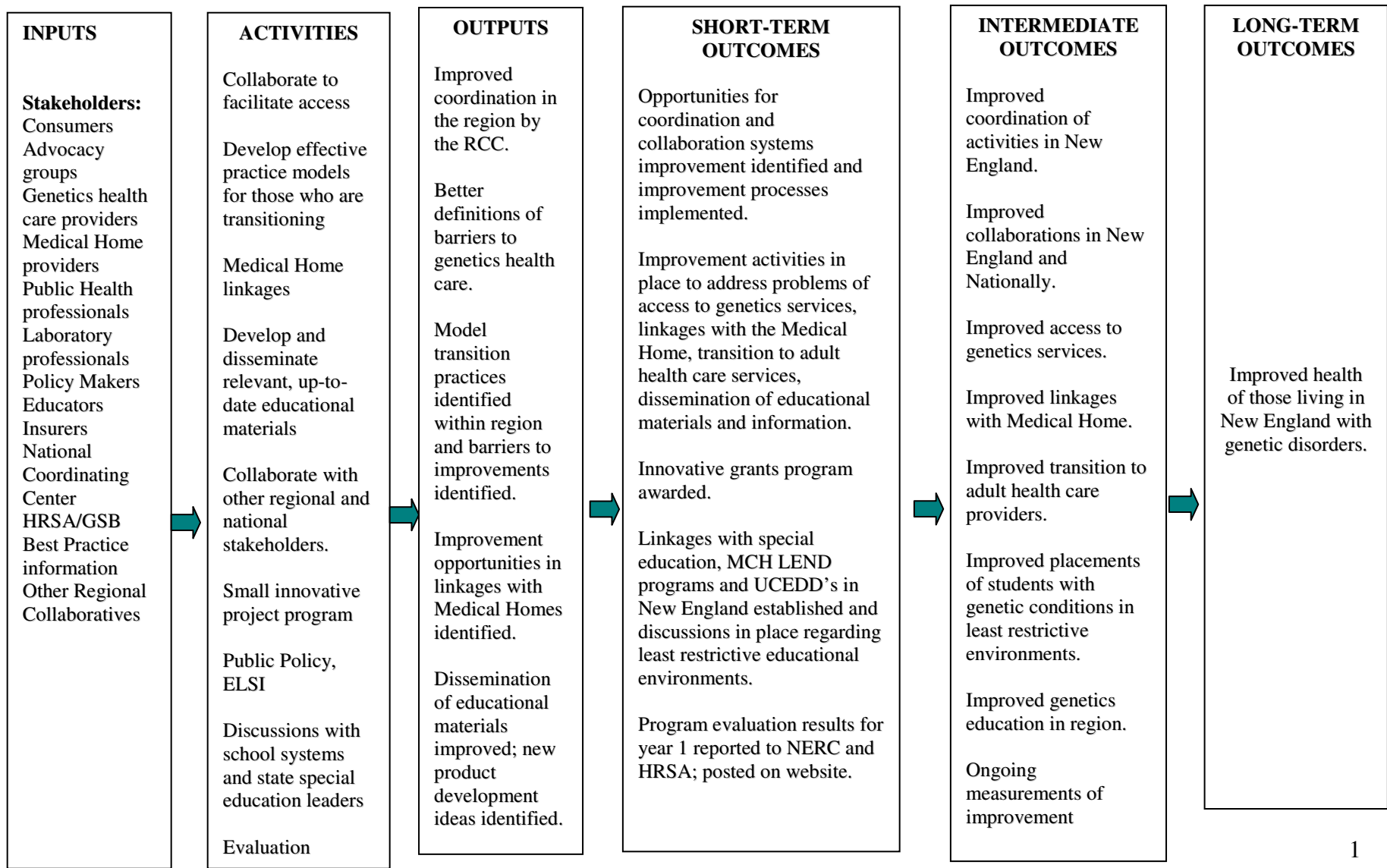


**ATTACHMENT 1 NERC LOGIC MODEL FIGURE**

**Goal: Improve the health of those with genetic disorders in New England through public health, consumer and provider collaboration.**



