

Proceedings

Western States Regional

Medicaid and Genetic Services Meeting

May 12, 2011

Seattle, Washington

A partnership of the Western States Genetic Services Collaborative, University of Washington Center for Genomics and Healthcare Equality, and western states Medicaid representatives

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Western States Regional Medicaid and Genetic Services Meeting

On May 12, 2011, twenty-two Medicaid and genetic services stakeholders from Alaska, California, Hawaii, Oregon and Washington met for one day in Seattle, Washington to identify regional challenges to Medicaid reimbursement of genetic services and develop plans to address identified challenges (see Attachment 1 – Participants). The meeting, sponsored by the Western States Genetic Services Collaborative (WSGSC, HRSA Grant No.U22MC03961) and the University of Washington Center for Genomics and Healthcare Equality, was a result of work planned by the Western States Genetic Services Collaborative Reimbursement Work Group (see Attachment 2 – WSGSC Reimbursement Work Group Members).

Background

In 2009, stakeholders in the Western States Genetic Services Collaborative (WSGSC) selected enhancing reimbursement for genetic services as a priority for the region. A Collaborative Work Group formed to identify needs and develop an action plan. The Work Group was comprised of stakeholders from Alaska, California, Hawaii, Idaho, Oregon, Washington, and Guam. Stakeholders included public health genetic leaders, family advocates, genetic counselors and a physician geneticist. Based upon input from other Collaborative stakeholders and work group member experience, the group set an initial goal of documenting which genetic services state Medicaid agencies cover. Findings from the survey are available on the Western States Genetic Services Collaborative website at

http://www.westernstatesgenetics.org/Proj_activities.htm.

The WSGSC Reimbursement Work Group then planned the Western States Regional Medicaid and Genetic Services meeting as an initial strategy to cultivate partnerships with state Medicaid representatives and to convene stakeholders to plan strategies to address challenges to Medicaid reimbursement of genetic services. Simultaneously, WSGSC Reimbursement Work Group members formed a partnership with researchers at the University of Washington Center for Genomics and Healthcare Equality in order to explore the feasibility of applying risk-benefit decision modeling tools to determining coverage for genetic services.

Meeting Process

The day-long meeting included the following sessions:

- **Current Regional Medicaid Policies for Genetic Services Coverage** – Jacquie Stock, Review of findings from Reimbursement Work Group Medicaid survey, stakeholder discussion and elaboration of findings.

- **Current Policy in Genetic Services Coverage—How do *you* vote?** – Debra Lochner Doyle, Scenarios in genetic services coverage, what’s the impact? Stakeholder electronic voting on questions related to which genetic services should be covered.
- **Identify, Prioritize Coverage Challenges** - Debra Lochner Doyle. Group identifies specific challenges to Medicaid reimbursement for genetic services, share observations with larger group, group prioritizes challenges to address.
- **Decision Modeling Tools for Genetic Services Coverage** – Lou Garrison, David Veenstra, Using quantitative benefit-risk health outcomes modeling tools to make coverage determinations for genetic services—a case study of warfarin therapy and genetic testing.
- **Decision Modeling Tools for Genetic Services Coverage—How do *you* vote?** – Lou Garrison, David Veenstra, and Greg Guzauskas. Discussion and stakeholder voting on alternative approaches to systematically assessing comparative effectiveness (benefits, harms, and costs) of genetic tests.
- **Rethink Genetic Services Coverage—Solutions** – Debra Lochner Doyle, Break into small groups, identify and describe approaches to address prioritized policy challenges, re-convene for small groups to share observations with larger group, group identifies and prioritizes solution strategies.

Meeting Outcomes

Current Policy in Genetic Services Coverage—How do *you* vote? – slides available at http://www.westernstatesgenetics.org/Proj_activities.htm.

Prioritized Regional Coverage Challenges

Stakeholders named and prioritized challenges to reimbursement as follows:

1. Non-licensed genetic counselors services are often not covered.
2. Providers lacking genetic specialty credentials may not be reimbursed for genetic services.
3. Reimbursement of genetic services is at times lower than cost to provide.
4. Coverage policies related to genetic services in the Affordable Care Act need to be specified.
5. Physicians who are not genetic specialists need information on prescribing and interpreting genetic testing.
6. Determining coverage on a case-by-case basis is inefficient.
7. Coverage of genetic tests of non-Medicaid enrolled parent to aid in child diagnosis is often not covered.
8. Medicaid directors need evidence-based information to assist with coverage determination decisions.

Although not prioritized, these challenges were also identified by stakeholders:

- Genetic tests performed by out-of-state laboratories may not be covered.
- Laboratory where genetic test performed may not be a Medicaid-enrolled provider so services not covered.
- Some gene patents are not scientifically valid and therefore testing not covered.
- Medicaid has limited resources and must prioritize coverage for a range of medical needs, thus genetic services is competing for prioritization.

Decision Modeling Tools for Genetic Services Coverage

Professors David Veenstra and Louis Garrison of the Center for Genomics and Healthcare Equality (CGHE) at the University of Washington presented decision modeling techniques to WSGSC members to seek their opinions on the methodology's potential usefulness to their decision-making. Topics included participants' interest in decision modeling, perceived challenges to utilization of decision modeling in respondents' professional environments, and potential case studies for evaluation using decision analysis. Following a brief presentation, the CGHE team asked participants to vote with anonymous electronic voting machines on ten Likert-style questions pertaining to their attitudes toward decision modeling. Participants had little prior exposure to decision modeling in their professional settings, but were generally in favor of utilizing decision model evidence in their assessments of genetic tests. They also recognized that budget constraints and the costs of genetics services were important considerations that a model should incorporate. The CGHE team proceeded to elicit ideas for future decision models they could develop in collaboration with the WSGSC; microarray testing for developmental delay and autism, whole exome sequencing, and telehealth genetic counseling services were among the suggestions.

