

Washington State Profile

General Socioeconomic/Political Variables*	WA
Total population	6,029,610
% population under 200% of FPL	32%
Medicaid expenditures \$/enrollee; number of enrollees	\$2605; 916,800
% population in each of 4 ethnic subpopulations (census data)	79% White 3% African American 7% Hispanic 11% Other
% population living in non-metropolitan areas	21%
% population living in federally designated medically underserved areas	31%**
Party of sitting governor	Democrat
Majority party in senate	Democrat
Majority party in house	Democrat

*Data was obtained from <http://www.statehealthfacts.org> accessed on 3/31/05.

**[2004] (Schueler, V. Washington Department of Community and Rural Health. Data collected from 2004 OFM County population data for full county MUAs, 2000 Census tract data on resident civilian population or 200% of poverty for population, and for a few cases extrapolating 2000 to 2004 data in rapidly growing counties.)

Legal and Regulatory Context*	WA
Y/N privacy statute	Requires consent to disclose genetic info
Y/N insurance discrimination statute	Laws to limit discrimination in health insurance (but do not specify genetic information)
Y/N employment discrimination statute	Y
Y/N GC licensure	N
Genetic services insurance mandates	
Other	

*<http://www.ncsl.org/programs/health/genetics/charts.htm>

Genetic Service Capacity	WA
MDs per capita* (total number)	Physicians & surgeons: 242.9 (14,985) Osteopathic physicians & surgeons: 9.5 (585) total Naturopathic physicians: 9.06 (559)
Genetic counselors per capita (total number)	.76 (46)
MDs with genetic specialties per capita (total number)**	
Clinical biochemical geneticists	.05 (3)
Clinical cytogeneticists	.32 (19)
Clinical molecular geneticists	.17 (10)
Clinical geneticists	.46 (28)
Clinical biochemical/molecular geneticists	0
Genetic nurses per capita (total number)	.15 (9)
PhD geneticists per capita	0 PhD Medical geneticists, no way to ID basic researchers
# genetic services clinics	14 (4 prenatal only, 1 pediatric only, 1 active duty military and dependents only)
Measure of capacity of clinics	Visits- prenatal: 6,358, clinical: 3,510; total: 9,868 (based on CY 2003 data)
# medical schools with genetics training programs	1 (University of Washington)
Measure of capacity of programs	2 fellows
# GC schools	0
Measure of capacity of schools	
Y/N state lab for non-newborn screening services	Yes, Laboratory for Metabolic Disorders of Inheritance @ CHRMC
Y/N HRSA planning grant (and year completed)	No, already had state plan
Y/N HRSA implementation grant (and year of completion)	yes, 2006
FTE genetic services coordinator	1.0 FTE (Deb Lochner Doyle)
Measure of where responsibility for genetic services fit w/in state hierarchy	within MCH, peer with birth defects and CSHCN (same division), consultant to Newborn Screening (different division); 4 steps to Governor

*per capita = per 100,000

**Some individuals may be counted in more than one specialty; number represents those that have been certified by the American Board of Medical Geneticists, not necessarily the number of individuals practicing in the specialty.

