

Overview of Graded Sections

MEDICAID FINANCIAL ELIGIBILITY GRADING RUBRIC				
GRADE	Eligibility for Parents of Dependent Children	Eligibility for Childless Adults	Eligibility for Pregnant Women	Eligibility for Children
A	138% of FPL or greater	138% of FPL or greater	Medicaid/CHIP eligibility of 220% of FPL or greater	Medicaid or CHIP eligibility of 300% of FPL or greater for all age groups
B	100%-137% of FPL	100%-137% of FPL	Medicaid/CHIP eligibility of 190% to 219% of FPL	Medicaid or CHIP eligibility of 195% to 299% of FPL for all age groups
C	90% to 99% of FPL	90% to 99% of FPL	Medicaid/CHIP eligibility of 150% to 189% of FPL	Medicaid or CHIP eligibility of 150% to 194% of FPL for all age groups
D	89% of FPL or less	89% of FPL or less	Medicaid/CHIP eligibility of 149% of FPL or less	Medicaid or CHIP eligibility of up to 150% for all age groups
F	No coverage	No coverage	No coverage	No coverage

MEDICAID SECTION 1115 WAIVERS RUBRIC

Pass: The state has not sought use of its section 1115 waivers to enact provisions in its Medicaid program that would be harmful to the rare disease community.

Fail: The state has sought use of its section 1115 waivers to enact provisions in its Medicaid program that are harmful to the rare disease community.

PRESCRIPTION DRUG OUT-OF-POCKET COST SHARING PROTECTIONS GRADING RUBRIC	
GRADE	Description
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

STEP THERAPY PROTECTIONS GRADING RUBRIC					
GRADE	Based on clinical practice	Timeline	Exceptions process	Categories of exceptions	Subsequent guidance from state
A	The state mandates a step therapy protocol process based off of clinical practice	The state mandates a clear and expedited timeline, including for emergency circumstances	The state mandates a clear exception process for patient and provider	The state step therapy protocols mandate five exceptions including: (1) The required Rx drug is contraindicated or will likely cause an adverse reaction or physical or mental harm to the patient; (2) The required Rx drug is expected to be ineffective based on the known clinical characteristics of the patient and the known characteristics of the Rx drug regimen; (3) The patient has tried the required Rx drug while under their current or a previous health insurance or health benefit plan, or another Rx drug in the same pharmacologic class or with the same mechanism of action and such Rx drug was discontinued due to lack of efficacy or effectiveness, diminished effect, or an adverse event; (4) The required Rx drug is not in the best interest of the patient, based on medical necessity; (5) The patient is stable on a Rx drug selected by their health care provider for the medical condition under consideration while on a current or previous health insurance or health benefit plan	The state has published subsequent guidance to implement step therapy protections
B	-	-	The state mandates a clear exception process for provider	The state step therapy protocols mandate at least four of the five exceptions above	-
C	The state mandates a step therapy protocol process, not based off of clinical practice	The state mandates a clear timeline	The state mandates an exception process	The state step therapy protocols mandate at least three of the five exceptions above	The state has not yet published subsequent guidance to implement step therapy protections
D	-	The state mandates an expeditious timeline	-	The state step therapy protocols mandate at least one of the five exceptions above	-
F	The state does not mandate a step therapy protocol process	The state does not have a specified mandated timeline	The state does not mandate an exception process	The state step therapy protocols mandate none of the five exceptions listed above	State has no step therapy protections

MEDICAL NUTRITION GRADING RUBRIC				
GRADE	Coverage Requirements for Commercial health Plans	Covered Disorders Requirements for Commercial Health Plans	Coverage Requirements for State-Run Programs	Covered Disorders Requirements for State-Run Programs
A	Coverage is required for both formula and low-protein nutrition with no limits on eligibility or coverage	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition	Mandated Medicaid coverage for medical nutrition with no age or eligibility restrictions (or through a supplemental program)	Covered disorders include all inborn errors of metabolism, eosinophilic disorders/FPIES and other conditions requiring medical nutrition
B	Coverage is required for formula and low-protein food but with age or dollar limits	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition	Mandated Medicaid coverage for formula and low-protein nutrition with restrictions (or through a supplemental program)	Covered disorders include all inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition
C	Coverage is required for both formula and low-protein nutrition but with age and dollar limits	Covered disorders include three or more metabolic conditions, but exclude eosinophilic disorders/FPIES and other medically necessary uses	Coverage for formula and low-protein nutrition is on a case-by-case basis	Covered disorders include three or more inborn errors of metabolism but exclude eosinophilic disorders/FPIES or other conditions requiring medical nutrition
D	Coverage is required but with limits on eligibility (such as age) or coverage (such as a dollar cap or formula only)	Covered disorders include two or fewer metabolic conditions (such as PKU-only)	Mandated Medicaid coverage for formula but no coverage of low-protein nutrition	Covered disorders include two or fewer metabolic conditions (such as PKU-only)
F	State does not mandate private insurance coverage of medical nutrition	State does not mandate private insurance coverage of medical nutrition	State does not mandate coverage for Medicaid. The state does not offer supplemental programs to provide coverage	State does not mandate coverage for Medicaid. The state does not offer supplemental programs to provide coverage

NEWBORN SCREENING GRADING RUBRIC							
GRADE	Screening for RUSP Core Conditions	Adding RUSP Conditions	Funding	DBS Use	Follow-Up	Quality	Advisory Committee
A	Screens for all core conditions	Conditions are added automatically	NBS program has a distinct stream of revenue AND Health Department can easily set fee	Uses for research and for QA/QC	Has a robust short-term and long-term program in place with funding	Has an excellent program in place OR has a good program in place with funding	Has an entity that includes a diverse membership AND meets more than once a year
B	Up to 3 that it does not screen	Health Department can easily add conditions on its own	NBS program has a distinct stream of revenue OR Health Department can easily set fee	Uses for QA/QC only	Has a short-term and long-term program	Has a good program in place	Has an external entity that meets more than once a year
C	4-5 that it does not screen	Health Department can add conditions on its own	Revenue comes from general funds and it is hard to change fee OR there are supplemented appropriations (e.g., Title V)	Retains for > 1 year but conducts no further research	Has a short-term program	Has a program in place	Has an external entity that only meets once a year
D	More than 5 that it does not screen	Legislature must approve the addition of conditions	The NBS fee and the resulting revenue are subject to the legislature	Retains for 6-12 months but conducts no further research	Has some education materials	Does not have a program OR only focuses on specimen collection	Does not have an external entity but has an internal entity
F	No screening	State does not add conditions	Does not have anything	Destroys in 6 months or less and conducts no further research	Does not have anything	Low quality	Does not have anything

Overview of Descriptive Sections

RARE DISEASE ADVISORY COUNCILS: Not graded – instead a description of the status of the council in the state was included.

INDIVIDUAL INSURANCE PROTECTIONS: Not graded – instead a description of the status of individual insurance protections in the state was included.