

ATTACHMENT 3 – UPDATED LOGIC PLAN
Western States Genetic Services (WSGS) Collaborative
Logic Model for Collaborative Planning and Evaluation

Project Period: June 1, 2007 to May 31, 2012

Environment

1. Large geographic region, isolated populations.
2. Large, diverse stakeholder groups with varying needs.
3. Culturally diverse region.
4. Public and private sector financing, policies, laws, and politics can change.

Vision

Individuals and families who have or are at risk for genetic conditions, especially those in underserved populations:

1. have the information they need to obtain timely, quality health services and to make decisions related to their genetic condition;
2. have access to high quality specialty genetic services as part of the coordinated, culturally appropriate, comprehensive care received within the context of a medical home.

Assumptions

1. Collaborative action and logic model are fluid and responsive to change.
2. Stakeholders are engaged.
3. Financing for Collaborative activities is adequate.

Purpose

The purpose of the WSGS Collaborative is to optimize the health and well-being of families with or at risk for genetic conditions, by taking a regional approach to coordinating, sharing, and improving access to genetic services in Alaska, California, Guam, Hawaii, Idaho, Oregon and Washington.

Resources

Funding

- Health Resources and Services Administration, Maternal Child Health Bureau
- Partners In-Kind

Partners

- State public health genetic services and newborn screening programs
- Family advocates
- Genetic specialists
- Primary care and allied health providers
- Evaluation consultants

Guiding Philosophies

1. Support and enhance services available in the community.
2. Use and build on resources already available.
3. Collaborate with others working on related activities.
4. Utilize new and emerging communication technologies (and do not use them when they are not efficient)
5. Incorporate the input of families, health care providers, state and local health agencies and other collaborators.
6. Emphasize sustainability

Activity and Outcome Areas*

Knowledge and Information
 Financing
 Quality Improvement
 Screening and Identification
 Diagnosis, Treatment, Management
 Population Health

Long Term Outcomes

- I. Improve effectiveness of **state genetics and newborn screening programs**.
- II. Improve **funding** for clinical genetics services, including diagnosis and management of conditions detected by NBS.
- III. Increase **access** to clinical genetics services, including diagnosis and management of conditions detected by NBS.
- IV. Increase capacity of **medical homes** to care for families with or at risk for genetic conditions.
- V. Increase genetics **training opportunities** for health care and public health work forces.
- VI. Increase, among professional and family groups represented in the Collaborative, **sharing of information** obtained from WSGSC activities.

*Source: Outcomes of Genetic Services Menu, WSGSC

Table 1. WSGSC Logic Model

Activities	Outputs	Short Term Outcomes 2009-2011 awareness, knowledge, beliefs, attitudes	Medium Term Outcomes 2012-2014 behavior, practice, policies
Knowledge and Information			
All Stakeholders			
<ol style="list-style-type: none"> 1. WIKI E-mail notices 2. E-mail updates 3. Meetings (in-person, telephone, webinar) 4. Website maintenance 5. Annual Regional Summit 6. Plan and submit articles, presentations, trainings 7. Annual update of Regional Plan: Logic Model, Evaluation Plan, Communications Plan, Work Plan. 8. Collect and submit NCC Evaluation data 9. Write and submit annual grant Progress Report to MCHB 10. Respond to MCHB and NCC information requests 11. Director and stakeholder participation in and consultation to local and national organizations and projects. (e.g. NSTRN, ACHDNC, NCC committees and work groups (Evaluation, Emergency Preparedness, Telemedicine, Adolescent Transition, Long Term FU/Data Collection). 12. Recruit and retain diverse stakeholders from Guam, AK, CA, HI, ID, OR, WA. (Stakeholders: public health genetics and newborn screening, medical geneticists, genetic counselors, family advocates, primary care providers, third party payers) 	<ol style="list-style-type: none"> 1-5. Record of E-mails, meetings, web updates, Summit 6. Publications, presentations, trainings records 7. Evaluation Plan 8-9. Progress Report with evaluation findings 10. NCC Evaluation reports 11-12. Meeting and work group records 	<ol style="list-style-type: none"> A. WSGSC stakeholders have increased opportunities to share or receive genetics related information as a result of WSGSC activities. B. WSGSC stakeholders increase their awareness of who other stakeholders are throughout the region and the roles stakeholders play in genetic and NBS services. C. Information sharing between WSGSC and other regions, and the WSGSC and NCC committees and HRSA is increased. 	<ol style="list-style-type: none"> A. WSGSC representative disseminate information from Collaborative activities to their respective constituent groups.

