

**MEDICAID ELIGIBILITY**

**MEDICAID ELIGIBILITY (CONTINUED)**

STATE	Medicaid Eligibility (% of FPL) for Childless Adults	NORD Grade	Medicaid Eligibility (% of FPL) for Parents of a Dependent Child	NORD Grade	Medicaid Eligibility (% of FPL) for Pregnant Women		NORD Grade	Medicaid Eligibility for Children (% of FPL for Family)				NORD Grade
					Medicaid Eligibility	CHIP-Funded Eligibility		Ages 0-1	Ages 1-5	Ages 6-18	Separate CHIP Ages 0-18	
AL	0%	F	18%	D	146%	N/A	D	146%	146%	146%	317%	A
AK	138%	A	139%	A	205%	N/A	B	208%	208%	208%	N/A	B
AZ	138%	A	111%	A*	161%	N/A	C	152%	146%	138%	205%	B
AR	138%	A	17%(\$)	A*	214%	N/A	B	147%	147%	147%	216%	B
CA	138%	A	114%	A*	213%	N/A	B	266%	266%	266%	The Separate CHIP in California covers certain children up to age 2 with incomes up to 317% of the FPL statewide; and it covers children up to age 19 also up to 317% of the FPL in three counties only.	A
CO	138%	A	73%	A*	200%	265%	A	147%	147%	147%	265%	B
CT	138%	A	155%	A	263%	N/A	A	201%	201%	201%	323%	A
DE	138%	A	92%	A*	217%	324%	A	217%	147%	138%	217%	B
DC	215%	A	221%	A	324%	N/A	A	324%	324%	324%	N/A	A
FL	0%	F	28%(\$)	D	196%	N/A	B	211%	145%	138%	215%	B
GA	0%	F	32%(\$)	D	225%	N/A	A	210%	154%	138%	252%	B
HI	138%	A	110%	A*	196%	N/A	B	313%	313%	313%	N/A	A
ID	138%	A	138%	A*	138%	N/A	D	147%	147%	138%	190%	C
IL	138%	A	138%	A	213%	N/A	B	147%	147%	147%	318%	A
IN	139%	A	19%(\$)	A*	255%	N/A	A	213%	163%	163%	255%	B
IA	138%	A	51%(\$)	A*	380%	N/A	A	380%	172%	172%	307%	A
KS	0%	F	38%	D	171%	N/A	C	171%	164%	164%	235%	B
KY	138%	A	24%(\$)	A*	200%	N/A	B	200%	142%	164%	164%	B
LA	138%	A	24%	A*	138%	N/A	D	217%	217%	217%	255%	B
ME	138%	A	105%	A*	214%	N/A	B	196%	162%	162%	213%	B
MD	138%	A	128%	A*	264%	N/A	A	322%	322%	322%	N/A	A
MA	138%	A	138%	A	205%	N/A	B	205%	155%	155%	305%	A
MI	138%	A	59%	A*	200%	N/A	B	217%	217%	217%	N/A	B
MN	205%	A	138%	A	283%	N/A	A	288%	280%	280%	N/A	B
MS	0%	F	23%(\$)	D	199%	N/A	B	199%	148%	138%	214%	B

STATE	Medicaid Eligibility (% of FPL) for Childless Adults	NORD Grade	Medicaid Eligibility (% of FPL) for Parents of a Dependent Child	NORD Grade	Medicaid Eligibility (% of FPL) for Pregnant Women		NORD Grade	Medicaid Eligibility for Children (% of FPL for Family)				NORD Grade
					Medicaid Eligibility	CHIP-Funded Eligibility		Ages 0-1	Ages 1-5	Ages 6-18	Separate CHIP Ages 0-18	
MO	0%	F	17%(\$)	D	201%	305%	A	201%	155%	155%	305%	A
MT	138%	A	29%	A*	162%	N/A	C	148%	148%	148%	266%	B
NE	0%	F	63%	D	199%	N/A	B	218%	218%	218%	N/A	B
NV	138%	A	31%(\$)	A*	165%	N/A	C	165%	165%	138%	205%	B
NH	138%	A	64%(\$)	A*	201%	N/A	A	323%	323%	323%	N/A	A
NJ	138%	A	30%(\$)	A*	199%	205%	B	199%	147%	147%	355%	A
NM	138%	A	43%(\$)	A*	255%	N/A	A	305%	305%	305%	N/A	A
NY	205%	A	138%	A	223%	N/A	A	223%	154%	154%	405%	A
NC	0%	F	42%(\$)	D	201%	N/A	B	215%	215%	138%	216%	B
ND	138%	A	50%(\$)	A*	152%	N/A	C	152%	152%	138%	175%	C
OH	138%	A	95%	A*	205%	N/A	B	211%	211%	211%	N/A	B
OK	0%	F	45%	D	138%	N/A	D	210%	210%	210%	N/A	B
OR	138%	A	38%(\$)	A*	190%	N/A	B	190%	138%	138%	305%	A
PA	138%	A	38%	A*	220%	N/A	A	220%	162%	138%	319%	A
RI	138%	A	121%	A*	195%	258%	A	266%	266%	266%	N/A	B
SC	0%	F	67%	D	199%	N/A	B	213%	213%	213%	N/A	B
SD	0%	F	54%(\$)	D	138%	N/A	D	187%	187%	187%	209%	B
TN	0%	F	98%(\$)	C	200%	N/A	B	200%	147%	138%	255%	B
TX	0%	F	15%(\$)	D	203%	N/A	B	203%	149%	138%	206%	B
UT	100%	A	47%	A*	144%	N/A	D	144%	144%	138%	205%	B
VT	138%	A	52%(\$)	A*	213%	N/A	B	317%	317%	317%	N/A	A
VA	138%	A	47%(\$)	A*	148%	205%	B	148%	148%	148%	205%	B
WA	138%	A	40%(\$)	A*	198%	N/A	B	215%	215%	215%	317%	A
WV	138%	A	18%(\$)	A*	163%	N/A	C	163%	146%	138%	305%	A
WI	A	B	100%	B	306%	N/A	A	306%	191%	156%	306%	A
WY	0%	F	52%(\$)	D	159%	N/A	C	159%	159%	138%	205%	B

**RARE DISEASE ADVISORY COUNCILS**

STATE	STATE RARE DISEASE ADVISORY BODY				STATUTES/ PROPOSED LEGISLATION
	YES/NO	STRUCTURE	APPOINTMENTS MADE?	STATUTORY REQUIREMENT MET?	
AL	Yes	Advisory Council within the DOH	Yes	No: Met for first time in 2018 but council has not filled all mandated positions.	HR 115 (2017)
AK	No	--	--	--	--
AZ	No	--	--	--	--
AR	No	--	--	--	--
CA	Yes	Rare Disease Advisory Caucus	28 members	N/A	Caucus
CO	No	--	--	--	--
CT	Yes	Temporary Legislative Task Force	Yes	Yes: Task Force has met several times	HB 6580 (2017)
DE	No	--	--	--	--
DC	No	--	--	--	--
FL	No	--	--	--	--
GA	No	--	--	--	--
HI	No	--	--	--	--
ID	No	--	--	--	--
IL	Yes	Advisory Commission established in the Department of Health	Yes	No: Commission has not filled all vacancies nor established a regular quorum.	HB 4576 (2017)
IN	No	--	--	--	--
IA	No	--	--	--	--
KS	No	--	--	--	--
KY	Yes	Advisory Council to Governor and legislature	Chair appointed	No: Council just passed and had not filled all vacancies or met yet.	SB 16 (2019)
LA	No	--	--	--	--
ME	No	--	--	--	--
MD	No	--	--	--	--
MA	Pro-posed	Advisory Commission established in the DOH	TBD	TBD	TBD
MI	Pro-posed	Advisory Commission established in the DOH	TBD	TBD	TBD
MN	Yes	Advisory Council administered by the University of Minnesota	TBD	TBD	SF 973
MS	No	Study of rare diseases in the state	N/A	N/A	S 2463 (2017)
MO	Yes	Advisory Council on Rare Diseases and precision medicine within the MO Healthnet Division	Yes	Yes	SB 995 (2018)

**RARE DISEASE ADVISORY COUNCILS (CONTINUED)**

STATE	STATE RARE DISEASE ADVISORY BODY				STATUTES/ PROPOSED LEGISLATION
	YES/NO	STRUCTURE	APPOINTMENTS MADE?	STATUTORY REQUIREMENT MET?	
MT	No	--	--	--	--
NE	No	--	--	--	--
NV	Yes	Advisory Council within the Department of Health and Human Services	Yes but not all have been made yet.	No: Positions still have to be filled	SB 315 (2019)
NH	Yes	Advisory Council within the Department of Health and Human Services	Yes	Yes: met for the first time in September, 2019 and appointments have been made	H. 237 (2019)
NJ	Pro-posed	Advisory council within the Deptment of Health and Human Services	TBD	TBD	A 2528
NM	No	--	--	--	--
NY	Yes	Workgroup to advise on rare diseases in collobration within the Department of Health and Department of Financial Services.	N/A	N/A	TBD
NC	Yes	Advisory Council on Rare Diseases established in the department of health	Yes	Yes: Council meets on a monthly basis and has published annual reports.	S235 (2015)
ND	No	--	--	--	--
OH	No	--	--	--	--
OK	No	--	--	--	--
OR	No	--	--	--	--
PA	Yes	Advisory Council within the DOH and Rare Disease Legislative Caucus	Yes	Yes: Council meets on a regular basis and published its first annual report.	H 239 (2017)
RI	No	--	--	--	--
SC	No	--	--	--	--
SD	No	--	--	--	--
TN	No	--	--	--	--
TX	Pro-posed	Advisory Council to Governor and legislature	TBD	TBD	TBD
UT	Pro-posed	Advisory Council within the Department of Health	TBD	TBD	HB 211
VT	No	--	--	--	--
VA	No	--	--	--	--
WA	No	--	--	--	--
WV	No	--	--	--	--
WI	No	--	--	--	--
WY	No	--	--	--	--

**MEDICAL NUTRITION COVERAGE**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?			WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?	
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	Statutes
AL	No	No mandated coverage	F	No mandated coverage	F	Medicaid coverage is on a case by case basis. Board of Health is authorized to create regulations to provide for treatment, including but not limited to advising dietary treatment. Regulations permit the health department to inform parents about department services, which may include treatment. Coverage for WIC.	C	PKU, CH, GALT, CAH, hearing, hemoglobinathy, BD, CF, AAD, FAOD, OAD, and other heritable diseases	C	Alabama AC §22-20-3 AAC §40-20-10-.01 et seq.
AK	Formula Only	Health insurers except fraternal benefit societies must cover formulas. Coverage limitations are allowed. PKU is the only metabolic condition covered.	D	PKU Only	D	Medicaid coverage. Department will reimburse enrolled providers for 80% of the costs of prescribed enteral and oral nutritional products if they are certified as medically necessary and identified as an enteral formula in the CMS Healthcare Common Procedure Coding System	B	PKU Only	D	Alaska AS §21.42.380 7 AAC 43.924 7 AAC 43.454 7 AAC 43.1960
AZ	Yes	Hospital & medical service corporations, health care service organizations, disability insurers and health benefit plans with prescription drug benefits must cover at least 50% of the cost of medical foods to treat inherited metabolic disorders up to \$5,000 annually. An accountable health plan shall cover at least 75% of the cost of the formula. The accountable health plan may limit the maximum annual benefit for formulas under this section to twenty thousand dollars. Coverage must include at least 50 % of the cost of low protein modified foods and formula and may be limited to maximum annual benefit of \$5000 to \$20,000.	B	Metabolic disorders that are part of the newborn screening (NBS) program: Involving amino acid, carbohydrate and fat metabolism; have standard methods of diagnosis, treatment and monitoring; & require specially processed or treated medical foods. Eosinophilic gastrointestinal disorder.	A	Mandated medicaid coverage; Children's rehabilitative services program provides nutrition to treat metabolic disorders and services for CF, including nutrition taken via tube that supplies 50% of daily caloric need or nutrition taken without a tube that supplies 100% caloric need. Limited WIC coverage.	A	AA, BD, CF, hemoglobinopathy, HCY, hypothyroidism, PKU, MSUD, OAD, storage disease and other conditions with similar treatment requirements.	A	ARS §§ 20-826.03, 20-1057-10, 20-1342.05, 20-1402.02, 20-2332 Ariz. Rev. Stat. Ann. §§ 20-2327
AR	Yes	Insurance Coverage of Formula applies after \$2,400 income tax credit. Insurance Coverage of Low Protein Foods applies After \$2,400 income tax credit. Metabolic Conditions Covered by Insurance: PKU, Galacto-semia, organic acidemias, amino acid disorders.	B	PKU, GALT, OAD, and AA	C	No mandated Medicaid coverage. For PKU and GALT, rules provide for formula and foods. For other metabolic conditions, rules provide for nutritional therapy as recommended by consultants. The Health Department reimburses providers ≤\$1,000 per person treated without insurance whose expenses exceed \$2,400. Tax credit applies up to \$2,400 annually per child for medical food & low protein modified food.	B	PKU, GALT, and other metabolic conditions.	C	ACA §20-15-304 ACA §23-79-701 et seq. AAR §17-16-07-001
CA	Yes	No limits on Insurance Coverage of Formula and of Low Protein Foods.	A	PKU Genetically handicapped persons program (GHPP): CF, hemoglobinopathies, and certain metabolic disorders. California children services (CCS): inborn errors of metabolism, food allergies, congenital and developmental disorders, CF and other lung disorders from metabolic & genetic defects.	A	GHPP provides inpatient, outpatient, & home treatment services to CCS clients under 21 with eligible conditions and GHPP clients over 21. Medi-Cal covers enteral nutritional supplements and replacements if used as a therapy to prevent serious disability or death in patients with conditions that preclude use of regular food.	A	Medi-Cal: conditions that preclude use of regular food.	A	California Health and Safety §1374.56 17 CCR §2932 22 CCR §40675 22 CCR §40715 22 CCR §41848, 41849 22 CCR §51313.3
CO	Yes	Insurance Coverage of formula & modular counterparts. No limits on coverage of low protein foods. Metabolic Conditions Covered by Insurance All Inborn Errors of Metabolism	A	Inherited enzymatic disorders caused by single gene defects involved in metabolism of amino, organic and fatty acids, including but not limited to PKU, maple syrup urine disease (MSUD), TYR, HCY, histidinemia, urea cycle disorders, hyperlysinemia, glutaric acidemias, MMA and propionic acidemia, severe food protein induced enterocolitis syndrome; eosinophilic disorders.	A	Medicaid coverage. Under the Colorado Children's Basic Health Plan, eligible children under 19 and pregnant women may receive formula for metabolic disorders.	B	Metabolic disorders	C	CRS §10-16-104 10 CCR 2505-3
CT	Yes	No limit on insurance coverage of Formula; no limit on coverage for low protein foods	A	CF, PKU and other metabolic diseases, hypothyroidism, GALT, SCD, MSUD, HCY, BD, CAH and other inborn errors of metabolism as prescribed by the health department. No coverage for food allergies, Eosinophilic disorders, FPIES or short bowel.	C	Medicaid coverage. Statute authorizes health department to include cost of treatment in setting fees and to purchase special infant formula, amino acid modified preparations, and low protein modified food products directly and without a purchase order.	A	Conditions listed for insurance	C	Connecticut CGSA §19a-55, 59a CGSA §38a-492c CGSA §38a-518c

**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?			WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?	
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	Statutes
DC	Legislation introduced this session	No mandated coverage	F	No mandated coverage	F	Medicaid coverage for enteral but not oral. Legislation requires the District to partially pay for treatment on a sliding scale if an infant's parents are indigent.	C	GALT, HCY, hypothyroidism, MSUD, PKU, and sickle hemoglobinopathy and other metabolic disorders identified by the committee of metabolic disorders	C	DCA §7-838 Proposed bill: B21-142
DE	Yes	Group and individual health insurance policies with pharmacy benefits must cover medical foods. Deductibles, coinsurance or other cost-sharing methods may apply. PKU benefits are required through 21 years of age for men and women through age 35.	B	PKU and other inherited metabolic diseases caused by an inherited abnormality of biochemistry, including any diseases for which the state screens newborns.	C	Medicaid coverage: Formula only. Statute declares intent to provide treatment. Under regulations, specialty formula fund allows the health department to cover costs of specialty formula to treat inherited metabolic disease not covered by insurance.	D	PKU and other inherited metabolic diseases caused by an inherited abnormality of biochemistry, including any diseases for which the state screens newborns	C	DC §16-201 DC §18-3355 DC §18-3571 DAC §16-4103
FL	Yes	Health insurance must cover enteral formulas to treat certain inherited diseases and up to \$2,500 annually for low protein modified foods to treat AAD and OAD until age 24.	C	Inherited fat, carbohydrate, amino & organic acid metabolism diseases or malabsorption as a result of congenital or neonatal defects	C	State supplies necessary dietary treatment for PKU and other metabolic diseases as medically indicated if not otherwise available and supplemental foods to eligible families under WIC.	C	PKU and other metabolic disease	C	FS §383.13 FS §627.42395
GA	No	No provision.	F	No mandated coverage	F	Medicaid coverage for enteral only, not oral. Health department may use state or federal funds, if available, including Maternal and Child Health Services Block Grant to provide therapy.	D	Genetic conditions such as PKU, GALT, HCY, MSUD, hypothyroidism, CAH, and other inherited metabolic and genetic disorders	C	GC §31-12-6
HI	Yes	Formula and low protein foods covered up to 80% of the cost. Accident and sickness insurance, employer group health policies, and individual and group hospital plans must cover medical foods and low protein modified food products to treat inborn errors of metabolism.	A	Inborn error of metabolism caused by inherited abnormal biochemistry characterized by congenital or neonatal onset metabolic defect of amino acid, organic acid, carbohydrate or fat.	C	Medicaid coverage provides for public assistance recipients for medical foods and low-protein modified food products to treat inborn errors of metabolism.	B	Inborn error of metabolism caused by inherited abnormal biochemistry characterized by congenital or neonatal onset metabolic defect of amino acid, organic acid, carbohydrate or fat	C	HRS §346-67 HRS §431:10A- 120 HRS §432:1-609
ID	No	No provision.	F	No mandated coverage	F	Medicaid covers only enteral. Local health agencies responsible for treatment and cure of infants. Under the Children's Special Health Program eligible patients are provided treatment services which includes provision of formula. Persons over eighteen (18) years of age with PKU may purchase formula from CSHP at CSHP's cost.	D	Local health agencies: PKU and other preventable diseases Medicaid: conditions that prevent use of traditional foods alone. State special health program: PKU only.	D	IC §39-910 IDAPA §16.03.09
IL	Formula only	Insurance: medical foods prescribed to a covered individual to treat inherited metabolic diseases. No limit on coverage.	D	Inherited metabolic diseases caused by inborn errors of amino or organic acids or urea cycle metabolism and treatable by dietary restriction of one or more amino acids State services: PKU, hypothyroidism, hemoglobinopathies, including sickle cell anemia, GALT, MSUD, HCY, inborn errors of metabolism	C	Medicaid coverage. Covers equipment, supplies, and formula. Statute creates a NBS program that provides support for all infants and individuals identified as having a disorder.	D	Inherited metabolic diseases caused by inborn errors of amino or organic acids or urea cycle metabolism and treatable by dietary restriction of one or more amino acids State services: PKU, hypothyroidism, hemoglobinopathies, including sickle cell anemia, GALT, MSUD, HCY, inborn errors of metabolism	C	IC §16-41-17-10 IC §27-8-24.1 IC §27-13-7-18
IN	Formula only	Insurance: medical foods prescribed to a covered individual to treat inherited metabolic diseases. No limit on coverage.	D	Inherited metabolic diseases caused by inborn errors of amino or organic acids or urea cycle metabolism and treatable by dietary restriction of one or more amino acids State services: PKU, hypothyroidism, hemoglobinopathies, including sickle cell anemia, GALT, MSUD, HCY, inborn errors of metabolism	C	Medicaid coverage. Covers equipment, supplies, and formula. Statute creates a NBS program that provides support for all infants and individuals identified as having a disorder.	D	Inherited metabolic diseases caused by inborn errors of amino or organic acids or urea cycle metabolism and treatable by dietary restriction of one or more amino acids State services: PKU, hypothyroidism, hemoglobinopathies, including sickle cell anemia, GALT, MSUD, HCY, inborn errors of metabolism	C	IC §16-41-17-10 IC §27-8-24.1 IC §27-13-7-18

