July 31, 2026

SUBMITTED ELECTRONICALLY

The Honorable Mehmet Oz, MD, MBA
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

Re: Medicaid Program; Community Engagement Requirement for Certain Individuals - CMS-2454-IFC

Dear Administrator Oz:

Thank you for the opportunity to submit comments on "Medicaid Program; Community Engagement Requirement for Certain Individuals" (the Rule).[1] We write to express our serious concern over the impact of the Rule on individuals and family caregivers affected by neuromuscular diseases (NMDs), as well as the healthcare teams that care for them.

The Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 75 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our community. MDA's mission is to empower the people we serve to live longer, more independent lives.

While each disease varies in its progression, affected muscles, and symptoms, and every individual's journey is unique, NMDs generally cause muscle weakness, fatigue, and are progressive, meaning symptoms grow worse over time. Some are present at birth, while others manifest in childhood or adulthood. NMDs are rare, with most caused by changes in one or more genes.

As we noted while the "One Big Beautiful Bill Act" (OBBBA) (Pub. L. 119-21).[2] was debated in Congress, the premise of requiring community engagement on top of unprecedented cuts and program restructuring to Medicaid therein, would be incredibly harmful to the NMD community.[3] We warned then that it would be functionally impossible to prevent the NMD

[1] Hereinafter "the Rule"
[2] Pub. L. No. 119-21, § 71119 139 Stat. 72 (2025) (hereinafter P.L. 119-21).
[3] Neuromuscular Advocacy Collaborative comments ahead of Senate consideration of PL 119-21. https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/6.16.2025%20Neuromuscular%20Advocacy%20Gro

community from coming to harm under the premise of the law. This Rule, which exceeds the framework of the law, only exacerbates our concerns. While we urge CMS not to finalize harmful provisions of the Rule (see below), we would also be remiss if we did not point to the fundamentally flawed premise of PL 119-21 in general.

The Rule goes far beyond the framework established by Congress implementing the Medicaid community engagement requirements under section 1902(xx) of the Social Security Act, as added by section § 71119 of PL 119-21. Of particular concern are the many restrictive policies in the Rule, especially provisions narrowing the definition of medical frailty, eliminating the state option to use sworn attestations, restrictive tests and documentation requirements for family caregivers, and other various verification requirements. In addition to departing from Congressional intent, the Rule risks dramatically worsening outcomes for those in the NMD community while increasing administrative and financial burdens on community members, health care providers, and states. **We request that CMS <u>not</u> finalize these harmful provisions of the IFR and instead adopt policies to improve access to care for individuals living with serious and chronic neuromuscular conditions.**

Definition of Medical Frailty:

The Rule's definition of medical frailty goes well beyond Congress's intent. From the outset, Congress has previously defined medical frailty in both statute and regulation as meaning: individuals with a disability, disabling mental health conditions, substance use disorders, functional impairments related to activities of daily living, or "serious or complex" health conditions.[4] Notably, PL 119-21 then created a broad exclusion to work reporting requirements for individuals who are medically frail,[5] recognizing the need for these populations to have a regular, consistent source of healthcare coverage to maintain their health and reduce the risk of avoidable hospitalizations. This recognition is particularly true for the NMD community who, given the progressive nature of NMDs, require access to highly specialized, ongoing care to manage the ever-changing nature of their condition(s). Crucially, Congress framed the definition this way with the intent to broadly protect those with disabilities and complex health conditions from losing the healthcare they need due to the community engagement requirement.

The Rule, however, added an entirely new feature to the definition, requiring that a condition "significantly impairs the individual's ability to comply with the community engagement requirement."[6] This addition flatly contradicts the canons of statutory interpretation. When Congress uses a term it has previously used, with an established regulatory definition, the only

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ups%20Oppose%20Reconciliation%20Cuts%20to%20Care%20-%20Final.pdf . *See also,* MDA comments ahead of full House consideration of PL 119-21.
https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/MDA%20House%20OBBBA%20Letter%20Final%20May%2020%202025%201.pdf *See also,* MDA comments ahead of full Energy and Commerce Committee consideration of PL 119-21
https://d3dkdvqff0zqx.cloudfront.net/groups/mda/attachments/5.12.25%20MDA%20Strongly%20Opposes%20E%26C%20Medicaid%20Reconciliation%20Package.pdf

[4] 42 U.S.C. 1396u-7. See also, 42 CFR 440.315

[5] Pub. L. 119-21, § 139, Stat. 312 (2025).

