General

ACTIVE STATE ROLE - ONGOING

395 INDIV. = ENFORCEMENT RIGHTS

* > % U.S. - UNREGULATED: E.g. DIRECT MARKETING

· PRIVATE COLLECTION

· Whelan v. ROE: PRIVACY: DECISIONAL + NON-DISCLOSURE

· FOCUS ON GENETIC TESTS % OTHER COLLECTION

· STATE Level SOLUTIONS

400 BERMAN SMART CARD - PROBLEMS

· CONSENT + INFORMATION

404 FRANCE: DATA + ENCRYPTION

Q> 406 ANY PARTIC. LAW = LEVEL OF ABSTRACTION

*> Germany: Judges = DUTY OF CRITICAL ASSESSMENT

409 INT'L CONFORMITY PROVISION

22. INT'L PRIVACY :

418 MORE FELT THAN DEFINED

KANTIAN RESPECT

420 RIGHT LEFT ALONE → POSITIVE STATE DUTY ≠ I/F

426 PRIVACY, CIVIL LAW STATES

429 Germany: INFO + AUTONOMY

23. POLICY FRAMEWORK:

423 INS. PRIVACY / REFORM + H.C. FINANCING

*> 420 SKINNER V. OKLAHOMA : EUGENICS

• JACKSON: Limits on Public Biol. EXPERIMENTS