HRSA Perspective

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Roadmap of Federal Agencies Along the Translational Pathway

**T1:** from concept to human studies

**T2:** from studies to guidelines

**T3:** from guidelines to widespread practice

**T4:** from practice into true benefit

- **Basic Research**
  - NIH
  - DOD/VA

- **Clinical Trials (Patients)**

- **Clinical Practice Guideline**
  - FDA/CMS

- **Clinical Practice**
  - CDC
  - DOD/VA

- **Healthcare Outcomes**
  - HRSA
  - AHRQ
  - PCORI
Health Resources and Services Administration (HRSA)
• America’s healthcare safety net - HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable.

Maternal and Child Health Bureau (MCHB)
• Provides leadership to improve the physical and mental health, safety and well-being of the maternal and child health population which includes all of the nation’s women, infants, children, adolescents, and their families, including fathers and children with special health care needs.
Genetic Services Branch

Vision
Genetic science is intrinsic to the understanding of health and well-being throughout the life course of an individual.

Mission
Provide national leadership to improve, expand, strengthen, and evaluate access to a system of genetic services and the quality of those services for children, youth, and adults across their life course.
Legislative Authority

• Title V Social Security Act Sec 501: To provide and promote family-centered, community-based, coordinated care for CSHCN and to facilitate the development of community-based systems of services for such children and their families

• Title V of the Social Security Act Sec 502(a): Authorizing funds for Special Projects of Regional and National Significance (SPRANS) for genetic disease testing, counseling, and information development and dissemination programs

• Newborn Screening Saves Lives Act of 2008, reauthorized in 2014
Genomic Medicine

- To optimize the impact of genomics discoveries, advances need to be integrated into activities that directly influence the health of the public
Entry Points into Genetic Services

- Infertility
- Multiple SABs
- Family history
- Carrier screening
- Prenatal screening/diagnosis
- Newborn screening
- Major/minor malformations
- Screening for growth, neurocognitive development, autism, hearing, vision
- Family history
- Pediatric cancers
- Adolescent and early adult onset degenerative conditions
- Family history
- Adult onset degenerative conditions
- Hereditary cancer, cardiovascular
- Common complex disorders
- Family history
Prerequisites for Genomic Medicine

- Evidence, value, outcomes
- Genetic services
  - Provider literacy, guidelines, clinical decision support tools to:
    - Identify, test/refer, communicate and use genomic information in treatment decisions
  - Genetic providers
    - Delivery models to reach everyone who needs services regardless of where they live or the family born into
- Payment
- Systems of care
Six indicators of a well-functioning system

- Families/individuals partners in decision making;
- Comprehensive, coordinated care through the medical home;
- Adequate insurance/financing to pay for needed services;
- Early and continuously for special health care needs;
- Community services are organized for easy use by families; and
- Services to transition to adult health care, work, and independence.
Regional Genetics Service Collaboratives (RCs)

Provide a regional infrastructure of public health genetics to improve, expand, and evaluate access to a system of genetic services and the quality of those services to improve health outcomes for children, youth and adults across their lifespan.

1. NEGRC: New England Genetics Collaborative
2. NYMAC: New York-Mid-Atlantic Consortium
3. SERC: Southeast Regional Collaborative
4. Region 4: Region 4 Genetics Collaborative
5. Heartland: Heartland Regional Genetics and Newborn Screening Collaborative
6. MSGRC: Mountain States Genetics Regional Collaborative
7. WSGSC: Western States Genetic Services Collaborative

National Coordinating Center - ACMG
Regional Genetic Services Collaboratives

• Develop partnerships to leverage resources and collaborate on solutions

• Identify geographic, population, and funding challenges to accessing genetic services and pose and test solutions

• Pilot projects, data collection related to genetic services

• Development of policy papers and forums to guide the development of services and insurance coverage
How do we evaluate what we’re doing?

- What are we doing?
- How well are we doing it?
- Is anyone better off because of it?
New paradigm of regional genetic services?
Going Forward

• What are the gaps that a public health approach can address?
• What are the failures in the market that HRSA can help address?
• Who needs genetic services that aren’t getting it?
• What is the needle we are trying to move?
• What will be the impact if we succeed?
Contact Information

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