Attachment 1: NERC WORK PLAN TABLE

<b>GOAL 1: ESTABLISH AND MAINTAIN THE NEW ENGLAND REGIONAL COLLABORATIVE CENTER (RCC).</b>						
<b>Strategy</b>	<b>Activities</b>			<b>Process Indicator</b>	<b>Outcome</b>	<b>Outcome Indicator</b>
	<b>Who</b>	<b>What</b>	<b>When</b>			
1.1 Establish the RCC and Management Team at IOD/UNH	JBM, JAN, APS	Set meeting dates, etc.	Q1, Y1	Meeting dates set.	Weekly meetings in place.	Meetings take place.
1.2 Establish the Collaborative Council (CC)	JBM, JAN, APS	Membership and meeting dates set	Q1, Y1	CC members set; roles defined; dates of meetings published; meeting rules established.	Monthly meetings set	Monthly meetings take place; minutes published on website.
1.3 Establish Advisory Committee (AC)	JBM, JAN, APS	Membership and meeting dates set	Q1, Y1	AC membership set; roles defined; dates of meetings published; meeting rules established.	Semi-annual meetings set.	Meetings minutes published.
1.4 Establish and Maintain Working Groups (WG): Transition; Medical Home, Access; Follow-up; Dissemination and Ed. Laboratory QA; NE Metabolic Consortium; Policy & ELSI; Special Education.	RCC, CC, AC	Membership and meeting dates set.	Q1, Y1	Membership defined; roles defined; MOU's signed and returned; meeting dates published; meeting rules established.	Working groups meeting schedule set.	Meeting schedule and minutes published on website.

1.5 Identify and invite representatives from other key groups to participate: AAP, AAFP, ACMG, NCSL, Family Voices, Genetic Alliance, CSHCN, EHDI, Birth Defects Surveillance, Federally Qualified Health Centers, Others TBA	RCC, CC, AC	List of invitees; invitation	Q4, Y1	List of invitees and list of those who accept for participation.	To be determined	
<b>GOAL 2: COLLABORATE TO FACILITATE ACCESS TO GENETICS SERVICES, EXPERTISE AND TECHNOLOGY PARTICULARLY FOR UNDERSERVED POPULATIONS AND IN RURAL AREAS.</b>						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
2.1 Implement ongoing regional quality improvement (QI) activity of clinical genetics services in rural areas of New England	JBM, Access WG	Convene clinical geneticists providing services to rural northern New England (NNE)—VT, NH, ME.	Q2, Y1	Meetings held	Quality improvement interests documented	Written summary of meeting and common interests in QI activities
		Assess expertise and need of each practice in QI of services in rural NNE	Q2, Y1	Needs assessment completed	Needs identified	Written summary of needs
		Create shared baseline re: QI activities	Q3, Y1	Shared baseline developed	Shared baseline of QI identified	Written summary of shared baseline
		Identify common clinical services improvement interests	Q3, Y1	QI activity identified	Activity identified	Written summary
		Identify local particular quality improvement needs	Q3, Y1	Local QI needs identified	QI needs identified by practice	Written summary of QI needs

		Implement quality improvement across NNE region	Q4, Y1	Activities documented	QI systems in place in each practice; quality of services and outcomes improved	Written documentation of QI process and health outcomes
2.2 Implement ongoing regional quality improvement activity of clinical genetics services in 2 urban areas of New England	JBM, Access WG	Contact clinical genetics services addressing needs of urban populations	Y2	Contact made	Interest in QI documented	Written summary
		Convene 3 urban clinical geneticists with interest in quality improvement activities		Meeting held	Specific QI activities discussed	Written summary
		Identify shared baseline of quality improvement activities across 3 sites		Shared baseline summarized	3 sites have shared baseline in QI	Written summary and supportive documents
		Identify local quality improvement needs		Local needs identified	QI plan developed	Plans documented
		Implement quality improvement activity in 3 urban practices	Y3	Completed, documented	QI implemented	Outcomes summarized in written document
2.3 Disseminate NERC clinical genetics quality improvement results	JBM, Access WG	Participate in American College of Medical Genetics Quality Improvement Special Interest Group (QSIG)	Y1-5	Attend meetings of ACMG QSIG	Increased awareness of NERC QI activities	Presentation published on NERC website; Notes of QSIG meeting on website
		Present at annual meeting of NERC, NERGG	Y4	Presentation made	Increased awareness of QI activities	Presentation on NERC website
		Written summary for NERC website	Y2-5	Summary written	Increase awareness and	Hits on website; requests for TA

