

Improvement and Integration of Health Services for Infants and Children with Genetic Conditions

Grant Initiative

- Improvement and integration of health services within a community or other geographic area within a State for infants and young children with genetic conditions

Objectives

- Facilitate implementation of performance-based evaluation for demonstration projects;
- Begin to identify common questions, variables, and approaches among the projects;
- Explore the development of a unified data dictionary for all funded projects.

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A Primer on Current Approaches to Performance-based Evaluation

In recent years, government programs have moved away from traditional academic evaluation techniques and shifted toward the industrial model of performance evaluation. Ongoing quality monitoring, improvement, and assurance activities can better serve families and communities than an evaluation that tells us only that we did not achieve program objectives in the end.

The report of the Institute of Medicine Committee on Using Performance Monitoring to Improve Community Health (Durch, Bailey, and Stoto, eds, 1997) found that three important developments led to a greater focus on community: (1) broader understanding of the nature of health and its determinants; (2) greater appreciation of the importance of community perspectives; and (3) increased interest in the use of performance measurement to improve the quality of health and other services in public and private settings.

As used by the [IOM] committee, the term 'performance monitoring' applies to a continuing community-based process of selecting indicators that can be used to measure the process and outcomes of an intervention strategy for health improvement, collecting and analyzing data on those indicators, and making the results available to the community to inform assessments of the effectiveness of an intervention and the contributions of accountable entities. (Durch, Bailey, and Stoto, 1997, page 4)

The IOM committee also concluded that performance indicators are needed to help stakeholders monitor impact and that sets of indicators are needed to assess performance. Performance monitoring uses these indicators in an ongoing process of resource inventories, review, reporting, and revision to programs and strategies as necessary.

At the same time, a group of evaluators who specialize in child and family services (including J. Lawrence Aber, Claudia J. Coulton, James P. Connell, Anne C. Kubisch, Kristin Moore, Lisbeth B. Schorr, Carol H Weiss, Heather Weiss, and their colleagues) have developed new models and approaches to evaluating community-based initiatives. Some are approaches to evaluating comprehensive community-based initiatives that pose challenges related to their complexity, environmental responsiveness, potentially broad impact, and lack of control or comparison group. This creative work has placed evaluators into new, more active research and much more interactive roles (Prudence Brown, 1995). With more evolutionary methods, the impact of a program or community-based initiative can be measured in ways that provide "sufficient quantification and precision to permit comparative analysis between communities, or over time, while at the same time allowing in-depth qualitative description and analysis" (Michael Bamberger, 1990). Much of this work focuses on community-level analysis and community-driven process.

The attached collection of materials is a primer that includes excerpts from a number of reports, articles, and books about the following topics:

- Monitoring performance to improve health at the community level;
- Defining appropriate outcomes/results that reflect program and community goals;
- Selecting valid and meaningful indicators/benchmarks;
- Using sample frameworks to classify and logically arrange concepts, outcomes, and indicators;
- Using multi-site collaboration to advance knowledge.

Performance measurement has been widely discussed in recent years. For State Maternal and Child Health Programs, Federal guidance now requires performance monitoring. The Title V Block Grant Measurement Performance System includes a set of National “core” performance measures and up to ten State “negotiated” performance measures that are categorized into three types; capacity, process, or risk factors. Examples of Block Grant performance measures that relate to this grant activity include:

- Percent of newborns in the State with at least one screening for each of phenylketonuria, hypothyroidism, galactosemia, hemoglobinopathies, (e.g., the sickle cell diseases) (combined);
- Percentage of newborns who have been screened for hearing impairment before hospital discharge;
- Percent of children with special health care needs in the State who have a medical/health home;
- The degree to which the CSHCN Program provides or pays for specialty and subspecialty services, including care coordination, not otherwise accessible or affordable to its clients;
- The degree to which the State assure family participation in program and policy activities in the State CSHCN Program;

Mark Friedman of the Fiscal Policy Studies Institute in Baltimore, MD constructed a model that states that all performance measurement aims to answer two sets of interlocking questions: how much (quantity) and how well (quality) in relation to effort (input, or what was done) and effect (output, or what was produced). This yields a four-quadrant matrix that can be used to decide what is most important and select performance measures that match priorities.