People Impacted by Genetic Conditions			
13. Maintain educational information about genetics on website.	13. List of web-site postings.	D. People impacted by genetic conditions have access to information about genetic resources.	B. Public health genetic services agencies, genetic specialty leaders and family organizations routinely exchange information about genetic resources.
Activities	Outputs	Short Term Outcomes 2009-2011 awareness, knowledge, beliefs, attitudes	Medium Term Outcomes 2012-2014 behavior, practice, policies
Health Care Providers			
14. Maintain educational information about genetics on website.	14. List of website postings.	E. Health care providers have access to information about genetic and NBS services.	
Financing			
Insurance			
15. Convene a Reimbursement Work Group to plan and implement a project that addresses reimbursement of genetic services in the Western region. 16. Convene a Medical Foods Reimbursement Work Group to plan and implement a project that addresses reimbursement for medical foods in the Western region.	15-16. Meeting minutes, Report of work group accomplishments and products	F. WSGSC stakeholders have an increased understanding of barriers and solutions to improved reimbursement for genetic services and medical foods.	C. Regional health insurance reimbursement for genetic services and medical foods is improved.

Quality Improvement			
Genetic Services			
<p>17. Disseminate to stakeholders information about national and regional quality improvement or outcomes measurement in genetic services.</p> <p>18. Consult to Heartlands collaborative in developing a quality assessment tool for public health genetics programs.</p>	<p>17-18. Record of disseminated information</p>	<p>G. WSGSC members have increased access to information about current thought in measuring impact or quality of genetic services.</p>	<p>D. Increase in the number of western states public health genetic services programs that measure outcomes to evaluate the effectiveness of their program.</p> <p>E. Increase quality improvement activities in state funded genetics and newborn screening programs.</p>
Activities	Outputs	Short Term Outcomes 2009-2011 awareness, knowledge, beliefs, attitudes	Medium Term Outcomes 2012-2014 behavior, practice, policies
Screening and Identification			
Newborn Screening, Maternal Serum Screening			
<p>19. Help states assimilate NCC emergency preparedness (EP) recommendations into regional and individual state plans. In addition, provide contingency planning updates and information to stakeholders (e.g. EMAC presentation).</p> <p>20. Collect and analyze data related to the diagnosis and treatment of VLCADD through NBS results.</p> <p>21. California NBS lab personnel to attend a Mayo Clinic MS/MS training to learn methods for determining cut-off levels.</p> <p>22. HI NBS and genetic specialists to provide technical assistance and consultation to Guam in developing Guam NBS program.</p>	<p>19. Update WSGSC website with emergency preparedness materials for Collaborative access, as well as give presentations which summarize any new EP developments</p> <p>20. Publication of large VLCADD study group discussing findings on diagnosis and treatment of the condition.</p> <p>22. Narrative of activities in Progress Report.</p>	<p>H. WSGSC stakeholders utilize the information to revise and/or develop emergency preparedness protocols (which hopefully take advantage of regional resources) in the event of natural or manmade disaster.</p> <p>I. Improved diagnostic protocols for use in NBS programs and improved treatment guidelines. WSGSC VLCADD study group is expected to be one of the largest to date.</p>	<p>F. Regional public health genetics and newborn screening services are improved or expanded as a result of WSGSC activities.</p> <p>G. Regional public health genetics and newborn screening contingency plans are known to regional public health stakeholders.</p>

