July 1st, 2026

Perrie Briskin, MPH
Deputy Secretary and Medicaid Director
Maryland Department of Health
201 W Preston St.
Baltimore, MD 21201

Re: Medicaid Final Rule Regarding Public Law 119-21 and Community Engagement Requirements

Dear Deputy Secretary and Medicaid Director Briskin,

On behalf of the EveryLife Foundation for Rare Diseases, we write to share recommendations and concerns regarding the implementation of Public Law 119-21, or the One Big Beautiful Bill, on the rare disease community in Maryland. The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community. These comments reflect the engagement of our coalition of rare disease stakeholders around our community's shared priorities to ensure that rare disease patients and families have access to affordable health insurance coverage and the care they need to manage their rare disease.

More than 30 million Americans currently live with one of the more than 10,000 rare diseases.[1] Rare disease patients often have highly complex, chronic health conditions that can require around-the-clock care. The rare disease community relies on Medicaid for access to coverage for diagnosis, treatment, medical equipment, home healthcare, and caregiving services. In many cases, Medicaid is the only insurance program that provides the comprehensive care that rare disease patients need.

Implementing Community Engagement Requirements is an administratively complex process that will significantly impact Medicaid beneficiaries. Our analysis of Medicaid TMSIS data using 1,680 known rare disease diagnosis codes identified 112,129 Medicaid beneficiaries who live with one or more rare diseases in Maryland.[2] While Public Law 119-21 (One Big Beautiful Bill) mandated community engagement requirements, states still have discretion on implementation and can take action to ensure that

[1]National Human Genome Research Institute. (2019, March 9). *Rare Diseases FAQ*. Genome.gov. https://www.genome.gov/FAQ/Rare-Diseases
[2] Ramani, S., McDannell, B., Sullivan, J., Kennedy, A., Trent, J., & Lewandowski, L. (2026). Medicaid Service Utilization by Beneficiaries with Rare Diseases. *Zenodo (CERN European Organization for Nuclear Research)*. https://doi.org/10.5281/zenodo.20819134

people with rare diseases maintain their access to care. As Maryland designs policies, processes, and community outreach plans, we urge you to consider a series of recommendations to minimize coverage loss and ensure that rare disease patients and caregivers who should be eligible for exclusions or short-term hardships are identified.

These recommendations include:

- Account for the rare disease coding gap when designing *ex parte* verification processes
- Account for the episodic nature of many rare diseases by limiting the lookback period to one month and reverification of compliance to once per 12-month period.
- Minimize unnecessary reverification requirements
- Create simple, inclusive documentation requirements
- Automatically exempt patients receiving home and community-based services
- Provide clear guidelines for caregivers of children under the age of 13 and people with disabilities
- Adopt all short-term hardship exemptions
- Collaborating with rare disease patients and organizations

Account for the rare disease coding gap when designing *ex parte* verification processes

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. While ex parte processes that minimize the need for additional beneficiary or healthcare provider action will minimize coverage losses for eligible beneficiaries, 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.

For the vast majority of rare diseases, diagnosis codes simply do not exist. Approximately 97% of the >16,000 rare diseases in the Mondo terminology, an open-source medical vocabulary, have no specific ICD-10-CM code[3]. 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.

A rare disease diagnosis takes, on average, more than six years and roughly 17 health-care encounters after symptoms begin.[4] During that time, there is no specific disease code to flag, yet these

[3] 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

[4] Yang G, Cintina I, Pariser A, Oehrlein E, Sullivan J, Kennedy A. The national economic burden of rare disease in the United States in 2019. Orphanet J Rare Dis. 2022 Apr 12;17(1):163. doi: 10.1186/s13023-022-02299-5.

patients are among the sickest and least able to sustain 80 hours per month of work[5]. Patients without a diagnosis despite years of specialist care carry the strongest evidence of medical severity and should be presumptively excluded pending confirmation.

