Genetic Service Providers – Concepts and Findings Emerging from the Genetics Workforce Study

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Overview

- Workforce analyses; health services research
- Genetics-related concepts, ? IOM Study
- Functional workforce analysis for genetics
- UMB study of genetic services and workforce
- Genetics workforce research agenda

Traditional Workforce Analyses

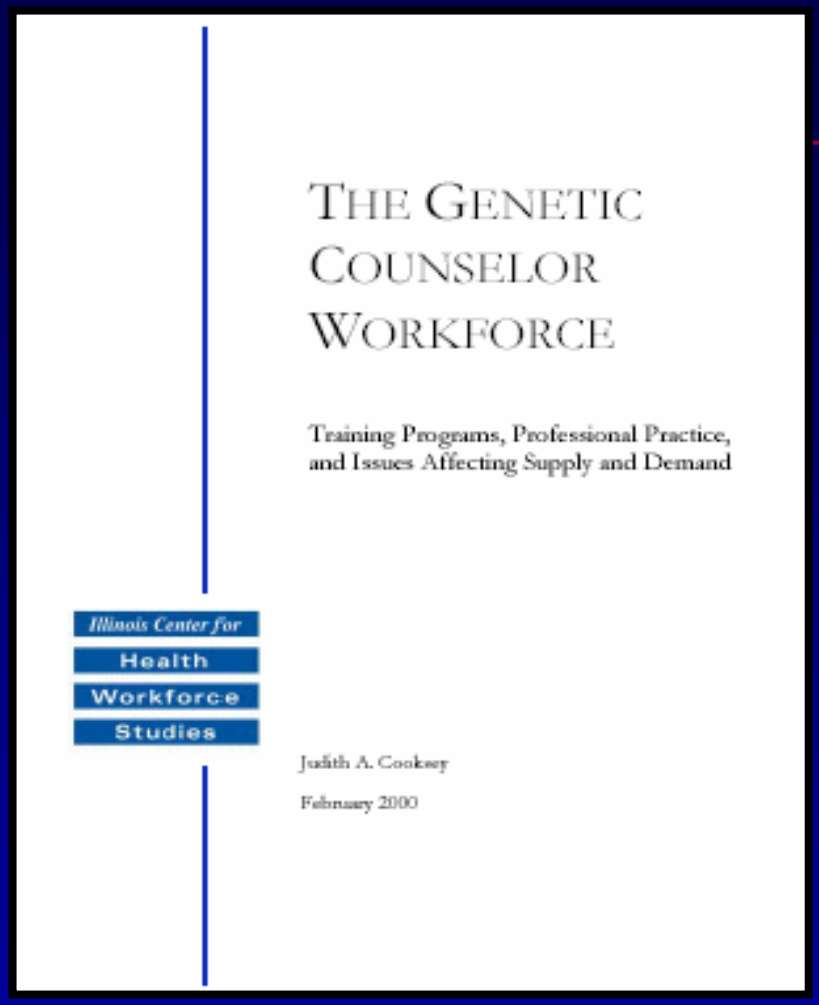
1. Describe the workforce

2. Assess shortage/surplus situation

   supply ~ demand

3. Forecast workforce supply and demand

Genetic Counselor Workforce, 2000



