



Regional Genetic Services Practice Model Evaluation

**Report on delivering genetic services via
outreach and telehealth in Guam and the western
states**

February 2011

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Background

The Practice Model, comprised of several projects throughout the western region, is an initiative of the Western States Genetic Services Collaborative (WSGSC). The purpose of the initiative is to increase access to genetic services for westerners who live far from genetic specialty providers including genetic counselors, medical geneticists and dietitians. Projects within the initiative offer an opportunity to test and demonstrate provision of medical genetic consultations, genetic counseling, or specialty dietitian services via outreach and telehealth visits. The WSGSC demonstrated and evaluated this regional practice model with funds from the Health Resources and Services Administration (HRSA). This report describes projects within the Practice Model and reports on evaluation findings for grant periods June 1, 2005 through May 31, 2010.

Alaska Geography and Population

Alaska is the largest of the fifty states and contains approximately sixteen percent of the United States' landmass or 586,412 square miles of land. The vast wilderness of Alaska is dotted with isolated villages, some with fewer than a dozen people. Many villages lack basic conveniences like running water and remain accessible only by small plane or boat. Intrastate air travel in Alaska often involves greater distances than interstate travel in the continental United States. Fares for air travel can be expensive. Throughout rural Alaska, also called the Bush, very few local economies exist. Many residents live off the land and its wildlife, and survival depends on hunting, fishing, trapping, and gathering wild berries. Because of its size, Alaska has widely diverse geographic, climatic, and demographic characteristics, all of which affect public health. With diverse cultures, sparse populations, severe temperatures, vast coastline, and outdoor lifestyles, Alaska experiences many unique health care challenges. One such challenge is providing adequate medical care and health care assistance to residents who live in remote areas of the state.

Alaska is not divided into counties, and while some boroughs have been formed, many of them have not elected to assume health powers. Much of the state remains "unorganized" with the state government fulfilling responsibilities otherwise normally handled by local county and municipal governments. Primarily, governmental health and social service functions have been, and continue to be, the responsibility of the state and federal governments - both of which increasingly carry out the services through various granting and contracting mechanisms. The native health corporations, the Alaska compact between the Indian Health Service and the individual tribes, the State of Alaska, and private entities provide health care in these areas through funding for public health nurses and other health care workers.

Hawaii Geography and Population

Hawaii is composed of seven populated islands located in four major counties: Hawaii, Maui, Oahu, and Kauai. Approximately 71% of Hawaii's population resides in the City and County of Honolulu on the island of Oahu, concentrated in the Honolulu metropolitan area. The neighbor island counties are Hawaii, Kauai (includes Niihau) and Maui (includes Molokai, and Lanai).

Ten percent of the state's land area is classified as urban. The City and County of Honolulu is the most urbanized with a third of its land area and 96% of its population in urban communities. The majority of tertiary health care facilities, specialty and subspecialty services are located in Honolulu. Consequently, neighbor island and rural Oahu residents often must travel to Honolulu for these services. Inter-island passenger travel is entirely by air. Air flights are frequent, but comparatively expensive. Three of the ten most expensive airfares per mile in the U.S. are the connections between Honolulu and Maui, Honolulu and Kona (on Hawaii island), and Honolulu and Kauai. This creates a financial barrier for neighbor island residents since round-trip airfare costs range from \$140-\$200.

In June 2006, a new low-cost airline carrier entered the market becoming the third inter-island jet carrier in Hawaii. With new competition, airfare costs dropped substantially to about \$80 per round-trip. However, in April 2009, Hawaii's second largest inter-island airline carrier entered bankruptcy and stopped passenger service resulting in a loss of 88,000 seats per week. While the state's two other carriers may make up 56,000 of those seats, ticket prices again increased to \$150-200 per round-trip.

Geographic access is further limited because public transportation is inadequate in all areas of the state except for the city of Honolulu. Residents in rural communities, especially on the neighbor islands, need an automobile in order to travel to major population centers where hospital, specialty, and subspecialty services are available. Because of the mountainous nature of the islands, road networks have been sparse and, in some places, limited to a single highway near the coast. Access to emergency care on neighbor islands often requires the use of helicopters or fixed-wing aircraft.

Guam Geography and Population

Guam is a U.S. territory situated in the middle of Micronesia and is geographically closer to urban centers in Southeast Asia than the closest state, Hawaii. Guam has a population of approximately 155,000 and its culture and population is unique as a result of its geography and ethnic diversity. Most patients who require immediate specialty care, including genetic services, must go off-island to Hawaii, the mainland United States, or Southeast Asia at a cost of over \$1,200 per person just for the flight. Thus, it is difficult for Guam to meet many of the public health standards that are well-established in the states. Guam has been designated by the federal government as a Medically Underserved Area, as well as a Health Professional Shortage Area.

Oregon Geography and Population

Oregon is divided geographically into four regions: a semi-arid desert in the east; the rugged Cascade Mountains stretching north and south through the middle of the state, coastal mountains, and a large sea level valley lying between the Cascades and coastal mountains. Almost 85% of Oregon's 3.6 million population is concentrated in the Willamette Valley, with 60% living in the Portland metropolitan area.

All Oregon physician geneticists practice in the Portland metropolitan area. Prenatal and cancer genetic counseling are also available in Eugene. Forty percent of Oregon's

population must travel over 80 miles to be seen by a physician geneticist and 15% must travel over 80 miles to be seen by a genetic counselor.

Travel for medical care is primarily by car. Because both Portland and Eugene are located in the western part of the state, families in Eastern Oregon must drive three to eight hours to see a physician geneticist or genetic counselor. Public transportation outside of Oregon's cities is very limited. Counties arranging transportation to Portland for health care for low income Oregonians often arrange a driver rather than providing the family with funds for public transportation.

Idaho Geography and Population

Idaho is just over 84,000 square miles in size, with 80% of the land either range or forest and 70% of it publicly owned. Idaho has no practicing medical geneticists. The number of practicing genetic counselors varies year to year. At present there are four genetic counselors practicing, all in the city of Boise. People living in Idaho would need to travel to Spokane, Seattle or Portland to see a medical geneticist.

Description of the Practice Model

Guam and all states in the western region, except California, participated in genetic service delivery models of either outreach or telehealth visits as shown in Figures 1 and 2. Visits are defined as a health care provider or providers participating in a session with a family. Outreach visits involved genetic providers traveling to communities remote from urban centers. In this report we use the term telehealth to refer to visits provided via interactive video-conferencing.

Figure 1. Genetic services provided via outreach trips from western urban centers to non-urban sites.