The EveryLife Foundation, along with experts in rare disease informatics, developed suggestions to support states' *ex parte* processes that can be found at the conclusion of this letter. Additionally, to reflect the complexity of conveying these recommendations in writing, the Mondo team has agreed to host an informational session to provide additional insights and guidance to states seeking to ensure their ex parte processes can identify rare disease beneficiaries who should be excluded.

Account for the episodic nature of many rare diseases by limiting the lookback period to one month and reverification of compliance to once per 12-month period.

The IFR requires that states verify a beneficiary's medical frailty exclusion at least every 12 months but allows states to require more frequent verification. The inclusion of a requirement that states verify that a beneficiary's condition significantly impairs their ability to work will add complexity to the administrative burdens already facing states and beneficiaries.

For patients with rare diseases, connecting a diagnosis to the ability or inability to work will be a difficult process. Patients face a variety of different circumstances regarding work, especially those with episodic conditions that involve periods of worsening health that disrupt work history. Verifying the impact of a diagnosis on a patient's ability to work will require additional effort from clinicians already strained by administrative burden and limited supply for most rare diseases. To account for the complex, episodic nature of rare diseases and the limited availability of experts, states should adopt a 1-month lookback period and require verification only once every 12 months.

Minimize Unnecessary Reverification Requirements

The EveryLife Foundation's analysis of Medicaid beneficiaries with documented rare diseases mapped known ICD-10-CM codes for rare diseases to the AHRQ HCUP Chronic Condition Indicator, finding that 69% of rare disease ICD-10-CM codes (1,014 of 1,465) map to chronic conditions.[6] Additionally, about 70% of rare diseases are genetic in origin, and many of these result in conditions that will never improve.[7] States should ensure that beneficiaries with chronic, lifelong, and progressive diseases are permanently excluded from community engagement requirements, with no repeat verification requirements.

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[5] 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

[6] Footnote 2.

[7] 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

Create Simple, Inclusive Documentation Requirements

The IFR limits self-attestation to specific instances, such as when an exclusion can't be verified *using ex parte* processes. However, the rule specifies that self-attestation can be accepted only on a broad basis through January 1st, 2028. Afterward, states can accept self-attestation only once during an enrollee's continuous coverage, and that attestation must be verified with additional data at the next reverification. States have some flexibility in designing requirements for the types of documentation that can substantiate medical frailty and for the providers eligible to certify compliance. Additionally, states are encouraged to create simple, plain-language screening tools to help enrollees determine whether they may qualify as medically frail.

For patients with rare diseases, this required documentation combined with the inability to self-attest will create barriers to coverage. On average, it takes more than 6 years and nearly 17 doctor visits, hospitalizations, and other health-related encounters to receive a rare disease diagnosis after symptoms begin.[8] This extensive diagnostic journey may make it difficult to get an exemption. In addition, many rare disease patients struggle with a diagnosis at all. By banning all self-attestation, patients with an undiagnosed rare condition will have increased difficulty securing an exemption.

Automatically Exempt Patients Receiving Home and Community-Based Services

Patients enrolled in Medicaid through a Home and Community-Based Services (HCBS) waiver pathway should automatically be exempt from work requirements due to their previously verified disability status and high-need, complex care needs. Rare disease patients often have highly complex, chronic health conditions that can require around-the-clock care. Nearly one-third were dually eligible for Medicare and Medicaid, and 44.7% qualified through home- and community-based services (HCBS) waivers, underscoring the importance of these pathways for access to care.[9]

The rare disease community relies on Home and Community-Based Services (HCBS) through the Medicaid waiver pathway to access medical equipment, home healthcare, services and supports to reside safely in the community, and paid caregiving services. In many cases, Medicaid is the only insurance program that provides comprehensive care and enables patients with rare diseases to access essential home care services that support the entire family. This data-informed approach will reduce administrative burden on patients and families with complex care needs, while saving the state valuable time in enrollment re-verification.