**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?			WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?	
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	Statutes
IA	No	Not mandated	F	No mandated coverage	F	Medicaid coverage. NBS refers diagnosed infants to University of Iowa special medical formula program. Client payments, sliding fee scales, donations and screening fee (last resort only) support purchase of formula. Medical assistance provides enteral nutrition therapy and oral nutrition products if they provide ≥51% of daily calories to eligible persons.	A	University of Iowa services: Inherited diseases of amino acid and organic acids. Medical assistance: metabolic or digestive disorder	C	IC §641-4.3(136A) IAC §441-78.1
KS	No	Not mandated	F	No mandated coverage	F	Medicaid coverage. Statutes allow health department to provide necessary treatment products as follows if funding is available and no other resource exists: 100% if ≤300% poverty level, 50% if 301-500% of poverty level, 25% if 501-700% of poverty level. 0% if over 700% poverty level.	B	State services: CH, GALT, PKU, MSUD and other genetic diseases being screened under the NBS program. MSUD and PKU	C	KSA §65-180 KAR 28-4-514
KY	Yes	Insurance Coverage of Forumla and Limits: \$25K annual limit on Food Insurance Coverage of Low Protein Foods and Limits: \$4K annual limit.	B	PKU/hyperphenylalaninemia, TYR Type I, II and II, MSUD, A- ketoacid dehydrogenase deficiency, Isovaleryl-CoA dehydrogenase deficiency, 3- methylcrotonyl-CoA carboxylase deficiency, 3- methylglutaconyl-CoA hydratase deficiency, 3- hydroxy-3-methylglutaryl-CoA lyase deficiency, B- ketothiolase deficiency, HCY, glutaric aciduria type I and II, lysinuric protein intolerance, non-ketotic, hyperglycinemia, propionic academia, gyrate atrophy, hyperornithinemia, hyperammonemia, homocitrullinuria syndrome, carbamoyl phosphate synthetase deficiency, ornithine carbamoyl transferase deficiency, citrullinemia, arginosuccinic aciduria, MMA & argininemia. Eosinophilic disorders; FPIES; Short bowel syndrome	C	Medicaid coverage may be requested. Health department may provide assistance for treatment referred to as drugs when recipients are out of hospital and costs are not covered by a public or private health benefit plan. Birth record fees help to support cost of treatment. Regulations state that WIC covers amino acid modified preparation and low protein modified food products for eligible recipients and individuals without private insurance and unable to use WIC, Medicaid or K-CHIP may qualify for assistance. The health department reimburses providers for actual cost plus 20% with proper documentation.	A	Same as insurance	C	KRS §205.560 KRS §213.41 KRS §304.17A- 139 806 KAR 17:150 806 KAR 17:500 902 KAR 4:035 902 KAR 4:040 907 KAR 1:479
LA	Yes	Insurance Coverage of Forumla and Limits: \$2400/yr Insurance Coverage of Low Protein Foods and Limits: \$2400/yr; Insurance: low protein modified food products formulated to have ≤1 gram of protein per serving (not naturally low in protein) used under the direction of a physician to treat inherited metabolic disease State services: special formulas not defined	B	Gglutaric academia, isovaleric academia, MSUD, MMA, PKU, propionic acidemia, TYR, urea cycle defects.	C	Mandated Medicaid coverage. Health department NBS program and WIC provide special formulas to treat inborn errors of metabolism if guidelines regarding clinical and dietary management services and administrative guidelines are followed. State employee benefits provide for same benefits as private insurance coverage requirements.	A	PKU, CH, BD, SCD, and GALT screening but treatment provision refers to PKU and other rare inborn errors of metabolism	C	LRS §22:246 LRS §22:469 LRS §22:1035 LR 48:6301 et seq. LR 32:319 et seq
ME	Yes	Individual and group nonprofit medical service plans, nonprofit health care plans, individual and group health insurance and HMOs must reimburse for metabolic formula and modified low protein food products. \$3,000 annual cap applies to food products.	B	Inborn error of metabolism, or genetically determined biochemical disorder in which enzyme defect produces a metabolic block that may have pathogenic consequences at birth or later. Eosinophilic gastroenteritis (must be laboratory- or biopsy-proven); Gastroesophageal reflux disease (GERD) that is nonresponsive to standard medical therapies; Malabsorption of cow milk-based or soy milk-based infant formula; Severe vomiting or diarrhea resulting in clinically significant dehydration requiring treatment by a medical provider; Symptomatic allergic colitis or proctitis; Symptomatic allergic proctitis.	A	Medicaid coverage.Only covers individuals under 18.	B	Inborn error of metabolism, or genetically determined biochemical disorder in which enzyme defect produces a metabolic block that may have pathogenic consequences at birth or later	C	MRSA 24§2320-D MRSA 24-A§§2745-D, 2837-D and 4238 02-031 CMR
MD	Yes	HMOs, individual hospital or major medical insurance policy, group or blanket health insurance policy, and nonprofit health service plan must cover medical foods and low protein modified food products. No limits on coverage.	A	Inherited metabolic disease caused by an inherited abnormality, including diseases for which the state screens newborns. Eosinophilic disorders; FPIES	A	Medicaid coverage. Children's medical services program specialized care coordination services and activities to facilitate a treatment program may include formula and medication to correct metabolic errors. Medical foods are authorized WIC foods.	A	Inherited metabolic disease caused by an inherited abnormality, including diseases for which the state screens newborns	A	Health-General §19-705.5 Health-General §15-807 COMAR 10.11.03.04 COMAR 10.54.03.03 COMAR 31.11.06.03 COMAR 31.11.12.03

**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?		WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?		Statutes
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	
MA	Yes	Blanket or general accident and sickness insurance, and non-profit hospital, hospital and medical service corporations must cover medical formulas for infants, children and pregnant women with PKU and enteral formulas and low protein modified food products up to \$2,500 annually.No limit on coverage of formula.	B	PKU, TYR, HCY, MSUD, propionic acidemia or MMA, maternal PKU Private and civil service insurance: inherited diseases of amino and organic acids.	C	Medicaid coverage. State has established rates of payment to be used by governmental units in making payment to eligible providers for enteral formula. State health plans cover formula and low protein foods.	A	Inherited disease of metabolism, including protein, fat, carbohydrate, vitamins, minerals and possibly fiber	C	MGL 32A§17A MGL 175§47C MGL 176A§8B,8L MGL 176B§4C,4K MGL 176G§4D 105 CMR 270.001 114.3 CMR 22M.G.L.A. 176B § 4K
MI	No	No provision	F	No mandated coverage	F	Michigan medical services program determines reimbursement policies for treatment of children with special health care needs (CSHCN). Appropriations allow provision of special formula for eligible clients with specified metabolic disorders as well as treatment for eligible patients with CF who are 21 or older.	B	PKU and other specified metabolic disorders	D	Act No. 246 Public Acts of 2008
MN	Yes	Accident and health insurers, HMOs, fraternal benefits societies and nonprofit health service plan corporations must cover special dietary treatment per doctor recommendation. No limit on coverage of formula or low protein foods.	A	Amino acid, organic acid, and fatty acid metabolic and malabsorption disorders  Cystic fibrosis  Eosinophilic colitis  Eosinophilic esophagitis (EOE)  Eosinophilic gastroenteritis  Food protein induced enterocolitis syndrome (FPIES)  IgE mediated allergies to food proteins (Coverage of amino acid based elemental formulas for enrollees diagnosed with an IgE mediated condition is limited to enrollees age five years and under.) Inborn errors of metabolism.	A	State medical assistance for needy persons covers parenteral and enteral nutrition products for eligible persons. Parenteral nutrition subject to limits similar to pharmacy services. State health department regulations require arrangements for medically indicated treatment, including referral to private insurance, medical assistance, MinnesotaCare, and Services for Children with Disabilities	A	PKU, hyperlysinemia, MSUD, or any other childhood or adulthood disease, conditions or disorders identified by the health commissioner State health department: hemoglobinopathy, PKU, GALT, hypothyroidism and CAH	C	MSA §62A.26 MSA §256B.0625 MAR 4615.0760 MAR 9505.0325
MS	No	No provision	F	No mandated coverage	F	Medicaid coverage: case by casis basis for eligible enrollees. WIC coverage for children under age 5	C	PKU Only	D	No Provision
MO	Yes	Expense-incurred or indemnity type health insurers, HMOs, group health self-insurers and health care plans managed by health care delivery entities must cover formula and low protein modified foods for children under six up to \$5,000 per year. Deductible, coinsurance or copayments may not exceed %50 of cost of food and formula.	B	PKU and any other inherited disease of amino or organic acid .Eosinophilic disorders; FPIES	A	Medicaid coverage. Subject to appropriations, the health department provides formula for children under five if all other sources have been exhausted, to children between six and 18.	C	linherited diseases of amino and organic acids	C	MRS §191.331 et seq. MRS §376.1219
MT	Yes	Group and individual medical expense disability insurance must cover treatment of inborn errors of metabolism, including clinical services, medical supplies, prescription drugs, nutritional management and medical foods. Durational limits, caps, deductibles, coinsurance and copayments may apply if terms same as other illnesses.	A	Inborn errors of metabolism that involve amino acid, carbohydrate, and fat metabolism for which medical standards of diagnosis, monitoring and treatment exist.	C	Medicaid coverage. The handicapped children's services program provides medical foods benefits to eligible children under 19 up to a maximum of \$12,000 per year.	B	Inborn errors of metabolism that involve amino acid, carbohydrate, and fat metabolism for which medical standards of diagnosis, monitoring and treatment exist.	C	MCA §32-22-131 ARM 37.57.110
NE	No	No provision	F	No mandated coverage	F	Medicaid coverage. Health department provides food supplement and treatment services to individuals with inherited metabolic disease. No fee exists for formula, but scale of fees for food supplements, which are capped at \$2,000 annually, may apply. May receive reimbursement of up to 50% for out of pocket expenses if medically-necessary amino-acid based elemental formulas are not covered by private insurance, medicaid, or WIC. Maximum reimbursement of \$12,000 during a twelve month period.	B	PKU, BD, MPS-1, MCAD, X-ALD, hypothyroidism, galactosemia, Pompe Disease. Inherited or child-onset diseases. Immunoglobulin E and non-Immunoglobulin E mediated allergies to multiple food proteins, food-protein-induced enterocolitis syndrome, eosinophilic disorders, or impaired absorption of nutrients caused by disorders affecting the absorptive surface, functional length, and motility of the gastrointestinal tract.	A	NRS §71-520

**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?		WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?		Statutes
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	
NV	Yes	Health insurance policies, contracts for hospital and medical service, and HMOs must cover enteral formulas and special food products. Annual cap of \$2,500 applies to food only.	B	Inherited metabolic diseases characterized by deficient metabolism or malabsorption caused by an inherited abnormality of body chemistry as a result of a congenital or neonatal defect of amino or organic acid, fat, or carbohydrate.	C	Mandated medicaid coverage: State provides medical services, including dietary supplements to eligible children under 19 with inborn errors of metabolism.	B	Inborn errors of metabolism, including but not limited to aminoaciduria, BD, CF, GALT, glycogen storage disease, HCY, MSUD, PKU, TYR and those detected by the NBS program	C	NRS §689A.0423 NRS §689B.0353 NRS §695B.1923 NRS §695C.1723 NAC 442.685 NAC 442.782 et seq.
NH	Yes	Individual, group or blanket accident or health insurance, health service corporations, and HMOs must provide coverage for enteral formulas and food products. Annual cap of \$1,800 for food products. Normal deductibles and coinsurance may apply.No coverage limit on formula.	B	Inherited diseases of amino or organic acids	C	Medicaid coverage. Coverage of enteral but not oral.	C	Same as insurance	C	N.H. Rev. Stat. Ann. § 415:6-c, 415:18-e, 420-A:17, 420-B:
NJ	Yes	Individual or group medical or health service corporation, health insurer, small employer health benefits, and HMO plans must cover therapeutic treatment of metabolic disease on same basis as other conditions. No limits on coverage of formula or low protein foods.	A	Inherited metabolic disease of abnormal body chemistry for which the state screens newborns. medically necessary non-standard infant formulas for infants diagnosed as having multiple food protein intolerance and the covered infant has not been responsive to trials of standard non-cow milk-based formulas, including soybean and goat milk	C	Medicaid coverage. State Health Benefits Program covers therapeutic treatment of inherited metabolic diseases at 3 specialty clinics.	A	Same as insurance	C	NJSA §§17:48A-7q, 17:48E-35.16, 17B:26-2.10, 17B:27-46.1r, §17B:27A-7.4 & 19.6, §26:2J-4.17, §52:14-17.29c Bill: A-018, S-265
NM	Formula Only	Individual and group health insurance policies, health care plans, certificate of health insurance, and managed care plans must cover treatment of genetic inborn errors of metabolism, including clinical services, medical , prescription drugs, nutritional management and medical foods. Durational limits, caps, deductibles, coinsurance and copayments may apply if terms same as other illnesses. No limits on coverage of formula or low protein foods.	A	Genetic inborn errors of metabolism of amino acid, fat and carbohydrate for which treatment standards exist	C	Medicaid coverage. Adults covered on case by case basis. Children's medical services program provides treatment to individuals under 21 at increased risk of physical or developmental conditions, adults with CF, and adults at risk of having a child with special needs.	B	CH, GALT, hyperphenylalanemia, PKU, BD, disorders of amino acid and carbohydrate transport and metabolism, lipidoses, CAH, hypothyroidism, hemoglobinopathies and other disorders	C	NMSA §59A-22-41.1 NMAC 7.30.3.1 et seq
NY	Yes	Requires coverage for enteral formulas whether administered orally or via feeding tube that are medically necessary. No coverage limit on formula. \$2,500 limit on low protein foods.	B	All inborn errors of metabloism. Specific diseases for which enteral formulas have been proven effective shall include, but are not limited to, inherited diseases of amino acid or organic acid metabolism; Crohn's Disease; gastroesophageal reflux with failure to thrive; disorders of gastrointestinal motility such as chronic intestinal pseudo-obstruction; and multiple, severe food allergies which if left untreated will cause malnourishment, chronic physical disability, mental retardation or death.	A	Medicaid coverage: case by case basis.	C	Same as insurance	A	Insurance Law §4322 §§ 3216, 3221, 4303. Bills: AB 3732, AB 4602, SB 2043
NC	No	No provision	F	No mandated coverage	F	Medicaid coverage. The NBS program provides treatment products or medications for identified children as indicated and when not otherwise available.	B	PKU, GALT, CH, CAH, SCD, and other hereditary and congenital disorders	C	NCGS §130A-125 10A NCAC 43H .0314
ND	Yes	Insurance companies, nonprofit health services corporations and HMOs must cover medical foods and low protein modified food products as part of prescription drug coverage. Annual cap of \$3,000 for low protein modified food products and medical foods applies.	B	PKU, MSUD	D	Medicaid coverage. The human services and health departments provide medical food at no cost to males under 26 and females under 45 and offer sale at cost to those older with PKU or MSUD regardless of income. Low protein modified foods are available to females under 45 and males under 22. Human services department may seek reimbursement from other government programs.	B	PKU, MSUD	D	NDCC §25-17-00.1 et seq. NDCC §26.1-36-09.7 NDCC §54-52.1-01 et seq. NDAC 75-03-35-01 et seq.

**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?		WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?		Statutes
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade	
OH	No	No provision	F	No mandated coverage	F	Medicaid coverage. Formula only. The director of health encourages and assists in the treatment of genetic diseases and provides for habilitation and rehabilitation.	D	PKU and specified Genetic disorders.	D	ORCA §3701.502
OK	No	No provision	F	No mandated coverage	F	Medicaid coverage: PKU only. Limited WIC coverage.	D	PKU Only	D	HCR 1044 (2004)
OR	Yes	For metabolic disorder, individual and group health insurance policies must cover medical foods. For malabsorption, health insurance policies must cover enteral formula. No limits on coverage of formula or low protein foods.	A	Inborn errors of metabolism that involve amino acid, carbohydrate and fat metabolism for which medically standard methods of diagnosis, treatment, and monitoring exist, including quantification of metabolites in blood, urine, or spinal fluid or enzyme or DNA confirmation in tissues and severe intestinal malabsorption	A	Mandated Medicaid coverage	A	Same as insurance	A	ORS §743A.070, 743A.188 Rev. Stat. § 743A.070
PA	Formula Only	No limit on formula coverage, but only covers 18 and under. Health insurance policies must cover nutritional supplements. Normal copayment and coinsurance may apply. Benefits are exempt from deductibles. No coverage of low-protein foods.	D	PKU, branch- chained ketonuria, GALT and HCY. Food protein allergies, food protein-induced enterocolitis, eosinophilic disorders, FPIES, and short-bowel.	C	Medicaid coverage: case by case basis. The WIC Program provides allowable foods to eligible pregnant, breast-feeding and postpartum women and children until age 5 who are at nutritional risk because of medical problems.	C	Nutritional risk, including conditions that predispose a person to nutritionally related medical conditions	A	Pa. Cons. Stat. tit. 40, § 3904 et seq. 028 Pa. Code §1101.1 et seq
RI	Yes	Accident and sickness insurers, nonprofit hospital and medical service corporations and HMOs must cover enteral formula and low protein modified food products with an annual cap of \$2,500. Normal copayment or deductibles may apply.	B	Inherited diseases of amino and organic acids.	C	Medicaid coverage. Public assistance pays for enteral nutrition products for eligible neonates, infants, children and adults up to \$2,500 per year.	B	Inborn errors of metabolism such as PKU, TYR, HCY, MSUD, propionic aciduria and MMA	C	Gen. Laws 1956, § 27-18-70 RIGL §23-13-14 RIGL §27-18-69 RIGL §27-19-60 RIGL §27-20-55 RIGL §27-41-73 RIGL §40-6-3.12
SC	No	No provision	F	No mandated coverage	F	Medicaid coverage. State covers enteral not oral for children and some parents of dependent children.	C	Unspecified inborn metabolic disorders	D	Medicaid Durable Medical Equipment Manual Section 2
SD	Formula only	Individual and group health insurers, nonprofit medical and surgical plans, hospital service corporations and HMOs must cover treatment NO coverage limits. No Coverage of low-protein foods.	D	PKU Only	D	Medicaid coverage. State covers enteral nutrition therapy and oral nutritional supplements for eligible children	A	Inborn errors of metabolism	C	SDCL §58-17-62 SDCL §58-18-41 SDCL §58-38-23 SDCL §58-40-21 SDCL §58-41-98 SDAR 67:16:42:01 et seq.
TN	Formula only	Health insurance policies, medical service plans, hospital and medical service corporation contracts, fraternal benefit societies, and HMOs must cover treatment.	D	PKU Only	D	Medicaid coverage. TennCare covers food supplements for individuals with PKU as required and for other metabolic disorders in children under 21.	B	Metabolic disorders and PKU	C	TCA §56-7-2505 TCRR 1200-15-2-.01 et seq.
TX	Formula only	Group health benefit plans issued by an insurer, HMOs, or group hospital service corporations must cover formulas to treat PKU and other heritable diseases. Coverage must mirror prescription drug benefits.	D	Heritable disease that may result in mental or physical retardation or death; PKU, other heritable diseases, hypothyroidism, or another disorder for which the state screens newborns. CHCSN: metabolic disorder, other medical condition and inborn metabolic disorders not listed. Eosinophilic disorders and FPIES.	A	Medicaid coverage. CHCSN program serves eligible individuals of any age. CSHCN provides nutritional services and products for identified metabolic disorders or other conditions. Medical food coverage is available to treat inborn metabolic disorders only.	A	Same as insurance	A	§1359.001 et seq. Health and Safety Code §33.031 et seq. TAC Health Services §38
UT	Yes	Accident and health insurers must cover dietary products as a major medical benefit.	A	Inborn errors of amino acid or urea cycle metabolism caused by an inherited abnormality of body chemistry treatable by dietary restriction	C	Medicaid coverage: case by case basis. WIC coverage may be considered upon request.	C	Same as insurance	C	Utah Code §31A-22-623 UAC R590-194. Bill: HB 230



**MEDICAL NUTRITION COVERAGE (CONTINUED)**

STATE	IS INSURANCE COVERAGE MANDATED?			WHAT DISORDERS ARE COVERED IN PRIVATE INSURANCE?		IS THERE STATE-FUNDED COVERAGE?			WHAT DISORDERS ARE INCLUDED IN STATE COVERAGE?		Statutes
	Mandated Private Insurance Coverage	Insurance Coverage Limitations	Grade	Covered Disorders For Private Insurance Mandate	Grade	State-Funded Coverage	Grade	Covered Disorders For State Coverage	Grade		
<b>VT</b>	Yes	An insurer must cover medically necessary medical foods. Coverage of low protein modified food products also required to at least \$2,500 annually.	B	Inherited metabolic disease caused by an abnormality of body chemistry for which the state screens newborns.	C	Mandated Medicaid coverage. The health department may accept children suffering from chronic diseases for treatment.	B	Same as insurance	C	ORCA §3701.502 18 VSA §4089e 18 VSA §115, 115a	
<b>VA</b>	No	No provision	F	No mandated coverage	F	Medicaid coverage: Tube feeding only. Subject to available funding, the health department assists eligible persons in obtaining dietary treatment. Financially eligible children under 21 and adults. Children and adults who do not meet financial eligibility may be able to purchase dietary products from the department.	D	Core panel of heritable disorders and genetic disease consistent with recommendations of the American College of Medical Genetics	C	12 VAC 5-71-10 et seq.	
<b>WA</b>	Formula Only	Disability insurance contracts, contracts or agreements for health care services must cover treatment for PKU. Formula only.	D	PKU Only	D	Medicaid coverage. The health department is authorized to include costs for specialty clinics that provide treatment services in the NBS fee. Individuals in state medical assistance plans are eligible to receive oral or tube-delivered enteral nutrition products if criteria met.	A	State programs: specialty clinics: hemoglobin diseases, PKU, CAH, CH, and other disorders for which the state screens newborns	C	RCW §48.20.520 RCW §48.21.300 RCW §48.44.440 RCW §48.46.510 WAC 246-650-991 WAC 388-554-300	
<b>WV</b>	Yes	Mandates coverage through age 20 for the treatment of severe protein-allergic conditions or impaired absorption of nutrients caused by disorders affecting the gastrointestinal tract.	B	Immunoglobulin E and non-immunoglobulin E mediated allergies to multiple food proteins, severe food protein-induced enterocolitis syndrome, eosinophilic disorders, impaired absorption of nutrients caused by disorders affecting the absorptive surface, function, length, and motility of the gastrointestinal tract.	A	Limited Medicaid coverage. Formula only. Must refer to the WV University Genetics Team.	D	PKU, GALT, IEM, Tyrosemia, Organic Acidemia Disorders	C	§16-22-3(c) SB 526 (2017)	
<b>WI</b>	No	No provision	F	No mandated coverage	F	State coverage is provided through the medical assistance program. Coverage includes special dietary treatment as prescribed by a physician	A	Nutritional risk, including conditions that predispose a person to nutritionally related medical condition	A	HFS 107.09	
<b>WY</b>	Yes	All individual and group health insurance policies providing coverage on an expense incurred basis, individual shall provide coverage for medical nutrition therapy	A	Inherited enzymatic disorders caused by single gene defects involved in the metabolism of amino, organic and fatty acids.	C	Medicaid coverage. Children's health insurance program covers medical foods for eligible persons	A	Inborn errors of metabolism involving amino acid, carbohydrate, and fat metabolism with an accepted diagnosis and treatment	C	KidCare CHIP Rules §8 W.S. 26-20-401	

Sources:

National PKU Alliance, State Coverage Database. <http://npkua.org/TakeAction/StateCoverage.aspx>

Children's Magic U.S., Coverage States. <http://childrensmagicus.org/coverage-states/>

American Partnership for Eosinophilic Disorders (Apfed), State Insurance Mandates for Elemental Formula. <http://apfed.org/advocacy/state-insurance-mandates-for-elemental-formula/>