					knowledge of clinical genetics QI	
		Submit manuscript to Genetics in Medicine	Y5	Manuscript submitted	Increase awareness and knowledge	Publication accepted
2.4 Provide Quality Improvement Technical Assistance to clinical genetics practices in NE and other regions.	JBM, Access WG	NE QI Technical Assistance team constituted	Y4	Team documented	Opportunity to improve genetics health care	TA team description written; business plan in place
		TA team marketed on NERC website	Y4	TA team on web	TA requests	Hits on website; no. of requests
		TA offered to all clinical genetics practices in NE	Y5	Letters sent to all clinical genetics practices	Requests from 3 additional sites	TA activities at 3 sites summarized.
		Quality improvement activities in 1 additional NE sites and in 2 sites outside NE region	Y5	Plans for each site established	TA to 1 NE and 2 national clinical genetics sites	TA provided
2.5 Provide Clinical Genetics Quality Improvement to Federally Qualified Health Centers in NE	JBM, Access QA, ACM G QSIG	Identify FQHC's in Region 1	Y2	FHQC list	Invitations sent to FHQC's in NE	
		Convene representatives of all to identify opportunities to improve access to genetics services	Y2	NE FHQC's convened	Interest in access to genetics services generated	Written report
		Conduct needs assessments of FQHC's concerning access to genetics services	Y2	Access needs identified	Opportunities to improve access identified	Written report

		Develop shared baseline among those FQHC interested in improving access	Y2	Shared baseline established	Shared baseline in place	Written report
		Develop mechanism to provide technical assistance for improvement in access to genetics services.	Y3-Y4	TA team in place	Activities to improve access in place at 6 site; lessons learned incorporated	TA requested by other FQHC's
		Provide TA for access to 3 FQHC's	Y4	TA provided	Improved access to genetics services in 3 sites	Written reports of Access improvement outcomes
		Provide TA for access to 3 additional FQHCs to be distributed by state and rural and urban	Y5	TA provided	Improved access in 3 additional sites	Written reports of access improvement outcomes

**GOAL 3. DEVELOP EFFECTIVE PRACTICE MODELS FOR ADOLESCENTS AND YOUNG ADULTS WITH GENETIC CONDITIONS WHO ARE TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE.**

Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
3.1 Collaborate with National Work Group	Waisbren & Transition WG	Conference Calls	Monthly	Calls take place	Needs and strategies identified for transition to adult care	Data collected on needs. Recommendations written and publicized
3.2 Assess preparedness on part of specialty	Waisbren, Transition WG,	Modify Survey IdentifY specialty centers,	Q1, Y1 Q2, Y1 Q2, Y1 Q3, Y1	Consensus reached All specialty centers listed Surveys mailed	Survey printed Surveys completed	Achieve 65% or greater response rate Assessment made

centers for assisting patients in their transition		Conduct mail survey, Follow-up by phone; Send surveys; Analyze data and publish	Q4, Y1	Missing surveys obtained Completed surveys sent Results obtained	Additional surveys completed HRTW receives surveys Results shared	of new programs are needed.  Publication of results in peer reviewed journal.
3.3 Assess preparedness on part of patients to manage the transition to adult healthcare	Waisbren, WG,	Modify Checklist, Pilot Checklist with patients Analyze data and publish results; Use tool for clinical purposes; Assess usefulness of tool	Q1, Y1 Q2, Y1  Q3, Y1 Q4, Y1  Years 2 - 5  Years 2-5	Consensus reached Meetings take place; patients receive checklist	Develop strategy to determine validity and reliability; Checklist piloted; Changes made; Manuscript published in peer reviewed journal;	A reliable and valid checklist is developed.  Patients who are ill-prepared to manage transition to adult healthcare are identified and provided with assistance.
3.4 Conference for adolescent sand adults with metabolic and other genetic disorders	Waisbren, National Work Group, Regional Work Group	Develop Planning Committee for Conference; Host Conference	Q1, Y1   Year 2	Plans created   Conference takes place	Agenda Participant list Publicity plan; Adults and Teens receive social support and information on transition	Greater numbers of patients make the transition to adult health care.
3.5 Develop Tool Kit for Transition to Adult Care	Waisbren, WG	Finalize Tool Kit for PKU; Adapt Tool Kit for other disorders Launch Tool	Q4, Y1  Years 2-5  Years-5	Tool Kit available on web. Tool Kits available on web.  Tool kits distributed	Educational materials and practical guides are available other genetic disorders.	# hits on website  Feedback from evaluation forms.