For example, in newborn screening, which is it more important to know:

- How many newborns were served (how much service)?
- How many initial and repeat newborn screening tests were completed (how much did we produce)?
- What was the percent of false positives (how well did we deliver service)?
- What percent of infants received newborn screening and appropriate follow-up and/or what percent of children with confirmed positive results received diagnostic and treatment services (how good were our products)?

Meeting Three

Other key lessons and concepts from the readings about new approaches to performance-based evaluation include the following:

- Uniform definitions of outcomes, indicators, numerators, denominators, and data categories greatly improve the quality of evaluations;
- Evaluators' roles are changing;
- Performance-based evaluation approaches require consensus development as a part of the process for selecting indicators;
- Collaboration among several evaluation efforts can multiply the impact of the results;

In these evolving approaches, performance measures should be:

- Quantifiable;
- Uniformly defined;
- Supported by available data that can be routinely collected;
- Related to outcomes desired and to severe or widespread conditions;
- Measures of both child outcomes and program process;
- Developed through a process that engages professionals and consumers;
- Based on consensus about priorities and commitment of stakeholders;
- Consistent with other related objectives and measures;

In addition, performance measures/indicators used should not be:

- Too big to measure;
- Interesting but not backed by data;
- Confusing or poorly defined;
- Too technical to make sense in the policy and community arenas;
- Disconnected from public policy;
- Invalid for diverse populations;
- Expressed in the negative;
- In conflict with community goals and values.

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Improvement and Integration of Health Services for Infants and Children with Genetic Conditions

Agenda

Friday, November 5, 1999

6:30 PM - 8:30 PM Networking Reception

Saturday, November 6, 1999

8:30 AM - 8:45 AM Welcome & Introductions
 Merle McPherson, MD, MPH

8:45 AM - 9:00 AM Charge to the Group
 Marie Mann, MD, MPH

9:00 AM - 10:00 AM Presentations by each of the funded projects.

10:15 AM - 11:15 AM Improving Outcomes through Research
 Research Indicators for Health Outcomes
 Betsy Shenkman, PhD
 Andrew Nelson, MPH
 Holly Grason, MA

11:15 AM - 1:00 PM Lunch Session with Family Perspectives

1:15 PM - 4:45 PM Small Group Work Sessions A & B
 Facilitator: Kay Johnson
 Resources: Betsy Shenkman, Donna Wegener,
 Joseph Telfair

Sunday, November 7, 1999

8:30 AM - 8:45 AM Next Steps
 Outcomes & Products
 Michele Lloyd-Puryear, MD, PhD
 Merle McPherson, MD

8:45 AM - 10:45 AM Work Session
 Project representatives comments
 Facilitators: Kay Johnson, Joseph Telfair

10:45 AM - 11:45 AM Summary & Adjournment

Establishing a Collaborative Health Outcome Network

Charge to the Group by Dr. Marie Mann, Deputy Chief, Genetic Services Branch, DSCSHN-MCHB-HRSA

As an introduction to our work today, I would like briefly to review current GSB activities. We have developed an interactive set of collaborative agreements, grants, and contracts that seek to advance and promote research, policy, service delivery, genetics literacy, professional practice, and consumer involvement.

- Newborn Screening Task Force;
- National Newborn Screening and Genetic Resource Center;
- Review of progress toward Title V Performance Measure on NBS;
- Research on managed care quality & contracts;
- “Genetic Awareness Coalition”;
- Consumer Network for Genetic Information and Services (proposed);
- Grants to:
 - a) Create State genetic plans, child health profiles, and integrated information systems (7 States);
 - b) Improve health outcomes through evaluative research (10 States);
 - c) Identify effective approaches to reduce ethno-cultural barriers to genetic services.
- Contracts for:
 - a) “Genetics in Primary Care” Faculty Development;
 - b) Studies of workforce issues for genetics;
 - c) Workshops for State policy makers.