HRSA, State Statutes and Regulations on Dietary Treatment of Disorders Identified Through Newborn Screening. <http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/reportsrecommendations/reports/statelaws.pdf>

Nutrica Metabolics, State Coverage Database. <http://www.medicalfood.com/Reimbursement/Coverage-by-State/>

**INDIVIDUAL INSURANCE PROTECTIONS - REINSURANCE (1332 WAIVERS)**

STATE	Has the state obtained a 1332 waiver to establish a reinsurance program?	Does the state's reinsurance program use an Attachment Point (reinsurance begins after a patient incurs a certain amount in costs) or Conditions (patients with certain conditions are eligible for reinsurance) based model?	Attachment Point for Reinsurance	What percent of costs does the reinsurance program cover for patients in the reinsurance program?	What is the cap on reinsurance?	Source
AL	No	N/A	N/A	N/A	N/A	N/A
AK	Yes	Reinsurance program is conditions based.	N/A	No percent is specified. Laws state that insurance provider will be reimbursed "partially or fully."	N/A	<a href="https://www.commerce.alaska.gov/web/Portals/11/Pub/Headlines/Alaska%201332%20State%20Innovation%20Waiver%20June%2015%202017.pdf?ver=2017-06-26-091456-033">https://www.commerce.alaska.gov/web/Portals/11/Pub/Headlines/Alaska%201332%20State%20Innovation%20Waiver%20June%2015%202017.pdf?ver=2017-06-26-091456-033</a>
AZ	No	N/A	N/A	N/A	N/A	N/A
AR	No	N/A	N/A	N/A	N/A	N/A
CA	No	N/A	N/A	N/A	N/A	N/A
CO	Yes	The DOI will reimburse qualifying individual health insurers for a % of an enrollee's claims between at attachment point and a cap.	Attachment point for reinsurance is \$30,000.	60%	The reinsurance program will cover costs at the specified coinsurance rate up to \$400,000.	<a href="https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-STC-CO-Signed.pdf">https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-STC-CO-Signed.pdf</a>
CT	No	N/A	N/A	N/A	N/A	N/A
DC	No	N/A	N/A	N/A	N/A	N/A
DE	Yes	Reinsurance program is attachment point based.	Attachment Point for reinsurance is \$65,000.	75%	The reinsurance program will cover costs at the specified coinsurance rate up to \$215,000.	<a href="https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-STC-Delaware-Signed.pdf">https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-STC-Delaware-Signed.pdf</a>
FL	No	N/A	N/A	N/A	N/A	N/A
GA	No	N/A	N/A	N/A	N/A	N/A
HI	No	N/A	N/A	N/A	N/A	N/A
ID	No	N/A	N/A	N/A	N/A	N/A
IL	No	N/A	N/A	N/A	N/A	N/A
IN	No	N/A	N/A	N/A	N/A	N/A
IA	No	N/A	N/A	N/A	N/A	N/A
KS	No	N/A	N/A	N/A	N/A	N/A
KY	No	N/A	N/A	N/A	N/A	N/A
LA	No	N/A	N/A	N/A	N/A	N/A
ME	Yes	State uses a combination of the two models. Patients with costs between \$47,000 and \$77,000 are eligible for reinsurance regardless of condition. Patients with costs exceeding \$77,000 are eligible if they have certain conditions.	Eligible for reinsurance once costs exceed \$47,000	90%	The reinsurance program will cover costs at the specified coinsurance rate up to \$77,000, any coverage of costs in excess of \$77,000 are on a conditions-based basis.	<a href="https://www.maine.gov/pfr/insurance/mgara/Complete%20Maine%201332%20Waiver%20Application%20and%20Exhibits.pdf">https://www.maine.gov/pfr/insurance/mgara/Complete%20Maine%201332%20Waiver%20Application%20and%20Exhibits.pdf</a>
MD	Yes	Reinsurance program is attachment point based.	No official value, estimated to be eligible for reinsurance once costs exceed \$20,000	80%	The reinsurance program will cover costs at the specified coinsurance rate up to \$250,000.	<a href="https://www.marylandhbe.com/wp-content/uploads/2018/08/Maryland_1332_State_Innovation_Waiver_to_Establish_a_State_Reinsurance_Program_UPDATED_August_15_2018.pdf">https://www.marylandhbe.com/wp-content/uploads/2018/08/Maryland_1332_State_Innovation_Waiver_to_Establish_a_State_Reinsurance_Program_UPDATED_August_15_2018.pdf</a>
MA	No	N/A	N/A	N/A	N/A	N/A
MI	No	N/A	N/A	N/A	N/A	N/A
MN	Yes	Reinsurance program is attachment point based.	Eligible for reinsurance once costs exceed \$50,000	80%	The reinsurance program will cover costs at the specified coinsurance rate up to \$250,000.	<a href="https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/Minnesota-Section-1332-Waiver.pdf">https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/Minnesota-Section-1332-Waiver.pdf</a>

**INDIVIDUAL INSURANCE PROTECTIONS - REINSURANCE (1332 WAIVERS) (CONTINUED)**

STATE	Has the state obtained a 1332 waiver to establish a reinsurance program?	Does the state's reinsurance program use an Attachment Point (reinsurance begins after a patient incurs a certain amount in costs) or Conditions (patients with certain conditions are eligible for reinsurance) based model?	Attachment Point for Reinsurance	What percent of costs does the reinsurance program cover for patients in the reinsurance program?	What is the cap on reinsurance?	Source
MS	No	N/A	N/A	N/A	N/A	N/A
MO	No	N/A	N/A	N/A	N/A	N/A
MT	Yes	Reinsurance program is attachment point based.	Attachment point is \$40,000.	60%	\$101,750 cap	<a href="https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-MT-Approval-STCspdf.pdf">https://www.cms.gov/CCIIO/Programs-and-Initiatives/State-Innovation-Waivers/Downloads/1332-MT-Approval-STCspdf.pdf</a>
NE	No	N/A	N/A	N/A	N/A	N/A
NV	No	N/A	N/A	N/A	N/A	N/A
NH	No	N/A	N/A	N/A	N/A	N/A
NJ	Yes	Reinsurance program is attachment point based.	Eligible for reinsurance once costs exceed \$40,000	60%	The reinsurance program will cover costs at the specified coinsurance rate up to \$215,000.	<a href="https://www.state.nj.us/dobi/division_insurance/section1332/180702finalwaiverapplication.pdf">https://www.state.nj.us/dobi/division_insurance/section1332/180702finalwaiverapplication.pdf</a> N/A
NM	No	N/A	N/A	N/A	N/A	N/A
NY	No	N/A	N/A	N/A	N/A	N/A
NC	No	N/A	N/A	N/A	N/A	N/A
ND	Yes	Reinsurance program is attachment point based.	Eligible for reinsurance once costs exceed \$100,000.	75%	The reinsurance program will cover costs at the specified coinsurance rate up to \$1,000,000.	<a href="https://www.nd.gov/ndins/sites/www/files/documents/Health%20Care%20Reform/Final%20North%20Dakota%201332%20Waiver%20Application.pdf">https://www.nd.gov/ndins/sites/www/files/documents/Health%20Care%20Reform/Final%20North%20Dakota%201332%20Waiver%20Application.pdf</a>
OH	No	N/A	N/A	N/A	N/A	N/A
OK	No	N/A	N/A	N/A	N/A	N/A
OR	Yes	Reinsurance program is attachment point based.	Eligibility for reinsurance has not yet been determined.	50%	The reinsurance program will cover costs at the specified coinsurance rate up to \$1,000,000.	<a href="http://healthcare.oregon.gov/DocResources/1332-application.pdf">http://healthcare.oregon.gov/DocResources/1332-application.pdf</a>
PA	No	N/A	N/A	N/A	N/A	N/A
RI	Yes	Reinsurance program is attachment point based.	Eligible for reinsurance once costs exceed \$40,000.	50%	The reinsurance program will cover costs at the specified coinsurance rate up to \$97,000.	<a href="https://healthsourceri.com/wp-content/uploads/190708_FinalApplicationPackage.pdf">https://healthsourceri.com/wp-content/uploads/190708_FinalApplicationPackage.pdf</a>
SC	No	N/A	N/A	N/A	N/A	N/A
SD	No	N/A	N/A	N/A	N/A	N/A
TN	No	N/A	N/A	N/A	N/A	N/A
TX	No	N/A	N/A	N/A	N/A	N/A
UT	No	N/A	N/A	N/A	N/A	N/A
VT	No	N/A	N/A	N/A	N/A	N/A
VA	No	N/A	N/A	N/A	N/A	N/A
WA	No	N/A	N/A	N/A	N/A	N/A
WV	No	N/A	N/A	N/A	N/A	N/A
WI	Yes	Reinsurance program is attachment point based.	Eligible for reinsurance once costs exceed \$50,000.	50-80%	The reinsurance program will cover costs at the specified coinsurance rate up to \$250,000.	<a href="https://oci.wi.gov/Documents/Regulation/WI%201332%20Waiver%20Application%20and%20All%20Attachments.pdf">https://oci.wi.gov/Documents/Regulation/WI%201332%20Waiver%20Application%20and%20All%20Attachments.pdf</a>
WY	No	N/A	N/A	N/A	N/A	N/A

**INDIVIDUAL INSURANCE MARKET PROTECTIONS - PRE EX**

STATE	Guaranteed Issue	Adjusted Community Rating	Prohibition on Pre-Existing	Individual Mandate
AL	No	No	No	No
AK	No	No	No	No
AZ	No*	No*	No*	No
AR	No	No	No	No
CA	No*	Yes	No*	State has a mandate in place
CO	Yes	Yes	Yes	No
CT	No*	Yes	Yes	No
DC	No*	No*	No*	State has a mandate in place
DE	Yes	Yes	Yes	No
FL	No	No	Yes**	No
GA	No	No	No	No
HI	No	No	Yes	No
ID	No	No	No	No
IL	No	No	Yes	No
IN	No	No	Yes	No
IA	No	No	No	No
KS	No	No	No	No
KY	No	No	No	No
LA	No	Yes	Yes**	No
ME	Yes	Yes	Yes	No
MD	No*	No*	No*	No
MA	Yes	Yes	Yes	State has a mandate in place
MI	Yes	No	No	No
MN	No*	Yes	No	No
MS	No	No	No	No
MO	No	No	No	No
MT	No	No	No	No
NE	No	No	No	No
NV	Yes	Yes	Yes	No
NH	Yes	Yes	Yes	No

**INDIVIDUAL INSURANCE MARKET PROTECTIONS - PRE EX (CONTINUED)**

STATE	Guaranteed Issue	Adjusted Community Rating	Prohibition on Pre-Existing	Individual Mandate
NJ	Yes	Yes	Yes	State has a mandate in place
NM	Yes	Yes	No	No
NY	Yes	Yes	Yes	No
NC	No	No	No	No
ND	No	No	No	No
OH	No	No	No	No
OK	No	No	No	No
OR	Yes	Yes	Yes	No
PA	No	No	No	No
RI	No	No	Yes	State has a mandate in place
SC	No	No	No	No
SD	No	No	No	No
TN	No	No	No	No
TX	No	No	No	No
UT	No	No	No	No
VT	Yes	Yes	Yes	State has a mandate in place
VA	Yes	Yes	Yes	No
WA	Yes	Yes	Yes	No
WV	No	No	No	No
WI	No	No	No	No
WY	No	No	No	No

\* State statute incorporates protection by reference to the ACA or includes a provision that renders the statute void in the event that the ACA is repealed or declared unconstitutional.

\*\*State provision only goes into effect only if a federal law repeals the ACA or the ACA is invalidated by the Supreme Court

**INDIVIDUAL INSURANCE PROTECTIONS - SKINNY PLANS**

STATE	ASSOCIATION HEALTH PLANS			SHORT TERM PLANS				
	Regulation of Fully Insured Association Health Plans	Regulation of Self-Funded Association Health Plans	Source	Does the state prohibit underwritten short-term, limited duration health coverage?	Does the state limit the initial contract duration of underwritten short-term, limited-duration health coverage to less than 364 days?	Does the state limit the total length of time a consumer may be enrolled in underwritten short-term, limited-duration health coverage to less than 364 days?	Other	Source
AL	No	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.		Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No		
AK	No		No			No		
AZ	No		No			No		
AR	No		No			No		
CA	Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP.	New association health plans are entirely prohibited or are prohibited from forming under the less-comprehensive standards.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	Underwritten short term plans are not allowed in this state.	N/A	N/A		"SB 1375 CA Ins Code § 10123.61"
CO	New association health plans are entirely prohibited or are prohibited from forming under the less-comprehensive standards.	New association health plans are entirely prohibited or are prohibited from forming under the less-comprehensive standards.	3 CCR 702-4	No		Yes, initial contract duration limited to 6 months		CO Rev Stat § 10-16-145
CT	Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP.	Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP. Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No		Yes, initial contract duration limited to 6 months		" CT HC Bulletin 123 CT Gen Stat § 38a-501a "
DC	No	Self-funded AHPs are prohibited from operating without first meeting the requirements for, and becoming licensed as, an insurer, a hospital and medical services corporation, a fraternal benefit society, or a health maintenance organization.	Section 31-3303.13c	No	Yes, initial contract duration limited to 3 months	Yes, underwritten short-term, limited-duration coverage cannot exceed 3 months per insurer in a 12 month period.		D.C. Code § 31-3303.13d
DE	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Fully-insured AHPs must comply with all insurance laws applicable to small employer groups.	No	Title 18: 1400 (1405)	No	Yes, initial contract duration limited to 3 months	Yes, policy prohibits issuance of multiple short-term plans consecutively and prohibits issuing a different short-term policy to the same individual more than once during any given year.		18 DE Reg. 1320

**INDIVIDUAL INSURANCE PROTECTIONS - SKINNY PLANS (CONTINUED)**

STATE	ASSOCIATION HEALTH PLANS			SHORT TERM PLANS				
	Regulation of Fully Insured Association Health Plans	Regulation of Self-Funded Association Health Plans	Source	Does the state prohibit underwritten short-term, limited duration health coverage?	Does the state limit the initial contract duration of underwritten short-term, limited-duration health coverage to less than 364 days?	Does the state limit the total length of time a consumer may be enrolled in underwritten short-term, limited-duration health coverage to less than 364 days?	Other	Source
FL	No	No		No	No	No		
GA	No	No		No	No	No		
HI	All AHPs must comply with state laws, regardless of the domicile of the association that has issued the policy.	All AHPs must comply with state laws, regardless of the domicile of the association that has issued the policy.		No	Yes, initial contract duration limited to 90 days	No		HI Rev Stat § 431
ID	Fully-insured AHPs must comply with all insurance laws applicable to small group insurers.	Self-funded AHPs must comply with all insurance laws applicable to self-funded health plans.	Title 41 Ch 40 Section 41-4004	No	No	No		ID Rev Stat § 41-5206
IL	Require that an association must be formed for a purpose other than offering insurance.	Require that an association must be formed for a purpose other than offering insurance.	215 ILCS 5/352	No	Yes, initial contract duration limited to 180 days	Yes, underwritten short-term, limited-duration coverage cannot exceed 180 days per insurer in a 240-day period.		215 ILCS 190
IN	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	No	No		
IA	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.		No	No		
KS	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	No	No		
KY	Require that an association must be formed for a purpose other than offering insurance.	Require that an association must be formed for a purpose other than offering insurance.	304.18-020	No	No	No		
LA	No	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	No	No		
ME	No	No		No	No	No		

**INDIVIDUAL INSURANCE PROTECTIONS - SKINNY PLANS (CONTINUED)**

STATE	ASSOCIATION HEALTH PLANS			SHORT TERM PLANS				
	Regulation of Fully Insured Association Health Plans	Regulation of Self-Funded Association Health Plans	Source	Does the state prohibit underwritten short-term, limited duration health coverage?	Does the state limit the initial contract duration of underwritten short-term, limited-duration health coverage to less than 364 days?	Does the state limit the total length of time a consumer may be enrolled in underwritten short-term, limited-duration health coverage to less than 364 days?	Other	Source
MD	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	Yes, initial contract duration limited to 3 months	No		" MD Insurance Bulletin 18-15 MD Ins Code § 15-1301"
MA	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Part I Title XXII Ch 176J	Underwritten short term plans are not allowed in this state	N/A	N/A		"MA Division of Insurance Bulletin 2018-03 MA Gen L ch 175 § 108"
MI	No	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	Yes, initial contract duration limited to 185 days	Yes, underwritten short-term limited-duration coverage cannot exceed 185 days per insurer in a 365-day period.		Mich. Comp. Laws § 500.2213b
MN	Require that an association must be formed for a purpose other than offering insurance.	Require that an association must be formed for a purpose other than offering insurance. Self-insured AHPs must have stop-loss insurance and must comply with the same laws applicable to group insurance.	60A.02 62A.10 Part 2765.1000 62H.04	No	Yes, initial contract duration limited to 185 days	No		MN Stat § 62A.65
MS	No	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Bulletin 2018-8	No	No	No		
MO	No	Self-funded AHPs are subject to the same remedies as the department of social services has with Medicaid.	376.433	No	No	No		
MT	No	No		No	No	No		
NE	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	44-7606	No	No	No		
NV	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	689B.020	No	Yes, initial contract duration limited to 185 days	Yes, underwritten short-term limited-duration coverage cannot exceed 185 days per insurer in a 365-day period.		NV Rev Stat § 689A
NH	Prior approval of insurance commissioner is required. Fully-insured AHPs are subject to the same statutory and regulatory requirements as any other group health insurance plan. AHP coverage would need to be rated in accordance with small group rating rules.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	INS NO. 18-045-AB	No	Yes, limits initial contract duration to 6 months	No		NH Rev Stat § 415:5

**INDIVIDUAL INSURANCE PROTECTIONS - SKINNY PLANS (CONTINUED)**

STATE	ASSOCIATION HEALTH PLANS			SHORT TERM PLANS				
	Regulation of Fully Insured Association Health Plans	Regulation of Self-Funded Association Health Plans	Source	Does the state prohibit underwritten short-term, limited duration health coverage?	Does the state limit the initial contract duration of underwritten short-term, limited-duration health coverage to less than 364 days?	Does the state limit the total length of time a consumer may be enrolled in underwritten short-term, limited-duration health coverage to less than 364 days?	Other	Source
<b>NJ</b>	Fully-insured AHPs must comply with all insurance laws applicable to small group insurers.	Self-funded AHPs must comply with all insurance laws applicable to self-funded health plans.	N.J.S.A. 17B:27A-2 to -16 & N.J.S.A. 17B:27A-17 to -56 & N.J.S.A. 17B:27C-1 to -12 & N.J.A.C. 11:4-56	Underwritten short term plans are not allowed in this state	N/A	N/A		NJ Rev Stat § 17B
<b>NM</b>	No			No	Yes, limits initial contract duration to 3 months	Yes, underwritten short-term limited duration coverage cannot exceed 3 months in a 6-month period.		
<b>NY</b>	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards. Sole proprietors must use the traditional individual insurance market to obtain coverage and cannot qualify as a "small employer group" in order to join an employer-based AHP. Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	Underwritten short term plans are not allowed in this state	N/A	N/A		NY Ins L § 4235(c)(1)(H) NY Ins L § 3217
<b>NC</b>	No	No		No	No	No		
<b>ND</b>	No	No		No	Yes, initial contract duration limited to 6 months	No		ND Code § 26.1-36
<b>OH</b>	No	No		No	No	No		
<b>OK</b>	No	No		No	No	No		
<b>OR</b>	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Coverage sold to individuals through associations is part of the individual market risk pool and must comply with individual market standards. Coverage sold to small businesses through an association is part of the small-group market risk pool and must comply with small-group market standards.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage. Self-funded AHPs must comply with all insurance laws applicable to self-funded health plans.	Bulletin No. DFR 2018-07	No	Yes, limits initial contract duration to 3 months	Yes, underwritten short-term, limited-duration coverage cannot exceed 3 months per insurer in a 5-month period.		OR Rev Stat § 743B.005
<b>PA</b>	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	689B.020	No	No	No		



**INDIVIDUAL INSURANCE PROTECTIONS - SKINNY PLANS (CONTINUED)**

STATE	ASSOCIATION HEALTH PLANS			SHORT TERM PLANS				
	Regulation of Fully Insured Association Health Plans	Regulation of Self-Funded Association Health Plans	Source	Does the state prohibit underwritten short-term, limited duration health coverage?	Does the state limit the initial contract duration of underwritten short-term, limited-duration health coverage to less than 364 days?	Does the state limit the total length of time a consumer may be enrolled in underwritten short-term, limited-duration health coverage to less than 364 days?	Other	Source
RI	No	No		Underwritten short term plans are not allowed in this state.	N/A	N/A		S 2391
SC	No	No		No	Yes, initial contract duration limited to 11 months	No		Bulletin 2018-08
SD	No	No		No	Yes, initial contract duration limited to 6 months	No		NY Ins L § 4235(c)(1)(H) NY Ins L § 3217
TN	No	No		No	No	No		
TX	No	No		No	No	No		
UT	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	Bulletin 2018-5	No	No	No		
VT	AHPs may not enroll any new employer members starting in 2020. Fully-insured AHPs must use community rating and cover the EHBs.	AHPs may not enroll any new employer members starting in 2020.	Title 8 Ch 107 Subchapter 001 Section 4079a	No	Yes, initial contract duration limited to 3 months	Yes, underwritten short-term limited-duration coverage cannot exceed 3 months in a 12-month period		"VDFR Rule I-2018-01 8 V.S.A. § 4062"
VA	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	Require that an association must be formed for a purpose other than offering insurance or be in existence for a minimum number of years before offering coverage.	38.2-3420	No	Yes, initial contract duration limited to 6 months	No		Administrative Letter 2000-8
WA	No	New association health plans are entirely prohibited or are prohibited from forming under the less-comprehensive standards.	Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.	No	Yes, initial contract duration limited to 3 months	Yes, underwritten short-term limited-duration coverage cannot exceed 3 months in a 12-month period		WSR 18-17-166
WV	No	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	WV DOL	No	No	No		
WI	No	No		No	No	No		
WY	Association must provide employers and residents with information about exchange plan rates and benefits compared to the AHP and must disclose if they are being compensated for the sale of the plan.	Self-funded AHPs must satisfy the same licensure and financial standards as commercial insurers.	§26-19-102(a)(ii)	No	Yes, initial contract duration limited to 6 months	No		Commonwealth Fund

Source:

Lucia, Kevin. "In the Wake of New Association Health Plan Standards, States Are Exercising Authority to Protect Consumers, Providers, and Markets." Commonwealth Fund, November 27, 2018.