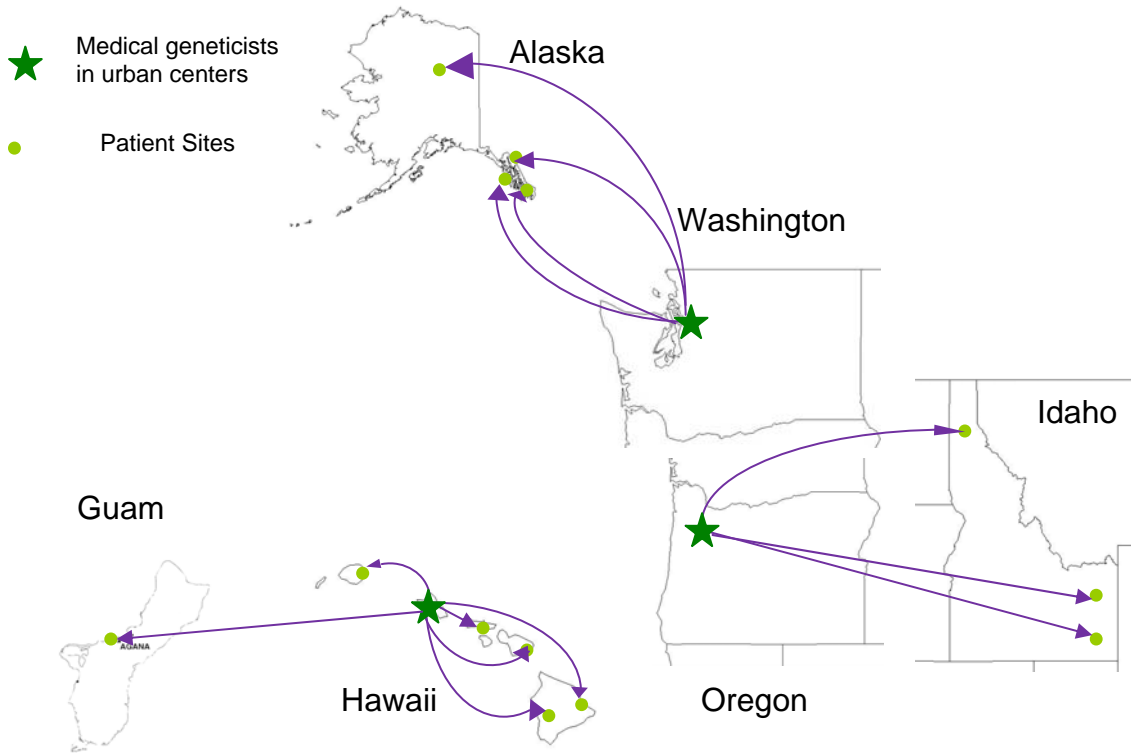
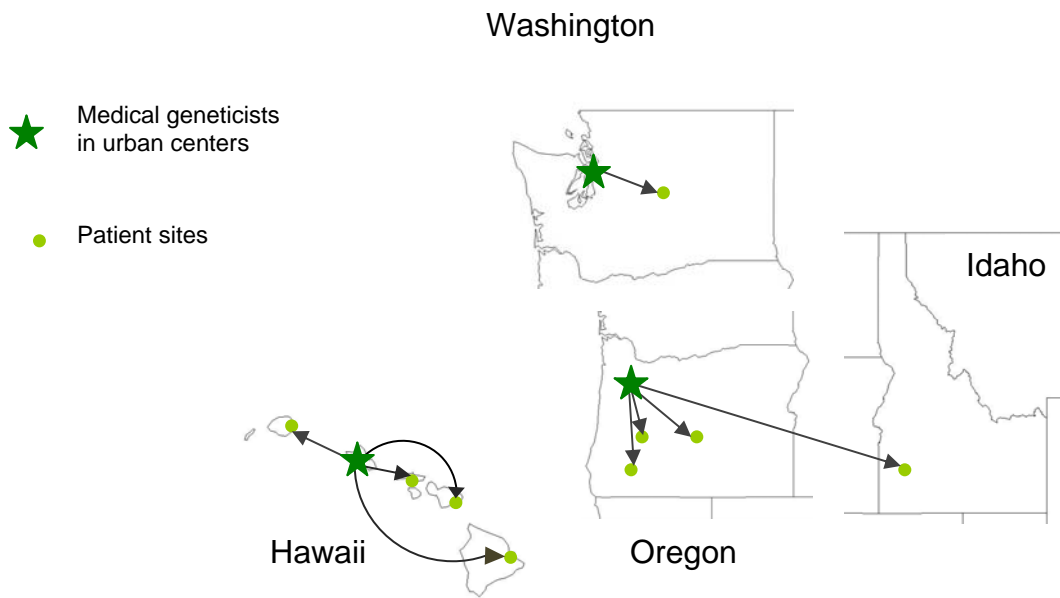


Figure 2. Genetic services provided via telehealth from western urban centers to non-urban sites.



WSGSC contributed at least partial funding for salary and/or travel costs in both outreach and telehealth projects as shown in Table 1. Participating partners paid for all other costs to deliver the services.

Table 1. WSGSC funding* for outreach and interactive-telehealth visits by patient and specialty sites, 2005-2008.

	Outreach	
	Patient Site	WSGSC\$*
Honolulu to Hilo, Maui, Kona, Waimea, Kauai, Molokai	MG + GC	salary + travel
Honolulu to Guam	MG + GC	salary + travel
Portland to Lewiston, Idaho Falls, Coeur d'Alene	MG + DT	salary + travel
Seattle to Anchorage, Juneau, Ketchikan, Fairbanks, Sitka	MG + GC	travel

	Telehealth		
	Specialty Site	Patient Site	WSGSC\$*
Between Honolulu and Hilo, Kauai, Maui	MG + GC	SW**	salary
Between Portland and Boise	MG + DT	GC**	salary
Between Portland and Bend, Medford	MG + DT	PHN**	salary
Between Seattle and Yakima, Washington	MG	GC	salary

*WSGSC supplied at least partial funding

MG – medical geneticist

GC – genetic counselor

DT – dietitian

SW** – social worker not funded by WSGSC

GC** - genetic counselor not funded by WSGSC

PHN** – public health nurse not funded by WSGSC

2009-2011 Changes to Regional Practice Model

During the 2009-2010 grant period the following components of the Regional Practice Model continued:

- Outreach to neighboring Hawaiian islands from Honolulu based medical geneticist and genetic counselors.
- Telehealth (interactive videoconferencing) services to neighboring Hawaiian islands from a Honolulu based medical geneticist and genetic counselor.
- Outreach to Idaho families with phenylketonuria from a Portland based metabolic geneticist and dietitian.

Telehealth services in Oregon were discontinued based upon evaluation findings from the previous year which indicated telehealth was not a cost effective approach for Oregon providers. Outreach services to Guam were temporarily suspended in 2009 to work with Guam insurers to achieve financing of genetic testing. Outreach services to Guam were reinstated in 2010. WSGSC funding for outreach to Alaska by genetic specialists from Seattle was discontinued in order to fund an Alaskan-based clinic coordinator to evaluate the best location for Alaskan genetic clinics.