		Kits		to Specialty Centers and Patient Advocacy Groups	Patients are better prepared to make transition to adult health care	
3.6 Assess NE state transition activities	Waisbren, Transition WG	Contact state Title V and PH depts. Re: funded transition projects	Q1, Y1	Contacts made to all states	Written summary of all Transition activities in NE Title V programs and Health Depts.	
		Collect all NE Transition projects	Q2, Y1	Contacts made to all funded Transition projects in NE states	Written summary	
3.6 Assess state of NE “transition teams” in Title V and state health depts..	Waisbren, Transition WG	Collect information regarding existing state transition teams	Q2, Y1	Contact made to all Title V and PH programs in NE	Status of state transition teams in written summary	
3.6 Develop state teams in 3 NE states		Develop state teams consisting of: PH, family, medical home provider, genetics specialist.	Q3, Y1	State teams defined	Written summary of state teams.	
		Convene state teams to assess needs for each state	Q3, Y1	State teams meet and discuss needs.	Written summary of state needs	
		Convene state	Q4, Y1	3 state teams meet and	Written summary	

		teams collectively to discuss “shared baseline”		discuss ‘shared baseline’ and particular differences and needs	of shared baseline	
		Plan for technical assistance for each state team	Q4, Y1	Each state team develops TA needs requests	TA plans documented	
		Provide TA to each state team, as needed	Y2	TA provided	TA process described	Improved Transition for those with genetic conditions.
3.7 Develop state teams in last 3 NE states	Waisbren, Transition WG	Repeat above processes	Y3	Same indicators as above	Same as above	Transition Teams in each state have shared baseline and particular needs met.
3.8 Present outcomes at annual meeting of NERC	Transition WG and State Teams	Each state team will present poster of Transition projects	Y4, Y5			NERC partners and NERGG annual meeting attendees will be aware of progress of Transition models .

**GOAL 4. DEVELOP AND STRENGTHEN LINKAGES AMONG THE GENETIC, NEWBORN SCREENING, AND OTHER SUBSPECIALTY SERVICES WITH THE MEDICAL HOME.**

Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
4.1 Establish Medical Home WG	Medical Home WG, RCC	Establish WG members	Q1, Y1	Membership list	Membership agreed upon	Membership list
		Establish WG	Q1, Y1	Meeting dates set.	Weekly	Meeting minutes.

		meeting schedule			meetings in place.	
		Establish partnership with the Primary Care Practice Network in NH, MA, CT.	Q2, Y1	Network members defined and listed.	Network in place	Network list published on website.
		Expand to include Primary Care Practice Networks in ME, RI and VT	Q4, Y3	Expansion completed	Improved linkages in all 6 NE states.	The Network is implemented in all 6 NE states.
4.2 Ensure that all children and families with genetics disorders have access to primary care and have an identified Medical Home	Tom Brewster, WG	Identify geographic areas in Region 1 that have a shortage of primary care physicians.	Q4, Y1	Workforce literature reviewed and analysis published on NERC website.	Workforce distribution in NE published.	Workforce distribution in NE published.
	Tom Brewster, WG	Increase the number of students that specialize in primary care in shortage areas	Q4, Y1	methods developed for encouraging students to practice in areas of need.		
	Tom Brewster, WG	Encourage existing health care systems and primary care practices to target areas with shortage of PCPs	Q4, Y1	Identify the largest health care systems and primary care practices in NE.		
4.3 Assure all children with genetic disorders	Tom Brewster,	Establish a <i>Healthcare</i>	Q3, Y1	Strategies developed to ensure financial		Reimbursement system is in place

in Region 1 have health insurance	WG	<i>Financing Work sub-Group</i>		support for Medical Home activities	that supports a Medical Home
4.4 Develop a plan to educate primary care providers, rural health organizations, specialty care providers, and families about the medical home	Medical Home WG, Education and Dissemination WG, RCC	Identify regional and national training initiatives.	Q1, Y1	List of training initiatives	To be determined by WGs
		Determine effectiveness	Q1, Y1	Written summary of effectiveness	
		Determine feasibility Review existing training initiatives based on criteria	Q3, Y1	Written criteria	
		Select training initiative for NE	Q4, Y1	List of initiatives	
		Select methods of training delivery	Q4, Y1	List of dissemination methods	
4.5 Create state teams of consultants to educate stakeholders about: <ul style="list-style-type: none"> <li>• Medical Home concepts</li> <li>• Benefits of Medical Home</li> <li>• Specialist providers roles in supporting Medical Home practices</li> <li>• Care coordination</li> <li>• How to develop and</li> </ul>	Medical Home WG, Education and Dissemination WG; RCC at UNH	Identify state teams consisting of primary care, reimbursement specialists, care coordinators, family members or advocacy group members	Q1, Y2	State consultant team lists	To be determined by WG's
		Revise training materials to meet local state needs	Q2, Y2	Training materials established and on website	
		Convene all state teams to review and finalize	Q3 Y2	Meeting minutes	