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[8] EveryLife Foundation for Rare Diseases. (2023, October 31). *Delayed Diagnosis Study - EveryLife Foundation for Rare Diseases*. https://everylifefoundation.org/delayed-diagnosis-study/

[9] Ramani, S., McDannell, B., Sullivan, J., Kennedy, A., Trent, J., & Lewandowski, L. (2026). Medicaid Service Utilization by Beneficiaries with Rare Diseases. *Zenodo*. https://doi.org/10.5281/zenodo.20819134.

Providing Clear Guidelines for Caregivers of Children Under the Age of 13 and People with Disabilities

States must provide patients with specific guidelines for how caregivers should document and report caregiving hours. Caregivers are exempt from community engagement requirements depending on their relationship to the patient, including caretaker relatives (living with the individual), family caregivers, and parents or guardians. These exemptions can be strengthened by explicitly including family members like siblings and grandparents, foster parents, kinship caregivers, or close family friends who support a patient's ability to secure health care.

Serving as a caregiver for patients with rare diseases is a substantial time commitment that often requires support from family caregivers and friends. Rare caregivers of adults spend about 37 hours a week providing care on average – about 12 more hours a week than general caregivers. Even more striking is the amount of care provided by rare caregivers of a child: 53 hours a week, on average, compared to 30 hours for general child caregivers.[10] Explicitly codifying the importance of these relationships will make it easier for families to verify exemptions or improve tracking for unpaid family caregiving. Given the importance of caregiving and the broader implications for the long-term care system if unpaid caregivers are forced to return to work, we encourage state legislatures to prioritize exemptions that protect caregivers, patients, and families.

Adopt All Short-Term Hardship Exemptions

States should adopt all short-term hardship exemptions permitted by the interim final rule, which outlines the optional exemptions states may implement for individuals experiencing a major life disruption. Short-term hardships are optional and must be available in all circumstances for states that adopt them. These exemptions will be key for individuals with rare diseases, who may spend extended periods in the hospital or need to travel outside their community for care. Nearly 18% of patients with a rare disease live in rural areas, and an additional 21% live in rural-and-suburban mixed areas.[11] This is particularly important when considering how many rare patients must travel for care.

According to a 2019 survey, 39 percent of respondents needed to travel 60 or more miles to receive care, creating physical and financial constraints that often contributed to missed work and school. For rare patients, 26 percent have reported missing school because of their rare disease and 62% of

[10] National Alliance of Caregiving (2018). Rare disease caregiving in America. Can be found at: NAC-RareDiseaseReport_February-2018_WEB.pdf

[11] Ramani, S., McDannell, B., Sullivan, J., Kennedy, A., Trent, J., & Lewandowski, L. (2026). Medicaid Service Utilization by Beneficiaries with Rare Diseases. *Zenodo*. https://doi.org/10.5281/zenodo.20819134

patients have been prevented from attending work.[12] In addition, a 2019 study found that among individuals with the 379 rare diseases studied, the average adult incurred over $1,300 in travel expenses alone while seeking care or attending clinical trials.[13] For patients with rare diseases, these short-term hardship exemptions will significantly impact their ability to maintain insurance while seeking specialized care.

Collaborating with Rare Disease Patients and Organizations

Patients, their families, caregivers, and the advocacy organizations that support them should be represented in designing and testing the new verification policies and processes, including the criteria for exemptions, the accessibility and design of the online enrollment system, community outreach plans, and educational content to ensure they account for the needs of the rare disease community.

This is particularly important because many beneficiaries remain unaware of how the new requirements will affect them. A recent survey found that about 55% of Medicaid enrollees are completely unaware that work requirements will become a condition of eligibility in January 2027. An additional 27% said that they have heard something but are unsure of the details.[14] In Maryland, the same survey found that 50% were completely unaware of work requirements.[15] Without strong patient engagement and notification, many enrollees will be unaware of requirements until it's too late.

There are several ways to include patient voices in implementation. In 2024, the Centers for Medicare & Medicaid Services (CMS) finalized the Ensuring Access to Medicaid Services Final Rule (CMS-2442-F), which expands and strengthens beneficiary voices. Medicaid Advisory Councils (MAC) and Beneficiary Advisory Councils (BAC) are valuable resources for patient engagement during H.R 1 implementation.