Evaluation Areas and Data Collection

To evaluate the Practice Model initiative, WSGSC Co-Directors, staff and clinicians collected data in the following areas:

- Project process
- Visit and patient characteristics
- Family and provider satisfaction
- Provider time and travel costs
- Family time and travel costs

Hawaii and Washington state projects submitted applications to relevant Institutional Review Boards (IRB) to apply for protection of human subjects. The Institutional Review Boards classified both Hawaii and Washington state projects as quality-improvement projects for business purposes, not research. Project staff and clinicians supplied information about processes of the various projects to Collaborative Co-Directors and the evaluator. Immediately after patient visits, a genetic counselor, social worker or public health nurse offered each family the opportunity to complete a written, self-administered questionnaire containing questions related to satisfaction about the visit. Providers completed written, self-administered questionnaires following visits. Project staff and clinicians estimated time and reported travel costs for both outreach and interactive telehealth projects.

Hawaii Findings

Starting in 2006, the Hawaii Practice Model project has included a combination of outreach and telehealth services provided by a Honolulu-based medical geneticist, genetic counselor and dietitian when appropriate. Services are provided to families living on neighboring Hawaiian islands. Since inception, among 428 patient visits in the Hawaii Practice Model project, 90% were outreach visits. Visits to patients in Hilo comprised one third of all visits. Visits are defined as a health care provider or providers participating in a session with a family. Data shown in each column are for the grant fiscal periods June 1-May 31 (Tables 2-4).

Table 2. Number of combined outreach and telehealth visits to Hawaii islands from Honolulu geneticist and genetic counselors

Site	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	Total
Hilo	8	40	33	38	31	150
Kauai	7	21	21	21	11	81
Kona	7	12	12	16	14	42
Waimea	0	7	12	14	7	59
Maui	8	21	16	18	15	78
Molokai	0	4	5	0	9	18
Total	30	105	99	107	87	428

Table 3. Number of outreach visits to Hawaii Neighboring Island from Honolulu geneticist and genetic counselors

Site	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	Total
Hilo	8	37	30	30	29	134
Kauai	7	15	21	16	5	64
Kona	7	12	12	12	14	38
Waimea	0	7	12	14	7	59
Maui	8	21	16	16	13	74
Molokai	0	4	5	0	8	17
Total	30	96	96	88	76	386

The number of telehealth visits from Honolulu to neighboring Hawaiian islands was variable over the past four grant periods, with the highest number of visits performed in the 2008-2009 grant period.

Table 4. Number of telehealth visits to Hawaii neighboring islands from Honolulu geneticist and genetic counselors

Site	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	Total
Hilo	0	3	3	8	2	16
Kauai	0	6	0	5	6	17
Kona	0	0	0	4	0	4
Maui	0	0	0	2	2	4
Molokai	0	0	0	0	1	1
Total	0	9	3	19	11	42

Hawaii Patient Visit Characteristics

Age data was available for 80 patients in the Hawaii outreach project. For outreach visits between 2005 and 2008, one third of patients were less than three years of age. Sixty-one percent of patients were less than six years of age.

Table 5. Distribution of age of patients in Hawaii outreach visits 2005-2008

Age Group	No.	%
0-2 years	29	36%
3-5 years	20	25%
6-12 years	18	23%
13-18 years	9	11%
>18 years	4	5%
	80	100%

Hawaii Outreach Patient Diagnoses

Diagnosis information is available for patients in thirty-five Hawaii outreach visits between 2005 and 2008. Three patients had more than one diagnosis or presenting symptom. Thirty-five of the 219 patients evaluated at a Hawai'i outreach clinic had diagnoses made prior to the clinic or as a result of the clinic. The diagnoses were varied and ranged from chromosomal conditions and single gene disorders to metabolic conditions and disorders of dysmorphology.

Hawaii Personnel Time

Tables 6 and 7 show the number of personnel hours required to provide outreach genetic services to neighboring islands. During outreach visits, the genetic counselor

and the medical geneticist are in the room together with the patient. The total number of personnel hours required per outreach visit decreased during the last two grant periods likely because, during the 2005-2006, 2006-2007, and 2007-2008 grant periods, data relating to personnel hours was collected retrospectively and was estimated by reporters. Personnel hours recorded during the 2008-2009 and 2009-2010 grant periods were collected prospectively as visits were performed.

Table 6. Number of hours for Hawaii outreach visits by professional type, grant year, and type of time

Grant Periods	Genetic Counselor	Medical Geneticist	Dietitian	Administrative Assistant	Off-Site Facilitator	Total
2005-2006						
patient time*	172	162		1	4	339
travel time	16	14			0	30
Total Hours	188	176		1	4	369
2006-2007						
patient time	570	544		4	13	1131
travel time	55	53			1	109
Total Hours	625	597		4	14	1240
2007-2008						
patient time	622	537	7	4	13	1183
travel time	54	53			1	108
Total Hours	676	590	7	4	14	1183
2008-2009						
patient time	276	235		4	7	522
travel time	52	52			0.5	104.5
Total Hours	328	287		4	7.5	522
2009-2010						
patient time	194	145			7	346
travel time	45	43			1	89
Total Hours	239	188			8	346

*Patient Time includes before, during and follow-up hours

Table 7. Total personnel hours per outreach visit by grant period

Grant Period	Total Genetic Counselor Hours	Total Medical Geneticist Hours	Total Hours	No. Outreach Visits	Total Personnel Hours per Visit
2005-2006	183	176	359	30	12
2006-2007	625	597	1222	96	13
2007-2008	676	590	1266	96	13
2008-2009	328	287	615	88	7
2009-2010	239	188	427	76	6

Table 8 shows the proportion of total service time that is travel time for the medical geneticist and genetic counselor. The proportion of total service time that is travel time has increased during the latest two grant periods. This is likely because patient time

drastically decreased over the last two grant periods resulting in the travel time making up a proportionately larger amount of the total personnel time. Because data collected for the 2008-2009 and 2009-2010 grant periods was collected prospectively, the proportion of total service time that is travel time is a more accurate reflection of the breakdown of time spent in during Hawaii outreach clinics.

Table 8. Proportion of total service time that is travel time for Hawaii outreach visits

Grant Period and Time	Genetic Counselor	Medical Geneticist
2005-2006		
patient time*	172	162
travel time	16	14
Total Hours	188	176
Travel Proportion	9%	8%
2006-2007		
patient time	570	544
travel time	55	53
Total Hours	625	597
Travel Proportion	9%	9%
2007-2008		
patient time	622	537
travel time	54	53
Total Hours	676	590
Travel Proportion	8%	9%

Grant Period and Time	Genetic Counselor	Medical Geneticist
2008-2009		
patient time	276	235
travel time	52	52
Total Hours	328	287
Travel Proportion	16%	18%
2009-2010		
patient time	194	145
travel time	45	43
Total Hours	239	188
Travel Proportion	19%	23%

*Patient Time includes before, during and follow-up hours

Hawaii Personnel Travel Costs

The travel cost per outreach visit increased each year as shown in tables 9-11.

