



For additional information on the grading methodology, please visit the State of the States Report: rareaction.org/stateofthestates

Medicaid Eligibility

Overall Grade: A

Eligibility for childless adults	A
Eligibility for parent of a dependent child	A
Eligibility for pregnant women	B
Medicaid and/or Children’s Health Insurance Program (CHIP) eligibility for children	A

Medicaid Section 1115 Waivers

Overall Grade: Pass

Illinois has not sought to use section 1115 waivers to enact provisions in its Medicaid program that would be harmful to the rare disease community.

Out-of-Pocket Costs

Overall Grade: F

Prescription drug cost sharing protections	F
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Step Therapy

Overall Grade: C

Based on clinical practice	A
Timeline	A
Exception process	C
Categories of exceptions	C
Subsequent guidance from state	F

Medical Nutrition

Overall Grade: C

Coverage requirements for commercial health plans	D
Covered disorders requirements for commercial health plans	C
Coverage requirements for state-run programs	D
Covered disorders requirements for state-run programs	C

Newborn Screening

Overall Grade: B

Screening for RUSP core conditions	B
Adding RUSP core conditions to the state panel	B
Funding for program	A
Use of dried blood spots (DBS)	B
Follow-up	A
Quality of program	B
Advisory committee	A

Rare Disease Advisory Councils

Illinois enacted legislation to create a rare disease advisory commission in 2017. The commission is not currently meeting statutory requirements because vacant positions remain.

Individual Insurance Market Protections

Pre-existing conditions protections: Illinois prohibits pre-existing conditions exclusions.

Short-term, limited-duration and association health plans: Illinois limits the initial contract duration of short-term, limited-duration health plans to 180 days and underwritten short-term, limited-duration coverage cannot exceed 180 days in a 240-day period. Illinois requires that an association form for a purpose other than offering insurance.

Reinsurance: Illinois has not yet sought a section 1332 waiver to establish a reinsurance program.