<ul style="list-style-type: none"> <li>use care plan</li> <li>• How to overcome barriers to reimbursement</li> <li>• How to develop and implement a plan to transition to adult services</li> </ul>		materials				
		Identify training opportunities	Q3, Y2	Training opportunities documented		
		Schedule trainings with primary care, rural health orgs, families	Q3, Y2	Schedule of trainings posted on website		
		Accomplish trainings in each state	Q4, Y2	Evaluations of trainings completed and reviewed		
4.6 Disseminate educational materials about Medical Home based on needs identified by WGs.	Medical Home WG, RCC at UNH	Identify existing on-line courses related to medical home	Y3	List developed		
		Adapt and offer webinars on medical home	Y3	Course offerings documented		
		Offer credits for webinars.	Y3	CEU, CME processes in place		
		Evaluate	Y3	Evaluation summary		
<b>GOAL 5. RCC WILL SERVE AS THE FOCAL POINT FOR EFFECTIVE GENETICS EDUCATION AND DISSEMINATION OF GENETICS INFORMATION.</b>						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
5.1 Continuously improve the NERC website	RCC, EDM WG	Web Solutions at RCC/UNH will continuously improve the NERC website	Q1, Y1	Agreement on priorities for website improvement	Improved content on website	No. of requests for NERC materials and web “hits” data.
		NERC website will maintain its presence on the	Q1, Y1	Agreement on presentation of	Improved content on	No. of requests for NERC materials and

		NERGG, Inc website		NERC on web	web	web “hits” data
5.2 Update Education, Dissemination and Marketing Plan	RCC, EDM WG	Education, Dissemination and Marketing Working Group (EDM WG) will develop 5-year marketing plan	Q1, Y1	Planning meetings completed	Plan agreed upon and updated from 2006 plans	Written 5-year plan completed and continuously updated (annual)
		Identify the educational needs of: <ul style="list-style-type: none"> <li>• Public Health professionals</li> <li>• Consumers, families, advocacy groups</li> <li>• Policy groups</li> <li>• Primary and specialty health care providers</li> <li>• Other Regional Collaboratives</li> </ul>	Q1, Y1	Methods of group identification and contacts completed	Key target groups identified	Written summary of target groups
		Needs assessment by group updated and completed	Q2, Y1	Needs identified by group	Needs assessment completed	Written summary of needs assessment
		Group-specific EDM plan in place	Q2, Y1	Plan addresses needs		Written plan summary
5.3 Continuously improve educational products and activities	EDM WG	Enhance the following existing resources: <ul style="list-style-type: none"> <li>• New England Genetic Resources Directory</li> <li>• Family Health History</li> <li>• Newborn Screening Brochures</li> <li>• Genetics Outreach Project to FQHC’s</li> <li>• Understanding Genetics</li> </ul>	Q1, Y1; Y2-5	Notes from monthly WG meetings	Documents on website	Written summary of updates quarterly.

		Guide				
5.4 Provide Genetics Education to Public Health Professionals	EDM WG	Review each state genetics plan re: education of PH colleagues	Q1, Y1	Plans reviewed	Needs identified	Written summary
		Develop plan to provide education to Dept. of PH (DPH)	Q2, Y1	Plan developed	Plan in place	Written summary
		Provide genetics education to 3 NE states DPH	Q1, Y2	Education activities	Improved knowledge	Written summary
		Provide education to 3 additional NE state DPH.	Q4, Y2	Education activities	Improved knowledge	Written summary
		Provide supplemental education to DPH's based on Y1-2 experiences	Y3-5	Education activities	Improved self learning	Written summary
5.5 Partner with stakeholders interested in promoting genetics literacy	EDM WG	Increase, improve, and updating the genetics content within <ul style="list-style-type: none"> <li>• Schools of Nursing</li> <li>• LEND programs</li> <li>• Community Health Centers</li> <li>• Public Health Schools</li> <li>• Public schools curricula</li> </ul>	Q1, Y1	WG minutes reflect plan	Plan in place	Written summary
		Agree upon list of key stakeholders	Q2, Y1	List generated		Written summary
		Prioritize target stakeholders	Q2, Y1	Targets listed		Written summary
		Assess needs and methods for target	Q3, Y1	Needs assessment done		Written summary
		Develop Educational plan	Y1	Plan completed		Written summary