Table 9. Personnel travel costs for Hawaii outreach visits by provider type and project year

Type of Cost	Cost 2005-2006 No. Visits=30	Cost 2006-2007 No. Visits=96	Cost 2007-2008 No. Visits=96	Cost 2008-2009 No. Visits=88	Cost 2009-2010 No. Visits=76
Medical geneticist meals	\$120	\$420	\$370	\$240	\$220
Medical geneticist air fare	\$410	\$1,080	\$1,496	\$2,037	\$1,959
Medical geneticist parking	\$40	\$140	\$130	\$120	\$137
Genetic counselor meals	\$120	\$420	\$370	\$240	\$220
Genetic counselor airfare	\$410	\$1,080	\$1,469	\$1,987	\$1,959
Genetic counselor parking	\$40	\$130	\$110	\$100	\$137
Car rental	\$60	\$199	\$206	\$295	\$189
Miles charge	\$13	\$41	\$45	\$49	\$20
Hotel	\$0	\$100	\$300	\$0	\$0
Hotel Parking	\$0	\$5	\$15	\$0	\$0
Total Cost	\$1,213	\$3,615	\$4,511	\$5,068	\$4,841

Table 10. Personnel travel cost per patient visit in Hawaii outreach visits by year

	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010
Number of visits	30	96	96	88	76
Personnel travel cost	\$1,213	\$3,615	\$4,511	\$5,068	\$4,841
Personnel travel cost per patient visit	\$40	\$38	\$47	\$58	\$64

Table 11. Personnel time and travel costs for Hawaii outreach visits by project year

Outreach Cost Categories	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010
Number of visits	30	96	96	88	76
Total personnel travel cost	\$1,213	\$3,615	\$4,511	\$5,068	\$4,841
Total personnel salary	\$17,979	\$61,109	\$62,760	\$31,488	\$21,423
Total cost	\$19,192	\$64,724	\$67,271	\$36,556	\$26,264
Total cost per visit	\$640	\$674	\$701	\$415	\$346

Hawaii-Guam Findings

Personnel time and cost data for Honolulu medical geneticist and genetic counselors to provide outreach services to Guam for a February 2010 genetics clinic are shown in Tables 12 and 13.

Table 12. Total number of personnel hours to provide genetic visits from Honolulu specialists to Guam by type of personnel and type of activity

Activity and Hours	Medical Geneticist	Genetic Counselor 1	Genetic Counselor 2	Project Admin Assistant	On-site facilitator	Total Combined Personnel
Hours preparing for outreach clinic	2	3	3	3	6	17
Hours during outreach clinic	30	30	30	0	16	106
Hours following up on outreach clinic	11.5	6.5	6.5	0	0	24.5
Total hours	43.5	39.5	39.5	3	22	147.5
Total travel time	22	22	22	0	0	66
Total time by personnel to provide outreach service	109	101	101	6	44	361
Proportion of hours that are travel	5%	5%	5%	NA	NA	5%

As shown in Table 13, total costs for the team to travel from Hawaii to Guam to provide thirty visits was \$13,124 or \$875 per visit.

Table 13. Total cost to provide genetic visits from Honolulu specialists to Guam by type of personnel and expense type

Travel Expense Type for No. Visits=30	Medical Geneticist	Genetic Counselor 1	Genetic Counselor 2	Total Personnel Combined
Amount reimbursed for meals	\$480	\$536	\$536	\$1,552
Airfare	\$1,273	\$1,273	\$1,273	\$3,819
Parking	\$5	\$0	\$0	\$5
Rental Car	\$0	\$0	\$230	\$230
Gas	\$0	\$0	\$18	\$18
Hotel	\$819	\$410	\$410	\$1,639
Internet	\$0	\$48	\$0	\$48
Phone call expenses for dictation	\$52	\$0	\$0	\$52
Weekly salary	\$2,885	\$1,438	\$1,438	\$5,761
Totals	\$5,514	\$3,705	\$3,905	\$13,124
Total cost per visit	\$367.60	\$247.00	\$260.33	\$874.93

Hawaii Family Satisfaction—Outreach Visits

Family satisfaction data was collected for outreach and telehealth visits during the 2005-2008 grant periods. The response rate to the family satisfaction survey among families who received an outreach visit was 68% (165/244). At least 95% of all respondents either agreed or strongly agreed with positive statements about communication, quality of care, and privacy aspects of outreach visits. Collection of family satisfaction data for both outreach and telehealth visits was discontinued in 2009 as families were generally satisfied with both types of visits.

Table 14 . Distribution of responses to Hawaii outreach family satisfaction survey.

	% Strongly Agree	% Agree	% Disagree	% Strongly Disagree	% NA	No.
Family Satisfaction						
information received before visit was helpful	51.5	41.2	1.8		5.5	165
staff introduced selves, described role	69.1	29.1	1.2		0.6	165
good conversation with specialist	75.9	23.5	0.6			166
specialist listened to information I provided	76.4	23	0.6			165
specialist responded to my questions	73	24.8	0.6		0.6	165
privacy protected	67.1	30.5	0.6		1.8	165
Family Satisfaction	% Strongly Agree	% Agree	% Disagree	% Strongly Disagree	% NA	No.
confident in quality of care	76.4	23	0.6			165
confident in clinic recommendations	77.4	22	0.6			164
would recommend outreach clinic to others	77.6	21.8	0.6			165
satisfied with visit	78.8	20.6	0.6			165
prefer outreach clinic to traveling	20.9	14.7	39.3	19	6.1	163
would come to outreach clinic again	78.2	20.6	1.2			165

Table 15 shows the percent of respondents to Hawaii outreach family satisfaction surveys who answered Yes or No to questions related to challenges to traveling for an outreach visit. Twenty-five percent reported they would not have received needed care for their child if they had not come to the outreach visit.

Table 15. Distribution of responses to Hawaii outreach family satisfaction survey—“Before today’s visit, what made it hard to get the specialty services your child needs?”

Family opinion No.=170	% Yes	% No
hard to pay for child care	77	23
costs too much to travel	57	44
miss work and wages	44	56
see local provider	31	69
not have gotten care my child needed	25	75
costs too much (insurance)	18	82
other	14	86
large hospital uncomfortable	11	89

Hawaii Family Satisfaction—Telehealth Visits

Information about demographic characteristics of family satisfaction survey respondents was not collected in Hawaii projects. The response rate to the family satisfaction survey among families who received a telehealth visit was 83% (10/12). At least 95% of all respondents either agreed or strongly agreed with positive statements about communication, quality of care, equipment and privacy aspects of telehealth visits. Fifty percent of respondents either agreed or strongly agreed with the statement “Despite the obstacles to receiving care in person, I would still prefer to travel to see the specialist.” While 80% checked Yes to the statement “it costs too much to travel”, as a reason for what made it hard to get specialty services. (See Tables 16 and 17)

Table 16. Distribution (percent) of responses to Hawaii telehealth visit family satisfaction survey

Family Satisfaction No.=10	Strongly Agree	Agree	Disagree	Strongly Disagree	Missing or NA
information received before visit was helpful	40	50	10		
staff introduced selves, described role	90	10			
good conversation with specialist	50	40			10
specialist listened to information I provided	70	30			
specialist responded to my questions	70	30			
privacy protected	60	40			
confident in quality of care	60	40			
confident in clinic recommendations	60	40			
would recommend telehealth to others	80	20			
satisfied with visit	80	20			
prefer traveling to telehealth	10	40	50		
would come to telehealth again					100
staff could work equipment	30	20			50
equipment worked well	60	40			

Table 17. Distribution of responses to Hawaii telehealth visit family satisfaction survey—“Before today’s visit, what made it hard to get the specialty services your child needs?”