Diagnosis, Treatment, Management

Medical Home

<p>23. Implement Portable Health Record research project.</p>	<p>23. Report to WSGSC stakeholders on project status and findings.</p>	<p>J. Families and primary care providers in the western region have access to a portable medical record template specifically for people with genetic or metabolic conditions. K. Findings from PHR project are disseminated on a national level (peer review publication and/or national organization web site posting (e.g. Family Voices, Genetic Alliance)</p>	
Activities	Outputs	Short Term Outcomes 2009-2011 awareness, knowledge, beliefs, attitudes	Medium Term Outcomes 2012-2014 behavior, practice, policies
Access to Specialty Genetic Services			
<p>24. Honolulu medical geneticist and genetic counselor provide in person genetics visits to HI neighbor islands and to Guam in April, 2011.</p> <p>25. Honolulu medical geneticist and genetic counselor provide genetics visits via interactive video-conference to patients on HI neighbor islands.</p> <p>26. Honolulu medical geneticist to provide NBS FU consultation to Guam.</p> <p>27. Honolulu genetic specialists to provide grand round consultations to Guam public health nurses and primary care providers.</p> <p>28. Idaho Outreach - OR medical geneticist and dietician provide in person genetics visits to ID PKU clinics in towns other than Boise.</p> <p>29. Provide financial support for AK genetics and metabolic clinic coordinator to attend outreach clinics.</p>	<p>24-29. Services and description in evaluation and progress report.</p>	<p>L. WSGSC participants have an increased understanding of the issues related to increasing access to genetics services for rural populations. M. Hawaii and Oregon Departments of Health and collaborators have the information to plan and implement the number and type of clinical genetic services required to provide statewide access to genetic services in a timely manner. N. AK Department of Health has information it needs to decide how to sustain administration of outreach genetics and metabolic clinics.</p>	<p>H. Public health leaders and genetic specialists in the WSGSC region use information from WSGSC activities to sustain programs to improve access to specialty genetic services.</p>

Table 2. WSGSC Logic Model—Indicators and Data Sources

<p align="center">Short Term Outcome 2009-2011 awareness, knowledge, beliefs, attitudes</p>	<p align="center">Indicator measure of outcome</p>	<p align="center">Medium Term Outcome 2012-2014 behavior, practice, policies</p>	<p align="center">Indicator measure of outcome</p>
Knowledge and Information			
All Stakeholders			
<p>A. WSGSC stakeholders have increased opportunities to share or receive genetics related information as a result of WSGSC activities.</p> <p>B. WSGSC stakeholders increase their awareness of who other stakeholders are throughout the region and the roles stakeholders play in genetic services.</p> <p>C. Information sharing between WSGSC and other regions, and the WSGSC and NCC committees is increased.</p>	<p>Description of number and type of information sharing opportunities resulting from WSGSC activities (WSGSC records)</p> <p>% of WSGSC stakeholders who report they are better informed about regional and national activities as a result of WSGSC participation</p>	<p>A. WSGSC representatives disseminate information from Collaborative activities to their respective constituent groups.</p>	<p>description of how representatives use information, to whom they distribute it, and % of WSGSC key stakeholders reporting they use WSGSC generated information (on-line survey, key informant interviews)</p>
People Impacted by Genetic Conditions			
<p>D. People impacted by genetic conditions have access to information about genetic resources.</p>	<p>Description of educational materials for families posted on website</p> <p>% of family advocates who report reading information on WSGSC website (on-line survey)</p>	<p>B. Public health genetic services agencies, genetic specialty leaders and family organizations routinely exchange information about genetic resources.</p>	<p>Extent to which stakeholders agree with survey statement related to sharing resources with other stakeholders (on-line survey)</p>
Health Care Providers			
<p>E. Health care providers have access to information about genetic and NBS services.</p>	<p>Description of information posted on site.</p>		

