

NEGC COLLABORATIVE EVALUATION UPDATE REPORT
By: Christopher Mausolff, Ph.D. & Peter Antal, Ph.D. Project Evaluation Staff
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Reflections on Project Activities 5/1/07-12/31/07

I. PERIOD OVERVIEW

This update report covers the period from May 1, 2007 to December 31, 2007. It provides a summary of activities by the Regional Coordinating Council (RCC), Working Groups and Evaluation Team during the period, an update on the status of core project components, and identifies recommendations for project improvement. As information flow among partners becomes standardized, the evaluation team will provide an ongoing quarterly report on the project's major activities.

The current New England Regional Genetics and Newborn Screening Collaborative (NEGC) grant (HRSA Grant #2 U22MC03959) officially began June 1, 2007. During this period, the structure and basic operations of the project have been created. The RCC, Collaborative Council, Advisory Committee, and most working groups have all been formed. Many of the working groups appear to be making good progress in their respective projects and the project is on track with meeting its objectives for the year. However, accurate assessment of working group progress is not yet possible as the Collaborative Council is still in the process of developing a viable system for collecting data on working group performance as well as finalizing logic models and outcome measures for core project outcome areas.

II. DESCRIPTION OF PRIMARY PROJECT ACTIVITIES

Project Administration

Between June, 2007 and December, 2007, the project developed the infrastructure to support the administrative offices of the NEGC. The NEGC set up Management Team meetings on a regular basis. The project director and project manager meet weekly, to address the operational and administrative needs of the NEGC. The Institute on Disability operational staff provides extensive budget and administrative support. Budget reports are available upon request, and the Operations Director has assisted in staff planning, office management, and assuring appropriate project administrative support. The IOD office staff also liaison with the UNH Office of Sponsored Research, assuring that federal reporting mechanisms are in place and the NEGC has structures in place to ensure staff is in compliance with the terms of the cooperative agreement. In 2007-2008, the NEGC established an office, initiated project subcontracts and sub-awards, and created the infrastructure required to run the RCC. In addition, the project staff meet frequently with the project evaluator to ensure that the goals and objectives of the grant are evaluated and reported in a standardized format. The NEGC also recruited and set up the initial meeting of the Advisory Committee in January 2008, ensuring that the group was representative of all states and appropriate consumer advocacy groups.

Kick-off Meeting May 3-4, 2007

The NERC organized a meeting May 3-4, 2007 to launch the project. The event was well attended by a diverse group of representatives from participating states. In small group sessions, participants refined goals and plans for the NERC. Suggestions were provided for best next steps for the project's success.

The Regional Coordinating Council

A RCC has been established at the Institute on Disability (IOD) at the University of New Hampshire. Dr. Moeschler is serving as Project Director and Ms. Philbrick-Schwartz as Project Coordinator. The Collaborative Council, Advisory Committees and most Working Groups have been created and are now meeting regularly. Planning teams have been established with each state public health department. Mission statements have been developed and approved, consumer representation assured, and goals and objectives initiated. The first months of the project for NEGC staff have been focused on creating a regional presence for the NEGC, establishing infrastructure to support the project, and recruiting and coordinating staff and regional representatives for working committees. The NEGC has opened offices, developed a website, made presentations, engaged in local, regional and national meetings, and responded to needs of funding agencies and stakeholders.

Working Group Summaries

The Quality Improvement Working Group

The Northern New England Clinical Genetics Collaborative, a subcommittee of the Quality Improvement Working Group (focused on clinicians representing centers in ME, VT, NH) has developed and field tested a classification system for patients with developmental delays and intellectual disabilities. The Working Group is also studying the potential of a registry to improve care coordination and tracking of patients with genetics disorders.

The Transitions Working Group

The Transitions Working Group has been working to improve the hand-off of patients from Boston Children's Hospital to Brigham and Women's Hospital. They have also been meeting with hospital representatives to establish a Maternal PKU Care Center in New England.

The Transitions Working Group is hosting a conference on May 17, 2008 for adults with metabolic and other genetic disorders. A questionnaire was sent out to 40 teen and adult patients to obtain their suggestions for the conference and to obtain information on barriers to care. Their input is being used to plan the conference.

A draft of the PKU Toolkit for Transition to Adult Care is almost complete. There will be two versions: an on-line version and a more in-depth paper version. The draft was discussed in a focus group in July of 12 teens and young adults with a variety of metabolic disorders.

A PKU Facebook Group has been established by the Transitions Working Group.

The Transitions Working Group is in the process of developing a checklist to assess the preparedness of patients with genetic disorders. A variety of checklists are being circulated to doctors to find out which they prefer.

The Transitions Working Group has been in contact with representatives from the insurance industry to coordinate efforts to assess the needs of patients with genetic disorders and to identify appropriate care providers and facilities.