Proposals for Improving Genetic Services Coverage

1. Pursue an activity to establish evidence base for comparative effectiveness of genetic counseling.
2. Convene regional genetic specialists to prepare guidelines for Medicaid to use in determining coverage decisions.
3. Convene work group to establish evaluation criteria Medicaid may use in determining coverage.
4. Work to establish specific CPT codes for genetic tests.
5. Create entity to establish "values" for genetic tests to aid in coverage determination.
6. Pilot use of a decision-modeling tool for microarray testing for autism spectrum disorders and/or whole exome sequencing.

7. Survey medical geneticists and other physicians to explore their opinions related to what genetic services should be covered by insurance, because physicians should be the ones to recommend what is medically necessary.
8. Develop a proposal for establishing a Regional Genetic Services Coverage Review Board to be used by regional Medicaid programs.

Next Steps

- The Western States Genetic Services Collaborative Reimbursement Work Group will meet to review meeting Proceedings and determine next steps for the Collaborative Work Group to pursue.
- Meeting Proceedings will be disseminated to Western States Genetic Services Collaborative stakeholders via the WSGSC website and at the annual WSGSC Regional Summit.
- Western States Genetic Services Collaborative will continue to partner with University of Washington Center for Genomics and Healthcare Equality and regional Medicaid representatives to explore creating and testing a decision-modeling tool to use in determining coverage for microarray tests for autism spectrum disorders.
- Western States Genetic Services Collaborative work group members will share these Proceedings with western states Medicaid representatives unable to attend the meeting and invite them to share their opinions related to challenges and solutions to Medicaid reimbursement for genetic services.

- **Attachment 1 – Participants**

Michael	Astion, MD, PhD	Division Chief, Laboratory Medicine, Seattle Children's
Sylvia	Au, MS, CGC	Director, WSGSC, Public Health Genetics, Hawai'i Department of Health
Isabel	Bickle	Medical Surgical Policy Analyst, Oregon Medicaid
Barb	Chambers	Parent Navigator/Program Manager, Stone Soup Group, Anchorage, Alaska
Michelle	Fox, MS, CGC	Genetic Counselor, UCLA Division of Genetics, Department of Pediatrics, Los Angeles, California
Lou	Garrison, PhD	Professor, Pharmacy, University of Washington, Seattle, Washington
Greg	Gouzakis, MSPH	Doctoral Student, University of Washington, Institute for Public Health Genetics & Center for Genomics and Healthcare, Seattle, Washington
Marilyn	Hartzell, MS	Public Health, Director, Child Development and Rehabilitation Center/Oregon Health and Sciences University, Portland Oregon
Rhona	Jack, MD	Director, Biochemical Genetic Testing Laboratory, Seattle Children's, Seattle, Washington
Debra	Lochner Doyle, MS, CGC	State Genetics Coordinator, Genetic Services Section, Washington Department of Health, Kent, Washington
Alex	Malter, MD	Medicaid Medical Director, Department of Health & Social Services, Juneau, Alaska
Sue	Richards, PhD, FACMG	Laboratory, Director, Clinical Molecular Genetics Oregon Health & Science University, Portland, Oregon
Amber	Roche, MPH	Health Services Consultant 3, Washington State Department of Health, Genetic Services Section, Kent, Washington
Laurie	Seaver, MD	Medical Director, Hawaii Community Genetics, Honolulu, Hawaii
Kerry	Silvey, MS, CGC	Public Health Genetics Specialist, Child Development & Rehabilitation Center, Oregon Health & Science University, Portland, Oregon
Jacquie	Stock, MPH	Seattle Children's Center for Children with Special Needs, Seattle, Washington
George	Tiller, MD	Regional Chief, Medical Geneticist Department of Genetics Kaiser Permanente Los Angeles Medical Center, Los Angeles, California
Karen	Tsuchiya, MD	Laboratory, Seattle Children's, Seattle, Washington
David	Veenstra, PharmD, PhD	Co-Investigator, University of Washington. Department of Pharmaceutics, University of Washington, Seattle, Washington

Bob	Wildin, MD	Clinical Geneticist, Idaho State Genetics Program / St. Lukes Regional Medical Center, Portland, Oregon
Thalia	Wood, MPH	Public Health Genetics, Children's Health Unit Manager Alaska Department of Health and Social Services, Department of Public Health, Anchorage, Alaska
Arthur	Yu, MS, CGC	Genetic Counselor, Hawai'i Department of Health Children with Special Health Needs Branch, Honolulu, Hawaii

Attachment 2 – Western States Genetic Services Collaborative Reimbursement Work Group Members

Participant	State	Stakeholder Type
Thalia Wood	Alaska	Public Health Genetics, Newborn Screening
Michelle Fox	California	Genetic Counselor
Michelle Strecker	California	Genetic Counselor, Director, Genetic Counseling and Communications, CombiMatrix Diagnostics
Margarita Gay	Guam	Public Health Genetics
Sansan Lee	Hawaii	Genetic Counselor
Erin Dola	Idaho	Genetic Counselor
Shelley Joyce	Oregon	Family Representative
Kerry Silvey	Oregon	Public Health Genetics, Genetic Counselor
Bob Wildin	Oregon	Medical Geneticist
Deb Lochner Doyle	Washington	WSGSC Lead, Public Health Genetics, Genetic Counselor
Jacque Stock	Washington	WSGSC Staff Lead, Family Representative