**STEP THERAPY PROTECTIONS**

STATE	Yes/No	Based on Clinical Practice	Grade for Clinical Practice	Timeline	Grade for Timeline	Exception Process	Grade for Exceptions Process	Categories of Exceptions	Grade for Exception	Subsequent Guidance from State	Grade for Guidance from State	Applicability	Response: grant/reject?	Provide Drug during Appeal Process?	Statutes/Proposed Legislation
AL	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
AK	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
AZ	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
AR	Yes	Yes	A	Must respond within 72 hours, if no response, request is granted	C	Providers have access to a convenient and accessible override procedure. No step therapy for mental health drugs.	C	If patient has already tried and failed the drug. (1)	D	-	F	All state-regulated commercial plans and state-employee health plans	Just response	No	SB 839(2017)
CA	Yes	Not specified	C	Must respond within 72 hours, except in case of urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	Requests for exceptions are to be made in the same manner as requests for prior authorization of prescription drugs.	C	None	F	-	F	All state-regulated commercial plans	Just response	No	AB 374 (2015)
CO	Yes	Not specified	C	No timeline	F	May not require step therapy for prescribed drugs that are on the formulary. Must have an override procedure available.	C	If the patient has already tried and failed the drug. (1)	D	-	F	All state-regulated commercial plans	Not specified	No	SB 17-203 (2017)
CT	Yes	Yes	A	Expediently	A	Access to convenient accelerated exception process. Step therapy regimens limited to 60 days.	B	If the patient has already tried and failed the drug, if the drug is expected to be ineffective, if the drug will likely cause an adverse reaction, or if the drug is not in the best interest of the patient based on medical necessity (3)	C	-	F	All state-regulated commercial plans and state Medicaid	Not specified	No	SB 394 (2014)
DE	Yes - effective March 2020	Yes	A	Must grant or deny a request within two business days, and grant or deny within 24 hours in case of emergency.	A	The patient and prescribing practitioner shall have access to a clear, convenient and readily accessible process.	A	If the patient has already tried and failed the drug, if the drug is expected to be ineffective, if the drug will likely cause an adverse reaction, if the drug is not in the best interest of the patient based on medical necessity, or if the patient is stable for the medical condition on a prescription drug (5)	A	-	F	All state-regulated commercial plans and state-employee health plans	Must either approve or deny request	No	HB 105 (2019)
DC	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
FL	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
GA	Yes - effective January 2020	Yes	A	Must grant or deny a request within two business days, and grant or deny within 24 hours in case of emergency. If no response, exemption automatically granted.	A	An evidence-based and updated protocol or program that establishes the specific sequence in which prescription drugs for a specified medical condition are deemed medically appropriate for a particular patient.	C	If the drug is contraindicated, likely to cause an adverse reaction or is expected to be ineffective, if the patient has already tried and failed the drug, or if the patient is stable for the medical condition on a prescription drug (4)	B	-	F	All state-regulated commercial plans and state-employee health plans	Must either approve or deny request	No	HB 63 (2019)
HI	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
ID	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
IL	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	Access to an exception process if the drug is not covered on the formulary, the plan is taking the drug off of the formulary for reasons other than safety or withdraw from market, or if step therapy is to be applied and the patient qualified based on one of the exceptions	C	If the patient has already tried and failed the drug, if the drug is expected to be ineffective, if the drug is contraindicated or likely to cause an adverse reaction. (3)	C	-	F	All state-regulated commercial plans	Must either approve or deny request	No	Public Act 099-0761
IN	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	Access to a clear and accessible exception process, published on the plan website and provided to covered individual in writing.	A	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, or if the drug is not in the best interest of the patient (4)	B	-	F	All state-regulated commercial plans and state-employee health plans	Must either approve or deny request	No	SB 41 (2016)

**STEP THERAPY PROTECTIONS (CONTINUED)**

STATE	Yes/No	Based on Clinical Practice	Grade for Clinical Practice	Timeline	Grade for Timeline	Exception Process	Grade for Exceptions Process	Categories of Exceptions	Grade for Exception	Subsequent Guidance from State	Grade for Guidance from State	Applicability	Response: grant/reject?	Provide Drug during Appeal Process?	Statutes/Proposed Legislation
IA	Yes	Yes	A	Must respond within five days, except in urgent situations, in which case must respond within 72 hours. If no response, request automatically granted.	A	The covered person and prescribing health care professional shall have access to a clear, readily accessible exception process.	A	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, or if the patient is already stable for the medical condition on a prescription drug (4)	B	-	F	All state-regulated commercial plans and state-employee health plans	Must either approve or deny request	No	HF 233 (2017)
KS	Yes - this is only for Medicaid only	Yes	A	Must respond within 72 hours, except in case of urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	The Department shall provide access for prescribing physicians to a clear and convenient process.	B	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, or if the patient is already stable for the medical condition on a prescription drug (4)	B	-	F	State Medicaid	Must either approve or deny request	No	House Sub. for SB 402 (2016)
KY	Yes	Yes	A	Must respond within 48 hours.	C	The prescribing practitioner shall have access to a clear and convenient process.	B	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, or if the drug is likely to be ineffective (3)	C	-	F	All state-regulated commercial plans	Must either approve or deny request	No	SB 114 (2012)
LA	Yes	Yes	A	Expediently	D	The prescribing physician shall be provided with and have access to a clear and convenient process to expeditiously request an override.	A	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, or if the drug is likely to be ineffective (3)	C	-	F	All state-regulated commercial plans and state Medicaid	Not specified	No	Act No. 312 (2013)
ME	Yes - effective January 2020	Yes	A	72 hours or two business days, whichever is less. In case of urgent situations, must respond within 24 hours.	A	The enrollee and providers have access to a clear, readily accessible and convenient process.	A	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, if the drug is likely to be ineffective, if the drug is not in the best interest of the patient, or if the patient is stable for the medical condition on a prescription drug (5)	A	-	F	All state-regulated commercial plans and state-employee health plans	Must either approve or deny request	No	HP 751 (2019)
MD	Yes	Yes	A	No timeline	F	Exception granted if the drug required by step therapy has not been approved by the FDA for the medical condition the patient has.	C	If the prescriber can prove that the patient is stable for a medical condition on a prescription drug in the past 180 days. (1)	D	-	F	All state-regulated commercial plans	Not specified	No	HB 1233 (2014)
MA	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
MI	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
MN	Yes	Yes	A	Must respond within five days, except in urgent situations, in which case must respond within 72 hours. If no response, request automatically granted.	A	Enrollees and prescribing health care providers shall have access to a clear, readily accessible and convenient process.	A	If the patient has already tried and failed the drug, if the drug is contraindicated or likely to cause an adverse reaction, or if the patient is already stable for the medical condition on a prescription drug (3)	C	-	F	All state-regulated commercial plans and public insurance market (including Minnesota Cares and Medical Assistance)	Not specified	No	HF 3196 (2018)
MS	Yes	Yes	A	Expediently	D	The prescribing practitioner shall have access to a clear and convenient process.	B	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, or if the patient has already tried and failed the drug (3)	C	-	F	All state-regulated commercial plans	Not specified	No	SB 2737 (2011)
MO	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	The patient and prescribing practitioner shall have access to a clear, convenient and readily accessible process.	A	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, if the patient has already tried and failed the drug, if the patient is stable for the medical condition on a prescription drug, or if the drug is not in the best interest of the patient (5)	A	-	F	All state-regulated commercial plans	Not specified	No	HB 2029 (2016)
MT	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
NE	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-

STEP THERAPY PROTECTIONS (CONTINUED)

STATE	Yes/No	Based on Clinical Practice	Grade for Clinical Practice	Timeline	Grade for Timeline	Exception Process	Grade for Exceptions Process	Categories of Exceptions	Grade for Exception	Subsequent Guidance from State	Grade for Guidance from State	Applicability	Response: grant/reject?	Provide Drug during Appeal Process?	Statutes/Proposed Legislation
NV	No	-	F	-	F	-	F		F	-	F	-	-	-	-
NH	No	-	F	-	F	-	F		F	-	F	-	-	-	-
NJ	No	-	F	-	F	-	F		F	-	F	-	-	-	-
NM	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	An enrollee and the practitioner prescribing the Rx drug shall have access to a clear, readily accessible and convenient exception process.	A	If the patient has tried and failed the drug, if the drug is contraindicated or likely to cause an adverse event, if the drug is expected to be ineffective, or if the drug is not in the best interest of the patient (4)	B	-	F	All state-regulated commercial plans, state employee health plans, and state Medicaid.	Must either approve or deny request	While exception request is pending, insurer must authorize continued coverage of the drug that is the subject of the exception request.	SB 11 (2018)
NY	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case an insurer must respond within 24 hours	A	Step therapy process for prescription drugs to be submitted in the same manner as a request for prior authorization for prescription drugs, and would require the plan or insurer to treat, and respond to, the request in the same manner as a request for prior authorization for prescription drugs.	A	If the patient has tried and failed the drug, if the drug is contraindicated or likely to cause an adverse event, if the drug is expected to be ineffective, or if the drug is not in the best interest of the patient (4)	B	Yes- FAQ	A	All state-regulated commercial plans, state employee health plans and state Medicaid.	Must either approve or deny request	No	A 2384 (2015)
NC	No	-	F	-	F	-	F		F	-	F	-	-	-	-
ND	No	-	F	-	F	-	F		F	-	F	-	-	-	-
OH	Yes -effective January 2020	Yes	A	Must respond within ten calendar days or in case of an emergency 48 hours.	A	Provider shall have access to a clear, easily accessible and convenient process, available on the issuer's website.	A	If the patient has tried and failed the drug, if the drug is contraindicated or likely to cause and adverse event, or if the patient is stable for the medical condition on a prescription drug (3)	C	-	F	All state-regulated commercial plans.	Must either approve or deny request	No	SB 265 (2019)
OK	Yes- effective Jan 2020	Yes	A	Must respond within 72 hours, or in case of emergent situation, 24 hours.	A	The health insurance plan provider shall provide to prescribing provider and patient access to a clear, convenient, and readily accessible process.	A	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, if the patient has already tried and failed the drug, if the patient is stable for the medical condition on a prescription drug, or if the drug is not in the best interest of the patient. (5)	A	-	F	All state-regulated commercial plans, state employee health plans, and state Medicaid.	Just response	No	SB 509 (2019)
OR	Yes	Yes	A	No timeline	F	A health care coverage plan that requires step therapy shall make clear explanations of the protocols and procedures easily accessible to prescribing practitioners.	B	No automatic exceptions.	F	-	F	All state-regulated commercial plans and state Medicaid	Not specified	No	HB 4013 (2014)
PA	No	-	F	-	F	-	F		F	-	F	-	-	-	-
RI	No	-	F	-	F	-	F		F	-	F	-	-	-	-
SC	No	-	F	-	F	-	F		F	-	F	-	-	-	-
SD	No	-	F	-	F	-	F		F	-	F	-	-	-	-
TN	No	-	F	-	F	-	F		F	-	F	-	-	-	-
TX	Yes	Yes	A	Must respond within 72 hours, except in urgent situations in which case must respond within 24 hours. If no response, request automatically granted.	A	Requires 60 days notification before the modification of a step therapy restriction becomes effective. Access to a convenient override procedure.	B	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, if the patient has already tried and failed the drug, if the patient is stable for the medical condition on a prescription drug, or if the drug is not in the best interest of the patient (5)	A	-	F	All state-regulated commercial plans	Must either approve or deny request	No	SB 680 (2017)

**STEP THERAPY PROTECTIONS (CONTINUED)**

STATE	Yes/No	Based on Clinical Practice	Grade for Clinical Practice	Timeline	Grade for Timeline	Exception Process	Grade for Exceptions Process	Categories of Exceptions	Grade for Exception	Subsequent Guidance from State	Grade for Guidance from State	Applicability	Response: grant/reject?	Provide Drug during Appeal Process?	Statutes/Proposed Legislation
UT	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-
VT	Yes	No	F	No timeline	F	Insurer may not require enrollees to fail the same medication more than once for continuously enrolled members.	F	If the patient has already tried and failed the medication (1)	D	-	F	All state-regulated commercial plans	All state-regulated commercial plans	No	H 107 (2013)
VA	Yes	Yes	A	Within 72 hours, except in emergency situations in which case 24 hours.	A	The patient and prescribing provider shall have access to a clear, readily accessible and convenient process.	A	The patient has already tried and failed the medication, the drug is contraindicated or likely to cause an adverse event, the drug is expected to be ineffective, or the patient is stable for the medical condition on a prescription drug (4)	B	-	F	All state-regulated commercial plans and state-employee health plans	All state-regulated commercial plans and state-employee health plans	No	H 2126 (2019)
WA	Yes - Effective Jan 2021	Yes	A	Within three days in non-urgent situations, within one business day in urgent situations.	A	The patient and prescribing practitioner must have access to a clear, readily accessible and convenient process.	A	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, if the patient has already tried and failed the drug, if the patient is stable for the medical condition on a prescription drug, or if the drug is not in the best interest of the patient (5)	A	-	F	All state-regulated commercial plans	All state-regulated commercial plans	Yes	Sub for HB 1879 (2019)
WV	Yes	Yes	A	No timeline	F	The patient and prescribing practitioner shall have access to a clear, convenient, and readily accessible process.	A	If the drug is contraindicated or likely to cause an adverse reaction, if the drug is expected to be ineffective, if the patient has already tried and failed the drug, if the patient is stable for the medical condition on a prescription drug, or if the drug is not in the best interest of the patient. (5)	A	-	F	All state-regulated commercial plans	All state-regulated commercial plans	No	HB 2300 (2017)
WI	Yes - effective Jan 2020	Yes	A	Within three days in non-urgent situations, within one business day in urgent situations.	A	Insurer, PBM, or utilization review organization shall provide access to a clear, readily accessible and convenient process to request an exception.	A	If the patient has already tried and failed the medication, if the drug is contraindicated or likely to cause an adverse event, if the drug is likely to be ineffective, or if the patient is stable for the medical condition on a prescription drug (4)	B	Yes	A	All state-regulated commercial plans and state-employee health plans	All state-regulated commercial plans and state-employee health plans	No	SB 26 (2019)
WY	No	-	F	-	F	-	F	-	F	-	F	-	-	-	-

Source:  
 National Psoriasis Foundation analysis of step therapy implementation in the states.  
<http://www.steptherapy.com/step-therapy-legislation-by-state/>

**PRESCRIPTION DRUG COST SHARING PROTECTIONS**

STATE	DRUG CAP		CO-PAY ONLY		Other Cost Sharing Prohibitions	Overall Grade	Statutes
	Type of Protection	Cost Limit	Yes/No	Requirement			
AL	No	--	No	--		F	
AK	No	--	No	--		F	SB 142 (2016)
AZ	No	--	No	--		F	HB 2078 (2014)
AR	No	--	No	--		F	HB 1592 (2017)
CA	Per-drug cap	\$250 dollar cap per prescription per month. \$500 per drug cap for Bronze plans	No	--		A	AB 339 (2015)
CO	Per-drug cap	Copay cannot be higher than 1/12th of the annual maximum out-of-pocket costs (MOOP) for a single drug	Yes	25% of plan designs in each metal tier are required to use a copayment structure for all drug tiers. Copay cannot be higher than 1/12th of the annual maximum out-of-pocket costs (MOOP) for a single drug	Requires oral parity for chemotherapy and no more than 50% of the drugs on a plan's formulary to treat a specific condition can be on the highest cost tier	A*	Bulletin B4.82 and Final Rule 4-2-58
CT	No	The Department will require that the maximum cost sharing allowed be calculated, for the overall plan of benefits and not specific categories of benefits, using the most recent CMS. CCIIO published AV Calculator.	No	--	Enrollee cost sharing amount shall never exceed 50% for the plan benefits provided and, for the individual and small group market, will continue to meet the standards of the ACA Metal Tiers.	A*	Bulletin HC-124
DE	Per-drug cap	\$100 cap per prescription per month. Only applies to specialty tier medications.	No	--	Cannot place all drugs of same class on a specialty tier. Requires oral parity for chemotherapy	B	SB 35 (2013)
DC	Per drug cap	Limits patient co-pay or co-insurance to \$150 per month per specialty drug up to a 30-day supply (\$300/90-day supply)	No	--	Cannot place all drugs of same on specialty tier	B	B21-0032 (2017)
FL	Chemo Only	\$50 cap for chemotherapy	No	--		D	Ch. 2013 -153
GA	Chemo Only	\$200 cap for chemotherapy	No	--		D	HB 943 (2014)
HI	None	--	No	--		F	HRS § 432:1-616 (2009)
ID	None	--	No	--		F	--
IL	None	--	No	--		F	HB 1825 (2011)
IN	None	--	No	--		F	--

**PRESCRIPTION DRUG COST SHARING PROTECTIONS (CONTINUED)**

STATE	DRUG CAP		CO-PAY ONLY		Other Cost Sharing Prohibitions	Overall Grade	Statutes
	Type of Protection	Cost Limit	Yes/No	Requirement			
IA	None	--	No	--		F	Senate File 478
KS	None	--	No	--		F	Ch 40-2, 184
KY	None	--	No	--		F	--
LA	Per drug cap and monthly cap	\$150 cap per prescription per month. Only applies to specialty tier medications. Separate law provides \$100 cap on chemotherapy. Annual cap of \$1,000 per individual, \$2,000 per family	No	--		B	SB 165 (2014)
ME	Annual Cap	Annual cap of \$3,500	No	--		A	LD 1691 (2012)
MD	Per-drug cap	\$150 cap per prescription per month. Only applies to specialty tier medications	No	--		B	HB 761 (2014)
MA	None	--	No	--		F	
MI	None	--	No	--		F	
MN	None	--	No	--		F	
MS	None	--	No	--		F	--
MO	Chemo Only	\$75 cap on orally administered anticancer treatment	No	--		D	SB 668 (2014)
MT	None	--	Yes	Each insurer is required to offer at least one plan with pharmacy benefits that are fixed dollar copayments for all tiers		A	Insurance commissioner action
NE	None	--	No	--		F	--
NV	None	\$100 cap for orally administered anticancer treatment per prescription	No	--		F	Senate Bill 266 (2013)
NH	None	--	No	--		F	HB 508 (2015)
NJ	None	--	No	--		F	AB 4520 (2012)
NM	None	--	No	--		F	Ch 59 Article 22
NY	Per drug cap	\$70 cap per prescription for plans following standard benefit design	No	--	Prohibits cost-sharing in excess of the cost-sharing, deductibles or coinsurance for non-preferred drugs or their equivalent. Separate law requires oral parity for chemotherapy	A	S. 5000 (2010)
NC	None	--	No	--		F	--

**PRESCRIPTION DRUG COST SHARING PROTECTIONS (CONTINUED)**

STATE	DRUG CAP		CO-PAY ONLY		Other Cost Sharing Prohibitions	Overall Grade	Statutes
	Type of Protection	Cost Limit	Yes/No	Requirement			
ND	None	--	No	--		F	Chapter 26 1-36
OH	None	\$100 cap on chemotherapy per prescription, per month for privately insured	No	--		F	SB 99 (2014)
OK	Chemo Only	\$100 per filled prescription for orally administered anticancer medication	No	--		F	SB 765 (2014)
OR	None	--	No	--		F	Chapter 743A.068
PA	None	--	No	--		F	HB 60
RI	None	--	No	--		F	H 5354 (2013)
SC	None	--	No	--		F	--
SD	None	--	No	--		F	SB 101 (2015)
TN	None	--	No	--		F	--
TX	None	--	No	--		F	Code 1369.204 (2012)
UT	Chemo Only	\$300 cap on chemotherapy	No	--		D	SB 189 (2013)
VT	Annual Cap	Annual cap of \$1,300 per individual, \$2,600 per family. Cap linked to IRS inflation adjustments	No	--		A	H. 559 (2012)
VA	None	-	No	--		F	SB 383 (2017)
WA	None	-	No	--		F	Chapter 48.46.274 (2012)
WV	None	-	No	--		F	HB 2493 (2015)
WI	Chemo Only	\$100 cap on chemotherapy	No	--		D	Act 186 (2013)
WY	None	--	No	--		F	WY Stat § 26-20-601 (2016)

Source:

SAIM Legislation by State.  
<https://www.saimcoalition.org/saim-legislation-by-state/>

DESCRIPTION	
GRADE	Prescription Drug Cost Sharing Protections
A	State has a total cap or per-drug cap on Rx cost sharing that applies to all Rx drugs
B	State has a total cap or per-drug cap on cost sharing for specialty-tier drugs only
C	The state has cost sharing limits for a small number of treatments
D	State only limits cost sharing for chemotherapy
F	State does not have a cap on cost sharing