Family Satisfaction	No.=10	No. Yes	No. No
costs too much to travel		8	2
other		6	4
If had not been able to use telehealth today, would have traveled to Honolulu		4	1
miss work and wages		2	8
If had not been able to use telehealth today, would have seen local provider		2	3
hard to pay for child care		1	9
costs too much (insurance)		1	9
large hospital uncomfortable		1	9
If had not been able to use telehealth today, would have waited until specialist came near my home		1	4
If had not been able to use telehealth today, would have not received services		1	4
not have gotten care my child needed		0	0

Oregon-Idaho Findings

Initially, the Oregon-Idaho Practice Model projects included both outreach and telehealth. For outreach visits, a medical geneticist and dietitian traveled from Portland to Idaho Falls and Coeur d'Alene. Telehealth visits involved a Portland medical geneticist and dietitian consulting to a patient on-site with a genetic counselor in Boise, Idaho and to a patient on-site with a public health nurse in Bend and Medford, Oregon. Telehealth visits were discontinued in 2009 due to costs to the provider site.

Oregon Visit Description—Telehealth Visits

The number of patients who received genetic consultations via telehealth increased over the past three grant years with a high of thirty-six patients in the most recent period. The average number of patients seen in one day increased from 1.17 the first year to 1.71 in the most recent grant year. Of forty-three clinics held, sixty percent consisted of one patient visit. In four of sixty-four visits an interpreter was present. (See Tables 18-20)

Table 18. Number of Oregon telehealth visits per day, 2005-2008

	2005-2006	2006-2007	2007-2008	Total
No. visits	7	21	36	64
No. *clinics	6	16	21	43
No. visits/clinic	1.17	1.31	1.71	1.49

*Clinic refers to visits provided on same day

Table 19. Distribution of number of visits per clinic day for Oregon telehealth visits, 2005-2008

No. of Patients per Clinic	No. of Clinics	% of Clinics
3	4	9.30%
2	13	30.23%
1	26	60.47%
	43	100.00%

Table 20. Distribution of patient site in Oregon telehealth visits, 2005-2008

Location	No. Patients	% Patients
Bend	26	41%
Medford	25	39%
Eugene	8	13%
Boise, Idaho	5	8%
Total	64	100%

Medical geneticists participated in 84% of consultations, genetic counselors participated in 45%, and dietitians participated in 20%. (See Table 18)

Table 21. Number and percent of telehealth visits by type of provider participating in the visit

Provider Type	No.	%
Medical geneticist + genetic counselor	25	39.06%
Medical geneticist	21	32.81%
Medical geneticist + dietitian	7	10.94%
Genetic counselor	4	6.25%
Dietitian	4	6.25%
Two dietitians	2	3.13%
Two medical geneticists	1	1.56%
Total	64	100.00%

Oregon Patient Visit Characteristics—Telehealth Visits

Visits for patients with metabolic conditions and other genetic conditions were evenly distributed. Visits for patients with phenylketonuria and cancer were the most common. (See Tables 22-23)

Table 22. Distribution of type of visit for Oregon telehealth visits

Visit Type	No.	%
Genetic condition other than metabolic	31	48.44%
Metabolic genetic condition	31	48.44%
Newborn screening metabolic condition	2	3.13%
Total	64	100.00%

Table 23. Distribution of diagnoses* in Oregon telehealth visits, 2005-2008

Diagnosis 1	No.	% of Visits
Phenylketonuria	13	20.31%
Cancer	10	15.63%
Unknown	8	12.50%
Ornithine transcarbamylase deficiency	4	6.25%
Biotinidase deficiency	2	3.13%
Medium-chain acyl-CoA dehydrogenase deficiency	2	3.13%
Gluteric aciduria type 1	2	3.13%
Albinism	1	1.56%
Autism spectrum disorder	1	1.56%

Autosome abnormality	1	1.56%
Breast cancer family history	1	1.56%
Carnitine palmitoyltransferase II	1	1.56%
Carnitine uptake deficiency	1	1.56%
Cavernous malformation	1	1.56%
Charcot-Marie-Tooth III	1	1.56%
Citrullinemia	1	1.56%
Cleft lip and palate	1	1.56%
Cornelia de Lange syndrome	1	1.56%
Down syndrome family history	1	1.56%
Dysmorphic cranial features	1	1.56%
Failure to thrive	1	1.56%
Fragile X syndrome	1	1.56%
Holt-Orum	1	1.56%
Hyperammonemia	1	1.56%
Isovaleric acidemia	1	1.56%
Left hemisphere hypertrophy	1	1.56%
Lesch-Nyhan syndrome	1	1.56%
Macrocephaly	1	1.56%
Methylmalonic acidemia	1	1.56%
Neurofibromatosis	1	1.56%
Noonan syndrome	1	1.56%
Tuberous sclerosis	1	1.56%
Wolf--Hirschorn syndrome	1	1.56%
Total=33 diagnoses (3 duplicated patients)	64	

* Some patients had more than one diagnosis

Oregon Family Satisfaction—Telehealth Visits

Tables 24-26 show the distribution of responses to the satisfaction survey completed by families participating in Oregon telehealth visits. Seventy-eight percent of respondents either disagreed or strongly disagreed with a statement that they would prefer to travel to see the specialist in person. Data is available from 32 respondents.

Table 24. Distribution of responses to Oregon telehealth visit family satisfaction survey

Patient Satisfaction	% Strongly Agree	% Agree	% Disagree	% Strongly Disagree	% NA	No.
The information I received <u>before the visit</u> helped me understand what was going to happen.	38.7	54.8	3.2		3.2	31
Staff could work the equipment.	66.7	33.3				12
The equipment worked well.		41.9	3.2	51.6	3.2	31
Before we started, each person introduced themselves and described their role.	61.3	33.3				30
The use of technology did not get in the way with being able to have a good conversation with the specialist.	61.3	38.7				31
The specialist listened and respected the information I provided.	74.2	25.8				31
The specialist responded to all of my questions.	77.4	22.6				31
Privacy of information about my child and my family was protected.	67.7	29			3.2	31
I feel confident in the quality of the care provided today.	71	29				31
I feel confident in the recommendations from today's visit.	67.7	32.3				31
I would recommend telehealth to other families.	79.3	20.7				29
Overall, I was satisfied with the visit today.	79.3	20.7				29
Despite the obstacles to receiving care in person, I would STILL prefer to travel to see the specialist.	3.6	17.9	42.9	35.7		28
Has telehealth made it any easier to get the care you need for your child?	96.4% Yes	3.6% No				28

**Table 25. Distribution of responses to Oregon telehealth satisfaction survey—
“Before today’s visit, what made it hard to get the specialty services your child needs?”**

Family Satisfaction	No.=32	%
I miss work and/or lose wages		62.5
It costs too much to travel		59.4
It costs too much (insurance)		28.1
It is hard to get and/or pay for child care		18.8
Going to a large hospital is not comfortable		9.4

Table 26. Distribution of responses to Oregon telehealth satisfaction survey—“If you had not been able to use telehealth to get specialty care today, what would you have done?”