Short Term Outcome 2009-2011 awareness, knowledge, beliefs, attitudes	Indicator measure of outcome	Medium Term Outcome 2012-2014 behavior, practice, policies	Indicator measure of outcome
Financing			
Insurance			
F. WSGSC stakeholders have an increased understanding of barriers and solutions to improved reimbursement for genetic services.	Findings from Reimbursement Work Group posted on website Action plan to address findings from Reimbursement Work Group Medicaid survey is developed and being implemented. % of stakeholders reporting they read the Reimbursement Work Group report (on-line survey or e-mail)	C. Health insurance reimbursement for genetic services in the region is improved.	% of WSGSC stakeholders who state reimbursement for genetic services have improved in their state since last year (on-line survey) Description of how WA state Genetics Services Section used 2009 reimbursement project results to improve reimbursement for genetics services.
Quality Improvement			
Genetic Services			
G. WSGSC members have increased access to information about current thought in measuring impact or quality of genetic services.	% of WSGSC stakeholders who report reading information about outcomes and QI disseminated by WSGSC (on-line survey and key informant interviews)	D. Increase in the number of western states public health genetic services programs that measure outcomes to evaluate the effectiveness of their program. E. Increase quality improvement activities in state funded genetics and newborn screening programs.	Description of how WSGSC stakeholders are using quality improvement and outcomes measurement tools (online survey or key informant interview) # of public health programs that use outcomes to evaluate their programs (on-line survey or key informant interview)

<p align="center">Short Term Outcome 2009-2011 awareness, knowledge, beliefs, attitudes</p>	<p align="center">Indicator measure of outcome</p>	<p align="center">Medium Term Outcome 2012-2014 behavior, practice, policies</p>	<p align="center">Indicator measure of outcome</p>
Screening and Identification			
Newborn Screening, Maternal Serum Screening			
<p>H. WSGSC stakeholders are aware of contingency planning information disseminated via WSGSC actions.</p> <p>I. WSGSC NBS stakeholders have improved diagnostic protocols for use in NBS programs and improved treatment guidelines.</p>	<p>% of WSGSC stakeholders who report reading contingency planning materials disseminated by WSGSC (online survey or key informant interview)</p> <p>% VLCAD study findings are published in peer reviewed publication</p>	<p>F. Regional public health genetics and newborn screening services are improved or expanded as a result of WSGSC activities.</p> <p>G. Regional public health genetics and newborn screening contingency plans are utilized when needed by WSGSC stakeholders.</p>	<p>% of public health NBS stakeholders who report NBS in their state has improved as a result of WSGSC activities (on-line survey or key informant interview)</p> <p>% of public health NBS stakeholders who report knowledge of what action to take related to their NBS programs in the event of an emergency or disaster in their state (online survey or key informant interview)</p>
Diagnosis, Treatment, Management			
Medical Home			
<p>J. Families and primary care providers in the western region have access to a portable medical record template specifically for people with genetic or metabolic conditions.</p> <p>K. Findings from PHR project are disseminated on a national level (peer review publication and/or national organization web site posting (e.g. Family Voices, Genetic Alliance)</p>	<p>% of WSGSC family advocates who report promoting the PHR and findings to their constituents.</p> <p>Description of national forums through which PHR project findings are disseminated.</p>		

<p align="center">Short Term Outcome 2009-2011 awareness, knowledge, beliefs, attitudes</p>	<p align="center">Indicator measure of outcome</p>	<p align="center">Medium Term Outcome 2012-2014 behavior, practice, policies</p>	<p align="center">Indicator measure of outcome</p>
Diagnosis, Treatment, Management			
Access to Specialty Genetic Services			
<p>L. WSGSC participants have an increased understanding of the issues related to increasing access to genetics services for rural populations.</p> <p>M. Guam, Hawaii and Oregon Departments of Health and collaborators have the information to plan and implement the number and type of clinical genetic services required to provide statewide access to genetic services in a timely manner.</p> <p>N. AK Department of Health has information it needs to decide how to sustain administration of outreach genetics and metabolic clinics.</p>	<p>Description of how Practice Model evaluation findings are disseminated and reviewed at least annually by WSGSC public health programs and specialists, and used to revise clinical activities</p> <p>% of WSGSC participants that report an increased understanding of issues related to delivery of genetics services “far away” from tertiary genetics centers (on-line survey or key informant interview)</p>	<p>H. Public health leaders and genetic specialists in the WSGSC region use information from WSGSC activities to sustain programs to improve access to specialty genetic services.</p>	<p>Proportion of WSGSC state genetics and metabolic program representatives that report using findings from the WSGSC practice model to plan, implement, or evaluate their program’s clinical services. (online survey or key informant interviews)</p> <p>AK state genetics program staff report using findings from clinic coordinator assessment to sustain administration of AK outreach clinics. key informant interview with AK CYSHN manager)</p>