		Feasibility and business plan	Q4, Y1	Feasibility addressed		Written summary
		Implement plan by stakeholders as feasible	Y2-5	Plan completed	Knowledge improved	Written summary
5.6 Develop and Implement Education, Dissemination and Marketing plan for Newborn Screening	EDM WG	Target activities: <ul style="list-style-type: none"> <li>• MSMS education for primary care physicians.</li> <li>• Interpretation of newborn screening laboratory results.</li> <li>• Disseminate information sheets</li> <li>• Develop region wide brochure EHDI, and</li> <li>• Translations of all</li> </ul>	Q1, Y1			
5.7 Plan and Develop Regional Conferences in Genetics		Develop specialized conferences for key stakeholders	Y2			
		Develop content for targets	Y2			
		Develop feasibility and business plans	Y2			
		Implement targeted conferences	Y3-5			
<b>GOAL 6. RC WILL DEMONSTRATE EFFECTIVE COLLABORATIONS WITH OTHER REGIONAL AND NATIONAL STAKEHOLDERS, SUCH AS THE NATIONAL COORDINATING CENTER, THE NATIONAL NEWBORN SCREENING AND GENETICS RESOURCE CENTER, CDC-SPONSORED CENTERS OF EXCELLENCE FOR BIRTH DEFECTS PREVENTION RESEARCH, CDC NEWBORN SCREENING BRANCH, NICHD, AAP, UNIVERSITY CENTERS OF EXCELLENCE IN DISABILITY (UCEDD’S), MCH LEADERSHIP EDUCATION IN NEURODEVELOPMENT DISABILITY EDUCATION PROGRAMS (LEND PROGRAMS).</b>						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			

7.1 Collaborate with National Coordinating Center	JBM, RCC, WG chairs	Collaborate with NCC on: Disaster preparedness, Quality improvement, Reimbursement, Electronic medical record, Data collection; Medical Home, Transition	Y1-5	Attendance at meetings; NERC members assuming lead roles when appropriate	To be determined
7.2 Collaborate with all NE Title V programs	RCC, WG chairs	Collaborate with each NE state Title V agency with emphases of: Medical Home, Transition, Access and Quality, ELSI, Policy, Education needs	Y1-5	WG meeting minutes; annual meeting summary notes documenting collaboration.	
7.3 Collaborate with all NE NBS programs	RCC, WG	Collaboration with NBS programs in all aspects	Y1-5	WG meeting minutes	
7.4 Collaborate with all NE NBS Advisory Committees	RCC, WG	Collaborate to support Committees as needed	Y1-5	WG meeting minutes	
		Ongoing communication with NBS coordinators re: ad hoc TA	Y1-5	WG meeting minutes	
7.5 Collaborate with Family Support and Advocacy Groups	RCC, WG chairs	Identify advocacy groups	Y1-5	WG meeting minutes	
		Generate list of all in NE	Y1-5	WG meeting minutes	
		Invite to participate in State Genetics teams	Y1-5	WG meeting minutes	
7.6 Collaborate with Genetics training programs in region	RCC, WG chairs	Collaborate with Brandies University Genetic Counseling	Y1-5	WG meeting minutes	

		Program				
		Collaborate with Clinical Genetics training programs in NE	Y1-5	WG meeting minutes		
7.7 Collaborate with NE LEND and UCEDDs	RCC, WG chairs	Collaborate with LENDs and UCEDDs in NE	Y1-5	Meeting minutes		
7.8 Collaborate with CDC Birth Defects surveillance programs in NE	RCC, WG chairs	Collaborate with state birth defects surveillance programs	Y1-5	Meeting minutes		
7.9 Collaborate with Regional and National AAP groups	RCC, WG chairs	Collaborate with AAP locally and nationally	Y1-5	Meeting minutes		
<b>GOAL 8. THE RC WILL UTILIZE A SMALL PROJECT GRANTS PROGRAM TO ACCOMPLISH UNANTICIPATED AND INNOVATIVE ACTIVITIES THAT EMERGE WITHIN THE REGION.</b>						
Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
8.1 Establish the RCC and Management Team at IOD/UNH	JBM, JAN, APS	Set meeting dates, etc.	Q1, Y1	Meeting dates set.	Weekly meetings in place.	Meetings take place.
8.2 Establish the Collaborative Council (CC)	JBM, JAN, APS	Membership and meeting dates set	Q1, Y1	CC members set; roles defined; dates of meetings published; meeting rules established.	Monthly meetings set	Monthly meetings take place; minutes published on website.
8.3 Establish Advisory Committee (AC)	JBM, JAN, APS	Membership and meeting dates set	Q1, Y1	AC membership set; roles defined; dates of meetings published; meeting rules established.	Semi-annual meetings set.	Meetings minutes published.

