Accessing Genetic Services: Financing and Policy Considerations

Mountain States Regional Genetics Network

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Addressing the Continuum of Needed Services

A continuum of care is needed for any condition which has a genetic etiology.

Population level vs. Individual level
Questions to Ask Across the Continuum

• What are the populations of concern?
• Are the needed services available?
• Are the needed services affordable?
• Are the needed services acceptable?
• Do the existing services represent quality?
Considerations Regarding Policies Related to Access

• Defining the populations and services we need to address
  ▪ Population demographics
  ▪ Urban/rural
  ▪ Health professional shortage areas

• Variations across the Mountain States
  ▪ Population
  ▪ Public and private insurance coverage
  ▪ Services distribution
Focusing on Children with Special Health Care Needs

- Living in urban areas
  - Below 35% in Wyoming and Montana
  - Between 68% and 92% in the other states
- % CSHCN who are between 0-17 generally represent between 12 and 14%, below US average of 15.1%
- Households with one or more CSHCN also at or below US average of 23%
Policies Need to Address:

• Overall health related policies
• Policies that directly or indirectly address genetic related issues
• Coverage
  ▪ Public and private insurance
  ▪ Direct financing
• Other interventions that address access issues
• Policy statement on access identifies the following concerns that need to be addressed:
  - Decrease barriers to diagnosis
  - Provide coverage for individuals with pre-existing conditions
  - Enable early disease detection and prevention
  - Ensure access to affordable treatments, including specialty drugs, medical foods and other emerging therapeutics
Addressing Financial Barriers

- “Insurance” coverage for services
  - Public insurance
  - Private insurance
- Defining who is covered
- Addressing what is covered
- Determining whether costs to patients are reasonable and/or affordable
- Ensuring that payment/reimbursement is adequate
- Developing approval for services that are not burdensome
There are Major Differences In Insurance Rates

• Overall the rates of uninsured and underinsured children in Mountain States are higher than the US average

• CSHCNs also are more likely to be:
  ▪ Uninsured during some period during the year
  ▪ Underinsured
Private Coverage for CSHCN Population

• Private insurance coverage rates are generally close to the US average of 57.4%
• Colorado has a higher rate of almost 66%
• Utah at 38.6% and New Mexico at 41.3% are considerably lower
Medicaid and CHIP Coverage Varies Across the States

• For all children, Medicaid covers between 40 and 64% of all children
  ▪  The National average is 43%
  ▪  5 states are at or above this average
  ▪  Nevada, Colorado and New Mexico cover 40%

• Medicaid or CHIP coverage is highly varied in the Mt. States
  ▪  Arizona (14.4%) and New Mexico (16.6) have the lowest rates
  ▪  Other states range from 29% in Nevada to 52% in Utah
Insurance Mandates Are Important Tools To Support Access

- Autism covered by all Mountain States
- Medical foods covered by all Mountain States
- Mental health parity only in Montana, Nevada, and Wyoming
- Telemedicine coverage in all but Wyoming
- What other mandates might be important?
Availability of Services Varies Across the Region

• Range of providers and their distribution
  ▪ Primary Care
  ▪ Specialty Services
  ▪ Those providing specific genetic services
    – Medical Geneticists
    – Genetic Counselors

• Location of facilities providing services

• Cultural competence and sensitivities
What are the Policies/Programs That Support Services?

- Federal and state legislation
- Federal programs including Title V, Indian Health Services, and other services programs
- Health professions support programs
- State programs
- Foundation initiatives
Range of Financial Strategies

• Medicaid and CHIP related policies
  ▪ Eligibility
  ▪ Buy-in programs
  ▪ Waiver related efforts
  ▪ Enrollment assistance

• Premium assistance efforts

• Expansion of relevant mandates and services covered

• Use of Title V funds
Program/Services Related Strategies

- EPSDT
- Enabling Services including:
  - Case management, transportation, translation, family support, respite care, benefit counseling, purchasing health insurance
- Early Intervention Programs
- Transition Services
- Provider related strategies
  - Educational efforts, subsidies and incentives
  - Telemedicine
National Issues to Watch

• Individual mandate impacts
• Pre-existing conditions
  ▪ Court cases
  ▪ Potential legislation
• Other changes/impacts of ACA
• Medicaid changes
• Federal budget
Implications for Regional Efforts

• Surveillance of changes at the national and state levels
• Sharing information across states
• Determining regional efforts
• Developing and testing new approaches and strategies
RESOURCES

• National Coordinating Center for Regional Genetics Networks
  ▪ NCC Lift Newsletter – Legislative, Insurance and Finance Tracking
  ▪ Medicaid database
  ▪ Access to Congressional Quarterly

• AAP Medicaid Fact Sheets

• National Academy for State Health Policy
RESOURCES (continued)

• National Center for Health Insurance and Financing for CYSHCN
  ▪ Financing Strategies
  ▪ State Data Chartbook
  ▪ Newsletters and policy documents
  ▪ Partner websites
• Center for Healthcare Strategies