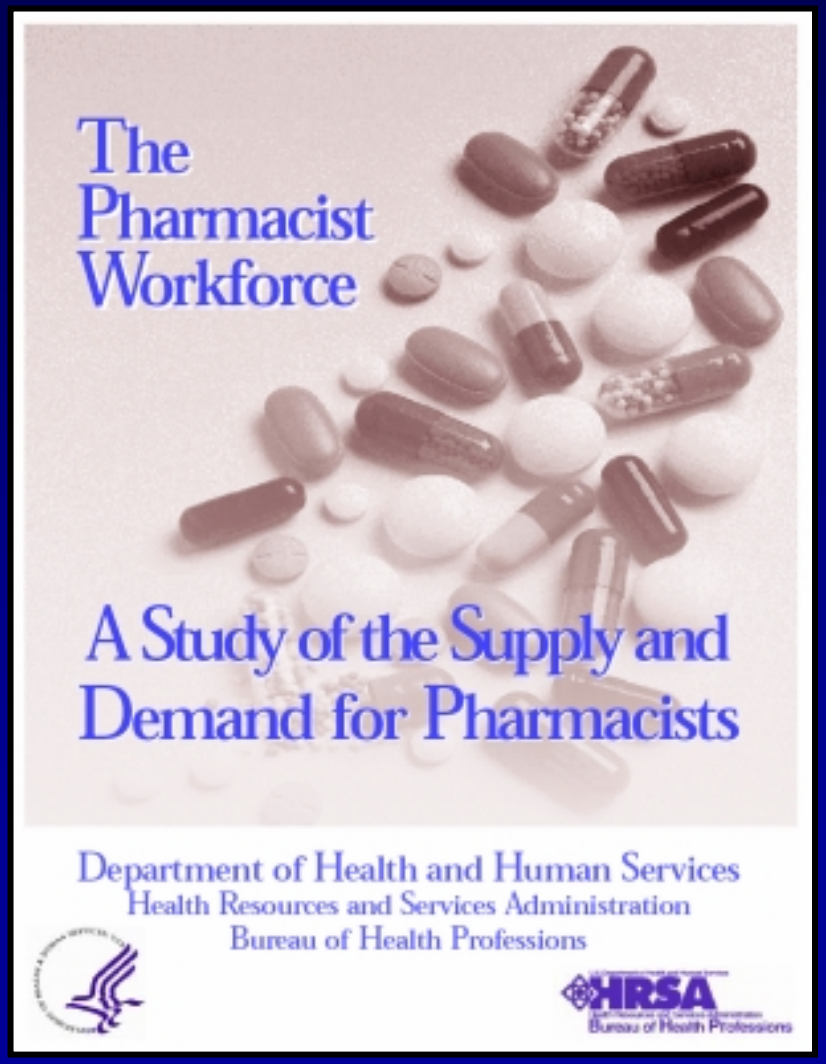
- Findings
  - Tight job market, reimbursement uncertain, expect demand to increase, limited diversity in profession
- Recommendations
  - Maintain current programs
  - Could not answer question of program expansion advisability
  - Need comprehensive genetics workforce study
  - Educate health insurers and managed care plans about genetic services

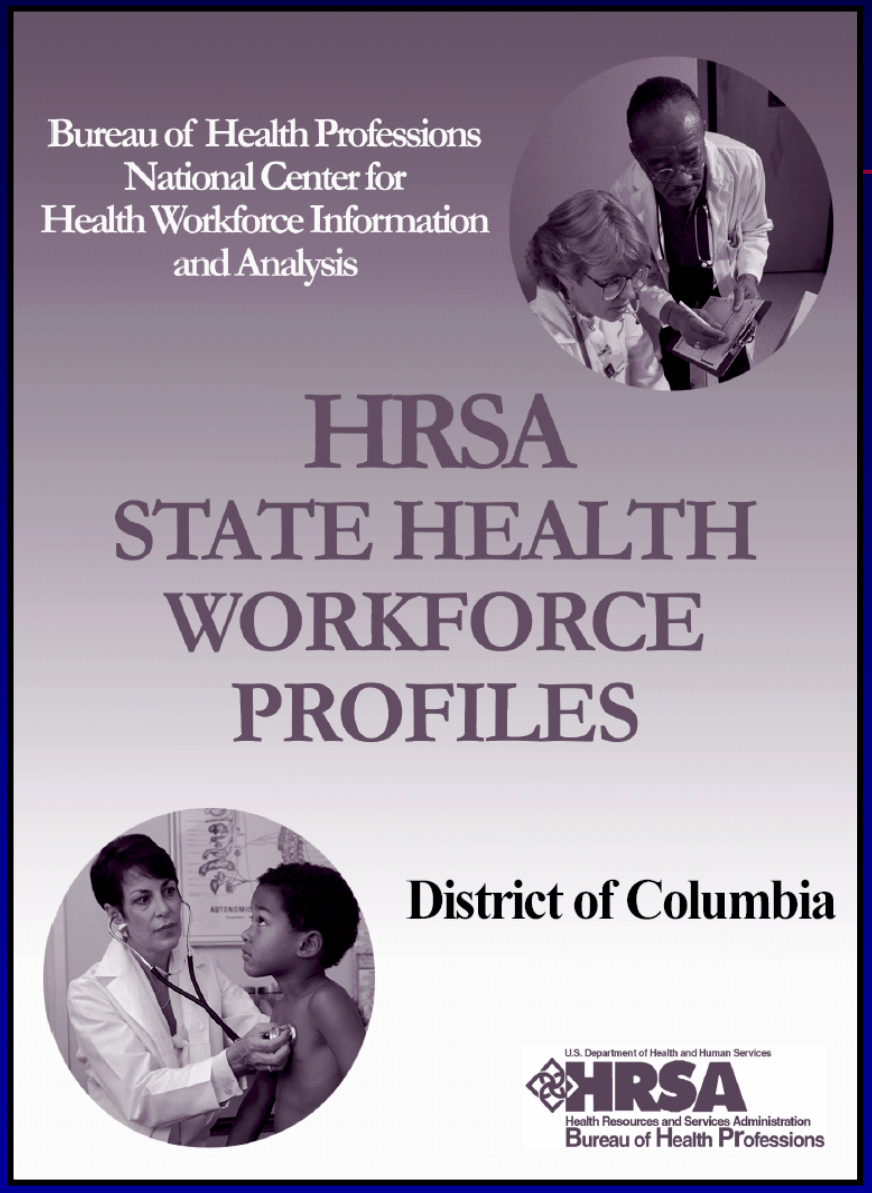
Funded by HRSA, Bureau of Health Professions (BHPr) and Maternal and Child Health Bureau (MCHB) Genetics Services Branch (GSB). Carried out by University of Illinois at Chicago (UIC) workforce center.