NEWBORN SCREENING

STATE	Region	Number of Screens	Second Screening Age	Number of Core Conditions/ Total Number	Screening Grade	RUSP Auto-Inclusion/Add Conditions	Pilot Studies Required	Time Frame of Implementation	Adding Screens Grade	Fee 1/2	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age	Data Retention	Data Retention Time	DBS Retention Time	Research of DBS	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	DBS Use Grade	Short-Term Follow-up	Long-Term Follow-up	Follow-up in Statute and/or Regs	Follow-up Grade	Quality in Statute/Regulation	Quality Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Statute	Regulation	Lab	Fiscal Note	Website	Additional Notes
AL	Southeast NBS & Genetics Collaborative (SERC)	2 (not mandated)	2-6 weeks	31/45	F	Department can add "other heritable disorders"	Yes	"As recommended and approved by administration and advisory council"	B	\$150	The newborn screening fee shall be set by the State Committee of Public Health based on the schedule of laboratory fees established by the Centers for Medicare and Medicaid Services (CMS) for use by Medicare and Medicaid.	General funds	General funds	B	48	Yes	20 or more	3 months	No	N/A	N/A	Religious waiver	F	Until baby is on treatment	Yes	Services include health assessments, treatment, and referrals to tertiary care centers.	B	No	D	Yes (ANSAC)	Annually	Yes	Consultants, physicians, parents, lab and followup staff, MOD, Sickle Cell Foundation	C	§ 22-20-3	420-10-1	Alabama Bureau of Clinical Laboratories		<a href="http://www.alabamapublichealth.gov/newbornscreening/">http://www.alabamapublichealth.gov/newbornscreening/</a>	
AK	Western States Genetic Services Collaborative (WSGSC)	1	N/A	31/53	F	"Other conditions may be tested for if the designated laboratory has a test method suitable to the department."	No	None	B	159.50 and 100 for non-requested repeats	7 ACC 80.030 & Sec.44.29.022: The Commissioner may establish fee through regulation (cannot be higher than the cost of administering the service, which the Commissioner can define)	Department of Health and Social Services	N/A	B	24-48	Yes	16-20 for normal, 20 or more for abnormal	3 years	No	N/A	N/A	Personal or Religious waiver	C	Until diagnosis is made/ruled out	No	No, except for PKU; "The department will provide the child's health care provider with a consultation with an appropriate medical specialist for a newborn child undergoing diagnostic testing due to abnormal screening results."	C	No	D	Yes	Semi-annually	Yes	Specialists, pediatricians, family practice, OB/GYN, direct entry midwives, families, hospital lab staff, hospital L&D/MBU staff, state NBS staff, regional lab staff, couriers	A	Sec. 18.15.200	7 ACC 27.510			<a href="http://dhss.alaska.gov/dph/wcfh/Pages/bloodspot/default.aspx">http://dhss.alaska.gov/dph/wcfh/Pages/bloodspot/default.aspx</a>	
AZ	Mountain States Genetics Regional Collaborative (MSGRC)	2	5-10 days	31	F	Director can add based on recommendations from the Advisory Committee that must include a cost-benefit analysis	No	None	B	\$36 for initial screen fee and \$65 for second screen fee	Director can establish fee by rule, but the fee for the first screen cannot exceed \$36.	NBS fund	General funds (appropriations) and Title V	B	24-36	Yes	20 or more	3 months (specimens of interest may be kept indefinitely)	QA/QC	No	N/A	Submitter must supply education to family. If after education is provided, the family refuses screen, a waiver must be signed and kept by the hospital and the lab.	B	Until diagnosis is made/ruled out	No	Yes "If tests conducted pursuant to this section indicate that a newborn or infant may have a hearing loss or a congenital disorder, the screening program shall provide follow-up services to encourage the child's family to access evaluation services, specialty care and early intervention services"	C	Yes- ""The director of the department of health services shall establish a newborn screening program within the department to ensure that the testing for congenital disorders and the reporting of hearing test results required by this section are conducted in an effective and efficient manner."	C	Yes	At least annually (met twice in 2018)	Yes	7 physicians, including endocrinology, pediatrics, neonatology, family practice, otology, and obstetrics; neonatal nurse practitioner; audiologist; parent of child with disorder; rep from insurance; director of Medicaid program; rep from hospital	B	Sec 36-694	R9-13-201 through R9-13-208			<a href="https://azdhs.gov/preparedness/state-laboratory/newborn-screening/index.php">https://azdhs.gov/preparedness/state-laboratory/newborn-screening/index.php</a>	
AR	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	31/ 32	C	"if reliable and efficient testing techniques are available, all newborn infants shall be tested for other genetic disorders by employing procedures approved by the State Board of Health"	No	None	B	121	Board of Health may determine the amount based on the Department's cost to process the specimens	NBS fund	N/A	A	24-72	Yes	20 or more	2 years	Research purposes and QA/QC	N/A	Yes	Parents can opt out for religious, medical, or philosophical reasons.	A	Until the baby receives diagnosis and treatment	Yes	All newborns with an abnormal screen receive appropriate medical follow-up.	B	No	D	Yes	Every quarter	Yes	Arkansas Newborn Screening Program	B	20-15-301	R 007.16.07-001			<a href="https://www.healthy.arkansas.gov/programs-services/topics/faqs-for-parents">https://www.healthy.arkansas.gov/programs-services/topics/faqs-for-parents</a>	



**NEWBORN SCREENING (CONTINUED)**

STATE	Region	Number of Screens	Second Screening Age	Number of Core Conditions/ Total Number	Screening Grade	RUSP Auto-Inclusion/Add Conditions	Pilot Studies Required	Time Frame of Implementation	Adding Screens Grade	Fee 1/2	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age	Data Retention	Data Retention Time	DBS Retention Time	Research of DBS	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	DBS Use Grade	Short-Term Follow-up	Long-Term Follow-up	Follow-up in Statute and/or Regs	Follow-up Grade	Quality in Statute/Regulation	Quality Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Statute	Regulation	Lab	Fiscal Note	Website	Additional Notes
CA	Western States Genetic Services Collaborative (WSGSC)	1	N/A	34/63	B	"The department shall expand statewide screening of newborns to include screening for adrenoleukodystrophy (ALD) and any other disease that is detectable in blood samples as soon as practicable, but no later than two years after the disease is adopted by the federal Recommended Uniform Screening Panel (RUSP), or enrollment of the act amending this subdivision, whichever is later."	No	2 years	A	141.25	Established and periodically adjusted by Director	NBS fund	N/A	A	12 to 48 hours	Yes	20 or more	Indefinitely	Research purposes and QA/QC	Yes	No	Religious waiver	A	Until diagnosis is made/ruled out and on treatment if needed	Yes	"shall refer the infant to a CCS center or a CCS paneled medical specialist for confirmatory testing and/or evaluation, diagnosis, and treatment"; "The Department shall collect a fee for each specimen record form provided and a program participation fee for all services provided."	A	"shall perform laboratory services, including, but not limited to, quality control, confirmatory, and emergency testing, necessary to ensure the objectives of this program"	A	No	N/A	N/A	California Newborn Screening Program	D	HSC.Division 106. Part 5. Ch 1. Article 2.	17.1.4.9.3			<a href="https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/nbs/default.aspx">https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/nbs/default.aspx</a>	
CO	Mountain States Genetics Regional Collaborative (MSGRC)	2	8-14 days	31/44	C	If the Department deems that a new condition should be added, it must report to the General Assembly.	No	None	D	111/0	The Executive Director of the Department of Public Health and Environment shall assess a fee that is sufficient to cover the direct and indirect costs.	NBS fund	N/A	A	by 48 hours	Yes	3 to 5	6 months	No	N/A	N/A	Personal objection	F	Until diagnosis is made/ruled out	Yes	"The state board shall promulgate rules to establish and maintain appropriate follow-up services on positive screen cases in order that measures may be taken to prevent death or intellectual or other permanent disabilities"	B	"The Laboratory shall have available for review a written quality assurance program plan covering all aspects of laboratory activity."	B	Yes	Quarterly	Yes	Must consist of at least nine members. The executive director of the department shall appoint members to the advisory committee. Members appointed to the committee must have training, experience, or interest in the area of hearing loss in children and should include representatives from rural and urban areas of the state, a parent who has a child with hearing loss, a representative of a patient and family support organization, a representative of a hospital, a representative from an organization representing culturally deaf persons, an American sign language expert who has experience in evaluation and intervention of infants and young children, and physicians and audiologists with specific expertise in hearing loss in infants.	B	25.4.1001-06	5 CCR 1005-4	Mandates lab hours to a minimum of 6 days a week every week		<a href="https://www.colorado.gov/pacific/cdphe/newbornscreening">https://www.colorado.gov/pacific/cdphe/newbornscreening</a>	<a href="https://leg.colorado.gov/sites/default/files/">https://leg.colorado.gov/sites/default/files/</a>
CT	New England Genetics Collaborative (NEGC)	1	N/A	32/65	B	Must be added legislatively	Yes	None	B	110	The Commissioner of Public Health sets the fees to be charged to cover all expenses of the program (including testing, tracking, and treatment). There is a floor of \$98.	General funds	N/A	A	24-48 (as soon as medically appropriate)	Yes	3 to 5	3 years	QA/QC	N/A	N/A	Religious waiver	B	Short-term follow-up performed by Nurse Consultants and Epidemiologist I	Yes	"The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover all expenses of the comprehensive screening program including testing, tracking and treatment."	A	Tests shall be performed by methods approved by the Department of Public Health.	C	Yes	Semi-annually	Yes	The Connecticut Newborn Screening Genetic Advisory Committee (GAC) is composed of geneticists, endocrinologists, hematologists, and immunologists from Yale, CCMC, and UCONN Health Center as well as representatives from CT birth hospitals, NICUs, patient advocacy groups and the CT NBS Program.	B	19a.368a.Sec 19a-55.	Sec 19a-55-1			<a href="https://portal.ct.gov/DPH/Laboratory/Newborn-Screening/Newborn-Screening-Program">https://portal.ct.gov/DPH/Laboratory/Newborn-Screening/Newborn-Screening-Program</a>	<a href="https://www.cga.ct.gov/2019/ACT/pa/pdf/2019PA-00117-R00HB-07424-PA.pdf">https://www.cga.ct.gov/2019/ACT/pa/pdf/2019PA-00117-R00HB-07424-PA.pdf</a>

NEWBORN SCREENING (CONTINUED)

STATE	Region	Number of Screens	Second Screening Age	Number of Core Conditions/ Total Number	Screening Grade	RUSP Auto-Inclusion/Add Conditions	Pilot Studies Required	Time Frame of Implementation	Adding Screens Grade	Fee 1/2	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age	Data Retention	Data Retention Time	DBS Retention Time	Research of DBS	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	DBS Use Grade	Short-Term Follow-up	Long-Term Follow-up	Follow-up in Statute and/or Regs	Follow-up Grade	Quality in Statute/Regulation	Quality Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Statute	Regulation	Lab	Fiscal Note	Website	Additional Notes
DE	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	2	7-28 days	31/52	C	Director of the Division of Public Health	No	None	B	135	The fee is determined annually in July based on the cost of the program.	NBS fund	N/A	A	24-72	Yes	20 or more	3 years	"will only be used for activities to improve the screening program and/or develop new screening tests"	No	No*	Parental choice	A	Until diagnosis is made/ruled out. **Lab and follow-up program are on call 24/7	Yes	"The Newborn Screening Program shall contact with abnormal results the parent or legal guardian and primary health care provider in writing and/or by telephone."	B	No	D	Yes	Every quarter	Yes	The Advisory Committee consists of 3 individuals or parents of individuals affected by disorders identified by the screening panel; an ethicist; an attorney not employed by the state of Delaware; 3 pediatric physicians; the Medical Director of the Division of Public Health; the Laboratory Director for the Division of Public Health; a representative from the Department of services for Children, Youth and their Families; the Chair of the Midwifery Council; and a member of the general public.	A	16 Dec.C. §122.1 & 122.3, 29 Del.C. §7904	Title 16, 4107, sections 1.0-11.0			<a href="https://www.nemours.org/services/support/naidhsupport/newborn-screening.html">https://www.nemours.org/services/support/naidhsupport/newborn-screening.html</a>	<a href="https://delcode.delaware.gov/title16/c008c/">https://delcode.delaware.gov/title16/c008c/</a>
DC	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	1	N/A	33/62	B	Mayor may, upon the advice of the Committee on Metabolic Disorders, issue rules pursuant to subchapter 1 of Chapter 5 of Title 2, requiring that hospitals and maternity centers make screening tests available for additional metabolic disorders.	N/A	N/A	B	0	N/A	Title V funds	Title V funds, appropriations	C	24-48	N/A	N/A	1 year	N/A	No	N/A	Consent is implied	D	Until diagnosis is made/ruled out; 1 FTE that does follow-up of abnormal screens	No	No	C	"regularly participates in the appropriate quality control program for such testing by the College or is currently certified by the United States Center for Disease Control and regularly participates in the appropriate quality control program for such testing by the Center or has a federal license under the Clinical Laboratories Improvement Act of 1967"	B	Yes (see additional notes)	N/A	Yes	The members of the Committee include subject matter experts from multiple health care systems and residents with direct experience who choose to serve the District voluntarily and who have a deep commitment to newborns and families.	B	Ch. 8B § 7-858.02	22.22-B21			<a href="https://dhealth.dc.gov/service/newborn-screening">https://dhealth.dc.gov/service/newborn-screening</a>	<a href="https://dhealth.dc.gov/release/notice-establishment-district-columbia-committee-metabolic-disorders">https://dhealth.dc.gov/release/notice-establishment-district-columbia-committee-metabolic-disorders</a>
FL	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	31/55	C	Newborns are tested for any condition included on the RUSP that the Council advises the Department should be included	No	After the Council makes its recommendation, the state has 18 months to implement if there is already a test in existence.	B	0	Department of Health has the authority to charge and collect fees (not to exceed \$15 for each live birth). Must also submit a certification of the annual cost in the budget request. The addition of a new condition must come with a legislative budget request for appropriations.	NBS fund	Newborn Screening services in Florida are jointly funded through a \$15.00 fee paid by birthing facilities for each live birth and the billing of the newborn screening tests performed by the Florida Newborn Screening Laboratory. Medicaid and private insurance companies are billed for the newborn screening tests. The Florida Newborn Screening Program does not bill families without insurance coverage.	B	24-48	Yes	6-10	6 months	QA/QC, use specimens for internal purposes (i.e. repeats)	No	No	Parents can object for any reason. There must be a written record.	B	Until diagnosis is made/ruled out	No	"Maintain a confidential registry of cases, including information of importance for the purpose of followup services to prevent intellectual disabilities, to correct or ameliorate physical disabilities, and for epidemiologic studies, if indicated. Such registry shall be exempt from the provisions of s. 119.07(1)."	C	"Assure the availability and quality of the necessary laboratory tests and materials."	A	Yes	At least semi-annually or upon call of the chairperson	No	15 members appointed by the State Surgeon General. The council shall be composed of two consumer members, three practicing pediatricians, at least one of whom must be a pediatric hematologist, one representative from each of the four medical schools in the state, the State Surgeon General or his or her designee, one representative from the Department of Health representing Children's Medical Services, one representative from the Florida Hospital Association, one individual with experience in newborn screening programs, one individual representing audiologists, and one representative from the Agency for Persons with Disabilities. All appointments shall be for a term of 4 years.	B	383.14	64C-7.001 through 64C7.012			<a href="http://www.floridahealth.gov/programs-and-services/childrens-health/newborn-screening/">http://www.floridahealth.gov/programs-and-services/childrens-health/newborn-screening/</a>	

NEWBORN SCREENING (CONTINUED)

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GA	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	32	B	Commissioner of Public Health can change the panel listed in regulation. In doing so, the Commissioner may seek the guidance of the Advisory Committee	No (but there is a feasibility study)	None	C	63	Department regulation	General funds	N/A	C	24-48	Yes	2 years or less	2 months to 2 years	Yes and QA/QC	Yes (may do so after 12 weeks, in writing)	Yes	Religious beliefs	A	Until baby is on treatment	No	"In the event of an abnormal test result from the NBS Card, the appropriate newborn screening follow-up provider shall notify the baby's physician or healthcare provider, and the parent or legal guardian, in accordance with the Georgia Newborn Screening Policy and Procedure Manual."	C	Yes	A	Yes	Semi-annually	Yes	Physicians and patient organization representatives/patient advocates	A	O.C.G.A. 31-12-2, 31-1-3.2	Chapter 511-5-5			<a href="https://dph.georgia.gov/NBS">https://dph.georgia.gov/NBS</a>	
HI	Western States Genetic Services Collaborative (WSGSC)	1	N/A	31/48	C	Any other disease that may be specified by the Department	Yes	None	B	99 (repeat screen is 41)	The Department of Health	NBS fund	N/A	A	24-48	Yes	6-10	1 year	QA/QC	No	Consent is implied	Religious beliefs	B	Until baby is on treatment	Yes	"Guidelines for care, treatment, and follow up of infants with positive test results;"	B	11-143-9 Laboratory Responsibilities	A	Yes	Semi-annually	No	Medical staff, state staff, parents, community agencies	B	HRS 6-321-291	HAR 11-143			<a href="http://health.hawaii.gov/genetics/programs/nbshome/">http://health.hawaii.gov/genetics/programs/nbshome/</a>	
ID	Western States Genetic Services Collaborative (WSGSC)	2	7-14 days	31/48	C	Phenylketonuria and such other tests for preventable diseases as prescribed by the State Board of Health and Welfare (the Director - 39-910)	No	None	B	100/0	Department regulation of fees	NBS fund	Title V funds	A	24-48	No	16-20	18 months	No	No	N/A	Religious beliefs	C	Until baby is on treatment	No	"report positive or suspicious results...to the person who registered the infant's birth, and make recommendations on the necessity of follow-up testing."	C	"All laboratories receiving dried blood specimens for newborn screening on infants born in Idaho must participate in the Newborn Screening Quality Assurance Program operated by the CDC."	A	Yes	Quarterly	Yes	Informal Stakeholders Committee. Currently committee of stakeholders includes: Idaho NBS Program Team; Dr. Perry Brown - CF Specialist; Dr. Leah Fleming - Metabolic Specialist; Dr. Ingrid Lundgren - Immune Deficiency Specialist	B	ID Stat. 39-909 through 910	IAC 16-02-12			<a href="https://healthandwelfare.idaho.gov/Children/NewbornScreening/tabid/870/Default.aspx">https://healthandwelfare.idaho.gov/Children/NewbornScreening/tabid/870/Default.aspx</a>	
IL	The Region 4 Genetics Collaborative (Region 4)	1	N/A	34/64	B	Tests for genetic, metabolic, and congenital anomalies as the Department may deem necessary	Yes	No formal time frame	B	118	The Department may levy additional fees according to such structure to cover the cost of providing this testing service and for the follow-up of infants with an abnormal screening test; however, additional fees may be levied no sooner than 6 months prior to the beginning of testing for a new genetic, metabolic, or congenital disorder.	NBS fund	N/A	A	24-48	Yes	20+	2-6 months	QA/QC	No	N/A	Religious beliefs	B	Until diagnosis is made/ruled out	Yes	Maintain a registry of cases, including information of importance for the purpose of follow-up services to assess long-term outcomes, Supply the necessary metabolic treatment formulas where practical for diagnosed cases of amino acid metabolism disorders, including phenylketonuria, organic acid disorders, and fatty acid oxidation disorders for as long as medically indicated, when the product is not available through other State agencies.	A	CLIA	B	Yes	Semi-annually	No	Specialists for all disorders; parents; other organizational liaisons; pediatricians; local health department nurses; and state newborn screening laboratory and follow-up staff	A	410 ILCS 240	ILAC 77.1i:661			<a href="http://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening">http://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening</a>	

NEWBORN SCREENING (CONTINUED)

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IN	Region 4	1	N/A	32/53	B	"Disorders detected by tandem mass spectrometry or other technologies with the same or greater detection capabilities as tandem mass spectrometry, if the state department determines that the technology is available for use by a designated laboratory under section 7 of this chapter" or "Inborn errors of metabolism that result in an intellectual disability and that are designated by the state department" or by legislation	No	None	B	100 (410 IAC 3-3-13)	"The state department shall set the fee and procedures for disbursement under rules adopted under IC 4-22-2. The fee must be based upon the projected cost of the program. The proposed fee must be approved by the budget agency before the rule is adopted."	NBS fund	N/A	A	24-48	Yes	20 or more	6 months without consent or 3 years with consent	Yes	No	Yes	Religious waiver	A	Until confirmatory testing	Yes, follow and provide care for patients through age 3.	Yes; "Sec. 10. (a) The state department shall develop the following: ... (2) A centralized program that provides follow-up, diagnosis, management, and family counseling and support, including equipment, supplies, formula, and other materials, for all infants and individuals identified as having one (1) of the disorders listed in section 2 of this chapter..."	A	"Yes; ""An approved laboratory must meet the following requirements in order to perform screening tests for disorders on dried blood samples from newborns or infants: (1) Complies with Public Law 90-174, the Federal Clinical Laboratory Improvement Act of 1988, and is accredited by the College of American Pathologists, or is accredited by the Joint Commission on Accreditation of Hospitals... (8) Maintains a written quality assurance program covering all aspects of its newborn screening activity, which is approved yearly by the department"	A	Yes	Monthly	Yes	Indiana Perinatal Genetics and Genomics Advisory Committee: the first task force meeting took place in December 2018 with participants from many groups, including geneticists, OB/GYNs, neonatologists, pediatricians, genetic counselors, disease specialists, laboratory specialists, Family and Social Services Administration, advocacy representatives, as well as local representatives from American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American College of Medical Genetics and Genomics, and others.	A	IC 16-41-17	3-3-1 through 3-3-14		http://iga.in.gov/legisla-	https://www.in.gov/isdh/27870.htm	
IA	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	31/53	C	"All newborns and infants born in the state of Iowa shall be screened for all congenital and inherited disorders specified by the center and approved by the state board of health."	Yes	No formal time frame	B	122	"The department shall annually review and determine the fee to be charged for all activities associated with the INSP. The review and fee determination shall be completed at least one month prior to the beginning of the fiscal year."	NBS fund	N/A	A	24	Yes	20+	5 years	Research purposes, QA/ QC purposes, Forensic uses by court order	No	Yes	Any reason	A	Until diagnosis is made/ruled out	Yes	"Follow-up programs shall be available for all individuals identified by the newborn screening as having an abnormal screen result." "The follow-up activities shall include care coordination, consultation, recommendations for treatment when indicated, case management, education and quality assurance."	A	"Yes; ""Develop specifications for and designate a central laboratory in which tests conducted pursuant to the screening programs provided for in subsection 1 will be performed."" Report to include ""results of quality assurance testing including any updates to the INSP quality assurance policies"""	A	Yes	Quarterly	Yes	Membership is nominated from list of specific agencies and organizations. Members appointed by director of IDPH	B	IC 0 136A	IAC 641.4			https://idph.iowa.gov/newborn-screening	

NEWBORN SCREENING (CONTINUED)

