

## Profiles of Genetic Services in Eight States by Topic

### General Socioeconomic/ Political Variables\*

	Washington	Arkansas	California	Indiana	Maine	Mississippi	Montana	Virginia
<b>Total population</b>	6,029,610	2,661,490	35,141,470	6,119,470	1,272,010	2,806,250	904,900	7,171,410
<b>% population under 200% of FPL</b>	32%	44%	39%	33%	37%	46%	41%	30%
<b>Medicaid</b> \$/enrollee # enrollees	\$2605 916,800	\$2966 504,300	\$2068 8,063,600	\$3905 755,500	\$6240 208,200	\$3000 595,800	\$4372 97,100	\$3615 681,300
<b>% population in each of 4 ethnic subpopulations</b>	79 % White 3% African American 7% Hispanic 11% Other	77 % White 16 % African American 3 % Hispanic 4 % Other	47% White 6 % African American 33 % Hispanic 14 % Other	86% White 8 % African American 3% Hispanic 3% Other	95% White 1% African American 1% Hispanic 3% Other	60% White 37% African American 1% Hispanic 2% Other	89% White 0% African American 3% Hispanic 8% Other	69% White 19% African American 5% Hispanic 6% Other
<b>% population living in non-metropolitan areas</b>	21%	52 %	1%	19%	64 %	23%	75%	20%
<b>% population living in federally designated medically underserved areas</b>	31%							
<b>Party of sitting governor</b>	Democrat	Republican	Republican	Republican	Democrat	Republican	Democrat	Democrat
<b>Majority party in senate</b>	Democrat	Democrat	Democrat	Republican	Democrat	Democrat	Republican	Republican
<b>Majority party in house</b>	Democrat	Democrat	Democrat	Democrat	Democrat	Democrat	Republican	Republican

\*Most information on socioeconomic and political factors was obtained from <http://www.statehealthfacts.org> accessed on 3/31/05.

**Legal and Regulatory Context\***

	<b>Washington</b>	<b>Arkansas</b>	<b>California</b>	<b>Indiana</b>	<b>Maine</b>	<b>Mississippi</b>	<b>Montana</b>	<b>Virginia</b>
<b>Y/N privacy statute</b>	Requires consent to disclose genetic info	Requires consent to disclose genetic info	Requires consent to disclose genetic info	N	N	N	N	Requires consent to disclose genetic info
<b>Y/N insurance discrimination statute</b>	Laws to limit discrimination in health insurance (but do not specify genetic information)	Laws to limit discrimination in health insurance	Laws to limit discrimination in health, life, disability, and long term care insurance	Laws to limit discrimination in health insurance	Laws to limit discrimination in health, life, disability, and long term care insurance	N	Laws to limit discrimination in health, life, disability, and long term care insurance	Laws to limit discrimination in health insurance
<b>Y/N employment discrimination statute</b>	Y	Y	Y	N	Y	N	N	Y
<b>Y/N employment discrimination</b>	N	N	Y	N	N	N	N	N
<b>Y/N GC licensure</b>	N	N	Y	N	N	N	N	N
<b>Genetic services insurance mandates</b>		Laws prohibit reproductive and therapeutic cloning					Laws permit therapeutic cloning, prohibit reproductive cloning	Laws prohibit reproductive cloning, unclear on legality of therapeutic cloning
<b>Other</b>								

\*Information on legal issues was obtained from <http://www.ncsl.org/programs/health/genetics/charts.htm>

**Genetic Services Capacity**

	<b>Washington</b>	<b>Arkansas</b>	<b>California</b>	<b>Indiana</b>	<b>Maine</b>	<b>Mississippi</b>	<b>Montana</b>	<b>Virginia</b>
<b>MDs per capita* (total)</b>	242.9 (14,985) physicians and surgeons 9.5 (585) osteopathic physicians and surgeons 9.06 (559) naturopathic physicians	189 (5,051) physicians and surgeons 6.9 (184) osteopathic physicians						
<b>Genetic Counselors per capita (total number)</b>	.76 (46)	.11 (3)	.83 (291)	.39 (24)	.71 (9)	0	.44 (4)	.47 (34)
<b>MDs with genetic specialties per capita (total number)** Clinical biochemical geneticists</b>	.05 (3)	.04 (1)	.09 (31)	.02 (1)	0	.07 (2)	0	.07 (5)
<b>MDs with genetic specialties per capita (total number) Clinical cytogeneticists</b>	.32 (19)	.04 (1)	.20 (71)	.11 (7)	.16 (2)	.18 (5)	.11 (1)	.21 (15)
<b>MDs with genetic specialties per capita (total number) Clinical molecular geneticists</b>	.17 (10)	0	.15 (51)	.02 (1)	0	.04 (1)	.22 (2)	.13 (9)
<b>MDs with genetic specialties per capita (total number)</b>	.46 (28)	.04 (1)	.43 (150)	.25 (15)	.39 (5)	.25 (7)	.22 (2)	.29 (21)