8.4 Establish the Grants Review Committee (RC)	JBM, JAN, APS	Membership and meeting dates set	Q1, Y1	Grants RC named and review process in place and agreed upon	Each reviewer understands role	RC meeting dates set in place and published
8.5 Dissemination of RFP and review process	APS, JBM	RFP posted on web, mailed, emailed	Q1, Y1	RFA posted on NERC website; distributed on regional mailing lists	RFP posted and mailed	RFP posted and mailed
8.6 Applications received	APS, JBM	Apps. In RCC	Aug 1, 2007	List of applications		Applications in RCC for review
8.7 Applications reviewed by all and awards made	RC, CC, APS, JBM		Sept. 1, 2007		Awards made; projects begin	
8.8 Grants projects completed	PI's		Aug 31, 2008			
8.9 Grants reporting complete	PI's, APS, JBM		Sept. 30, 2008	Report received		Report recv'd
8.10 Poster Presentation at annual meeting	PI's		Dec 2008	Presentation made	Increase awareness	Poster
8.11 Manuscript prepared and sent for publication	PI's		March 2008	Completed and sent	Dissemination	Manuscript
8.12 Plans to incorporate results of innovative projects into NERC working plan	RCC, PIs	Develop implementation plan	Y2-5	Implementation plan complete	NERC response to implications	Written response plan
<b>GOAL 9. THE RC WILL PROVIDE OPPORTUNITIES TO INCREASE DISCUSSIONS WITH SCHOOL SYSTEMS AND STATE SPECIAL EDUCATION LEADERS TO IMPROVE ACCESS AND SUPPORT TO EDUCATIONAL SERVICES IN THE LEAST RESTRICTIVE ENVIRONMENT.</b>						
<b>Strategy</b>	<b>Activities</b>		<b>Process</b>	<b>Outcome</b>	<b>Outcome Indicator</b>	

	Who	What	When	Indicator		
19.1 Include a staff member from the OSEP funded North East Regional Resource Center on the NERC Advisory Committee.	JAN	Send invitation and meeting dates	Q1, Y1-Y5	Invitation sent and accepted	Participation on the Advisory Committee	Special Education/504 issues are part of the NERC agenda and vice versa.
9.2 Convene Special Education Working Group	JAN	Send invitation and meeting dates	Q1, Y1 -Y5	Invitation sent and accepted	Specific issues are addressed in planning document.	Annual plan for addressing special education/504 issues is developed.
9.3 Meet New England LEND programs to discuss the role of LENDs in improving outcomes for students with Genetic conditions.	JAN JBM	Schedule conference call	Q2, Y1 -Y5	Conference call is scheduled	LEND programs become engaged with the NERC as partners to address special education issues.	Students with Genetic conditions receive quality special educational/504 services.
9.4 Meet to discuss the role of the UCEDDs in NE in improving outcomes for students with genetic conditions.	JAN	Schedule conference call	Q2, Y1 -Y5	Conference call is scheduled	UCEDDs become engaged as partners with the NERC to address special education issues.	Students with Genetic conditions receive quality special educational/504 services.
9.5 Disseminate information about the NERC to all state Special Education Directors.	JAN	Letter is prepared	Q2, Y1	Letter is sent	Special education directors are aware of NERC and specific concerns related to students with Genetic conditions.	Students with Genetic conditions receive quality special educational/504 services.
9.6 Disseminate information about the	JAN	Letter is prepared;	Q2, Y1	Letter is sent; conference call	PTIs in New England states are aware of	Students with Genetic conditions receive

NERC to all Parent Training and Information Centers (PTIs)		conference calls are proposed.		is set up.	NERC and specific concerns related to students with Genetic conditions.	quality special educational/504 services.
9.7 Develop educational best practices component to the NERC website	AS	NERC Web site is designed and materials are gathered	Q4,Y1 -Y5	NERC Website has special education best practices component	Practitioners, families, and community members have access to state of the art information on special educational practices.	Students with Genetic conditions receive quality special educational/504 services.
9.8 Develop state specific plans for improving special education/504 services for students with Genetic conditions.	JAN	Suggestions for state and local practice improvement are developed.	Q4, Y2-Y5	Suggestions are sent to all collaborators (UCEDDs, LENDS, PTI's, SPED Directors.	SEAs and LEAs communicate needed changes.	Specific actions related to improvement are documented in each state.