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KS		1	N/A	31	C	The Secretary of Health and Environment shall adopt rules and regulations as needed to require, to the extent of available funding, newborn screening tests to screen for treatable disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American college of medical genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System"	Yes	No formal time frame	B	0	No fee collected	No fee collected	State funded NBS fee fund	B	24-48	Yes	20+	30 days (confirmed cases are de-identified and stored indefinitely)	QA/QC	No	N/A	Religious beliefs	B	Until confirmatory testing is performed	Yes	Provide a follow-up program by providing test results and other information to identified physicians; locate infants with abnormal newborn screening test results; with parental consent, monitor infants to assure appropriate testing to either confirm or not confirm the disease suggested by the screening test results; with parental consent, monitor therapy and treatment for infants with confirmed diagnosis of congenital hypothyroidism, galactosemia, phenylketonuria or other genetic diseases being screened under this statute; and establish ongoing education and support activities for individuals with confirmed diagnosis of congenital hypothyroidism, galactosemia, phenylketonuria and other genetic diseases being screened under this statute and for the families of such individuals. Maintain a registry.	A	As indicated on the form with DBS collection kit	B	Yes	Semi-annually	No	Physicians, a genetic counselor, patient advocates, a dietician, a hospital association representative, and an ethicist.	B	Kansas Stat. 65.180	KAR 28:4:501 through 521			<a href="http://www.kdheks.gov/newborn_screening/index.html">http://www.kdheks.gov/newborn_screening/index.html</a>	
KY	The Region 4 Genetics Collaborative (Region 4)	1	N/A	35/59	A	"Tests for inborn errors of metabolism or other inherited or congenital disorders and conditions for newborn infants as part of newborn screening shall be consistent with the U.S. Department of Health and Human Services' Recommended Uniform Screening Panel"	Yes	No formal time frame	A	123	The Secretary of the Cabinet of Health	NBS fund	Agency funds as needed	A	24-48	No	N/A	3 months	No	No	N/A	Religious beliefs	F	Until diagnosis is made/ruled out	No	(10) Submitters that are responsible for the collection of the initial blood spot specimen and pulse oximetry testing for newborn screening shall: (a) Provide to an infant's parent or guardian educational materials regarding newborn screening and pulse oximetry testing; (b) Designate a newborn screening coordinator and physician responsible for the coordination of the facility's newborn screening compliance by having a newborn screening protocol;	C	"a qualified laboratory means a clinical laboratory not operated by the cabinet that is accredited pursuant to 42 U.S.C. sec. 263a, licensed to perform newborn screening testing in any state, and reports its screening results using normal pediatric reference ranges"	C	Yes	Every other month	Yes	Lab and follow-up; university specialists and dietician; university lab personnel; genetic counselors	B	KRS 214.155	902 KAR 4:030			<a href="https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/newborn-screening.aspx">https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/newborn-screening.aspx</a>	

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LA	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	31/34	C	The Louisiana Department of Health shall, after consultation with medical geneticists from each of the state's medical schools and by rule adopted in accordance with the Administrative Procedure Act, add to the genetic conditions tested for in Subsection A of this Section; however, no approved test for any genetic condition added shall be given to any child whose parents object thereto.	No	No formal time frame	C	30	No information	NBS fund	General funds, Medicaid	B	Greater than 24 hours	Yes	20+	1 month	Yes and QA/QC purposes	No	Yes	Any reason	A	Until diagnosis is made/ruled out and/or baby is on treatment	Yes	The Louisiana Department of Health and the other state departments and agencies cooperating with it shall, in cooperation with the attending physician, provide for the continued medical care, dietary, and other related needs of such children where necessary or desirable.	A	Yes; "B.(1) The Louisiana Department of Health shall establish and maintain a diagnostic laboratory for each of the following purposes: (a) Conducting experiments, projects, and other undertakings as may be necessary to develop tests for the early detection of phenylketonuria, congenital hypothyroidism, galactosemia, sickle cell diseases, biotinidase deficiency, and other genetic conditions."	A	Yes	Annually	No	There shall be representation from all medical schools within the state. The disciplines of genetics, pediatrics, obstetrics, and hematology shall be represented. Representation from OPPHS shall include but not be limited to nutrition, laboratory, social work, handicapped children's services, maternal and child health and the physicians connected with these programs. There shall be two consumer representatives.	C	LA Rev Stat 40:1081	LAC 48 Part V Book 2 of 2 CH 63				<a href="http://ldh.la.gov/index.cfm/page/470">http://ldh.la.gov/index.cfm/page/470</a>	
ME	New England Genetics Collaborative (NEGC)	1	N/A	31/55	C	The Department will consider changes in conditions to be screened as requested by the Joint Advisory Committee, the medical community or the public. The Department reviews the recommendations from the Advisory Committee on Heritable Disorders in Newborns and Children and the Recommended Uniform Screening Panel (RUSP), and data from medical experts and other newborn screening programs, when considering a new condition. Rule-making to add conditions will be conducted in accordance with 5 MRS §§ 8001-11008.	No	No formal time frame	C	110	Commissioner	NBS fund	N/A	A	24-48	Yes	20+	Indefinitely	QA/ QC purposes (released only with parental consent)	Yes	Yes	Religious beliefs	B	Until the baby is on treatment	Yes	"Follow-up programs for newborn testing, with emphasis on the counseling and education of women at risk for maternal phenylketonuria (PKU);"	B	Defined by the Department	C	Yes	Semi-annually	Yes	Parents, representatives from hospitals, genetic counselors, specialists, nurses, state staff, NICU representatives, family advocate, and specialty clinic coordinator	B	MRS 22:2:3:261	Rule 10 144c283				<a href="https://www.maine.gov/dhhs/mecdc/population-health/cshn/bloodspot-screening/">https://www.maine.gov/dhhs/mecdc/population-health/cshn/bloodspot-screening/</a>	

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MD	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	2	7 days	34/61	B	Determined by the Department of Health (statute)	No	No formal time frame	B	106	The Secretary	NBS fund	N/A	A	Collected at the hospital after the baby has been eating for at least 24 hours (or the latest possible time before the baby is discharged)	Yes	20+	25	Yes	No	No	Religious beliefs	A	Until diagnosis is made/ruled out	Yes	""Coordinating the reporting, follow-up, and treatment activities with parents, caregivers, and health care providers;""	A	"Laboratory Oversight. The Department shall ensure that a laboratory holding a permit to offer or perform first-tier, supplemental, or second-tier tests to identify congenital and hereditary disorders in newborn infants is subjected to regulatory oversight that includes surveys and proficiency testing as set forth in: (1) COMAR 10.10.02; and (2) COMAR 10.10.05."	A	Yes	Quarterly	Yes	#VALUE!	B	Code of Maryland Article Health General 13-101 through 112	CoMar 10-52-12			<a href="https://health.maryland.gov/laboratories/Pages/Newborn-Screening.aspx">https://health.maryland.gov/laboratories/Pages/Newborn-Screening.aspx</a>	
MA	New England Genetics Collaborative (NEGC)	1	N/A	32/66	B	Conditions determined by Commissioner	No	No formal time frame	B	133.9	Newborn Screening Program	NBS fund	N/A	A	24-48	Yes	20+	15	Yes and QA/QC purposes	No	Yes	Religious beliefs	A	Until the baby is on treatment	Yes	""Yes; ""a reasonable charge for the testing of newborns for those diseases or disorders screened for pursuant to 105 CMR 270.006 and for notification and follow-up to ensure treatment of affected newborns""	A	"For the purposes of quality assurance, quality improvement and ongoing evaluation of the effectiveness of the Newborn Blood Screening Program, including the determination of those disorders and diseases that should be included in the Department's Newborn Blood Screening Program, the health care provider shall report to the Newborn Blood Screening Program"	A	Yes	Annually	No	Membership of the committee shall include, but not be limited to, parents and other consumers, practicing pediatricians, public health officials, neonatologists, obstetricians, clinicians and researchers specializing in newborn diseases and disorders, clinical geneticists, birth hospital representatives, Newborn Blood Screening Program professionals, medical ethicists, and other experts as needed to represent a variety of related fields such as emerging technologies and health insurance.	C	General Laws I, XVI, 111, 110A	105 CMR 270			<a href="https://nensp.umassmed.edu/">https://nensp.umassmed.edu/</a>	

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MI	The Region 4 Genetics Collaborative (Region 4)	1	N/A	33/57	B	Conditions determined by the Department	No	No formal time frame	B	135.29	Health department	NBS fund	N/A	A	24-30	No	N/A	Up to 100 years	Yes and QA/ QC purposes	No	Yes	None	A	Until diagnosis is made/ruled out	Yes	No; "the results shall be reported to the infant's parents, guardian, or person in loco parentis. A person is in compliance with this subsection if the person makes a good faith effort to report the positive test results to the infant's parents, guardian, or person in loco parentis."	B	Be consistent with nationally recognized standards for laboratory accreditation and federal law.	C	Yes	Annually	No	10 member Quality Assurance Advisory Committee represents specified stakeholders	C	MI Public Health Code 333.5431	None				https://www.michigan.gov/md-	
MN	The Region 4 Genetics Collaborative (Region 4)	1	N/A	35/61	A	Conditions determined by State Board of Health	No	No formal time frame	B	150	Subject to legislature	NBS fund	N/A	B	24-48	Yes	20+	Indefinitely for specimens collected after August 1, 2014	With the written, informed consent of a parent or legal guardian, the Department of Health may use blood samples and test results for public health studies or research not related to newborn screening, and upon approval by the Department of Health's Institutional Review Board, share samples and test results with external parties for public health studies or research.	Yes	Yes	Any reason	A	Until diagnosis is made/ruled out	Yes	"Testing, recording of test results, reporting of test results, and follow-up of infants with heritable congenital disorders, including hearing loss detected through the early hearing detection and intervention program in section 144.966, shall be performed at the times and in the manner prescribed by the commissioner of health." Provide medical nutrition for some.	A	"laboratory quality control assurance and improvement"; "collection of information on the efficacy and reliability of various tests for heritable and congenital disorders"	A	Yes	Semi-annually	Yes	"Membership of the committee shall include, but not be limited to, at least one member from each of the following representative groups: (1) parents and other consumers; (2) primary care providers; (3) clinicians and researchers specializing in newborn diseases and disorders; (4) genetic counselors; (5) birth hospital representatives; (6) newborn screening laboratory professionals; (7) nutritionists; and (8) other experts as needed representing related fields such as emerging technologies and health insurance"	A	MN Statutes 144.125	MAR 4615.0300 through 0760			http://www.health.state.mn.us/newborn-screening/		
MS	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	32/63	B	"specified by the State Board of Health and as recommended by the American Academy of Pediatrics"	No	No formal time frame	B	110	State health officer	General funds	N/A	B	24-48	No	N/A	1 year	No	No	N/A	Religious beliefs	D	Until diagnosis is made/ruled out	Yes	"The Newborn Screening Program will be responsible for assuring that all infants with positive, questionable, and repeat screening tests are appropriately followed."	A	Yes, Rule 1.4.4. Quality Control	A	Yes	Semi-annually	Yes	The advisory committee shall be appointed by the Executive Director of the State Department of Health, and shall include at least two (2) pediatricians and one (1) consumer representative from a family that has experience with a newborn infant with an abnormal screening test. The State Department of Health shall maintain a list of each of the conditions included in the comprehensive newborn screening program, which shall be made available to physicians and other health-care providers who are required to provide for newborn screening testing under Section 41-21-203.	B	#VALUE!	MSDH Rules 15:4:1:1			http://www.msdh.state.ms.us/msdh-site/_static/41,0,101.html		



NEWBORN SCREENING (CONTINUED)

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MO	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	34/60	B	Determined by the Department of Health	Yes	No formal time frame	B	95	Health department	MO Public Health Services Fund	Federal Funds	B	24-48	Yes	20+	5 years	Yes and QA/QC	Yes	Yes	Religious beliefs	A	Until diagnosis is made/ruled out	Yes	"The department shall develop and institute educational programs concerning phenylketonuria and other metabolic and genetic diseases and assist parents, physicians, hospitals and public health nurses in the management and basic treatment of these diseases" "...activities related to the screening, diagnosis, and treatment, including special dietary products, of persons with metabolic and genetic diseases; and follow-up activities that ensure that diagnostic evaluation, treatment and management is available and accessible once an at-risk family is identified through initial screening"	A	Committee must ensure "that high quality is maintained."	C	Yes	Semi-annually	No	"The ""Missouri Genetic Advisory Committee"", consisting of fifteen members, is hereby created to advise the department in all genetic programs including metabolic disease screening programs, hemophilia, sickle cell anemia, and cystic fibrosis programs. Members of the committee shall be appointed by the governor, by and with the advice and consent of the senate. The first appointments to the committee shall consist of five members to serve three-year terms, five members to serve two-year terms, and five members to serve one-year terms as designated by the governor. Each member of the committee shall serve for a term of three years thereafter.  2. The committee shall be composed of persons who reside in the state of Missouri, and a majority shall be licensed physicians. At least one member shall be a specialist in genetics; at least one member shall be a licensed obstetrician/gynecologist; at least one member shall be a licensed pediatrician in private practice; at least one member shall be a consumer, family member of a consumer or representative of a consumer group; at least one member shall be a licensed physician experienced in the study and treatment of hemophilia; at least one member shall be a specialist in sickle cell anemia; and at least one member shall be a specialist in cystic fibrosis.  3. Members of the committee shall not receive any compensation for their services, but they shall, subject to appropriations, be reimbursed for actual and necessary expenses incurred in the performance of their duties from funds appropriated for that purpose."	B	RSMO XII.191.300 through 380	19 CSR 25-36.010				<a href="https://health.mo.gov/living/families/genetics/newborn-screening/">https://health.mo.gov/living/families/genetics/newborn-screening/</a>	
MT	Mountain States Genetics Regional Collaborative (MSGRC)	1	N/A	31/32	C	Department	No	No formal time frame	B	134	Public Health Laboratory	State Laboratory Funds	N/A	B	24-48	No	3-5	1 year	QA/QC	No	N/A	Any reason	B	Until diagnosis is made/ruled out	Depends on the condition. There are consultants available for each group of conditions.	The department shall contract with one or more providers qualified to provide followup services, including counseling and education, for children and parents of children identified with metabolic or genetic disorders to ensure the availability of followup services.	B	CLIA, and on website: "To ensure the best possible outcomes, the MTPHL has just recently begun monitoring the following quality indicators. As part of quality improvement, each birthing facility receives a quarterly report of their performance in these quality indicators: Time from birth to collection of initial screening specimen (Target 24 - 48 hours), Time from collection of initial screening specimen to delivery in the MTPHL (Target 3 days), Time from delivery to result (Target 5 days), Percent of specimens received with missing critical information (Target less than 3%), Percent of specimens submitted that are satisfactory for testing (Target is greater than 97%)"	B	No	N/A	N/A	Montana's Newborn Screening Program	D	MCA 50.19.2	MT Rule 37.57.3			<a href="https://dphhs.mt.gov/public-health/csrs/NewbornScreeningPrograms">https://dphhs.mt.gov/public-health/csrs/NewbornScreeningPrograms</a>		

NEWBORN SCREENING (CONTINUED)

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NE	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	34/37	B	Department	No	No formal time frame	B	80.5 (20)	Department	\$20 given to the Department; the remainder is not regulated by the state	Title V funds	B	24-48	Yes	20+	3 months (or longer if approved for research; research cannot occur prior to passage of 90 days)	Yes and QA/QC	No	Yes	None	A	Until diagnosis is made/ruled out, if treatment is indicated, when that starts	Yes	Yes; NE NBS Follow-Up Program recommended by the Newborn Screening Advisory Committee and adopted by the NE Newborn Screening Follow-up Program	B	"Reports with results from CDC QA program;" "The testing laboratory must use only the standardized test methods provided for in the contract with the Department and the methods used must produce results for which the specified cutoff value, or cutoff value and algorithms for assigning presumptive positive results are appropriate."	A	Yes	Quarterly	Yes	Members appointed by Chief Medical Officer of Dept. of Health and Human Services. Includes 4-5 consumers or parents of patients affected by screened conditions, laboratory representatives of pathology and chemistry, Pediatric, Neonatology and Family Practitioners, Pediatric subspecialist MD's to represent all types of conditions screened (e.g. Endocrine, Hematology, Metabolic etc.), metabolic nutritionists and APRN, Medicaid, Hospital Association and March of Dimes, and a Medical Ethicist. Non-voting participants include the program (management, follow-up and lab) representatives.	A	NRS 71-519	NAC Title 181-2-001 through 010			http://dhhs.ne.gov/Pages/Newborn-Screening.aspx	
NV	Mountain States Genetics Regional Collaborative (MSGRC)	2	10-14 days	31/57	C	State Board of Health	No	Contingency on funding	B	81/0	N/A	NBS fund	The Newborn Screening Program is supported entirely with fees generated by birth registrations. Each person who is legally responsible for registering the birth of a child shall submit a fee of \$81 to the Division of Public and Behavioral Health.	B	24-48	Yes	20+	1	No	No	N/A	Refusal form	D	Until diagnosis is made/ruled out	No	"Discuss the condition with the parent, parents or other persons responsible for the care of the infant and inform them of the treatment necessary for the amelioration of the condition."	C	No, beyond certain instructions around timing	D	Yes	Quarterly	Yes	Hemoglobin is mandated but the rest is voluntary but all is combined. Committee members include specialty physicians in metabolic, hemoglobinopathies, cystic fibrosis, endocrine, immune disorders; metabolic dietician; neonatologist; birth hospital newborn screening coordinator, newborn screening program staff, march of dimes coordinator; hearing coordinator, cchd coordinator, and other guest representatives from state public health and hospital associations	A	NRS 442.008	NAC 442.020			https://med.unr.edu/nsph/newborn-screening	The Nevada State Public Health Laboratory (NSPHL) is part of the University of Nevada, Reno. As such, the governance of the NSPHL is by the Nevada System of Higher Education (NSHE) Board of Regents.
NH	New England Genetics Collaborative (NEGC)	1 if infant is health, 2 for infants born premature or with low birth-weight	For low birth weight: at 2, 6, and 10 weeks of age, then monthly until the baby reaches a weight of 1500 grams. For premature: at two weeks of age or at birthing facility discharge, whichever is earlier	31/39	C*	Additional disorders shall be added to the newborn screening panel based upon, but not limited to, the following considerations: (a) The disorder is well-defined with a known incidence. (b) The disorder is associated with significant morbidity and/or mortality. (c) The disorder can be detected with a screening test that is ethical, safe, accurate, and cost-effective. (d) Effective treatment exists for the disorder, and that early treatment, meaning before the onset of symptoms, is more effective in improving health outcomes than later treatment.	Yes	No formal time frame	C	71	Commissioner of Department of Health and Human Services	NBS fund	N/A	A	48	Yes	Less than 2	6 months	Yes	No	Yes	Parents can refuse for any reason	A	Until the baby is on treatment	No	No	D	He-p 3008.18: Quality Assurance	A	Yes	Statute indicates annually (committee last met in 2015)	No	"(b) The NSAC shall be comprised of at least one individual from each of the following: (1) Health care sub-specialists with expertise relative to newborn screening. including, but not limited to, such specialties as: (2) A member of the health and human services oversight committee, as established by RSA 126-A:13, appointed by the chair of that committee; (3) A genetic counselor; (4) A parent of a child affected by a disorder for which there is a nationally recommended newborn screening test; (5) A midwife practicing outside the hospital setting; (6) A representative from the New Hampshire Pediatric Society; (7) A nurse with child health experience; (8) A representative from the New Hampshire Chapter of the March of Dimes; (9) A representative from the New Hampshire Hospital Association; (10) A representative from the department's public health laboratory; (11) The department's medical director or designee; (12) A representative from the department's maternal and child health program; (13) A representative from the department's children with special health care needs program; (14) A representative from the department's medicaid program; (15) A representative from a health insurance provider; and (16) A representative from the New Hampshire Academy of Family Practitioners. (c) Additional staff from the department may participate in the NSAC, but shall not be voting members."	C	NH RSA Title X 132:10-a	NH Rules He-P 3008			https://www.dhhs.nh.gov/dchs/mch/newborn.htm	

**NEWBORN SCREENING (CONTINUED)**

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NJ	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	1	N/A	33/57	B	Conditions determined by Commissioner	Yes	No formal time frame	B	150	Commissioner	Laboratory revolving fund	General funds	B	24	Yes	20+	23 years	Yes	No	Yes	Refusal form	A	Borderline - until diagnosis is made/ ruled out or 3 months (whichever comes first). Presumptive - until diagnosis is made/ ruled out or one year (whichever comes first).	Yes	The Commissioner shall provide a program of reviewing and following up on positive cases in order that measures may be taken to prevent mental retardation or other permanent disabilities; S 8:18-1.10. Responsibilities of the Follow-up Program	A	"shall be done by the testing laboratory according to recognized clinical laboratory procedures."	C	Yes	Semi-annually	Yes	The Newborn Screening Advisory Review Committee (NSARC) shall include, but need not be limited to, medical, hospital, and public health professionals, scientific experts, and consumer representatives and advocates.	C	NJ Stats 26:2-11	#VALUE!				<a href="https://www.nj.gov/health/fhs/nbs/index.shtml">https://www.nj.gov/health/fhs/nbs/index.shtml</a>	
NM	Mountain States Genetics Regional Collaborative (MSGRC)	2	10-14 days	31/49	C	Determined by the Secretary, considering the recommendations of the New Mexico Pediatric Society of the American Academy of Pediatrics	Yes	No formal time frame	B	138/0	Department of health	NBS fund	N/A	A	24-48	No	N/A	1 year	QA/QC	Yes (parents can request the card during the retention period)	N/A	Any reason	B	Until diagnosis is made/ruled out	Yes	"In the event of positive or questionable screening test results, the department of health's children's medical services newborn screening program and or contracteed outreach lab short-term follow up program will immediately contact and inform the PCP of the need for further testing."	A	"The fees collected from purchase of the kits shall be utilized by the program for testing, quality assurance, and follow up of newborn screening conditions."	A	Yes	Annually	Yes	Specialists, genetic counselors, nutritionists, parent advocate and staff from the Department of Health	C	NM Stat 24-1-6	7.30.6 NMAC			<a href="https://nmhealth.org/about/phd/fhb/cms/nbgs/">https://nmhealth.org/about/phd/fhb/cms/nbgs/</a>		
NY	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	1	N/A	35/60	A	Commissioner or legislation	No	No formal time frame	B	0	N/A- Paid with special funds from the New York State and Federal governments.	Special Revenue Account	Private/public partners	B	24-48	No	N/A	Up to 27 years	Yes	Yes	Yes*	Religious beliefs	A	Until confirmatory testing is performed and/or diagnosis is made/ruled out	Yes	Section 69-1.8 Follow up review, tracking and educational activities	B	"According to recognized clinical laboratory procedures"	C	No	N/A	N/A	New York State Newborn Screening Program	D	NY Laws PBH-25-1-2500-a	NYCRR Title 10 Ch II Subch. H Subpart 69.1-69.9			<a href="https://www.wadsworth.org/programs/newborn/screening">https://www.wadsworth.org/programs/newborn/screening</a>		
NC	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	31/37	C	"Commission shall amend the rules as necessary to ensure that each condition listed on the Recommended Uniform Screening Panel developed by the Secretary of the United States Department of Health and Human Services and the Advisory Committee on Heritable Disorders of Newborns and Children (the RUSP) is included in the Newborn Screening Program"	Yes	No formal time frame	A	128	The Commission, in consultation with the Secretary	NBS fund	N/A	A	24-48	Yes	3-5	5 years	QA/QC	No	N/A	When parents object to screening	B	Until confirmatory testing is normal or baby has seen a specialist and is on treatment	Yes	"Development of follow-up protocols to assure early treatment for identified children, and the provision of genetic counseling and support services for the families of identified children."	B	No	D	Yes	Quarterly	Yes	North Carolina Newborn Screening Advisory Committee	B	NC Statutes 130A-125	10A NCAC 43H.0314			<a href="https://publhealth.nc.gov/wch/families/newborn-metabolic.htm">https://publhealth.nc.gov/wch/families/newborn-metabolic.htm</a>	Commission is exempt from rule making with respect to adding screening tests for Pompe disease, Mucopolysaccharidosis Type I (MPS I), and X-Linked Adrenoleukodystrophy (X-ALD)	