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<b>number) Clinical geneticists</b>								
<b>MDs with genetic specialties per capita (total number) Clinical biochemical/molecular geneticists</b>	0	0	.01 (5)	.02 (1)	0	0	0	.01 (1)
<b>Genetic nurses per capita (total number)</b>	.15 (9)	.11 (3)	.08 (29)	.05 (3)	.16 (2)	.07 (2)	0	.13 (9)
<b>PhD geneticists per capita (total number)</b>	0	0	.05 (17)	.07 (4)	.08 (1)	.07 (2)	0	.08 (6)
<b># genetic service clinics</b>	14 (4 prenatal only, 1 pediatric only, and 1 active duty military and dependents only)							
<b>Measure of capacity of clinics</b>	Visits Prenatal: 6,358; clinical: 3,510; total 9,868 (based on CY 2003 data)		28,000 referrals per year to prenatal diagnostic centers 950 children recommended for referral to CA Children Services Special Care Clinics					
<b># medical schools with genetics training programs</b>	1			1				

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<b>Measure of capacity of schools</b>	2 fellows							
<b># GC schools</b>	0	0	1	1				1
<b>Measure of capacity of GC schools</b>				5 graduates/yr				6 graduates/yr
<b>Y/N state lab for non-newborn screening services</b>	Y, Laboratory for Metabolic Disorders of Inheritance @ CHRMC				Y			
<b>Y/N HRSA planning grant (year completed)</b>	N, already had state plan	N		Y (2002)	N	Y (2002)	N	N
<b>Y/N HRSA implementation grant (year completed)</b>	Y (2006)	N		Y (2006)	N	N	N	N
<b>FTE genetic services coordinator</b>	1		1		1			
<b>Measure of where responsibility for genetic services fits w/in state hierarchy</b>	Within MCH, peer with birth defects and CSHCN, consultant to newborn screening, 4 steps to governor							

\*Per capita = per 100,000

\*\* Some individuals may be counted in more than one specialty; number represents those who are certified by the American Board of Medical Geneticists (ABMG), not the number of individuals practicing in the specialty.

### Newborn Screening\*

	<b>Washington</b>	<b>Arkansas</b>	<b>California</b>	<b>Montana</b>	<b>Indiana</b>	<b>Maine</b>	<b>Mississippi</b>	<b>Virginia</b>
<b>Responsible agency</b>	Washington State Department of Health, Community and Family Health, Maternal and Child Health, Genetic Services	Arkansas Dept of Health, Newborn Screening Program	California Department of Health Services, Primary Care and Family Health, Genetic Disease Branch, Newborn Screening Section	Montana Department of Public Health and Human Services, Health Policy and Services Division, Family and community Health			Genetic Services Division of the Mississippi State Department of Health	Virginia Department of Health, Virginia Department of General Services, Division of Consolidated Laboratories
<b># diseases on NBS panel pre-1998</b>	4 (hemoglobinopathies, CAH, CH, PKU)							
<b># diseases on NBS panel 2005</b>	9 (added biotinidase deficiency, MSUD, MCAD, homocystinuria, galactosemia) Hearing screening is voluntary	4	4 currently (26 to be added 8/05)	4	30	9 mandated	40	9
<b>Type of follow up (diagnostic vs treatment)</b>	1. Diagnostic via Laboratory for Metabolic Disorders of Inheritance @ CHRMC (paid for by the NBS program and MCH block grant), and referral to 16	Retesting, counseling, medical information	Diagnosis, education, monitoring			Provides comprehensive genetic services (risk assessment, diagnosis, counseling, and education) to Maine families who have or who are at increased risk of having	Mississippi offers free genetic counseling to parents – education, treatment and follow-up	Two metabolic treatment programs genetic testing, counseling, and education

