Regional Genetics Service Collaboratives; update and discussion

Sara Copeland, MD
Chief, Genetics Services Branch
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U.S. Department of Health and Human Services (HHS)
Health Resources and Services Administration (HRSA)
Maternal and Child Health Bureau
Division of Children and Youth with Special Health Needs
Genetics Services Branch

Changes in 2012

- MCHB
  - Dr. Lu was appointed Administrator for the Bureau, his interest and training is in OB/GYN, lifecourse theory and quality improvement
- Branch chief
  - Michele Puryear took a position at NIH
  - Sara moved to branch chief
- Hemoglobinopathies
  - New nurse consultant working to coordinate national efforts- HP2020 and HUMLO
  - Lorraine Brown left, are going to be replacing her

Plans for 2013

- NBS turns 50!!!!
  - CDC is working with APHL and HRSA to develop a year long celebration of the first states who mandated NBS screening 50 years ago
  - Will be a celebration in conjunction with the May 2013 SACHDNC meeting
  - Major events are planned for the May 2013 APHL annual symposium

Looking at impact and data!

Evolving emphasis

- HRSA
  - Evaluation
  - Quality Improvement
  - Collaboration
- MCHB
  - What are we currently doing, what can we do better and how to we move forward?
- DCSHN
  - How to fit our core outcomes into the lifespan model and ensure all people get the services they need

Getting to the Results- Quantifying Impact

- What are our desired results?
  - What is the end product we hope to achieve?
- What indicators do we have?
  - Measure to quantify the achievement of a result
- What performance measures should be used?
  - How to we measure how well a program is working?

Division of Children with Special Health Needs

6 Core Outcome Measures- Program Results

- **Family/Professional Partnerships**
  - Families are partners in decision making at all levels
- **Medical Home**
  - Coordinated, ongoing, comprehensive care within a medical home
- **Insurance**
  - Adequate private and/or public insurance to pay for the services needed
- **Early and Continuous Screening**
  - Early and continuous screening for special health care needs
- **Integrated Community-Based Services**
  - Services organized so families can use them easily and are satisfied with services received
- **Transition to Adult Life**
  - Youth receive services to make transition to all aspects if adult life including health care, work and independence

7

Indicators HP2020 application

- HP2020 Measures
  - MICH-31: Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems.
  - MICH-30: Increase the proportion of children, including those with special health care needs, who have access to a medical home.
  - MICH-32.2: Increase the proportion of screen-positive children who receive follow-up testing within the recommended time period.
  - DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.
  - MICH-32.3: (Developmental) Increase the proportion of children with a diagnosed condition identified through newborn screening that have an annual assessment of services needed and received.

What is the expectation for the Heartland?

- Develop programs to impact the indicators
- Be able to measure the impact of your programs
- Report on the impact of your programs in a manner that ties back to the indicators (HP2020 measures) you have chosen
- Will likely require use of proxy measures or inference about the impact on the national measures

Measuring the impact!

- How much did you do?
- How well did you do it?
- Is anyone better off?

How might this look?

- What percent of children with special health needs followed by the clinics in your region, have an identified medical home?
  - Do you have a definition of what qualifies as a medical home? Use that as the standard?
- How many specialty clinics in your region have transition clinics? What percent of eligible children participate in the clinic and are on track to transitioning to adult care?
  - What is the goal for the transition program? How is success measured? The reporting on this measure should be based on these standards.
- What percentage of eligible NBS children in the clinics in the Region have annual needs assessments?
  - What qualifies as a needs assessment? Using this as the standard, what percent qualify?

Take Home Points

- Agency emphasis, MCHB emphasis and Division emphasis
  - How are we improving care, how can we do it better and what is the impact of our efforts?
- All new projects have quality and impact measures as part of the guidance
- We will need to be able to demonstrate our value
  - Data is important
- We aren't asking you to answer or prove utility for the nation, just the impact of the Heartland's programs!

"…no intervention, program or project, regardless how dear or favored, is beyond the scrutiny of being measured, monitored and documented for impact…"

Quote from CDC Blood Disorders Conference Book - March 2012

Living up to expectations!

- Development of case definitions and NBS QI measures
  - Standardizing mechanisms to measure what we do at a national level regarding NBS
  - Developed via consensus of clinicians and NBS programs
- Next steps for the case definitions
  - Ask states to use the metrics developed for classification, compare to the workgroups classifications
  - Work out the kinks
- Next steps for the NBS QI measures
  - Ask states to review the measures and definitions and develop consensus for testing at the state level
  - Develop a web based program that can track the measures (as automated as possible)

Contact:

Sara Copeland, MD
Chief, Genetics Services Branch
scopeland@hrsa.gov
301-443-8860