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ND	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	31/52	C	Conditions determined by State Health Council	No	No formal time frame	B	75	Fee is administered and collected by the laboratory	Not touched by ND program	General funds, grant funding	B	24 hours	Yes	20+	18 years	QA/QC	Yes (parents can request the card)	Yes	May refuse for any reason	B	Until diagnosis is made/ruled out	Yes	"Yes, registry of metabolic and genetic diseases, provision of medical foods for people with certain ages with certain diseases; ""Coordinate with or refer individuals to public and private health care service providers for long-term followup services for metabolic diseases and genetic diseases""	B	No	D	Yes	Quarterly	Yes	Variety of people from across the state and Iowa (i.e. Stan Berberich and Carol Johnson), genetic counselors, physicians, Medicaid representative, hospital association, March of Dimes, early hearing detection and intervention program staff, family members, and state staff	B	ND Century Code 25-17	NDAC 33-06-16			<a href="https://nbs.health.nd.gov/">https://nbs.health.nd.gov/</a>	
OH	The Region 4 Genetics Collaborative (Region 4)	1	N/A	33/46	B	Conditions listed in rules	Yes	No formal time frame	C	74.61	Council recommends, Director approves	NBS fund	N/A	A	24 hours - 5 days	Yes	20+	2 years	QA/QC, new test implementation and validation	No	N/A	Religious beliefs	B	Until diagnosis is made/ruled out	No	"Referring children who receive abnormal screening or rescreening results to providers of follow-up services"	C	No	D	Yes	3 times per year	Yes	The council consists of fourteen members appointed by the director including individuals and representatives of entities with interest and expertise in newborn screening, including such individuals and entities as health care professionals, hospitals, children's hospitals, regional genetic centers, regional sickle cell centers, regional cystic fibrosis centers, newborn screening coordinators, and members of the public.	A	ORC	OAC 3701-55			<a href="https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Newborn-Screening/welcome-to-newborn-screening">https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Newborn-Screening/welcome-to-newborn-screening</a>	
OK	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	31/54	C	Board of Health	No	No formal time frame	B	137.28	Board of Health	N/A	N/A	B	24 hours	Yes	20+	42 days	QA/QC, at parental request for further testing for research	No	Yes	Religious beliefs	B	Until diagnosis is made/ruled out	Yes	Cases should have a referral to a pediatric sub-specialist and the parent should be referred for enrollment in newborn screening long-term follow-up services as designated by the NBS program, in coordination with specialty clinic	B	CLIA	C	Yes	Quarterly	Yes	Newborn Screening Programs and Pediatrics Committee of the Oklahoma Genetics Advisory Council (OGAC)	A	OSC	OAR 310-550			<a href="https://www.ok.gov/health/Family_Health/Screening_&amp;_Special_Services/Newborn_Screening_Program/index.html">https://www.ok.gov/health/Family_Health/Screening_&amp;_Special_Services/Newborn_Screening_Program/index.html</a>	<a href="https://www.ok.gov/health2/documents/Newborn%20screening%20rules%20and%20regulations.pdf">https://www.ok.gov/health2/documents/Newborn%20screening%20rules%20and%20regulations.pdf</a>
OR	Western States Genetic Services Collaborative (WSGSC)	2	7-15 days	33/53	B	Conditions listed in rules	Yes	No formal time frame	C	80/0	Oregon Health Authority	Funds support public health lab as a whole	N/A	B	24-48	Yes	6-10 for normal, 16-20 for abnormal	1 year	Yes, QA and method development activities, program evaluation and quality improvement (p 31)	Yes	Yes	Religious beliefs	B	Until diagnosis is made/ruled out	Yes, "Some done through association with Oregon Health & Science University"	"The practitioner must communicate abnormal results to the parent or guardian of the infant and recommend appropriate medical care"	B	CLIA, other specific methods established by department of health, outlined in regulation 333-024-0230	A	Yes	Semi-annually	Yes	Medical consultants, parents, March of Dimes, Oregon Center for Children & Youth with Special Health Care Needs, genetic counselors, Oregon Pediatric Society, Maternal Child Health program	B	ORS 433.285	OHA Rules 333-24			<a href="https://www.oregon.gov/oha/ph/LaboratoryServices/Newborn-Screening/Pages/index.aspx">https://www.oregon.gov/oha/ph/LaboratoryServices/Newborn-Screening/Pages/index.aspx</a>	

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PA	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	1	N/A	31/38	C	The department, with the approval of the Newborn Screening and Follow-up Technical Advisory Committee	No	Within two years of addition to the RUSP but also added non-RUSP conditions	D	0	Appropriations	General funds	Title V block grant and State Funds	C	24-48	Yes	20+	1 year	No	No	N/A	Religious beliefs	D	Until diagnosis is made/ruled out	No	"the Department will assist with referral for diagnosis, treatment, and other follow-up services for the newborn child through designated treatment centers or clinical specialists."	C	Collection of sample "according to consensus standards developed by National Committee for Clinical Laboratory Standards"	D	Yes	3 times per year	Yes	Newborn Screening and Follow-up Technical Advisory Board: specialists, parents, laboratory representatives, genetic counselors, etc.	A	PA Statutes 35.3.621 through 625	PA Code 28.1 through 5, 11 through 12, and 21 through 31			<a href="https://www.health.pa.gov/topics/programs/Newborn-Screening/Pages/Newborn%20Screening.aspx">https://www.health.pa.gov/topics/programs/Newborn-Screening/Pages/Newborn%20Screening.aspx</a>	
RI	New England Genetics Collaborative (NEGEC)	1	N/A	34/34	B	Conditions listed in rules	No	No formal time frame	C	162.98	Health Department	NBS fund	N/A	A	24-48	Yes	20+	23 years	No	No	N/A	Religious beliefs	C	Until diagnosis is made/ruled out	No	No	C	"the Department will assist with referral for diagnosis, treatment, and other follow-up services for the newborn child through designated treatment centers or clinical specialists. (1) the Department will assist with referral for diagnosis, treatment, and other follow-up services for the newborn child through designated treatment centers or clinical specialists."	C	Yes	Bi-monthly	Yes	Representatives include staff from birthing hospitals, public health, physicians, specialists, neonatologists	B	RI General Laws 23-13-14	216-RICR-20-05-01			<a href="http://health.ri.gov/programs/detail.php?pgm_id=21/index.php">http://health.ri.gov/programs/detail.php?pgm_id=21/index.php</a>	
SC	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	31/55	C	Department	Yes	No formal time frame	B	127	Health Department	NBS fund	MCH Title V Funds, mentions the tobacco settlement in the statute	A	24-48	Yes	3-5 for normal, 16-20 for abnormal	1 year, abnormal can be kept for longer	QA/QC	No	N/A	Religious beliefs	B	Until diagnosis is made/ruled out	No	"The attending physician shall initiate appropriate medical follow-up and diagnosis when abnormal test results occur... Appropriate genetic counseling should be offered to all families of children with abnormal test results as outlined in the Official Departmental Instructions."	C	"CLIA standards;""The Laboratory, in conjunction with the Bureau of Maternal and Child Health, shall adopt standards for the quality assurance and interpretation of approved tests and for the collection of specimens.""	B	Yes	As needed	Yes	NBS Advisory Committee: Specialty care providers, primary care providers, program leadership and staff convened as needed by specialty.	B	SC Code 44-37-40	SC Code of Regs 61-80 through 61-92			<a href="https://www.scdhec.gov/health-professionals/lab-certification-services/newborn-metabolic-screening">https://www.scdhec.gov/health-professionals/lab-certification-services/newborn-metabolic-screening</a>	
SD	Heartland Genetics and Newborn Screening Collaborative (Heartland)	1	N/A	31/50	C	Determined by state Department of Health	No	No formal time frame	B	75	N/A	No holding, fee goes to contracted lab	N/A	B	24-48	Yes	Less than 2	1 month	No	No	N/A	None	F	Until diagnosis is made/ruled out	No	"Upon notification by a designated laboratory of a positive screening result for an infant, the department shall work with the newborn's physician to locate the infant and facilitate the entry of the infant into further diagnostic and medical management services."	C	No	D	No	N/A	N/A	South Dakota Newborn Screening Program	D	SDLRC 34-24-16	ARSD 44:19			<a href="https://doh.sd.gov/family/newborn/blood-spot/">https://doh.sd.gov/family/newborn/blood-spot/</a>	

**NEWBORN SCREENING (CONTINUED)**

STATE	Region	Number of Screens	Second Screening Age	Number of Core Conditions/Total Number	Screening Grade	RUSP Auto-Inclusion/Add Conditions	Pilot Studies Required	Time Frame of Implementation	Adding Screens Grade	Fee 1/2	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age	Data Retention	Data Retention Time	DBS Retention Time	Research of DBS	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	DBS Use Grade	Short-Term Follow-up	Long-Term Follow-up	Follow-up in Statute and/or Regs	Follow-up Grade	Quality in Statute/Regulation	Quality Grade	Advisory Committee	AC Meeting Frequency/Actual	AC Voluntary	AC Membership	AC Grade	Statute	Regulation	Lab	Fiscal Note	Website	Additional Notes
TN	Southeast NBS & Genetics Collaborative (SERC)	1	N/A	34/70	B	Determined by state Department of Health	Yes	Between 6 months- 1 year following the occurrence of a number of items (such as the development of a reliable test)	B	145	Commissioner	Department of Health	N/A	B	24-48	Yes	20 or more	1 year, confirmed positive identities indefinitely	QA/QC	No	N/A	Religious beliefs	B	Until diagnosis is made/ruled out	No	"newborn screening follow-up program"	C	"development of a reliable test or series of tests for screening newborns for specific genetic, metabolic, or other heritable conditions using dried blood spots or other testing and quality assurance testing methodology for such specific genetic, metabolic or the heritable conditions testing"	B	Yes	Quarterly	Yes	Genetics Advisory Committee: members include geneticists, hematologists, pulmonologists, immunologists, neonatologists, and a lawyer. The committee is chaired by the Assistant Commissioner of Family Health and Wellness and a Division Director from the Division of Laboratory Services.	B	#VALUE!	Tennessee Department of Health Rules 1200-15-01			<a href="https://www.tn.gov/newborn-screening">https://www.tn.gov/newborn-screening</a>	
TX	Mountain States Genetics Regional Collaborative (MSGRC)	2	7-14 days	32/55	B	"Newborn screening in Texas includes the disorders found on the national Recommended Uniform Screening Panel for which funds are available and allocated for the screening."	No	As funding allows	A		Commissioner	NBS fund, general revenue fund	The department administers the NBS account and may solicit and receive gifts, grants, and donations from any source for the benefit of the account.	A	24-48	Yes	20+	By default, up to 2 years. With parental decision form indicating permission, up to 25 years	Yes	Yes	Yes	Religious beliefs	A	Until diagnosis is made/ruled out	Yes	Yes, asks for updated info from specialists and families to ensure they are still receiving care and treatment; "The executive commissioner by rule may establish the amounts charged for newborn screening fees, including fees assessed for follow-up services, tracking confirmatory testing, and diagnosis."	A	"the department shall obtain the use of screening methodologies and hire the employees necessary to administer newborn screening" "The department shall periodically review the newborn screening program to determine the efficacy and cost-effectiveness of the program and determine whether adjustments to the program are necessary to protect the health and welfare of this state's newborns"	B	Yes	Required 3x per year, at least one time in person	No	At least four physicians (at least two specializing in neonatal-perinatal medicine), at least two hospital representatives, at least two persons who have family members affected by a condition that is screened for, at least two healthcare providers involved in the delivery of screening services, follow up, or treatment	A	Texas Health and Safety Code 2-B-33-A	TAC 25.1.37.D		<a href="http://www.dshs.state.tx.us/lab/newbornscreening.shtm">http://www.dshs.state.tx.us/lab/newbornscreening.shtm</a>	<a href="https://legiscan.com/TX/bill/">https://legiscan.com/TX/bill/</a>	
UT	Mountain States Genetics Regional Collaborative (MSGRC)	2	7-28 days	32/52	B	PKU and "other heritable disorders which may result in an intellectual or physical disability or death and for which a preventive measure or treatment is available and there exists a reliable laboratory diagnostic test method"	No	No formal time frame	B	115.07	Legislature	NBS fund	N/A	B	24-48	Yes	20+	Minimum 90 days	Yes, and QA/QC	Yes	Yes (need consent for it to be identified)*	Religious beliefs	A	Until diagnosis is made/ruled out	No	"the department may charge fees for... (d)the administrative cost of follow-up contacts with the parents or guardians of tested infants."	C	"The Department may use residual blood spots for newborn screening quality assessment activities."	C	Yes	Quarterly	No	(1) Newborn Screening Advisory Committee shall be composed of at least 9 members as follows: (a) an individual with an advanced degree (MS/PhD/MD) in genetics or other relevant field, who will serve as Chair; (b) a representative from the Utah Hospital Association; (c) a community pediatrician; (d) the Director of the Division of Disease Control and Prevention; (e) an advocate or a consumer of a newborn screening services; (f) clinical consultants for the Newborn Screening program; (g) a representative from the Utah Public Health Laboratory (h) a representative from the Newborn Screening Follow-up Program; (i) a representative from the research community with knowledge about disorders considered for future addition to the newborn screening panel. (2) The Department Executive Director shall approve committee membership with counsel from the advisory committee. (3) The term of committee members shall be four years; (a) members may serve up to three additional terms as requested; (b) if a vacancy occurs in the committee membership for any reason, a replacement shall be appointed for the unexpired term in the same manner as the original appointment; (c) a majority of the committee constitutes a quorum at any meeting. If a quorum is present, the action of the majority of members shall be the action of the advisory committee. (4) The committee shall: (a) advise the Department on policy issues related to newborn screening services; (b) provide guidance to programs and functions within the Department having to do with newborn screening services and (c) evaluate potential tests that could be added to newborn or population screening and make recommendations to the Department.	A	Utah Code 26-10-6	Rule 438-15		<a href="http://health.utah.gov/newborn-screening/">http://health.utah.gov/newborn-screening/</a>		
VT	New England Genetics Collaborative (NEGC)	1	N/A	35/43	A	Disorders listed in rules and on website	No	No formal time frame	C	203	Health Department	NBS fund	N/A	A	24-48	Yes	Less than 2	1 year unless parent requests otherwise	No	Yes (may be destroyed earlier than 1 year at the written request of the infant's parent(s) or legal guardian(s))	N/A	May opt out for any reason	D	Until baby is on treatment	No	No	C	According to American Academy of Pediatrics, CDC, and other recognized experts	B	Yes	As needed	Yes	Includes consumers; public health professionals; primary care; hospital medical, NICU, and laboratory representatives; state hospital association; and consulting specialists in genetics/ metabolics; endocrinology; hematology; infectious diseases; Cystic Fibrosis	A	VSA	CVR 13-140-057		<a href="https://www.healthvermont.gov/children-youth-families/health-care-children-youth/newborn-screening">https://www.healthvermont.gov/children-youth-families/health-care-children-youth/newborn-screening</a>		

NEWBORN SCREENING (CONTINUED)

STATE	Region	Number of Screens	Second Screening Age	Number of Core Conditions/ Total Number	Screening Grade	RUSP Auto-Inclusion/Add Conditions	Pilot Studies Required	Time Frame of Implementation	Adding Screens Grade	Fee 1/2	Increase Fee	Fee Holding Location	Other Funding Source	Funding Grade	Initial Age	Data Retention	Data Retention Time	DBS Retention Time	Research of DBS	Parents May Request Disposal of DBS Samples	Consent for DBS Research	Opt Out Policy for Screening	DBS Use Grade	Short-Term Follow-up	Long-Term Follow-up	Follow-up in Statute and/or Regs	Follow-up Grade	Quality in Statute/Regulation	Quality Grade	Advisory Committee	AC Meeting Frequency/ Actual	AC Voluntary	AC Membership	AC Grade	Statute	Regulation	Lab	Fiscal Note	Website	Additional Notes
VA	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NY-MAC)	1	N/A	33/33	B	"consistent with, but not necessarily identical to the [RUSP]"	No	No formal time frame	A	138	Commissioner	NBS fund	N/A	A	24	Yes	20+	Normal 6 months, abnormal 10 years	QA/QC	No	N/A	Religious beliefs	B	Until diagnosis is made/ruled out	No	"Upon receiving the notification described in subsection A of this section, the Newborn Screening Program at the Virginia Department of Health shall refer the newborn's parent or guardian to the Care Connection for Children network for care coordination services."	B	"The testing laboratory shall perform required initial and secondary tests using validated analytical test methods and establish normal ranges and notification protocols as defined in the contract with the department. The testing laboratory may seek the advice of the Newborn Screening Subcommittee of the Virginia Genetics Advisory Committee."	A	Yes	Semi-annually	Yes	Membership consists of 20 voting members including representation from major medical centers and higher institutions of learning, parents, American Academy of Pediatrics, Virginia Hospital & Healthcare Association, March of Dimes, etc. and represents multiple professions that contribute to the NBS system including midwives, genetic counselors, geneticists, pediatricians and obstetricians. Workgroups of the Advisory Committee may be formed in between meetings to address certain issues and report back to the larger committee.	A	VA Code 32.1-65	VAC 12.5.71			<a href="http://www.vdh.virginia.gov/newborn-screening/">http://www.vdh.virginia.gov/newborn-screening/</a>	NBS does not use additional funds, but the care coordination program uses title V funds.
WA	Western States Genetic Services Collaborative (WSGSC)	2	7-14 days	33/36	B*	Determined by State Board of Health	Yes	No formal time frame	B	84.2/0	Health Department	NBS fund	N/A	A	18-48	Yes	20+	21 years	Yes, also forensic studies and additional testing that is not research based	Yes	Yes	Religious beliefs	A	Until the baby is on treatment	Yes	"The services and facilities of the department, and other state and local agencies cooperating with the department in carrying out programs of detection and prevention of intellectual disabilities and physical defects shall be made available to the family and physician to the extent required in order to carry out the intent of this chapter and within the availability of funds."	B	Instructions on specimen collection.	D	Yes	Ad hoc	Yes	Newborn Screening Panel Advisory Committee	C	70.83 RCW	WAC 246-650			<a href="https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/NewbornScreening">https://www.doh.wa.gov/YouandYourFamily/InfantsandChildren/NewbornScreening</a>	
WV	New York-Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)	1	N/A	31/38	C	Conditions specified by the state Health Commissioner	No	No formal time frame	B	125	Reviewed periodically by the Commissioner	NBS fund	Title V funds	A	24 or prior to discharge	No	20+	3 months	No	No	N/A	None	F	Until diagnosis is made/ruled out	No	"Assistance with referrals shall be offered by the Bureau in cooperation with other state agencies to children determined to be afflicted with any disease specified in section 4 or 6 of this rule for medical and dietary needs."	C	Screening according to CLIA standards	C	Yes	Semi-annually	Yes	Lab and Follow-up, pediatric specialists, other members with an interest in Newborn Screening	B	WV Code 16-22-1-5	CR 64-91-1 through 11			<a href="http://www.wvdhhr.org/nbms/">http://www.wvdhhr.org/nbms/</a>	
WI	The Region 4 Genetics Collaborative (Region 4)	1	N/A	33/49	B	Disorders listed in rules	N/A	Lab test implementation period 6 months-1 year	C	109	Health Department	State Laboratory of Hygiene	N/A	B	24-48	Yes	20+	1 year	Yes, and QA/QC	No	Yes	Religious purposes, personal convictions	A	Until diagnosis is made/ruled out	No	"The department shall provide necessary diagnostic services, special dietary treatment as prescribed by a physician for a patient with a congenital disorder as identified by tests under this section, and follow-up counseling for the patient and his or her family. The department shall include as part of the fee established by rule amounts to fund the provision of diagnostic and counseling services, special dietary treatment, and periodic evaluation of infant screening programs, the costs of consulting with experts"	C	Determined by state laboratory with approval for Department of Health; Additional tests for research and evaluation	C	Yes	Semi-annually	Yes	Seven subcommittees serve on an umbrella committee, committees constituted of individuals whose areas of expertise and experience include medicine and science; statistics and epidemiology; ethical, legal, social and policy analysis; laboratory medicine; and include representation from practicing physicians, the newborn screening program and individuals with target conditions or their parents.	A	WI Statutes, Ch. 253.12	WI Admin. Code DHS 115.01-06			<a href="http://www.slh.wisc.edu/clinical/newborn/">http://www.slh.wisc.edu/clinical/newborn/</a>	
WY	Mountain States Genetics Regional Collaborative (MSGRC)	2	7-14 days	31/52	C	Determined by Advisory Committee	No	Incumbent upon contracted lab	B	84/0	Department of Health determines fees in consultation with the advisory committee	NBS fund	General funds	A	24-48	No	3 to 5 years	6 months	No	No	N/A	Can opt out for any reason, but must sign waiver	D	Until the baby is on treatment	No	"The fees assessed under §§ 8(a) and (b) of this Chapter cover the reasonable costs of the initial and second bloodspot specimen collection for the same child, initial confirmatory testing, courier services, laboratory services, specialty follow-up services, program education and other services necessary to maintain functionality and sustainability of this self-funded program."	C	"Screening shall be conducted in accordance with accepted medical practices and in the manner prescribed by the state department of health"; instructions on specimen collection	C	Yes	As needed	No	State health officer, president of Wyoming state medical society, member designated by WY state pediatric society, board certified OB/GYN	C	#VALUE!	Wyoming Administrative Rules Ref No,			<a href="https://health.wyo.gov/familyhealth/newborn/index.html">https://health.wyo.gov/familyhealth/newborn/index.html</a>	