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	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					genetic conditions/birth defects, by coordinating services and referrals to genetic agencies		
<b>NBS mandated services</b>			Y	Y	Y	Required by law on all infants, with a second test required if initial screen is done prior to 24 hours	Y	Y
<b>Y/N mandates explicit in statute</b>	Yes – State Board of Health has the authority to revise NBS panel				Y		State law now requires that all babies born in Mississippi be tested for forty genetic disorders	Y
<b>If no, who decides mandated services</b>								

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<b>Criteria for inclusion</b>			1. important health problem in terms of frequency, seriousness, and high costs of care 2. associated with disease/known symptoms 3. effective treatment exists that improves quality of life 4. easy to detect, reliably and economically 5. adequate methods of confirmation and follow-up					
<b>Decision making authority for test inclusion</b>	State Board of Health							
<b>Y/N state lab for NBS</b>	Y	Y	Y		Y	Y		Y
<b>If no, Y/N contract with other public lab</b>							Unclear – reads like a number of different labs perform tests	
<b>If no, Y/N contract with private lab</b>			Y					

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<b>NBS fees and intent of fees (e.g., cover all screening; cover all screening and f/u; etc)</b>	Total \$40.40 - \$3.50 of the total is used for specialty clinics	\$14.83	\$78.00	\$39.34 (PKU, GAL, CH - \$9.88 CF - \$10.00 MS/MS - \$2.00 BIO - \$4.00 CAH.)	\$62.50	\$47	\$70 to defray the cost of maintaining a central registry, for lab testing and follow-up on positive and repeat tests	\$32
<b>Assessment of fee (how processed)</b>	Hospitals are billed based on number of births							
<b>Other funding sources for NBS (public funds, private insurance, Medicaid, patient pay)</b>	Grant funding, and maternal child health block grant funds							
<b>Coordination of NBS</b>			Y					
<b>Y/N pilot projects</b>	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\***

	<b>Washington</b>	<b>Arkansas</b>	<b>California</b>	<b>Indiana</b>	<b>Mississippi</b>	<b>Maine</b>	<b>Montana</b>	<b>Virginia</b>
<b>Responsible agency</b>	Department of Health Community and Family Health Division Office of Maternal Child Health	Department of Health	California Department of Health Services Primary Care and Family Health Division	Indiana State Department of Health Maternal and Child Health Services Health Systems Development Section	Department of Health Health Services Child and Adolescent Health Services	Department of Human Services Bureau of Health Division of Community & Family Health	Montana Department of Public Health and Human Services Health Policy and Services Division Family and Community Health Bureau	Virginia Department of Health Division of Child and Adolescent Health
<b>Name</b>	Genetics Services Section	Healthy Hearing	Genetic Disease Branch	Genomics Program	Division of Genetics	Genetics and Newborn Screening Program	Genetics Services	Pediatric Screening and Genetic Services
<b>Responsible for screening activities (not mandated newborns screenings for metabolic disorders)</b>	Early Hearing Loss Detection, Diagnosis, and Intervention Program	Healthy Hearing	Prenatal Screening Section oversees the Expanded Alpha-Fetoprotein Screening Program	N	N	N	N	Virginia Early Hearing Detection and Intervention Program
<b>Responsible for birth defects surveillance activities</b>	N	N	N	The Genomics Program received grant funding to enhance the Indiana Birth Defects and Problems Registry	Mississippi Birth Defects Registry	The Genetics Program conducts birth defects surveillance	N	Virginia Congenital Anomalies Tracking and Prevention Project is a population-based birth defects surveillance programs

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								developed through a cooperative agreement with the CDC
<b>Education Programs</b>	The Family Health History Initiative is a federal-state collaborative effort to increase awareness of the importance of family health history		Hemoglobin trait toll free line  Sickle cell counselor training and certification program	Statewide Folic Acid Campaign  The Genomics Program publishes a quarterly educational newsletter and administers a visiting speaker program	Case Management and Provider Education provide education to hospitals, nurseries, laboratories, and health department clinics	The Genetics Program provides counseling and education to families who have or who are at increased risk of having genetic conditions/birth defects		
<b>Treatment Programs and Services</b>								
<b>Genetic clinics or centers</b>	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	N		Fifteen genetic centers/programs provide services, including: counseling; genetic evaluation and testing; prenatal diagnosis; cytogenetic analysis; ultrasonography; perinatal services for and	Clinical Genetics provides clinical screening, counseling, and follow-up for a broad range of genetic related disorders			Four Regional Genetic Centers provide genetic testing, counseling, and education for all residents, especially those with very limited resources