In addition, patient advocacy organizations are a valuable resource. Engaging community members, especially those living with or providing care for individuals with complex, high-need conditions, is essential to designing programs that reflect real-world experiences and maximize the benefits of the therapy. Patient advocacy organizations bring important disease-specific expertise that is often difficult to find elsewhere. In addition, we're happy to facilitate connections to rare disease advocates in Maryland, including members of the existing Rare Disease Advisory Council.

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[12]"Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." National Organization for Rare Disorders, 2020

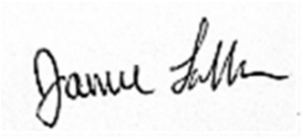
[13] EveryLife Foundation for Rare Diseases. (2025, October 7). *Burden study landing - EveryLife Foundation for Rare Diseases*. https://everylifefoundation.org/burden-study/

[14] The Health Management Academy. (n.d.). *What 70 million Medicaid recipients don't know about their coverage*. https://hmacademy.com/blog/medicaid-enrollee-awareness-survey-2026

[15] See footnote 14

Medicaid is an essential, life-saving program for many in the rare disease community, and the EveryLife Foundation for Rare Diseases remains committed to ensuring that patients can access the care they need. If we can support your implementation process, please reach out to Kathryn Poe at kpoe@everylifefoundation.org.

Sincerely,



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Appendix 1.
We asked families to share stories about the important role Medicaid plays in their lives. While not all are relevant to the implementation of the Community Engagement Requirement, these stories showcase the unique and vital role Medicaid plays in supporting rare disease patients and families.

Maryland Resident Michelle S.

"My daughter started on Medicaid when she turned 18 and within the state of Maryland, that automatically came with her Social Security benefits. The level of coverage under the special program she is under, which is a rare and expensive management program, has been very good overall in terms of paying for all appointments and procedures even out of state specialists. I pay nothing out-of-pocket for her. However, there's a home care component under Medicaid that has been very limited to say the least. We got very few hours initially, and the administrative process for appeals to gain more hours took months. The initial process to even get hours took literally nine months, and the agencies that they use for these services are very questionable. I have further concerns as my husband is getting ready to retire and in our state once he retires, my daughter automatically has benefits associated with his retirement, but within two years following that she goes onto Medicare, which is going to be a nightmare and I'm very concerned about losing my Medicaid specialized coverage, which is highly superior."

Maryland Resident Kristi A.

"My daughter has a rare disease, KAT6B, and has many other disabilities, including deaf blindness, autism, feeding issues, a G-tube, and much more. My daughter should qualify for a Medicaid Waiver in our state based on all her disabilities. However, due to the number of disabled children and adults needing to have Medicaid support, we have been put on a waitlist, which has about a 7-10 year wait. With the massive cuts to Medicaid, the question now being raised is how much longer will that wait become and difficulty of being able to get on a Waiver. Medicaid is so critical to families like ours and to our community as they provide support that no private insurance company contracted with private employers will typically cover, e.g., wheelchairs, g-tube supplies, diapers, and many other medical needs that are very costly and required on a routine basis. Medicaid is sometimes the only available means that can help provide these life-saving supplies, medical services and care support. So many families have to leave their jobs and private insurance to care for their loved ones, which keeps them from affording healthcare at all. Medicaid can at least provide that lifeline for their loved one living with a rare genetic disorder or medical complexities, like my daughter. If something happens to my husband or I, I don't know how my daughter will survive without some basic healthcare, like Medicaid can provide her. Private insurance for someone like my daughter is enormously expensive and in-home care takes most of what we earn. As medical costs continue to sharply rise, greater and faster than the pace of standard cost of living, families like mine will be greatly impacted, both in our savings and ability to work, as less caregivers will be forced to take pay cuts in an economy that continues to get more expensive by the day."

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
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