Sources:  
 NewSTEPS. <https://www.newsteps.org/data-visualizations>  
 Baby's First Test. <https://www.babysfirsttest.org/>

**MEDICAID- SECTION 1115 WAIVERS**

**MEDICAID- SECTION 1115 WAIVERS (CONTINUED)**

STATE	Work Requirement	Eligibility and Enrollment Restrictions	Benefit Restrictions, Copays, Healthy Behaviors	Behavioral Health	Delivery System Reform	Block Grant	Managed Long-term Services and Supports (MLTSS)	Home- and Community-based Services (HCBS)	Grade
AL	Yes (pending)	No	No	No	No	No	No	No	F
AK	No	No	No	Yes (approved)	No	No	No	No	P
AZ	Yes (approved but not yet implemented) 6	Premiums for the expansion population (approved); disenrollment for lack of payment for expansion population (approved); remove retroactive eligibility for all (approved)	Healthy behavior incentives for expansion population (approved)	Yes (approved & pending)	Yes (approved)	No	Yes (approved)	Yes	F
AR	Yes (set aside by court)	Premiums for expansion population (approved); QHP premium assistance for expansion population (approved); remove retroactive eligibility for expansion population (set aside by court); limited expansion (not approved)	Limited NEMT removal (set aside by court)	No	No	No	No	Yes	F
CA	No	No	No	Yes (approved)	Yes (approved)	No	Yes (approved)	No	P
CO	No	No	No	Yes (pending)	No	No	No	No	P
CT	No	No	No	No	No	No	No	No	P
DC	No	No	No	Yes (approved)	No	No	No	No	P
DE	No	Limited removal of retroactive eligibility (approved)	No	Yes (approved)	No	No	Yes (approved)	No	P
FL	No	Remove retroactive eligibility for expansion population (approved)	No	Yes (approved)	Yes (approved)	No	No	No	F
GA	Yes (proposed)	Partial expansion (proposed); premiums for partial expansion population (proposed); disenrollment for lack of payment (proposed)	No	No	No	No	No	No	F
HI	No	Limited removal of retroactive eligibility (approved)	No	Yes (approved)	No	No	Yes (approved)	No	P
ID	Yes (pending)	No	No	No	No	No	No	No	F
IL	No	No	No	Yes (approved)	No	No	No	No	P
IN	Yes (approved and implemented; currently suspended) 7	Premiums for all (approved); coverage loss and lock-out for lack of payment for expansion population (approved); tobacco premium surcharge for all (approved); remove retroactive eligibility for expansion population (approved); remove reasonable promptness for all (approved); lock-out for failure to timely renew for expansion population (approved)	Healthy behavior incentives for all (approved); remove NEMT for expansion population (approved); ER copay (approved)	Yes (approved)	No	No	No	No	F

STATE	Work Requirement	Eligibility and Enrollment Restrictions	Benefit Restrictions, Copays, Healthy Behaviors	Behavioral Health	Delivery System Reform	Block Grant	Managed Long-term Services and Supports (MLTSS)	Home- and Community-based Services (HCBS)	Grade
IA	No	Premiums for expansion population (approved); disenrollment for lack of payment for expansion population (approved); remove retroactive eligibility for all (approved)	Healthy behavior incentives for expansion population (approved); remove NEMT for expansion population (approved); ER copay (approved)	No	No	No	No	No	F
KS	Yes (blocked by legislature) 8	Lifetime limit on eligibility (not approved)	No	Yes (approved)	Yes (approved)	No	Yes (approved)	No	P
KY	Yes (rescinded by Governor) 9	Premiums for all (rescinded); coverage loss and lock-out for lack of payment (rescinded); remove retroactive eligibility for all (rescinded); remove reasonable promptness for all (rescinded); lock-out for failure to timely renew for all (rescinded); lock-out for failure to timely report eligibility changes (rescinded)	Healthy behavior incentives for all (rescinded); remove NEMT for all (rescinded); copays in the form of My Rewards Account (MRA) deduction above statutory limit for all (rescinded); fees for missed appointments for all in the form of MRA deduction (rescinded)	Yes (approved)	No	No	No	No	P
LA	No	No	No	Yes (approved)	No	No	No	No	P
ME	Yes (blocked by Governor)	No	No	No	No	No	No	No	P
MD	No	Limited removal of retroactive eligibility* (approved)	No	Yes (approved & pending)	No	No	No	No	P
MA	No	Limited removal retroactive eligibility (approved); partial expansion (not approved)	Limited NEMT removal (pending); closed formulary (not approved)	Yes (approved)	Yes (approved)	No	No	No	P
MI	Yes (approved but not yet implemented; Governor has signaled opposition) 10	Premiums for expansion population (approved); coverage loss and lock-out for lack of payment for expansion population (approved); requirement of Health Risk Assessment (HRA) for expansion population (approved)	Healthy behavior incentives for expansion population (approved)	Yes (approved)	No	No	No	No	F
MN	No	No	No	Yes (approved)	No	No	No	No	P
MS	Yes (pending)	No	No	No	No	No	No	No	F
MO	No	No	No	No	No	No	No	No	P
MT	Yes (pending)	Premiums for expansion population (approved); coverage loss and lock-out for lack of payment for expansion population (approved)	No	Yes (approved)	No	No	No	No	F
NE	Yes (proposed, not yet submitted) 11	Tiered benefit structure; remove retroactive eligibility (proposed, not yet submitted)	No	Yes (approved)	No	No	No	No	F



**MEDICAID- SECTION 1115 WAIVERS**

**MEDICAID- SECTION 1115 WAIVERS (CONTINUED)**

STATE	Work Requirement	Eligibility and Enrollment Restrictions	Benefit Restrictions, Copays, Healthy Behaviors	Behavioral Health	Delivery System Reform	Block Grant	Managed Long-term Services and Supports (MLTSS)	Home- and Community-based Services (HCBS)	Grade
NV	No	No	No	No	No	No	No	No	P
NH	Yes (set aside by court)	Removed and then changed to a limit of retroactive eligibility for expansion population (set aside by court)	No	Yes (approved)	Yes (approved)	No	No	No	F
NJ	No	No	No	Yes (approved & pending)	Yes (approved)	No	Yes (approved & pending)	Yes	P
NM	No	Sought to create premiums with coverage loss for lack of payment and remove retroactive eligibility and reasonable promptness, was approved but not implemented, now applying to undo	Healthy behavior incentives for all (approved)	Yes (approved)	Yes (approved)	No	Yes (approved)	Yes	P
NY	No	No	No	Yes (approved)	Yes (approved)	No	Yes (approved & pending)	No	P
NC	No (currently under consideration)	No	No	Yes (approved)	Yes (approved)	No	Yes (approved)	No	P
ND	No	No	No	No	No	No	No	No	P
OH	Yes (approved but not implemented)	No	No	Yes (approved)	No	No	No	No	F
OK	Yes (pending)	No	No	No	No	No	No	No	F
OR	No	No	EPSDT waiver related to delivery system reform	No	Yes (approved)	No	No	No	P
PA	No <sup>12</sup>	No	No	Yes (approved)	No	No	No	No	P
RI	No	Limited removal retroactive eligibility	No	Yes (approved)	Yes (approved)	No	Yes (approved)	Yes	P
SC	Yes	Time limit on coverage; authority to cap enrollment	Restriction on free choice of family planning provider for non-expansion population (pending)	No	No	No	No	No	F
SD	Yes (pending)	No	No	No	No	No	No	No	F
TN	Yes (pending)	Limited removal of retroactive eligibility (approved)	Restriction on free choice of family planning provider for non-expansion population (pending); closed formulary (pending)	Yes (pending)	Yes (approved)	Yes	Yes (approved)	Yes	F
TX	No	Waive MAGI financial methodology (pending) for the Healthy Women family planning waiver	Restriction on free choice of family planning provider for non-expansion population (pending) for Healthy Women waiver	No	Yes (approved)	No	Yes (approved)	No	P

STATE	Work Requirement	Eligibility and Enrollment Restrictions	Benefit Restrictions, Copays, Healthy Behaviors	Behavioral Health	Delivery System Reform	Block Grant	Managed Long-term Services and Supports (MLTSS)	Home- and Community-based Services (HCBS)	Grade
UT	Yes (approved along with full expansion) <sup>13</sup>	Limited removal of retroactive eligibility (approved), partial expansion (not approved); premiums for expansion population (pending); coverage loss and lock-out for lack of payment for expansion population (pending); remove retroactive eligibility for expansion population (pending); remove reasonable promptness for expansion population (pending); remove hospital presumptive eligibility (pending); lock-out for intentional program violations (IPV) (pending); authority to cap enrollment (pending); full expansion with enrollment caps (pending); per capita cap (PCC) (pending); full expansion (approved)	Copays above statutory limit for expansion population (pending); waive EPSDT for 19 and 20 year olds for all (approved)	Yes (approved & pending)	No	No	No	No	F
VT	No	No	No	Yes (approved & pending)	Yes (approved)	No	Yes (approved)	Yes	P
VA	Yes (pending; Governor has requested CMS to pause its review) <sup>14</sup>	Premiums for expansion population (pending); coverage loss or lock-out for lack of payment for expansion population (pending); remove reasonable promptness for expansion population (pending)	Health behavior incentives for expansion population (pending); ER copay (pending)	Yes (approved)	Yes (pending)	No	Yes (pending)	No	F
WA	No	No	No	Yes (approved)	Yes (approved)	No	No	Yes	P
WV	No	No	No	Yes (approved)	No	No	No	No	P
WI	Yes (approved but not implemented)	Premiums for non-expansion population (approved); coverage loss and lock-out for lack of payment for non-expansion population (approved); require HRA for non-expansion population (approved); expansion to 100% FPL without enhanced matching funds (approved)	Health behavior incentives for non-expansion population (approved); ER copay (approved)	Yes (approved)	No	No	No	No	F
WY	No	No	No	No	No	No	No	No	P

**MEDICAID- HOME- AND COMMUNITY-BASED SERVICES (HCBS)**

**MEDICAID- HOME- AND COMMUNITY-BASED SERVICES (HCBS) (CONTINUED)**

STATE	Waiver	Covered Populations	Tax Equity and Fiscal Responsibility Act (TEFRA) Authority	State Plan Amendment (SPA)	Total Waiting List Enrollment in 2017
AL	1915(c)	HIV/AIDS; intellectual disability (ID) 3+; physical disability (PD) 18-60; technology dependent (TD) individuals 21+; aged 65+ & disabled (physical and other) all ages	No	No	4,194
AK	1915(c)	Aged 65+ & PD 21-64; autism & intellectual disability/developmental disability (ID/DD) 21+; MF 0-21; autism & ID/DD 0+	Yes	1915(k)	629
AZ	1115	DD, PD, Aged	No	No	0
AR	1915(c) & TEFRA-like (1115)	Aged 65+ & PD 21-64; autism & ID/DD 0+	Yes*	1915(i)	2,834
CA	1915(c)	Autism & ID/DD 0+; medically frail (MF) & TD 0+; HIV/AIDS 0+; PD (and other) 21-64; aged 65+	No	1915(i)	7,683
CO	1915(c)	Brain injury (BI) 16+; MF 0-17; aged 65+, PD 18-64 & HIV/AIDS 18+; autism 0-5; DD 0-20; DD 18+; mental illness (MI) 18+; HIV/AIDS 0+	No	1915(i)	3,115
CT	1915(c)	BI 18+; PD 18-64; aged 65+; DD 18+ & ID 3+; autism 3+; MI 22+; autism 3-4	No	1915(k) & 1915(i)	5,001
DC	1915(c)	ID/DD 18+; aged 65+ & PD 18-64	Yes	1915(i)	0
DE	1915(c)	Autism & ID 12+	Yes	No	0
FL	1915(c)	HIV/AIDS 0+; autism & ID/DD 3+; MF (familial dysautonomia) 3-64; MF 0-20; BI 18+; MF (cystic fibrosis) 18+; aged 65+, PD 18-64, BI 18-64, HIV/AIDS 18-64 & MF 18-64; aged 65+ & PD 60-64 (alzheimers)	No	No	71,016
GA	1915(c)	Aged 65+ & PD 0-64; ID/DD 0+; MF & TD 0-5; MI & serious emotional disturbance (SED) 4-17; PD 21-64	Yes	No	7,810
HI	1915(c)	ID/DD 0+	No	No	0
ID	1915(c)	Autism & ID/DD 18+; aged 65+ & PD (and other) 18-64; autism & ID/DD 0-17; autism & ID/DD 3-6	Yes	1915(i)	0
IL	1915(c)	Aged 65+ & PD 22-64; autism & ID/DD 18+; BI 0+; MF & TD 0+; aged 65+ & PD 60-64; PD 0-59; autism & ID/DD 3-21	No	No	19,354
IN	1915(c)	BI 0+; aged 65+ & PD (and other) 0-64; autism & ID/DD 0+; MI 18-20 & SED 6-17	No	1915(i)	1,404
IA	1915(c)	PD 18-64; PD 0-64; SED 0-17; aged 65+; ID 0+; HIV/AIDS 0+; BI 0+	No	1915(i)	8,004
KS	1915(c)	MF & TD 0-21; BI 16-64; autism & ID/DD 5+; PD 16-64; aged 65+; autism 0-5	No	No	4,484
KY	1915(c)	BI 18+; PD (and other) 0-64 & aged 65+; ID/DD 3+; TD 0+; ID/DD 0+	No	No	6,091
LA	1915(c)	Aged 65+ & PD 22-64; autism & ID/DD 0+; autism & ID/DD 0-18; autism & ID/DD 3+; MI & SED 5-17	No	No	65,989
ME	1915(c)	Aged 65+ & PD 18+; autism & ID 5-21; autism & ID 18+; BI 18+	Yes	No	1,515
MD	1915(c)	MF 0+; DD 0+; autism 1-21; PD 18-64; aged 65+ & PD 16-64; BI 22+; MI 18-21 & SED 6-17; DD 0-21; DD 0+	No	1915(k) & 1915(i)	35,143
MA	1915(c) & 1115	BI 22+; ID 22+; aged 65+ & PD 60-64; autism 0-8; MI & PD 18-64	Yes	No	0
MI	1915(c)	Aged 65+ & PD 18-64; MI & SED 0-21; autism & ID/DD 0-17; ID 0+	Yes	1915(i)	3,223
MN	1915(c)	Aged 65+; BI 0-64; PD (and other) 0-64; ID/DD 0+	Yes	No	237

STATE	Waiver	Covered Populations	Tax Equity and Fiscal Responsibility Act (TEFRA) Authority	State Plan Amendment (SPA)	Total Waiting List Enrollment in 2017
MS	1915(c)	Aged 65+ & PD 21-64; PD (and other) 16-64; autism & ID/DD 0+; BI 0+	Yes	1915(i)	13,465
MO	1915(c)	HIV/AIDS 21+; autism 3-18; PD 18-64; ID/DD 0-17; autism & ID/DD 0+; ID/DD 0+; MF & DD 21+; PD (and other) 18-63; BI 21-65	No	No	0
MT	1915(c)	Aged 65+ & PD (and other) 0-64; autism 0-4; ID/DD 0+; MI 18+; ID/DD 16+; SED 6-17	No	1915(k)	2,156
NE	1915(c)	Aged 65+ & PD 0-64; autism & ID/DD 0+; BI 18-64; autism 0-17; autism & ID/DD 21+	Yes	No	3,142
NV	1915(c)	Aged 65+ & PD 0-64; ID 0+; 65+	Yes	No	1,173
NH	1915(c)	Autism & ID/DD 0+; BI 22+; autism & ID/DD 0-21; aged 65+ & PD (and other) 18-64	Yes	No	105
NJ	1115 & 1915(c)	Autism & ID/DD 21+; Children with autism; Children with ID/DD; adults with MI; children with SED	No	No	0
NM	195(c) & 1115	Autism & ID/DD 0+; MF 0+; aged & PD	No	No	17,862
NY	1915(c)	PD (and other), MF, TD, autism & ID/DD 0-20; MI 18-20; SED 0-18; BI 18+; autism & ID/DD 0+; aged 65+ & PD 0-64	No	1915(k) & 1915(i)	*Un-known*
NC	1915(c)	Autism & ID/DD 0+; aged 65+ & PD 18-64; MF 0-20; BI 22+	No	No	14,487
ND	1915(c)	Aged 65+ & PD (and other) 18-64; MF 0-21; autism 0-11; ID/DD 0+; TD 18+; MF 3-17	No	No	11
OH	1915(c)	PD 0-59; aged 65+ & PD 60-64; ID/DD 0+; aged 65+ & PD 18-64; autism & ID/DD 0+;	No	1915(i)	68,644
OK	1915(c)	Aged 65+ & PD 21-64; ID 3+; ID 21+; ID 3-17; ID 18+; MF & TD 19+; PD 20-64; aged 65+	Yes	No	7,701
OR	1915(c)	PD 0-17; ID/DD 0-17; MF 0-17; ID/DD 18+; aged 65+ & PD 18-64	No	1915(k)	110
PA	1915(c)	Autism 0+, ID 0+ & DD 0-8; PD 18-59; aged 65+ & PD 60-64; HIV/AIDS 21+; aged 65+ & PD 21-64; ID/DD 0-2; autism 21+; DD 18-59	No	No	9,504
RI	1115	Aged, blind, or disabled	Yes	1915(k)	0
SC	1915(c)	ID 0+; MF 0-18; TD 21+; PD (and other) 0-64; autism 3-10; HIV/AIDS 0+; aged 65+ & PD 18-64; SED 4-18	Yes	No	10,409
SD	1915(c)	Aged 65+ & PD (and other) 18-64; ID/DD 0+	Yes	No	350
TN	1115 & 1915(c)	ID 0+; DD 0-5;	Yes	No	7,428
TX	1915(c) & 1115	MF 0-20; SED 3-18; aged 65+ & PD 21-64; ID/DD 0+; DD 0+; medically needy	No	1915(k) & 1915(i)	281,381
UT	1915(c)	MF & TD 0-20; BI 18+; aged 65+ & PD (and other) 18-64; autism & ID/DD 0+; aged 65+; autism 2-6; MF 0-19	No	No	2,974
VT	1115	Aged 65+ & PD 21+; BI; MI; DD	Yes	No	0
VA	1915(c)	Autism & ID/DD 0+; autism & ID/DD 18+; TD 0+; aged 65+ & PD (and other) 18-64 (Alzheimer's); aged 65+, PD 0-64 & TD 0+; SED 0-21	No	No	12,266
WA	1915(c) & 1115	Aged 65+ & PD (and other) 18-64; autism & ID/DD 8-20; autism & ID/DD 18+; autism & ID/DD 0+; DD 3+	No	1915(k)	0
WV	1915(c)	Aged 65+ & PD 18-64; ID/DD 3+; BI 3+	Yes	No	2,092
WI	1915(c)	PD (and other) 0-21; PD (and other), SED, autism & ID/DD 0-21; SED 0-21; aged 65+, PD (and other) 18-64 & ID/DD 18+; ID/DD 18+;	Yes	No	4,198
WY	1915(c)	Aged 65+ & PD 19-64; BI 24-64; SED 4-17; ID/DD 0-20; BI 21+; ID/DD 0+	No	No	194

## Medicaid Section 1115 Waivers and Home- and Community-based Services (HCBS) Sources:

1. KFF: Medicaid Waiver Tracker. <https://www.kff.org/medicaid/issue-brief/medicaid-waiver-tracker-approved-and-pending-section-1115-waivers-by-state/>
2. Kids' Waivers. <https://www.kidswaivers.org/#about>
3. Medicaid State Waivers List. <https://www.medicare.gov/medicaid/section-1115-demo/demonstration-and-waiver-list-index.html>
4. KFF: Medicaid HCBS Survey. <https://www.kff.org/report-section/states-focus-on-quality-and-outcomes-amid-waiver-changes-long-term-services-and-supports-reforms/>
5. HHS HCBS. <https://aspe.hhs.gov/system/files/pdf/76201/primer10.pdf>
6. 2017 HCBS Wait Lists. <https://www.kff.org/report-section/key-questions-about-medicare-home-and-community-based-services-waiver-waiting-lists-appendix-tables/>
7. <https://www.azahcccs.gov/AHCCCS/Initiatives/AHCCCSWorksCommunityEngagement/>
8. <https://khn.org/morning-breakout/indiana-becomes-second-state-in-recent-weeks-to-pump-the-brakes-on-medicare-work-requirement-plans/>
9. <https://www.kcur.org/post/kancare-compromise-gives-legislature-final-say-medicare-work-requirement#stream/0>
10. <https://thehill.com/policy/healthcare/474783-kentucky-gov-beshear-rescinds-medicare-work-requirements>
11. <https://thehill.com/policy/healthcare/472643-michigan-governor-calls-for-pause-in-medicare-work-requirements>
12. <http://dhhs.ne.gov/Pages/Heritage-Health-Adult-Demonstration.aspx>
13. <https://why.org/articles/wolf-republicans-resume-tug-of-war-over-medicare-work-requirements/>
14. <https://www.slttrib.com/news/politics/2019/12/23/feds-approve-full/>