Family Satisfaction	No.=32	%
Would have traveled to Portland		56.3
Would have waited until specialist came near to my home in an outreach clinic		40
Would have seen local provider		18.8
Would have not gotten the care my child needed		12.5

Oregon Personnel Time

Personnel involved in the Oregon telehealth project estimated the amount of time spent for patients before, during and after the visit as show in Table 27 below. Personnel estimated their time for the number of patients shown in the center row of the table. Dividing the number of patients by the estimated time spent offers an estimated number of hours per patient for each type of personnel. Totaling these estimated average hours per patient across all types of personnel involved in a telehealth visit yields an estimated number of personnel hours for one telehealth visit.

Table 27. Estimated number of hours per patient visit by personnel type in the Oregon telehealth visit project

	GC	MG	DT	PAA	AA	MA	OF	ORT	OHSUT	Total Est.
No. hours*	18.50	21.75	19.75	27.50	1.75	0.25	3.43	1.83	4.67	
No. Patients	9	15	8	15	7	1	2	9	2	
Hrs/patient	2.06	1.45	2.47	1.83	0.25	0.25	1.71	0.20	2.33	12.56

*Total hours spent before, during and after seeing patients for the number of patients seen listed in row below.

GC-genetic counselor; MG-medical geneticist; DT-dietitian; PAA-assistant; AA-assistant; MA-medical assistant; OF-patient site facilitator; OHSUT-specialist site technician

Oregon Personnel Travel Cost

Cost data was not collected for the Oregon outreach projects funded by WSGSC. However, personnel reported travel costs for a sample outreach clinic to Boise Idaho where thirty-six patients were seen. The travel costs were estimated for a medical geneticist, dietitian and medical assistant to fly to Boise and spend one overnight. The estimated total cost for such a trip was \$1,439, which results in an estimate of \$39.98 travel cost per patient for sample outreach visits to patients in Boise with metabolic conditions.

Oregon Outreach to Idaho

During the 2009-2010 grant period, the Practice Model was adapted to include only outreach visits by a Portland-based geneticist and dietitian to PKU clinics in three Idaho towns. Tables 28-30 show the number of visits provided by town and grant period.

Table 28. Number of outreach visits to Idaho PKU clinics by Oregon medical geneticist and dietitian

	2006-2007	2007-2008	2008-2009	2009-12/31/2009	Total
Idaho Falls	18	24	12	19	73
Lewiston	8	9	8	7	32
Coeur d'Alene	7	8	0	11	26
Total	33	41	20	37	131

Table 29. Number of Outreach PKU Clinics in Idaho by Oregon Medical Geneticist

	2006-2007	2007-2008	2008-2009	2009-12/31/2009	Total
Idaho Falls	2	2	1	2	7
Lewiston	1	1	1	1	4
Coeur d'Alene	1	1	0	1	3
Total	4	4	2	4	14

The average number of patient visits per clinic during the most recent grant year decreased compared to the previous two years with the exception of the clinics in Couer d'Alene where the average number of patient visits per clinic increased to eleven.

Table 30. Average number of visits per Idaho PKU outreach clinic

	2006-2007	2007-2008	2008-2009	2009-12/31/2009
Idaho Falls	9	12	12	9.5
Lewiston	8	9	8	7
Coeur d'Alene	7	8	0	11

Washington Findings

The Washington project was funded primarily by the Washington State Department of Health Genetic Services Section with a Maternal Child Health Bureau grant ((Project #H91MC00219 from the Maternal and Child Health Bureau (Title V, Social Security Act) #1126, Health Resources and Services Administration, Department of Health and Human Services)). WSGSC contributed partial funding to years two and three of the Washington project for a pilot interactive telehealth conference project. The project was administered by the Medical Genetics Division at Seattle Children's and evaluated by staff at Seattle Children's Center for Children with Special Needs. Medical geneticists at Seattle Children's provided consultation to patients referred by genetic counselors at the Central Washington Genetics Program, a Washington State Department of Health (DOH) funded Regional Genetics Clinic administered by Yakima Valley Memorial Hospital. Telehealth equipment was located at the Seattle campus, Children's Village in Yakima, and an outreach clinic in Wenatchee. DOH funds the Regional Genetic Clinics (RGC) to assure access to specialty genetic services. As part of routine RGC activity, genetic counselors receive and triage referrals from community providers, determining whether referred patients might benefit from a medical genetics consultation. In the telehealth pilot, genetic counselors were to routinely review a list of patients awaiting a clinic visit from a CHRMC-based medical geneticist in order to identify patients who would be eligible for a telehealth visit. Criteria for whether a patient was eligible for a telehealth visit included: 1) needed visit was a follow-up visit; 2) minimal physical examination was deemed necessary; or 3) needed visit was an urgent initial visit. If a telehealth consultation could be scheduled prior to the next time the medical geneticist would be in Yakima for an in-person clinic, the genetic counselor then offered the patient the opportunity to see the physician earlier via telehealth. At initial contact and at the time of the telehealth visit, genetic counselors gave the patient information about what to expect during the telehealth visit.

The WSGSC also contributed funds for a team of genetic specialists to travel to Anchorage, Fairbanks, Juneau, Ketchikan and Sitku to provide outreach clinics.

Washington Methods

Alaska public health genetic services and newborn screening program collected data on the location and number of patients who received outreach visits from the Seattle specialty team.

Qualitative information about the telehealth project process and visits and quantitative satisfaction data at each visit was collected. Genetic counselors and physicians supplied both verbal and written feedback to evaluation staff at team meetings. Questionnaires related to satisfaction with the telehealth visit were completed by a family member of pediatric patients or the adult patient themselves, interpreters present during the visit, referring providers, genetic counselors and medical geneticists. During the final year of the project, satisfaction questionnaires were also completed by a

sample of patients receiving in-person medical genetic consultations at the Yakima clinic.

Genetic counselors and medical geneticists completed questionnaires immediately after each visit. During the three years of the project, three genetic counselors and two medical geneticists participated in patient visits. Genetic counselors were to use a prescribed protocol to offer patients and interpreters the opportunity to complete a satisfaction questionnaire immediately following their telehealth or in-person visit with the medical geneticist. Once the medical geneticist's consultation report was mailed to the referring provider, evaluation staff mailed a cover letter and satisfaction questionnaire to referring providers, asking them to complete and return the survey.

Information about cost and billing was obtained from Seattle Children's contract manager, Children's University Medical Group (the physician billing office for CHRMC), CHRMC Information Systems department, and YVMH finance office. All qualitative and quantitative data was collected, entered and analyzed by evaluation staff at the Center for Children with Special Needs. Tables 31-33 report on data from September 1, 2004 – April 30, 2007.