The Pharmacist Shortage, 2000

- Demand outpaced supply
- Prescription volume - a useful demand measure
- Automation and labor substitution could reduce dispensing time & demand
- Population pharmaceutical care needs may sustain demand

Request from Congress to Sec of HHS. Carried out by HRSA, Bureau of Health Professions (BHPr) and involved pharmacist workforce researchers at UIC and Western University CA.



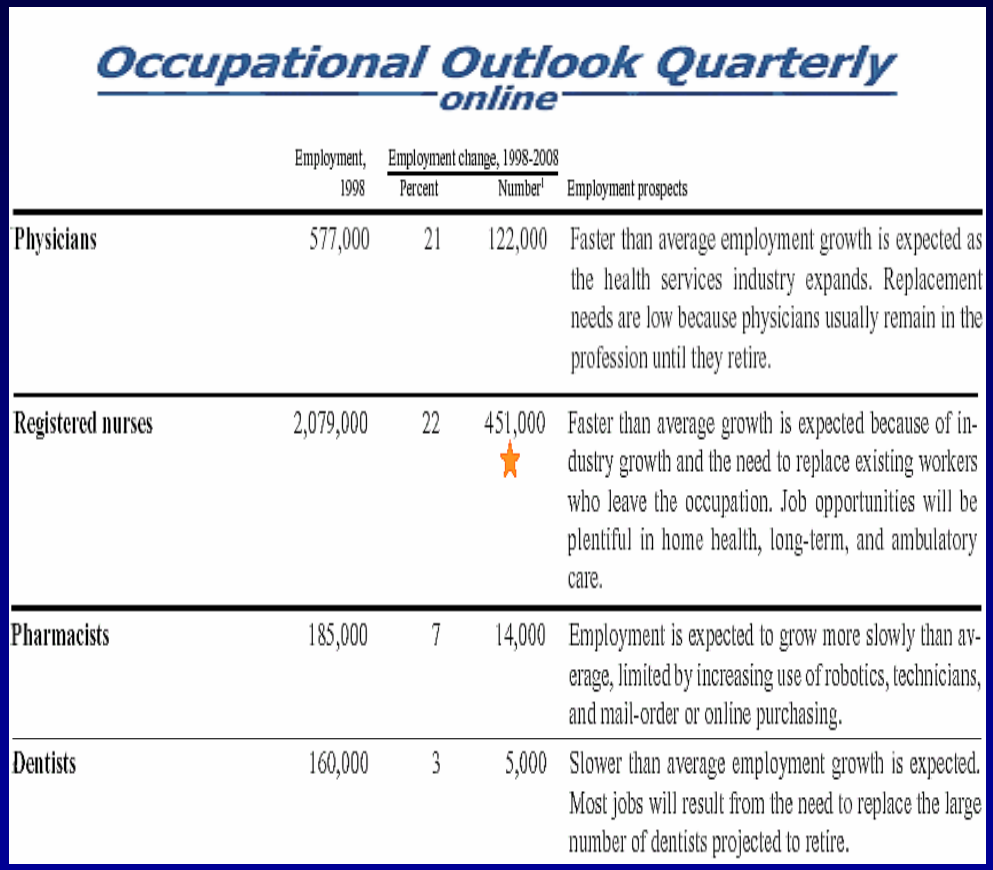


State Level Workforce Description

- State planning resource describes 25 professions
- New report on state-level health workforce in rural America WWAMI Research Center, (Washington)

Funded by HRSA, Bureau of Health Professions (BHPr). Conducted by NY Center for Health Workforce Studies.

Forecast Workforce Demand



Occupational Outlook Quarterly online

	Employment, 1998	Employment change, 1998-2008 Percent	Number[1]	Employment prospects
Physicians	577,000	21	122,000	Faster than average employment growth is expected as the health services industry expands. Replacement needs are low because physicians usually remain in the profession until they retire.
Registered nurses	2,079,000	22	451,000	Faster than average growth is expected because of industry growth and the need to replace existing workers who leave the occupation. Job opportunities will be plentiful in home health, long-term, and ambulatory care.
Pharmacists	185,000	7	14,000	Employment is expected to grow more slowly than average, limited by increasing use of robotics, technicians, and mail-order or online purchasing.
Dentists	160,000	3	5,000	Slower than average employment growth is expected. Most jobs will result from the need to replace the large number of dentists projected to retire.

Bureau of Labor Statistics (BLS)

- Complex economic modeling
- Forecasts growth by industry and occupation
- Limitation of methodology
- Information used by career and guidance counselors
- Data used for workforce planning and analysis

Health Services Research