**GOAL 10. THE RC WILL COMPLETE BOTH QUANTITATIVE AND QUALITATIVE EVALUATIONS OF PROCESSES AND OUTCOMES OF ALL GOALS, ACTIVITIES AND PROJECTS UNDERTAKEN BY THE NERC.**

Strategy	Activities			Process Indicator	Outcome	Outcome Indicator
	Who	What	When			
10.1 Establish monthly Management Team meetings to review project progress (formative evaluation)	JBM APS	Meetings schedule	Q1,Y1	List of meetings and minutes; evaluation format established	Ongoing review of project activities and outcomes	Activities are completed/revised in a quality fashion.
10.2 Empowerment evaluation strategy is	PA	Establish meeting time	Q3,Y1	Empowerment evaluation strategy is presented.	Advisory Committee and NERC supports and adopts use of Empowerment	Ongoing revision and improvement in NERC activities.

presented to Advisory Committee					Evaluation Strategy	
10.3 Review meeting minutes of Advisory Committee, Management Team, and Working Groups.	PA	Content and pattern analysis is conducted	Q4, Y1-5	Evaluation report is available to key stakeholders	NERC reinforces or revises current strategies for improving services	Organizational structures operate efficiently and effectively.
10.4 Conduct annual survey	PA	Survey is developed and posted on the website	Q4, Y1-5	Survey results are compiled	Information is available to key stakeholder for the purpose of refinement and redesign.	Satisfaction is high among all stakeholders.
10.5 Work with the NCC to develop outcome measures that can be used to assess project outcomes.	JBM PA	A list of outcome measures is developed	Q1, Y2	Outcome measures are reviewed by the key stakeholders	Project activities are aligned with outcome measures	States have outcomes to develop shared baselines and monitor changes in genetic and newborn screening services over time.
10.6 Implement final web-based survey	PA	Survey is field-tested and on the website	Q2/Y5	Results are reviewed by Advisory Committee, Management Team, Collaborative Council, and Working Groups	Documentation of project successes and challenges guides the development of a new application for funding.	Successful Phase II Reapplication.

### **New England RC Innovative Projects Program**

The New England Genetics and Newborn Screening Collaborative proposes to establish a Project Program to fund innovative projects that address the needs of the region (which largely modeled on a similar program design from the Heartland RC).

The primary goal of the NERC is to improve the health and well-being of those with genetic disorders.

The aim of the New England Regional Collaborative Projects Program is to address the needs of the region, particularly those that are innovative and address new or emerging issues. Therefore, the rationale of the New England Projects Program is to provide a mechanism for innovative solutions to these problems and to stimulate synergy and cooperation between states and regions. Results of these projects will inform practices, programs, funding, and policy at the state, regional and federal levels.

Needs assessments done to date in the New England region demonstrated five priority areas:

1. Public Policy and Ethical, Legal and Social Issues
2. Practice Models and Delivery Systems
3. Education, Technical Assistance, Dissemination
4. Genetics Services
5. Public Health Infrastructure
6. Follow-up

In addition, there are particular needs for addressing problems with transition from pediatric to adult health care and the need to develop and strengthen linkages among the genetic, newborn screening, and other subspecialty services with the Medical Home.

Topics of high priority include:

1. Practice models of care, especially related to linking children with genetic conditions to the medical home;
2. Practice models that target an underserved population;
3. Practice models that address transition of care from pediatric to adulthood;
4. Practice models that improve access to services, fill gaps in services and meet unmet needs, including utilization of telemedicine technologies;
5. Practice models that address quality improvement of services;
6. Projects that involve data collection or evaluation to lay the groundwork for program growth, particularly for public health genetics and newborn screening programs or chronic disease programs.

7. Projects by consumers or advocacy groups that address improving issues of access, cultural competence, and consumer participation in practice and policy development.

## II. ELIGIBILITY REQUIREMENTS

Specialty and primary health care providers, professional organizations, public health officials, consumer support organizations, and others interested in genetics services who reside in Maine, New Hampshire, Vermont, Massachusetts, Rhode Island and Connecticut may apply.

Projects must specifically address priorities listed in objectives above. Collaborations between professionals at different institutions or organizations in two or more states are encouraged and will receive priority. The project should be envisioned as a model that could be expanded throughout the New England region or in other regions. These collaborations can be with states beyond the New England region. New collaborations are encouraged.

NOTE: Visiting faculty or professionals, residents, interns, and pre-doctoral trainees are not eligible to be principal investigators or co-investigators.

## III. SUBMISSION PROCEDURES

To be determined

NE Map