Your grants were designed to enhance the structures for improvement and integration of health services within a community or other geographic area within a State for infants and young children with genetic conditions. Part of the structure is outcome evaluation. In addition, we see the potential for you, as grantees, to assist in demonstrating techniques for monitoring the performance of systems of care. Performance monitoring—in today’s parlance—is a cycle that includes:

- Continuing, community-based process;
- Selecting indicators to measure process and outcomes;
- Collecting and analyzing data on indicators;
- Making results available.

Together, the: 2010 Objectives, HRSA strategic goals, MCHB strategies, the performance objectives of the National Agenda for CSHCN, and Title V Block Grant performance measures for States create a framework for monitoring performance and measuring outcomes at the national and State levels. However, there is not yet a systematic method for monitoring systems of care. Under this framework, your demonstration projects can test approaches to performance-based evaluation at the system level and identify common definitions, indicators, outcomes/results, and data resources.

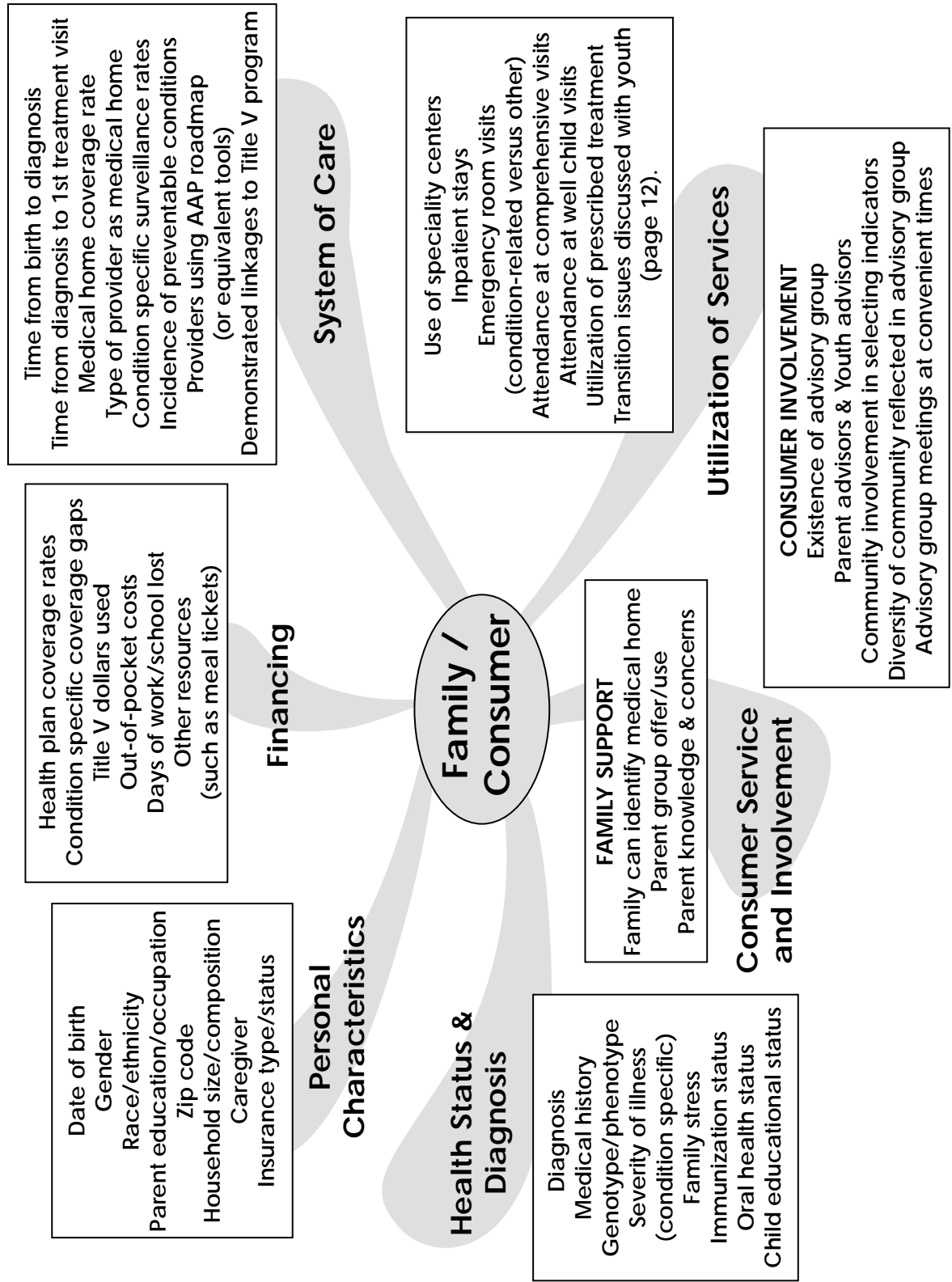
Your projects seek to help families improve the health outcomes of their children. They also aim to integrate services and information in order to make the system of care perform better and have a greater impact on outcomes.

