A Roadmap for States: Data-Driven Work Requirement Exemptions for Rare Disease Patients and Caregivers

Why a claims-based approach alone misses the rare disease patients who most need an exemption, and what states can do about it

Context. To remain eligible for Medicaid after January 2027, most adults ages 19–64 who enrolled through the ACA expansion must complete 80 hours per month of qualifying activity or qualify for an exclusion or exception[1]. Congress wrote the requirement to apply to able-bodied adults who can work, and deliberately excluded nine populations, including the **medically frail** and certain **caregivers**. On June 1, CMS released an Interim Final Rule (IFR) to provide implementation guidance to states. To limit documentation burden, states were directed to first rely on automated healthcare data-based screening to flag exclusions at scale, without requiring patients to submit documentation. While not specified in statute, CMS is also requiring that states verify the condition qualifying a patient as medically frail significantly impairs their ability to work, adding a significant complication to data-based verification strategies. Prior to the release of the June 1st IFR, most states expected to rely on lists of diagnosis and procedure codes to confirm the population considered medically frail. For individuals living with and caring for those with rare diseases, an automated, code-driven process alone will systematically miss the very patients the statute was written to protect unless it is built around the coding gap and includes clear alternative verification processes.

Why a claims-based screen cannot capture all rare disease patients

The codes mostly do not exist. Approximately **97% of the >16,000 rare diseases in the Mondo terminology have no specific ICD-10-CM code**[2]. Patients without a specific code are recorded under nonspecific parent terms (“other specified,” “unspecified,” NOS) or symptom-only R-series codes, where they are indistinguishable from the far larger, able-bodied populations the requirement is meant to reach.

The diagnostic odyssey makes them invisible in coding. A rare disease diagnosis takes, on

Disease (example and exemption type)	Current coding status	Why a codes-only screen misses
SLC6A8 creatine transporter deficiency (MONDO:0010305) Exclusion: Caregiver for child likely disabled	No dedicated ICD-10-CM code; captured only under nonspecific intellectual disability categories (e.g., F70-F79 "unspecified intellectual disabilities") and epilepsy codes (G40)	Severe intellectual disability, profound speech delay, and intractable seizures require intensive parental care, but nonspecific codes reading "unspecified intellectual disability" and "seizures" leave this invisible to claims.
POLG-related mitochondrial disease (MONDO:0008199) Exclusion: Patient (adult); highly likely medically frail	No specific ICD-10-CM code; typically coded under nonspecific categories (G11.9 ataxia, R26.9 gait disorder, E88.9 metabolic disorder)	Progressive ataxia, neuropathy, cognitive decline, and seizures make work impossible, yet in claims the patient is indistinguishable from a large population with general ataxia or metabolic issues, many of whom are able-bodied.
Undiagnosed patient on the diagnostic odyssey Exclusion: Patient; highly likely medically frail or caregiver for disabled child	Often only R69 (“illness, unspecified”) or scattered symptom (R-series) codes across encounters and specialties; or no code	Among the sickest and least able to sustain 80 hours per month, yet entirely unreachable by any disease-code screen.

average, more than six years and roughly 17 health-care encounters after symptoms begin[3]. During that time, there is no specific disease code to flag[4], yet these patients are among the sickest and least able to sustain 80 hours per month of work. Patients without a diagnosis despite years of specialist care carry the strongest evidence of medical severity and should be presumptively excluded pending confirmation.

The undercount is very large, and the data back this up. A 2023 Medicaid analysis using a crosswalk of 1,465 rare disease ICD-10-CM codes identified approximately **6.1 million** beneficiaries with a rare disease nationwide, including **112,129 in Maryland**[5]. Because that crosswalk can only see the small fraction of rare diseases that have any usable ICD-10-CM code, **6.1 million is an undercount**. The true number, including everyone still on the diagnostic odyssey, is substantially higher.

How the IMO Health, Mondo, and Epic integration changes verification

The Mondo disease ontology exists to reconcile rare disease definitions across communities and knowledge sources, the fragmentation of which has historically hindered diagnostics and care. Mondo provides a rigorous, computational framework that fills the extraordinary gap of 97% of rare disease codes not available in health systems. Because of this capability, in Epic's February 2026 update, health systems using IMO Core can now apply Mondo Disease Ontology codes directly in the EHR, where more than 5,000 new rare disease codes have already been added, with thousands more being added in the next release. This changes the exclusion verification process in two ways:

- For the **state** (data-driven screening): a Mondo code is a specific, machine-readable rare disease code, whereas in non-IMO systems, there was only a nonspecific code or none. It makes automated (ex parte) identification feasible, and its built-in crosswalks (to ICD, Orphanet, OMIM) let states map a diagnosis to disabling or chronic categories automatically.
- For **providers** and patients (documentation burden): a single Mondo code consolidates evidence that would otherwise be scattered across years of records, making an exclusion or short-term exception far easier to substantiate and serving as durable proof across reverifications.

Recommendations to States

Auto-identification reduces the state's administrative overhead and reduces burdens on many patients, but a clear, comprehensive solution is needed for rare disease patients and caregivers who will be missed. A system that misses eligible patients isn't just harmful to patients; it is a budget failure for the state.