Education, Marketing and Dissemination Working Group

The Dissemination, Marketing and Education Working Group and the New England Public Health Genetics Education Collaborative (NEPHGEC) have been working together to improve the

implementation of genetics education strategies in the region. The projects of this joint effort include the New England Genetics Resource Directory, a genetics outreach project for community health centers, a family health history training module project, and the publication of *Understanding Genetics: A Guide for Patients and Professionals*. The group has also developed a regional newborn screening brochure that has been translated into multiple languages. It is available at the website of the New England Regional Genetics Group: <http://www.nergg.org/nbsbrochures.php>

The Working Group developed *Understanding Genetics: A Guide for Patients and Professionals* in conjunction with the Genetic Alliance. The guide provides in-depth information about the diagnosis of genetic conditions, newborn screening, collecting family health histories, genetic counseling, and genetic tests and their applications. It is available at the Genetics Alliance website: http://www.geneticalliance.org/ws_display.asp?filter=understanding.genetics.download.

The Family Health History Awareness curriculum is an ongoing project of the Working Group. They are expanding it into a multi-media format, using innovative ways to reach new audiences, and developing modules to meet the needs of specific audiences such as primary care providers, nurses, social workers and public health staff. The presented material includes the importance of family history, taking and interpreting family histories, and use of the information. The curriculum will be presented to audiences throughout the New England region.

Laboratory Quality Assurance Working Group

The Laboratory Quality Assurance Working Group is focused on a project to develop more accurate cut-off scores for a wide range of genetic disorders. They have analyzed hundreds of thousands of tests in an effort to substantially reduce the number of false negative and false positive screening results. The researchers are currently applying their algorithms to data from other states (e.g. New York and Wisconsin), to test the generalizability of their work.

Long-Term Follow Up Working Group

The Long-Term Follow Up Working Group has been meeting with state public health officials in Region One to create a regional core data base. A conference call has also been held with state privacy representatives. The participants noted that a regional data set would be helpful in evaluating outcomes since many of the disorders are rare and that a regional cohort would provide greater numbers. Additionally New England has a significant border baby issue due to the small geographic region and densely populated borders. One goal is to develop an interstate data sharing agreement while respecting the individual state privacy laws.

Medical Home Working Group

The Medical Home Working Group (MHWG) has been in transition for the first year of the grant. In May 2007, just before the cooperative agreement was awarded to the NEGC, the Medical Home working group met and created a revised work plan to begin June 1, 2007. After June 1, the group experienced a transition in leadership but is now fully engaged in initiating the new work plan. Over the next 18 months, the work group will meet in March 2008 with a follow-up meeting in May 2008. These meetings will review the medical home elements of the work plan, discuss any needed revisions or modifications, and agree on a final plan by May 31, 2008. The MHWG will consider and determine the general design for a pilot program to test a new process of primary care medical home-based, longitudinal care of children with genetic conditions identified through newborn screening including the potential use of registries, planned care methods, decision support mechanisms, explicitly articulated co-management with specialists, and transparent application of family- and patient-centered practices. A finalized pilot program will be designed and developed during the following fiscal year for implementation in the catchment areas of at least two New England pediatric metabolic disorders clinics by spring 2009.

Special Education Working Group

No activities during period. Group will be formed in Spring 2008.

Public Policy & ELSI

No activities during period. Group will be formed in Spring 2008.

Evaluation Team Activities

Evaluation Start Up

In consultation with management staff, the evaluation team developed an evaluation plan for the project and created several data collection tools to aid in project documentation, including a “Meeting Tracker” form and a survey assessing collaboration within the Working Groups and the support services provided by the RCC. Evaluation staff sought and obtained approval from the UNH Institutional Review Board (IRB) in October to evaluate grant activities.

Meeting Participation

The evaluation team has participated in key NEGC meetings, including planning meetings in May, and the September and November meetings of the Collaborative Council. A summary report was created for the kick off event and feedback provided on collaborative council meetings. Participation in these meetings has helped the evaluation team to stay current on Working Group progress, obstacles, and lessons learned.

National Benchmarks

The evaluation team has been actively involved in the creation of national benchmarks for regional genetics programs. Dr. Antal has participated on the conference calls and has regularly solicited input from NEGC members on key issues leading to their creation.

Technical Assistance

The evaluation team has developed logic models and provisional performance measures for seven Working Groups. The purpose of this effort is to ensure quality performance measures for improved project accountability.

III. COMPLETION OF KEY OBJECTIVES

Key: 1. Completed as planned, 2. Completed - deviated substantially from plans, 3. In progress - satisfactory, 4. In progress - unsatisfactory, 5. Initiation of activity deferred, 6. Activity abandoned, 7. Not scheduled to initiate this period.