A total of 37 visits were provided between 9/24/2004 and March 17, 2007 by three different genetic counselors and two medical geneticists. The average number of patients seen per day for which visits were scheduled was 1.5. Tables 31-33 show the distribution of patient characteristics for telehealth visits.

Table 31. Distribution of patient age in Washington telehealth visits

Patient age in years	No. of patients
<1	1
1	2
2	1
3	3
4	1
5	2
6	6
8	2
11	1
12	4
17	1
18	1
28	1
30	1
Total	27
Mean age for 0-21 YO's=7 years, SD=.98	

Table 32. Distribution of patient gender, ethnicity and visit type for Washington telehealth visits

Gender	No.	%	Ethnicity	No.	%	Type	No.	%
females	17	59%	Hispanic or Latino	16	53%	follow-up	32	86%
males	12	41%	Caucasian	12	40%	initial	5	14%
Total	29	100%	Mixed ethnicity	2	7%	Total	37	100%
			Total	30	100%			

Table 33. Diagnoses of patients receiving medical genetic consultation via interactive telehealth conference between Yakima and Seattle, September 1, 2004 - April 30, 2007

Diagnosis	No. of Visits
achondroplasia	1
arthrogryposis	1
Autism	1
Bannayan-Riley-Ruvalcaba syndrome	1
Beckwith-Wiedemann syndrome	1
brain malformation	1
carnitine palmitoyltransferase deficiency Type I	2
chromosome abnormality	1
developmental delay	6
duodenal atresia	1
Freeman Sheldon syndrome	1
glycogen storage disease	1
hypertelorism	1
Marfan syndrome	1
mosaic chromosome 10	1
mucopolysaccharidosis VI	1
neuromuscular unspecified	1
neurofibromatosis	2
Noonan syndrome	1
overgrowth	1
polydactylism	1
Russell-Silver syndrome	1
skeletal dysplasia	1
subcorticate band heterotopia	1
Turner syndrome	1
unknown	2
Von Hippel-Lindau syndrome	2
Wolf-Hirschhorn syndrome	1
Total	37
Total diagnoses	28

Washington Satisfaction—Telehealth Visits, Family and Provider

As shown in Table 34 families were equally satisfied with telehealth and in-person consultations. Families had the highest mean satisfaction for telehealth visits compared to interpreters and referring providers.

Table 34. Participant satisfaction* with medical genetics consults provided via interactive telehealth conferencing from Seattle Children's Hospital to Central Washington Genetics Program, 2004-2007

*Overall satisfaction, based upon responses to post-visit satisfaction questionnaire

5=strongly agree - 1=strongly disagree	Mean of means from all satisfaction questions	No. of participants	No. visits
families – telehealth visits	4.90	29	29
families – in-person visit	4.81	28	28
interpreters	4.87	11	11
referring providers	4.36	19	19
genetic counselors	4.73	3	37
medical geneticists	4.45	2	23

Table 35 shows that most of the respondents who completed post-visit satisfaction surveys were mothers of pediatric patients for whom the visit was scheduled. Two adult patients completed satisfaction surveys after telehealth visits.

Table 35. Respondent relation to patient among Washington family satisfaction surveys

*Respondent relation to patient-telehealth visits	No.
mother	26
father	7
grandmother	2
self	2
** Respondent relation to patient-in person visits	No.
mother	8
father	2
both parents	2
grandmother	2
self	2

Washington—Telehealth Visits Insurance Billing and Reimbursement

Medical genetic consultations were billed from Seattle Children's. Third party reimbursement for consultations varies based upon individual insurance plan. Insurers reimbursed for telehealth at the same rate as in-person visits, according to Children's University Medical Group billing office. The rate of reimbursement ranges from 25-96%.

Table 36. Percent of charges covered by insurance for medical genetic consultations provided via telehealth conferencing from Seattle Children's to Central Washington Genetics Program, September 2004-March 2007

ICD9	CPT Code	CPT Code Description	Hours Billed*	Insurance or Plan Name	Insurance Covered Y/N	% Insurance Covered	Charges
759.89	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
271	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
758.6	99244	Office Consult	60 minutes	FC Cigna	Y	41%	\$342.75
759.7	99245 GT	Office Consult	80 minutes	CHPW	Y	25%	\$442.50
759.89	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$239.25
243	99215 GT	Off OtPt Vst	40 + minutes	Molina WVC	Y	35%	\$139.25
759.7	99245 GT	Office Consult	80 minutes	Molina	Y	26%	\$442.50
742.4	99215 GT	Off OtPt Vst	40 + minutes	Premera/Regence	Y	96%	\$239.25
315.2	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	Refunded/ 0	\$237.75
330.8	99245 GT	Office Consult	80 minutes	Regence	Y	68%	\$442.50
780.39	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	35%	\$237.75
756.4	99215 GT	Off OtPt Vst	40 + minutes	none		write off	\$237.75
312.9	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
758.5	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
758.39	99245 GT	Office Consult	80 minutes	DSHS	Y	25%	\$442.50
756.4	99244 GT	Office Consult	60 minutes	Premera	N		\$342.00
755.5	99215 GT	Off OtPt Vst	40 + minutes	CHPW	Y	36%	\$237.75
277.5	99911 C	No Charge	unknown	none			\$0.00
754.89	99911 C	No Charge	unknown	DSHS			\$0.00
780.39	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	36%	\$237.75
759.82	99911 C	No Charge	unknown	Regence HO			\$0.00
781.3	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	37%	\$237.75
783.42	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	37%	\$237.75
759.7	99215 GT	Off OtPt Vst	40 + minutes	DSHS	Y	37%	\$237.75
237.71	99215 GT	Off OtPt Vst	40 + minutes	Health Comp	Y	54%	\$237.75
756	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	37%	\$237.75
759.7	99215 GT	Off OtPt Vst	40 + minutes	DSHS	y	34%	\$256.50

Source: CUMG Office, Children's Hospital and University Hospital Medical Group Billing used time in CPT Book

Genetic counseling services provided during telehealth conferencing at Central Washington Genetics Program were not a billable service because the counselor and physician saw the patient at the same time. Also, Yakima Valley Memorial Hospital's contract with Medicaid and other insurer's precludes billing for telehealth. (Source: Kathy Pratt, Charge Description Master Specialist, Yakima Valley Memorial Hospital)

Alaska Outreach

A total of 1,269 genetic specialty outreach visits were provided to Alaskan residents between 2006 and 2010 with partial funding from the WSGSC. Between 2006 and 2008, WSGSC partially funded travel of genetic specialists from Seattle, Washington to provide outreach services in Alaska. These services were terminated in 2008. During the 2008-2010 period, the WSGSC partially funded an outreach clinic coordinator to help in planning for optimal approaches to serving rural and frontier populations in Alaska. Visit data by town is available for 2006-2008, and total visits for 2008-2010.