- Organization
- Financing
- Delivery models
- Staffing/workforce
- Access to care
- Outcomes

Genetics: Concepts and Terminology

- Genetic conditions or disorders
- Genetic testing
- Genetic services
- Genomic medicine… new genetics… genomic basis of common/complex diseases
- Genetics workforce

Perhaps a Useful Model to Consider – The Policy Debate on Primary Care

Primary Care: Concepts, Evaluation, and Policy

Barbara Starfield
1992

- Concepts of primary care
  - first contact care
  - longitudinality and managing care
  - comprehensiveness of services
  - coordination and referral process
- Evaluation and policy issues
  - practitioners, education
  - practice – community-based, medical records, information systems
  - organization, financing and access to care
  - practitioner-patient interactions
  - quality and outcomes

Primary Care

America's Health in a New Era

IOM Study 1996
See SACGHS handout for Executive Summary and recommendations.

"After decades of relative neglect in a health care system that placed most of its emphasis on specialization, high technology, and acute care medicine, the value of primary care is again recognized as a part of the wave of reform that is sweeping the US health care industry"

"It would be impossible to overemphasize the importance the committee attached to the new definition. Committee members continually referred to it when formulating recommendations on issues such as who is a primary care clinicians, what should be the content of education and training programs in primary care, and what items should be included in the research agenda for primary care."

Clinical Genetic Services

- *What* services are included?
- *How* are services organized – systems approach and patient perspective?
- *Where* are the services provided?
- *Who* provides the services?

- What are emerging models of services?
- What information is generated and how is it shared and accessed?
- How are the costs of genetics services covered?