Challenges for this meeting are to identify and focus on your role in:

- Testing utility of indicators;
- Measuring the service delivery process;
- Measuring child and family outcomes;
- Measuring the quality of care;
- Using a common data dictionary; and
- Developing items for minimum data set.

The Genetic Services Branch and the leadership of MCHB are committed to assisting you in these demonstration project activities and to using the lessons learned from your work.

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Conclusions and Next Steps: An “Ah Ha” Experience

Participating grantees provided feedback regarding Meeting Three. Before the close of the meeting, each participant was asked what they had found notable or had discovered (that made them say “Ah ha”). Five themes emerged from this discussion.

1. Genetic Services

- We need to identify the unique characteristics of comprehensive genetic services;
- We need to define genetics and genetic disease;
- States could or should be asked to address the gap between professionals and the public in terms of the interest in genetics.

2. Linkages between Programs for Children with Special Health Care Needs and Genetic Services.

- Is there a linkage? Yes, if one looks at the components of the system of care. In the case of CSHCN programs and the Title V resources that should be dedicated to their systems of care and services, the state needs to decide how much attention should be given to genetics;
- Transition is another area of joint concern—children with genetic conditions and other children with special needs fall off the map in adulthood;
- Traditionally, genetics activities were separate from CSHCN programs. This meeting provided an articulation of the common values and goals shared by genetics projects and programs for CSHCN, revealing the fit with the National Agenda and directions for 2010;
- CSHCN is a big umbrella and many diseases are included. We see new potential to make linkages.

3. Genetics in the Larger Context of Title V

- We have discussed multiple levels of interrelationship between Title V programs. The tentacles of MCHB permeate Federal, State, and local activities and programs;
- How can university-based genetics programs be connected to or find a place in the work of State MCH programs?
- Now we see that our projects can help MCHB and strengthen state programs. Our projects have a responsibility to sit down with State Title V staff, tell them about their needs, and discuss opportunities for collaboration, coordination, and support;
- My knowledge of Title V increased exponentially during this meeting;
- I want to learn more about Title V. I simply am not well informed about all the State-level programs and activities.

4. Family and Consumer Involvement

- I really learned about the importance of family involvement;
- I know that parental involvement is important. Now, it seems to me that we have been giving lip service to the concept of family and consumer involvement. This meeting helped us see new ways to approach it;
- We learned about the importance of using consumer input;
- We identified a specific need for specific disease coordinators to work together and work in more effective ways with consumer organizations;
- What we learned about family involvement can be shared at an upcoming meeting of academic and treatment center directors, endocrinologists, and family/consumer representatives.

5. Coordinating and Integrating Care

- As program developers, we have developed a strong program. Now, we have to get beyond identifying resources and services and move toward the point of integration and coordination of a system of care;
- The discussion led to rethinking what care coordination means and how it relates to the grant project.

6. Joint Project Efforts

- There is a great deal commonality among the project, but we also need flexibility. It may be difficult to come together and find common ground;
- A “one-size fits all” approach will not work. We need to make distinctions (e.g., sickle cell versus cystic fibrosis). We need to decide how much effort goes into general versus specific measures.