Newborn Screening*	WA
Responsible agency	WA State DOH Epidemiology, Health Statistics, and Public Health Laboratories Division Public Health Laboratories Office of Newborn Screening
# diseases on NBS panel pre-1998	4 (hemoglobinopathies, CAH, CH, PKU)
# diseases on NBS panel 2005	9 (added biotinidase deficiency, MSUD, MCAD, homocystinuria, galactosemia) Hearing screening is voluntary
Type of follow up (diagnostic vs. treatment)	1. Diagnostic via Laboratory for Metabolic Disorders of Inheritance @ CHRMC (paid for by the NBS program and MCH block grant), and referral to 16 pediatric audiologists for hearing evaluation 2. Treatment via specialty clinics for Hgb, and metabolic disorders – there is no state support for treatment of CAH or CH or hearing loss.
NBS mandated services	
Y/N mandates explicit in statute	Yes – State Board of Health has the authority to revise NBS panel
If no, who decides mandated services	
Criteria for inclusion	
Decision making process in implementing criteria	SBOH determines tests
Y/N state lab for NBS	Y
If no, Y/N contract with other public lab	
If no, Y/N contract with private lab	
NBS fees and intent of fees (e.g., cover all screening; cover all screening and f/u; etc)	Total \$40.40 - \$3.50 of the total is used for specialty clinics
Assessment of fee (how processed)	Hospitals are billed based on number of births
Other funding sources for NBS (public funds, private insurance, Medicaid, patient pay)	Grant funding, and maternal child health block grant funds
Coordination of NBS	
Y/N pilot projects	Yes DEW-IT study and TEDDY study regarding juvenile diabetes

* Most information on Newborn Screening was obtained from <http://genes-r-us.uthscsa.edu/>

State Genetics Programs*	WA
Responsible agency	Department of Health. Community and Family Health Division. Office of Maternal Child Health.
Name	Genetics Services Section.
Responsible for screening activities (not mandated newborns screenings for metabolic disorders)	Early Hearing Loss Detection, Diagnosis, and Intervention Program
Responsible for birth defects surveillance activities	N
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Education Programs	The Family Health History Initiative is a federal-state collaborative effort to increase awareness of the importance of family health history.
Treatment Programs and Services	
Genetic clinics or centers	Regional Genetic Clinics provide services such as: review of family and medical history, physical examination, laboratory testing, genetic counseling and education, and management or referral to other specialists.
Metabolic or hemoglobinopathy treatment centers	
Advisory Committee or Council	Y
Other	Living Room Forums are discussions among Washington residents to understand how the public views advances in medical genetics and the ethical and societal issues they raise.

*Resources for the State Genetics Programs table include:
<http://www.doh.wa.gov/cfh/mch/Genetics/default.htm>; US Department of Health and Human Services. Health Resources and Services Administration. Title V: A Snapshot of Maternal and Child Health. 2004 October.; <http://www.in.gov/isdh/programs/mch/gdp.htm>;
<http://www.maine.gov/dhhs/bohdcfh/gen/gentxt/tindex2.htm>;
<http://www.msdh.state.ms.us/msdhsite/index.cfm/41.758.101.pdf/MSGeneticsPlan2003%2Epdf>;
<http://www.healthyarkansas.com/moms/moms.html#Infants>; <http://www.vahealth.org/genetics/servgp.htm>

Children with Special Health Care Needs Program*	WA
Responsible Agency	Department of Health. Community and Family Health Division. Office of Maternal Child Health.
Name of program	Children with Special Health Care Needs Program.
Role of genetics in CSHCN program	Y
Genetics Related Eligibility Criteria	Children under 18 years who have or are at risk for developing a serious or chronic condition such as: sickle cell anemia, cystic fibrosis, or metabolic disease.
Specialty genetic testing and counseling clinics	
Nutrition services	Nutrition for Children with Special Health Care Needs is a collaboration between the CSHCN Program and the Center on Human Development and Disability at the University of Washington.
Other services	
Amount (%) federal-state Title V block grant expenditures used for CHSCN in FY 2003	\$5,822,065 (22.1%)

* Resources for the CSHCN table include: <http://cshcnleaders.ichp.edu/TitleVDirectory/directory.htm>; and <http://www.dphhs.state.mt.us/hpsd/pubheal/healsafe/famheal/pdf/clinic99.pdf#xml=http://search2.discoverimgmontana.com/cgi-bin/texis.cgi/webinator/search/xml.txt?query=genetic+services&pr=DPHHS&prox=page&rorder=500&rprox=500&rdfreq=500&rwfreq=500&rlead=500&sufs=0&order=r&cq=&id=424127341>