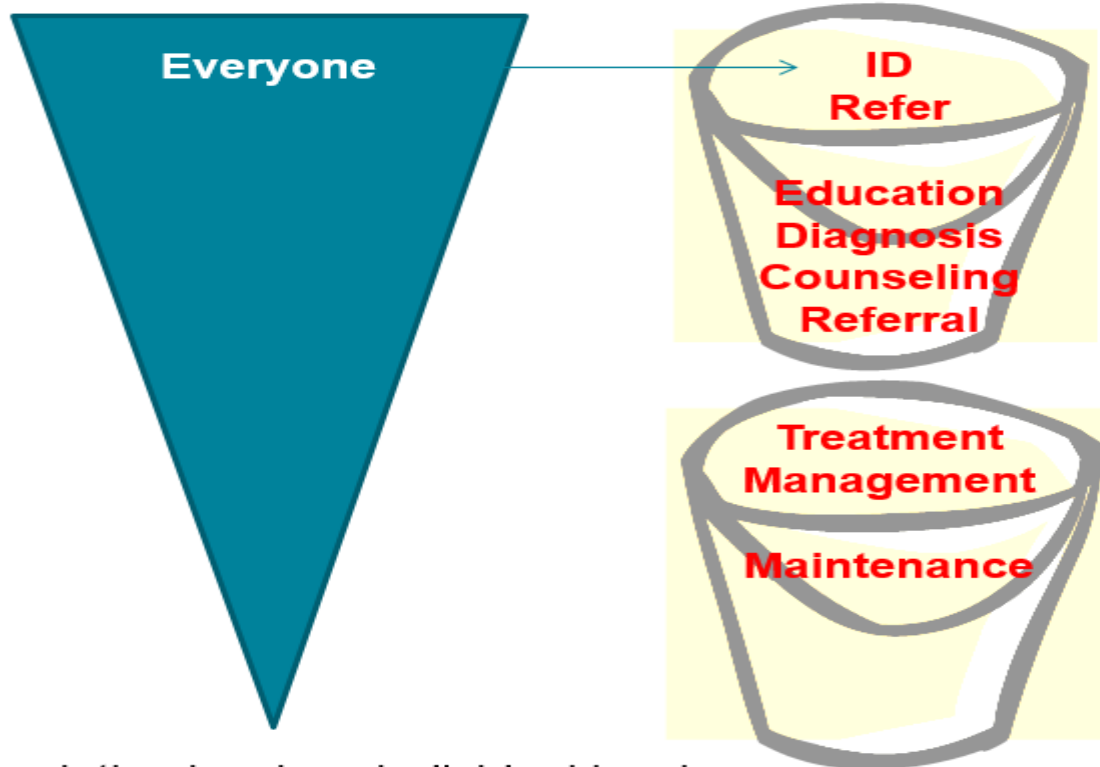


Accessing Genetic Services: Financing and Policy Considerations

**Mountain States Regional Genetics
Network**

October 2, 2018

Addressing the Continuum of Needed Services



Population level vs. Individual level

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

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

American College of Medical Genetics Policy Statement

- 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