

Genetic Services Policy Project

Spring 2006

Advisory Board Meeting



Resource Center for Health Policy



DELIVERY SYSTEM ISSUES



PROVIDER SUPPLY

- ❖ Limited number of trained geneticists
- ❖ Rural and frontier supply issues
- ❖ Licensure of genetic counselors
- ❖ Centers of excellence vs. specialty vs. primary care
- ❖ Adult vs. pediatric vs. prenatal
- ❖ Adolescent transition issues
- ❖ Competing professional interests (research vs. clinical practice)

NON-GENETIC PROVIDERS

- ❖ Increased demand for genetic services
- ❖ Direct to provider marketing
- ❖ Impact on quality and coordination of care?

"RETAIL" GENETICS

- ❖ Consumer knowledge base
- ❖ Availability of genetic counseling
- ❖ Quality monitoring
- ❖ Insurance coverage
- ❖ Privacy and confidentiality
- ❖ Regulation ?

ALTERNATIVE MODELS

- ❖ Telemedicine
- ❖ Changes in state licensure
- ❖ Shared state, regional or national resources

INSURANCE AND FINANCING ISSUES



PROVIDER REIMBURSEMENT

- ❖ Reimbursement for time intensive services (vs. procedures)
- ❖ Coding/reimbursement for genetic counselors
- ❖ Reimbursement of multiple provider types
- ❖ Adequate severity adjustment

INSURANCE COVERAGE

- ❖ Criteria for coverage of emerging technologies
- ❖ Criteria for coverage of “off label” drugs
- ❖ Appropriate use of CEA
- ❖ Coverage of young adults
- ❖ Coverage of testing for non-enrollees

PUBLIC PROGRAMS

- ❖ Expanding criteria for newborn screening
- ❖ Impact of NBS expansion on states and other stakeholders
- ❖ Cross state variation
- ❖ Implications of increasing life expectancy

EVOLVING INSURANCE MARKETS

- ❖ Increasing consumer share
- ❖ Growth of health savings accounts
- ❖ Retrenchment of employers

KNOWLEDGE, LITERACY, AND TRAINING ISSUES



Training Focus

- ❖ Historical prenatal and pediatric focus
- ❖ Growing adult services

PROVIDERS OF GENETIC SERVICES

- ❖ Scientific knowledge base
- ❖ Ethical, legal, social knowledge base
- ❖ Updating knowledge around new technologies
- ❖ Appropriate use of family history
- ❖ Scope of practice
- ❖ Quality monitoring
- ❖ Cultural competency

CONSUMER ISSUES

- ❖ Knowledge base
- ❖ Availability of information
- ❖ Usefulness of information
- ❖ Fear of discrimination
- ❖ Impact of marketing
 - ❖ Content of advertising
 - ❖ Impact on expenditures
 - ❖ FDA labeling

ETHICAL, LEGAL, SOCIAL, AND ECONOMIC ISSUES



HISTORY

- ❖ Informed consent
- ❖ Discrimination
- ❖ Public support
- ❖ Impact of religious/spiritual beliefs
- ❖ Enhancement interventions?

CURRENT CULTURAL ISSUES

- ❖ Differential incidence
- ❖ Institutional racism
- ❖ Cultural competency of providers
- ❖ Media messages

THE ROLE OF ADVOCACY

- ❖ Affected populations
- ❖ Organization and resources
- ❖ Impact on services
- ❖ Impact on policy

CURRENT PUBLIC POLICY

- ❖ Regulation
- ❖ Taxation
- ❖ Public programs
- ❖ Government as purchaser
- ❖ Information provision
- ❖ The power of doing nothing

CURRENT LEGAL ISSUES

- ❖ Privacy and discrimination laws
- ❖ Informed consent
- ❖ Conscience clauses
- ❖ Wrongful birth
- ❖ Coverage limits
- ❖ Intellectual property

CURRENT ECONOMIC ISSUES

- ❖ Who pays for what services?
- ❖ Who decides?
- ❖ What is the role of markets?

HISTORY OF SCIENCE

- ❖ Little impact of genetics before sequencing
 - ❖ Little attention
 - ❖ Few resources
- ❖ After sequencing, research progressive
 - ❖ Single gene disorders
 - ❖ Complex, multiple gene disorders
 - ❖ Gene/environment interactions

CHANGING SCIENCE ISSUES



What Genetic Tests Can Do

- ❖ Confirm Identity
 - ❖ Identify your body after an accident
 - ❖ Tell if you were at a crime scene
- ❖ Expand a Family Tree
 - ❖ Determine if an ancestor was someone famous
 - ❖ Help find unknown parents, siblings or other relatives
 - ❖ Describe where your ancestors came from
 - ❖ Determine paternity

What Genetic Tests Can Do

- ❖ Help Predict a Medical Condition
 - ❖ Diagnose a genetic disorder like Huntington's disease
 - ❖ Warn you of a predisposition to addictions
 - ❖ Suggest which drugs might be most effective for you
 - ❖ Suggest certain foods or supplements to choose or avoid
 - ❖ Assess your risk with a mate of passing a genetic disease to a child

PROMISE VS. CURRENT DELIVERY

- ❖ Media fueled expectations
- ❖ Few current effective clinical applications
- ❖ Public trust of science
- ❖ Pace of change
- ❖ Long-term effects

CHANGING OUTCOMES

- ❖ Changing model for medicine
- ❖ Conditions are signaling errors
- ❖ Targeted interventions → improved outcomes
- ❖ Utility of prediction, personalization, prevention
- ❖ Increased life expectancy

FUTURE IMPACT

- ❖ Depends on:
 - ❖ Research funding
 - ❖ Scientific discovery
 - ❖ Provider response
 - ❖ Consumer response
 - ❖ Payer response
 - ❖ Public policy response



Thank you for
being here
today !