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				management of high risk pregnancies; preconception counseling; risk prediction and testing for inherited cancers; outreach and education; risk assessment and counseling for teratogen exposures; and data collection and analysis				
<b>Metabolic or hemoglobinopathy treatment centers</b>		N	Maternal PKU program		Hemoglobinopathy Services provides screening, education, treatment, and follow-up for sickle cell disease patients			Metabolic Treatment Services/Phenylketonuria Management offers two programs through the University of Virginia and Virginia Commonwealth University
<b>Advisory Committee or Council</b>	Y			Y		Y		Y
<b>Other</b>	Living Room Forums are discussions among							Virginia Sickle Cell Awareness Program is a

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	Washington residents to understand how the public views advances in medical genetics and the ethical and societal issues they raise							<p>joint effort between the Department of Health, Division of Women's and Infants' Health, and the Medical College of Virginia</p> <p>Virginia Infant Screening and Infant Tracking System is a tracking and data management system that supports the Virginia Early Hearing Detection and Intervention Program, Birth Defects, Virginia Newborn Screening Services, and At-Risk (For</p>

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								Developmental Delay)

\*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 (CSHCN) Programs\*

	Washington	Arkansas	California	Indiana	Maine	Montana	Mississippi	Virginia
<b>Responsible Agency</b>	Department of Health Community and Family Health Division Office of Maternal Child Health		Department of Health Services Primary Care and Family Health Division Children's Medical Services Branch	Department of Health	Department of Human Services Bureau of Health Division of Community & Family Health	Department of Public Health and Human Services Health Policy and Services Division Family and Community Health Bureau	Department of Health Office of Health Services Bureau of Child/Adolescent Health	Department of Health Office of Family Health Services Division of Child and Adolescent Health
<b>Name of program</b>	Children with Special Health Care Needs Program		Children's Services	Children's Special Health Care Services	Children with Special Health Needs Program	Special Health Services	Children's Medical Program	Children with Special Health Care Needs Program
<b>Role of genetics in CSHCN program</b>	Y	N	Y	Y	Y	Y	Y	Y
<b>Genetics Related Eligibility Criteria</b>	Children under 18 years who have or are at risk for developing a serious or chronic condition such as: sickle cell		Conditions that may be covered and examples include blood disorders (hemophilia, sickle cell anemia); endocrine,	Children under 21 years with conditions including: chromosomal disorders resulting in loss of motor function or	Eligible conditions may include PKU and other inborn errors of metabolism, cystic fibrosis, and spina bifida	In general, full financial assistance is provided for metabolic disorders  Limited assistance is	Children under 21 years with conditions including: cystic fibrosis, sickle cell anemia, hemophilia, and spina	Children under 21 years of age are eligible for services  Persons of any age are permitted in

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	anemia, cystic fibrosis, or metabolic disease		nutritional, and metabolic diseases (thyroid problems, PKU, diabetes); birth defects (cleft lip/palate, spina bifida); sense organ disorders (hearing loss)	expressive language function, cystic fibrosis, hemophilia requiring factor replacement at least 2 times/year, and inborn errors of metabolism that have a potential for significantly improved outcome  Services are extended to persons with cystic fibrosis who are over 21 years		available for children with cystic fibrosis	bifida  Individuals with cystic fibrosis, sickle cell, or hemophilia may be eligible for services into adulthood	the Hemophilia Program
<b>Specialty genetic testing and counseling clinics</b>						Outreach clinics for genetic evaluation services		A statewide network of genetic centers provides genetic testing and counseling
<b>Specialty clinics for genetic disorders</b>			Special care centers for cystic fibrosis, endocrine/metabolic, hemophilia, sickle cell, and		Specialty Clinics and Programs within the CSHN include two spina bifida clinics, two PKU/metabolism	Outreach clinics for metabolic disorders and cleft/craniofacial disorders		Statewide hemophilia program provides care coordination and payment

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			spina bifida		clinic, three cystic fibrosis clinics, and one hemophilia clinic			of treatment for persons of all ages with inherited bleeding disorders
<b>Nutrition services</b>	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				Nutrition counseling	Dietary supplement foods for the management of a metabolic disorder and non-prescriptive supplements for a child with inborn errors of metabolism	A nutritional support team provides nutrients and supplements for certain metabolic disorders	
<b>Other services</b>					Routine, preventive dental care for children with hemophilia		Hemophilia Advisory Committee	

\* 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.discoveringmontana.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>