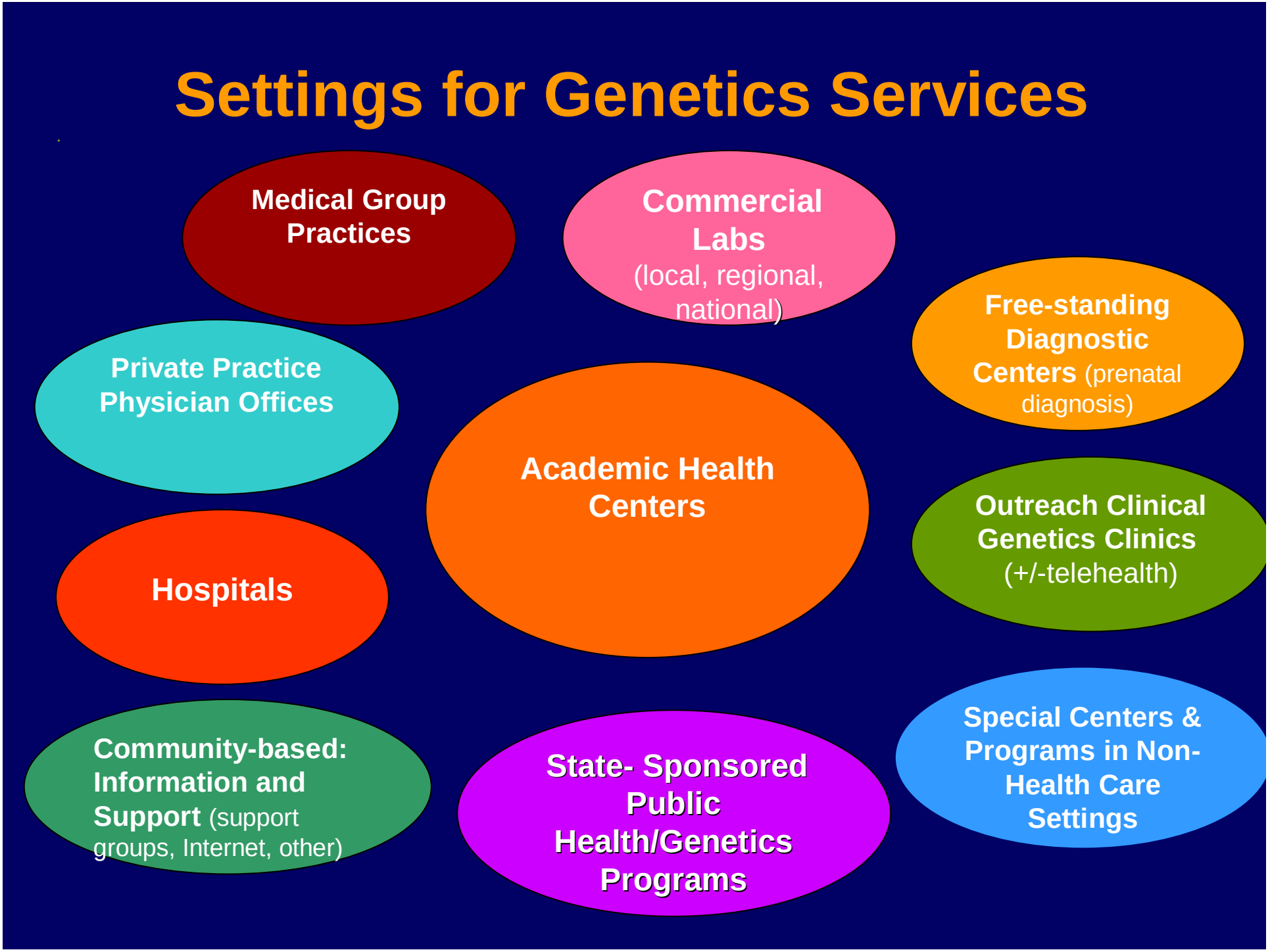
Preliminary Findings - 1

- Clinical genetics is a small specialty area
  - Genetic specialists
  - Training programs and trainees
  - Geographic distribution
  - Limited diversity among the professionals
- Genetic test availability influences demand for services

Preliminary Findings - 2

- Diffusion of medical innovation/technology
  - Academic health centers
  - Medical specialists, nursing specialists
  - Primary care physicians
- Market factors are important drivers
  - Financial incentives
  - Competition
  - Reimbursement design