7. Meeting Process and Follow-up

- From an evaluation perspective, we see the relevance of some of the existing tools;
- Performance evaluation doesn't have to be as overwhelming as it initially appeared. The jargon of this process is not impenetrable, but it is new;
- A broad spectrum of ideas and values are represented in this room. This was an enlightening two days that provided ideas about what to do;
- In reading before meeting, I thought that we would be told what to do. The feeling now is not that we were told but that we were a part of a process. I feel supported and empowered by the process. We get the sense that MCHB wants us to succeed;
- We thought we would be told what to do. In coming to the tables, we learned here about ways to empower clients and to empower ourselves by sharing ideas among projects.;
- On the way home, I will write a letter from to the DOH director to express our desire to link the project with larger efforts;
- I now have more faith that our project can have a larger impact.

Key Questions for Projects

1. What are the goals of our project?
2. What are we improving, integrating, and evaluating?
3. What data are available for monitoring on this topic?
4. How will providers and consumers be involved in the evaluation process?
5. What definitions are we using now in our grant project?
6. What desired results/outcomes have been identified? Who identified these?
7. What indicators/benchmarks do we have in mind? Do they refer to both child outcomes and program/services system process?
8. What larger state or community initiatives affect our work?
9. How does our framework fit with established national/federal goals, objectives, and performance measures?
10. How can we collaborate with other grant projects to achieve greater improvements?

Next Steps and Future Possibilities

Proposed Next Steps

1. Revisit and confirm suggested topics

Genetic Services Branch-MCHB-HRSA will:

- Post “mind map” showing results of brainstorming activity on the Internet;
- Circulate list of potential indicators through e-mail list;
- Identify and share existing tools, instruments, and definitions;
- Maintain electronic communication to enable grantees to share results of their community-level priority setting;
- Identify and share core elements including definitions, data sources, and indicators available for use by grantees;
- Determine the availability of resources for the possible activities listed below.

Grantees will:

- Review and comment on mind map and indicators list;
- Participate in e-mail list;
- Share tools, instruments, and definitions;
- Continue a process to refine definitions and indicators.

Meeting Three

2. Soliciting additional community/consumer perspectives

MCHB will:

- Solicit consumer input on meeting products;
- Collaboration with Alliance, Family Voices, and ICHP to identify tools, instruments, and definitions;
- Provide technical assistance and advice regarding strategies to optimize consumer and community participation in process.

Grantees will:

- Identify ongoing supports and/or training and technical assistance that grantees will need to optimize the participation of community in process;
- Engage the consumer representatives on state grant team to lead grantee efforts to convene a consumer panel for each project;
- Define a process for actively involving consumers in selection of indicators.

Possible Future Activities:

The group reached consensus on the potential value of the following activities. However, the availability of Federal, State, and local resources to undertake such activities was uncertain. If funds can be identified, the following should be pursued.

- Electronic information sharing and network;
- Common data definitions;
- Common performance measures for demonstration projects;
- Common database;
- Annual meeting of grantees;
- Qualitative studies to determine best practices;
- Evaluation of process - from this meeting to end of grants.

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The Role of the Community and Families in a Process to Select Performance Indicators

- A community is composed of consumers, health professionals, and others. All stakeholders should be involved in the process of selecting outcomes.
- An effective performance monitoring strategy has the support of diverse constituencies. The group who guides this effort should represent a broad cross-section of cultural, political, racial, geographic, and philosophical viewpoints. Health professionals cannot do this alone.
- Families are essential in this process. Formal mechanisms for recruiting, engaging, and compensating families should be a part of the process.
- In selecting indicators, consumers can answer questions such as: What does this have to do with my life and the lives of the people I know? What are the implications for receiving those services? Do these indicators reflect our community values?
- To select performance measures and outcome indicators, each grantee must identify the most effective modality for the community and families they are serving (e.g., focus groups, brief telephone interviews, community meetings).
- Key community organizations and constituencies should be identified and linked to the process.
- Remember that improving the conditions of children and families starts and ends at the local level, with families in their communities.

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