Table 37. Number of outreach visits to Alaska rural and frontier populations partially funded by WSGSC

Alaskan Town	No. Visits 2006-2007	No. Visits 2007-2008	No. Visits 2008-2009	No. Visits 2009-2010	Total
Anchorage	197	232			
Bethel	5	1			
Fairbanks	58	76			
Juneau	24	21			
Ketchikan	7	5			
Sitku		4			
Total	291	339	324	315	1269

Across the Practice Model—Number and Type of Visits

Ninety-two percent of all visits in the Practice Model were outreach visits while 8% were telehealth visits. Table 38 shows the number of outreach visits, by state and grant period. Data regarding duplicate patients is not available. Fifty-nine percent of outreach visits were provided in Alaska while twenty-seven% of outreach visits were provided by a Honolulu genetics team who traveled to patients in Guam and other Hawaiian islands. Outreach to Guam was suspended between 2007 and 2009 after project staff determined working for health insurance reimbursement for genetic testing was necessary in that territory before continuing outreach clinics. Excluding Guam, the number of outreach visits increased each year until the 2009-2010 grant period.

Table 38. Number of outreach visits in the Practice Model by state in which services were provided and grant year

Grant Year	Alaska	Guam	Hawaii	Idaho	Total
2005-2006			30		30
2006-2007	95	25	96	33	249
2007-2008	108		96	41	245
2008-2009	324		88	20	432
2009-2010	315	30	76	46	467
Total	842	55	386	140	1423

Table 39 shows the number of telehealth visits received by western families living far from genetic specialists. All counts reflect unduplicated patients with the exception of Oregon where there are 54 unduplicated patients receiving 59 visits. Of the 126 genetic consultations provided via telehealth conferencing between 2005 and 2010, 47% were in Oregon. Washington State discontinued telehealth visits after a three-year trial project. WSGSC provided no funding for the first year of the Washington project.

Table 39. Number of telehealth visits in the Practice Model by state for which services were provided and grant year

Grant Year	Hawaii	Idaho	Oregon	Washington	Total
2005-2006		3	4	10	17
2006-2007	8	1	20	10	39
2007-2008	4	1	35	0	40
2008-2009	19	0	0	0	19
2009-2010	11	0	0	0	11
Total	42	5	59	20	126

Across the Practice Model—Visit and Patient Characteristics

Visit and patient characteristic data was collected for Hawaii outreach visits and Oregon and Washington telehealth visits up until 2008. Table 40 shows similarities and differences with regard to type of visit and age of patients seen in these two programs.

Table 40. Distribution of visit and patient characteristics in Hawaii outreach and Oregon and Washington telehealth visits

Characteristic	Hawaii Outreach Visits No.=80	Oregon Telehealth Visits No.=64	Washington Telehealth Visits No.=37
Initial visit	51%	68%	14%
Follow-up visit	49%	32%	86%
Metabolic diagnosis		48%	8%
<12 months old	8%	25%	4%
12-35 months old	30%	20%	11%
3-13 years old	46%	23%	70%
14-20 years old	11%	8%	7%
>= 21 years old	5%	23%	7%

Qualitative Findings

Project staff and clinicians report the following challenges to each type of service delivery model:

Challenges Present in Both Outreach and Telehealth Visit Models

- Specialists might not have time to add travel to existing case load
- Specialists might not have time to add new patients to existing case load
- In some instances, if medical geneticist and genetic counselor are together with patient, genetic counselor can not bill patient

Challenges to Outreach Delivery Model

- Higher number of specialist personnel hours due to travel, varies based upon travel distance, time and costs
- Personnel travel time and costs not reimbursed by insurance and thus services provided at the expense of provider organizations or public health funds

Challenges to Interactive Telehealth Conferencing Model

- Non-billable professional time to identify and triage patients
- Some physical examinations must be doctor hands-on
- Some patient populations elect in-person
- Provider willingness to participate necessary
- Intra and inter-organization systems slow to change procedures
- Adds layer of complication onto existing service types
- Partnership or inter-agency agreements must be created and maintained
- Increased non-billable coordination and management time to maintain all program aspects, including quality
- Technical or equipment aspects still not perfect
- Professional with patient might not be able to bill (duplicate billing)
- Costs to provide services are shifted from patient to health care system and/or public health

Discussion and Conclusions

Findings from the Practice Model evaluation can assist public health agencies and tertiary centers in planning access projects, but the following factors should be considered:

1. There were differences in genetic specialists time between states as well as between service delivery models
2. There were salary differences between same types of specialists
3. Travel time differences between outreach clinic locations
4. Costs of travel changed over time
5. Differences in genetic specialists time for initial vs follow-up visits
6. Varied costs for connectivity between each set of sites (T1 line, ISDN line, Internet)
7. Procedures changed over time
8. Type of specialists and personnel at originating site varied from state to state

Recommendations specific to telehealth projects:

- Success more likely with a physician geneticist “champion”
- Visit indications that worked the best
 - Metabolic management for known patients
 - Follow-up medical geneticist consultation
 - Pre and post test genetic counseling for adult-onset conditions
 - Genetic counseling when physical exam not needed

- Add logistics responsibilities to existing clinic administrative/support staff rather than hiring a separate coordinator for telehealth
- Make the telehealth equipment as accessible as possible for the genetics specialist
- Schedule telehealth visits as “clinics” - as many patients at one originating site on the same day
- Add genetics to an existing telehealth system if one exists

In Guam and the six states in the western region (Alaska, California, Hawaii, Idaho, Oregon and Washington), genetic specialty providers are located primarily in tertiary centers in California, Honolulu, Portland and Seattle. California has the largest number of practicing medical geneticists and genetic counselors, yet California did not participate in the regional model due to the vast size and population in their state and the limited amount of funding available for the entire region. Through Collaborative Director-led initiative, public health agencies in the remaining participating states formed partnerships with specialty clinicians working in private, non-profit tertiary centers to provide genetic consultation via outreach or inter-active telehealth visits. The process of planning and negotiating which specialists provided services to what areas is an example of successful regional collaboration for the involved states and territory. Service delivery models varied state to state because the health service delivery system is different in each state and the number and type of genetic specialists and where they practice also differs from state to state.

We found that patients were generally satisfied with the genetic services they received via outreach or telehealth visits. The proportion of patients who reported they would prefer to travel to see a specialist in-person was different for patients in Hawaii compared to patients in Oregon. Though not specifically detailed herein, we also found that providers express general satisfaction with offering genetic services via outreach and telehealth visits, if they have time available in their schedule to add either travel time or additional patients.

The most useful regional practice models to increase access to genetic services for people who live far from specialists vary from state to state depending upon several factors:

- What public-private partnerships can be developed and sustained
- The distance required for travel and the rising cost of travel compared to personnel, equipment and technical costs for delivery of telehealth
- What portion of costs for either travel or telehealth, not paid with public grant funds, can be paid by partnering organizations
- Commitment or availability of medical geneticists and genetic counselors to provide additional services in ways other than patient visits at their immediate work site

Over the coming year, the Western States Genetic Services Collaborative will continue to explore how best to sustain improved access to genetic services in the region based upon Practice Model findings.