The Mondo team comprises informatics experts with deep expertise in healthcare data systems. The EveryLife Foundation for Rare Diseases, a national, non-profit patient advocacy organization focused on ensuring our healthcare systems account for the unique complexities inherent in rare diseases, is pleased to work closely with the Mondo team to offer insights to states seeking to make their ex parte verification strategies as comprehensive as possible. The Mondo team has generously offered to hold an informational session for state Medicaid teams in mid to late July to provide additional insights and recommendations for coding strategies. Please indicate your interest in participating here; additional information will be provided by July 15.

Short-term: what states can do now with existing systems

- **Do not rely on dedicated rare disease codes alone.** Build a proxy or composite flag to catch people on the diagnostic odyssey or those likely to have complex, genetic, and multi-system diseases without specific codes. For example, an exome or genome sequencing claim (CPT 81415-81417 or 81425-81427) combined with a threshold of specialist visits, hospitalizations, or clustered nonspecific and

symptom codes (including R69, “illness, unspecified”) over a defined period can trigger a presumptive exclusion or manual review.

- **Use the Mondo-in-Epic and IMO crosswalk**[6] where available to identify rare disease patients and verify medical-frailty determinations, rather than making patients provide additional documentation. Mondo’s hierarchical structure allows states to make policy determinations at intermediate, high-level nodes. This enables states to group related conditions based on shared, high-impact phenotypic evidence, simplifying the burden of building the exclusion list while maintaining clinical precision.
- **Accept high-signal qualifying indicators,** such as involvement of a rare disease specialty center, genetics clinic, or Undiagnosed Diseases Network site where diagnosis codes are unavailable.
- **Minimize unnecessary reverification requirements using the data.** In our crosswalk, **69% of rare disease ICD-10-CM codes (1,014 of 1,465) map to chronic conditions**[5,7] under the AHRQ HCUP Chronic Condition Indicator. Additionally, about 70% of rare diseases are genetic in origin, and many of these result in conditions that will never improve[8]. States should designate the chronic, lifelong, and progressive diseases permanently excluded, with no repeat documentation.
- **Default to the least burdensome path** when data are insufficient: presumptive eligibility for exclusion plus a simple pathway to submit documentation. States should be careful to avoid documentation requirements that necessitate new in-person encounters or impose administrative burdens on physicians, especially given the extremely limited availability of rare disease specialists.
- **Create well-vetted, easy-to-follow instructions.** Rare disease patients and caregivers should be able to easily understand if they are subject to community engagement requirements, if they qualify for an exclusion or short-term exception, and what action they must take to verify their status. Materials should reflect the complexities highlighted above and engagement with the community in their design.

Long-term: CMS, CDC, and Congress can embrace structural fixes to ensure rare disease patients are visible in healthcare data.

- **CMS should require Mondo** rare disease codes to support deterministic analysis of exclusion eligibility in systems such as T-MSIS, so that rare disease patients are countable and verifiable using ex parte strategies. **CDC and NCHS should move quickly to reform the ICD-10-CM coding process, including support for the coordinated bulk-request framework proposed by Mondo** [9] **and use of code R69 (“illness, unspecified”)** [10]. NCHS has paused new ultra-rare and genetic-condition code proposals through spring 2027 because genetic conditions are scattered across ICD-10-CM chapters and lack an organizing structure. Moving quickly to enable the addition of codes iin large, coordinated batches rather than one at a time (each of which often takes years) will reduce the number of rare disease patients missed by data-driven verification processes.
- **Support progress towards ICD-11 adoption.** ICD-11 is integrating Mondo directly, and will give rare diseases the native, granular representation that ICD-10-CM lacks today.

Sources

1. Arrington, [r-Tx-19] JC. An act to provide for reconciliation pursuant to title II of H. Con. Res. 14. 1 Jul 4, 2025. Available: https://www.congress.gov/bill/119th-congress/house-bill/1/text
2. McMurry J, Matentzoglu N, Bailey K, Berg J, Jason C, Chute C, et al. Which rare diseases are best suited to diagnostic AI? A systematic selection framework. Zenodo; 2026. doi:10.5281/ZENODO.20520796
3. EveryLife Foundation for Rare Diseases / Lewin Group. The National Economic Burden of Rare Disease Study. 2021. Available: https://www.burdenstudy.org
4. McMurry J, Sizer A, Allaway R, Boerkoel C, Chen AJ, Colquitt J, et al. Critical bottlenecks in Rare Disease research and care: A community perspective. Zenodo; 2025. doi:10.5281/ZENODO.14907384
5. Ramani S, McDannell B, Sullivan J, Kennedy A, Trent J, Lewandowski L. Medicaid service utilization by beneficiaries with rare diseases. Zenodo; 2026. doi:10.5281/ZENODO.20819133
6. Bookner M. Operationalizing rare disease knowledge in clinical workflows. In: IMO Health [Internet]. 25 Feb 2026 [cited 23 Jun 2026]. Available:

https://www.imohealth.com/resources/operationalizing-rare-disease-knowledge-in-clinical-workflows/
7. Chronic Condition Indicator Refined (CCIR) for ICD-10-CM. [cited 23 Jun 2026]. Available: https://hcup-us.ahrq.gov/toolssoftware/chronic_icd10/chronic_icd10.jsp
8. Nguengang Wakap S, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, et al. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. Eur J Hum Genet. 2020;28: 165–173. doi:10.1038/s41431-019-0508-0
9. MONDO CDC COORDINATION https://form.fillout.com/t/fcP2cRCG13us
10. Hernandez HW. Improving Diagnostic Uncertainty Coding in ICD-10-CM and ICD-11. In: R69 Initiative [Internet]. Available: https://www.r69initiative.org