No.	Objective	Status	Comment
1	<i>ESTABLISH AND MAINTAIN NEGC</i>		
1.1	Establish the RCC and Management Team at IOD/UNH	3	Completed
1.2	Establish the Collaborative Council	1	Completed
1.3	Establish the Advisory Council	1	Completed
1.4	Establish and maintain working groups	4	Working groups for special education and public policy still need to be established.
1.5	Identify and invite representatives from other key groups to participate	3	Completed
2	<i>QUALITY IMPROVEMENT</i>		
2.1	Implement ongoing regional QI activity of clinical genetics services in rural areas	3	
2.2	Disseminate NEGC clinical genetics QI results	3	
3	<i>TRANSITIONS</i>		
3.1	Collaborate with national work group	3	On-going
3.2	Assess preparedness of specialty centers for assisting transition	3	
3.3	Assess preparedness of patients to manage transition	3	
3.4	Plan conference for adults and adolescents with genetic disorders	3	
3.5	Develop toolkit for transition to adult care	3	
3.6	Assess NE state transition activities	3	

4	<i>MEDICAL HOME</i>		<i>New MH leadership effective 1/1/08, work plan may change</i>
4.1	Establish MH working group	1	Completed
4.2	Promote family centered care coordination for children with genetic disorders	5	
4.3	Educate providers	5	
4.4	Streamline access to educational information	3	
4.5	Facilitate access to genetic services	5	
4.6	Develop and implement MH mini-grant program	6	Mini grant program developed for NEGC not work group level
5	<i>EDUCATION</i>		
5.1	Continuously improve the NEGC website	3	On-going
5.2	Continuously improve educational products and activities	3	On-going
5.3	Provide genetics information to public health professionals	3	Publications completed and on web
5.4	Partner with stakeholders interested in promoting genetics literacy	3	On-going
5.5	Develop and implement Dissemination, Education and Marketing plan	3	On-going

6	<i>DEMONSTRATE EFFECTIVE COLLABORATIONS</i>		<i>Members of Work Groups and Advisory Council working with or members of all indicated groups and key stakeholders listed</i>
6.1	Collaborate with National Coordinating Center	3	On-going
6.2	Collaborate with all NE Title V programs	3	
6.3	Collaborate with all NE NBS Programs	3	On-going
6.4	Collaborate with all NE NBS Advisory Committees	3	
6.5	Collaborate with Family Support and Advocacy Groups	3	
6.6	Collaborate with genetics training programs in region	3	
6.7	Collaborate with NE LEND and UCEDDs	3	On-going, PI is Director of NH LEND
6.8	Collaborate with CDC Birth Defects surveillance programs in NE	3	
6.9	Collaborate with Regional and National AAP and AAFP groups	3	On-going
7	<i>SMALL PROJECT GRANTS INNOVATIVE PROJECTS PROGRAM</i>		
7.1	Establish the grants review committee	1	Completed
7.2	Dissemination of RFP and review process	3	Completed
7.3	Applications reviewed by committee and awards made	7	Will be completed 2/22/08
8	<i>SCHOOL SYSTEMS</i>		<i>Targeted 2009: NEGC will convene a group of leaders in this area by 3/08 to brainstorm goals and objectives</i>
8.1	Include Northeast Regional Resource Center on NEGC Advisory Committee		
8.2	Convene Special Education working group	5	
8.3	Meet New England LEND programs regarding role in improving student outcomes	3	
8.4	Meet to discuss the role of the UCEDDs in NE in improving student outcomes	3	
8.5	Disseminate information about NEGC to all state Special Education Directors	3	
8.6	Disseminate NEGC information to all Parent Training and Information Centers	3	
8.7	Develop Educational best practices component to NEGC website	3	
9	<i>QUANTITATIVE AND QUALITATIVE EVALUATIONS</i>		
9.1	Monthly management team meetings to review project progress	3	Met as needed with the project director. Shifting to monthly meetings in 2008.
9.2	Empowerment evaluation strategy presented to the Advisory Committee	2	Advisory Committee did not meet until 2008. Presentation made to management team and collaborative council.
9.3	Review minutes of Advisory Committee, Management Team and Working Groups	3	Reviewed available data – however, limited information available from working groups due to delays in data submission.
9.4	Participate on national outcome measurement efforts	3	
9.5	Conduct annual survey	7	Survey to be implemented in May of 2008.
9.6	Participate in reporting of project activities to funder.	4	Reporting deadline of 12/31/07 passed for four baseline measures

		due to be reported to HRSA due to differences in interpretation of the measures by project staff. Information to be sent to HRSA
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IV. PROJECT CHALLENGES AND RECOMMENDATIONS

The evaluation team is looking for an efficient way to track the progress of the working groups in achieving Year One Workplan Objectives. To date, limited information has been made available on work group meetings due to a lack of submission of meeting minutes. Management staff may wish to dedicate resources for a graduate student or dedicated staff time to participate in all work group conferences (via phone) to act as minute taker for these meetings. A program coordinator is being hired to allow NEGC staff to work more directly with Coordinating Council members. The evaluation team will be working with project staff to determine how best to collect this information so that all stakeholders can stay informed of project progress.

The evaluation team has not yet received substantial feedback from the working groups on the logic models or related performance measures. Several questions still need to be answered by the working groups. Are these elements too ambitious for the scale of the project? Are they required by funders? Should responsibility for performance measurement be left with the working groups themselves? It will be critical to complete these models and accountability mechanisms to ensure that all partners are clear about each group's goals, key activities, data tracking needs, and opportunities for collaboration.

The Medical Home working group has been in transition, and Carl Cooley, MD has now been appointed Committee Chair. A meeting is planned of the work group not later than March 2008 to develop a revised work plan for this area.