Settings for Genetics Services

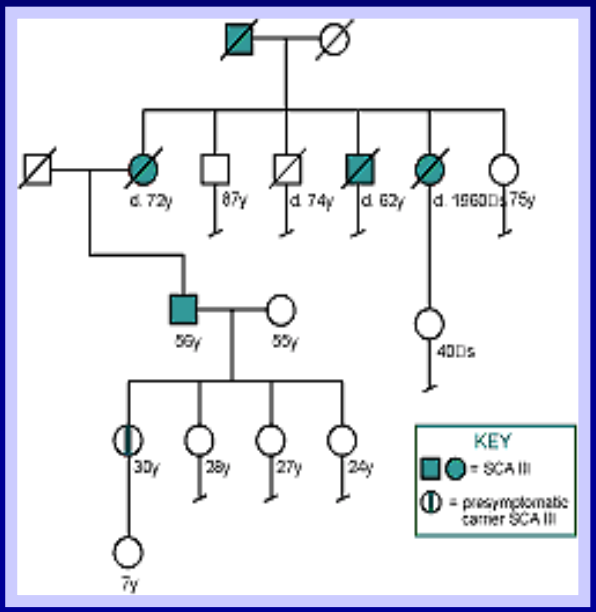


Functional Assessment of the Genetics Workforce

- Who is qualified to provide specific services?
- What roles do various providers play in specific settings where services are provided?
- Do the providers and roles differ by various categories of services? (e.g., pediatrics, reproductive, adult, state-sponsored/public health)

Family History and Risk Assessment

Pedigree showing transmission of trait through family



Genetic Counseling

Components of the Genetic Counseling Process

1. Information gathering
2. Diagnosis
3. Risk assessment
4. Information giving
5. Psychological assessment and counseling
6. Help with decision making
7. On-going client support

[Modified from: AP Walker (1997)]

Genetic Testing

- Laboratory/corporate entity
- Director and staff
- Test processing
- Results reporting/ interpretation
- Other services - counseling

GeneTests

Diagnosis and Risk Assessment, Management Plans

Familial cancer risk assessment

Diagnosis and management for rare conditions

Genetic conditions in children

Genetic Services Continued – Consider Providers For

- Specific therapeutic interventions
- Care coordination, supportive or rehabilitative services
- Family-related genetics issues and follow-up

What factors determine who can provide services?

- Competency – education and training
- Regulation – state licensure and practice acts
- Local market factors (eg history, organizations, supply/demand, etc)
- Setting & organizational structure
- Reimbursement by insurers (federal, private)
- Inter-professional collaboration – collaborative practice, teams, outreach
- Political strength and vision of the profession
- Advocates and public interest

Assessing Genetic Services and the Health Workforce (3 yr: 2001-2004)

Purpose of Research Project:

- To describe current models for organizing, staffing, and delivering clinical genetic services
- To identify emerging service models and professionals engaged in models
- To identify the factors that are driving changes and demand for services
- To establish a foundation for further health services research.

1 – Specific Professions in Study

- Clinical genetics specialists – survey research
  - MD & PhD Medical Geneticists 2003
  - *Genetic Counselors (study by NSGC) 2002*
  - Nurses in Genetics 2004
- Physicians that provide genetic services
  - Primary care physicians
  - Medical specialists and subspecialists *
- Nurses and other health professionals that provide genetic services*

* *Not systematically studied – could be included in sample for GSM project*

Findings - Medical Geneticist Survey*

- Written survey of all ABMG diplomates
  - Conducted Jan 2003, excluded the 169 new 2002/2003 diplomates
  - Mailed to 1,600 diplomates with US addresses, 56% RR
- Estimated count of active board certified geneticists
  - 1,400 diplomates active in genetics, 900 MD (or MD/PhD) and 500 PhD
- Demographics and Education
  - 50% women, mean age 52 years,
  - Few members of minority groups (9% Asian, 4% Black, Hispanic, Other)
  - Highly educated (23% of MDs also had PhD)
  - MDs GME: 71% Pediatrics 11% Internal Med 10% Ob/Gyn 6% Path
  - Laboratory Genetics: 61% of all geneticists have a laboratory specialty:

    Biochemical – 13% Molecular – 19% Cytogenetics 29%

*preliminary findings

Geneticists – Time Effort*

Aggregate **Time Effort - % time spent in**

	All	MDs	PhDs
Patient Care	28	43	3
Clinical Lab	24	9	51
Research	21	20	22
Education	8	9	7
Administration	10	9	10
Other	9	10	7

Overall 86% of MDs and 16% of PhDs report some patient care time

*preliminary findings

Geneticists' Professional Practice*

Primary Work Setting

	All	MDs	PhDs
Academic Medical Center	62	66	55
Hospital	9	8	11
Commercial Lab	10	3	21
Med Practice/HMO	9	12	3
Other settings	7	10	10

Work effort (mean): 52 hrs/wk, 48 wks/yr, 2,496 hrs/yr

*preliminary findings

Geneticists - Patient Care*

	All MDs Geneticists	Pediatrics trained	Other (Internal med, Ob/Gyn)
Reproductive patients	11%	7%	67%
Infants, children, adolescents	74%	81%	6%
Adults	18%	11%	27%
Wait time for new pt < 1 mo	52%	45%	62%
New patient visits per year	240	288	240
Visit time: new patient	75 min	80 min	60 min
Follow-up visits per year	192	192	192
Visit time: follow-up patient	40 min	46 min	30 min

And, 30% of practices could accept many new patients

*preliminary findings

MD Geneticists

- Newest and smallest recognized medical specialty, few new entrants into profession
- Limited patient care time (split between genetics and non-genetics patient care)
- Time in research, education, administration
- Majority are pediatrics trained. Is training sufficiently broad for evolving patient mix??
- Very few genetics patient visits per year, but time intensive visits, ?efficiency gains

Medical Specialties

(AMA, self reported specialty, board certified 2001)

All Physicians (836,200)	556,700
Internal medicine	97,200
Family Medicine	53,500
Pediatrics	46,500
General Surgery	37,500
Anesthesiology	36,800
Obstetrics and Gynecology	29,000
Psychiatry	24,700
Cardiology	19,400
Neurology	9,000

2 – Genetic Services Models (GSM)

Purpose: To describe models of organizing and delivering clinical genetic services and the roles of health professions in services.

Research Design: In-depth studies of representative communities across the US to describe five categories of services.

- Prenatal or reproductive genetic services
- Genetic services for children
- Genetic services for adult onset conditions
- State sponsored genetics programs
- Clinical genetics laboratory services

Sampling Frame: Metropolitan areas (state), 4 communities selected from 12 CTS sites; about 55 interviews/community; total ~ 220 interviews.

U Texas Workforce Center studying US-Mexico Border communities.

The CTS Sites

Factors Affecting Genetic Services

- Overall health care organization, financing, policies
- Genetics technology advances and clinical applications
- Professional practice and varied adoption of genetic framework
- Consumer awareness/interest
- Local health care market factors

GSM Findings – Factors Driving Services Models

- New genetic tests +++
- Individual leadership/institutional vision
- Geneticists' roles as genetics generalists and experts in specific conditions
- Laboratory competition undermines AHC
- Outpatient, cognitive services = low $$
- Safety net funding and services from states affects access (+ and -)
- Varied laboratory/biotech strategies and models
- Genetic counselors' flexibility, but market challenges

GSM Findings
Services and Providers

- Most services still relate to counseling, testing, and test interpretation
- Small numbers of genetic specialists - ? problem
- Mixed forecasts for timeline on therapeutics to be available for practice
- Restrictive market for cognitive services, *except*
  - With procedures (amniocentesis for prenatal diagnosis)
  - Potential – testing or biotech therapy requires experts to safely implement
- So far – limited big picture view/expectations from interviewed specialists

Research Agenda: Genetics Related Workforce

Needed: Policy Level (? primary care model)

IOM or other public/private open forum group

- Define and characterize concepts, functions, information systems needs, access issues, impact on clinical practice, research agenda

Federal Agencies: Current Involvement

- ELSI Research Agenda – 13-year research agenda
- HRSA: MCHB Genetics Services Branch
- HRSA Bureau of Health Professions, other Bureaus
- CDC: public health and genetics
- Other agencies

Priority Workforce Specific Research*

- What is future supply and demand for clinical geneticists and genetic counselors? Are training programs producing sufficient new entrants into these professions.
- Current and emerging roles, credentialing
  - Medical specialists and subspecialists
    - Oncologists, neurologists, gastroenterologists, cardiologists, many, many other specialties
  - Advanced practice nurses in various specialties
    - Oncology nurses, women's health, pediatrics, many other areas
  - Public health genetic service providers, genetic epidemiologists
  - Therapists – counseling and rehabilitation specialties
  - Pharmacists

** Draft list prepared by presenter and team*

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- HRSA Project Officer
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Research Project Funders

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