[6] Medicaid Program; Community Engagement Requirement for Certain Individuals, 91 Fed. Reg. 33373 (June 3, 2026) (interim final rule) (IFR).

reasonable interpretation is that Congress meant to apply the term as universally understood.[7] The definition of medical frailty has always turned on the five factors laid out above, and it is therefore completely baseless for the Centers for Medicare and Medicaid Services (CMS) to have implicated one's ability to work into the definition. CMS should rescind this aspect of the rule and broadly shield people with disabilities and chronic conditions like NMDs from the burdensome requirement of affirmatively proving exclusion from the community engagement requirement.

While the Rule wrongfully adds additional requirements to the medical frailty standard, it at the same time imposes undue limitations as well. The Rule prohibits states from adding criteria to the medically frail standard.[8] In contrast, the text of PL 119-21 does not specifically prohibit additional state criteria, and Congress, as mentioned above, hews to very specific interpretations of statutory canon allowing for state interpretation and addition. The plain meaning of the terms "medically frail" and "special needs" is broad enough to include criteria beyond the five identified in the Rule and states ought to be afforded that flexibility, given the serious risks to the health of the neuromuscular community when coverage is disrupted. We urge CMS to finalize flexibility for states to make reasonable additions to broaden medical frailty criteria to ensure populations Congress intended to insulate from community engagement requirements, including the NMD community, are properly excluded.

The Problem of the Medical Frailty Definition as Applied to the NMD Community:

Apart from the considerable problems of statutory interpretation in the Rule, the Rule as currently constructed will also be deeply harmful to the NMD community. According to internal MDA data, nearly 40% of the neuromuscular community relies on Medicaid for key services, including home care (which makes work and community engagement possible for many living with an NMD), specialists, therapies, life-sustaining equipment, and more[9]. We are particularly concerned with the Rule's impact on individuals with slower progressing or later onset conditions, such as Becker muscular dystrophy, generalized myasthenia gravis, oculopharyngeal muscular dystrophy, and facioscapulohumeral muscular dystrophy (FSHD), among others. Many in this category will have a difficult time successfully proving that they meet this new medical frailty standard because the variability of their symptoms and disease progression causes them to be able to work at times and not at others. Even with advances in treatment, individuals affected by certain neuromuscular conditions can still experience flare-ups of their symptoms that can cause unpredictable changes in their ability to work. At bottom, regardless of the specific nature of their disease, members of the NMD community are doubtless in the class of people whom Congress intended to protect, and yet due to the Rule's baseless expansion of the definition, will fall through the cracks of this vital protection and lose access to vital care.

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[7] *See generally,* Katzmann *Judging Statutes* at 23-29. *See also generally,* Stevenson, CANONS OF CONSTRUCTION (adapted from Scalia & Garner)https://www.law.uh.edu/faculty/adjunct/dstevenson/2018Spring/CANONS%20OF%20CONSTRUCTION.pdf

[8] Tolbert, KAISER FAMILY FOUNDATION, "CMS Requires More Restrictive Definition of Medical Frailty in New Medicaid Work Requirements Rule", June, 2, 2026. https://www.kff.org/quick-insights/cms-requires-more-restrictive-definition-of-medical-frailty-in-new-medicaid-work-requirements-rule/

[9] https://www.mda.org/science/movr

Further, members in the NMD community often face what is referred to as a "diagnostic odyssey": the long and frustrating journey through multiple specialists and tests to ultimately receive their diagnosis, which can take multiple years. This is driven by a number of factors such as the rarity of these conditions,[10] difficulty in accessing or affording genetic testing (for another wide variety of reasons),[11] and the small number of physicians that treat a given condition and the various difficulties in accessing those specialists.[12] Dovetailing with those concerns are those created by allowing states to look back up to three months in verifying compliance with the requirement.[13] Given both the difficulty of obtaining a diagnosis in the first place and in seeing qualified providers when one does have a diagnosis (often community members can travel up to 60 miles to receive care),[14] it will be incredibly difficult for community members subject to this lookback to be able to work with their healthcare providers to obtain documentation proving an exception in time to avoid a catastrophic gap in coverage. As referenced earlier, given the difficulty of obtaining a diagnosis in general, it will also be difficult for those in the community who are seeking a diagnosis to see a neurologist to obtain necessary documentation especially considering the three-month lookback period.

For individuals newly diagnosed with a NMD and unable to work, many apply for Supplemental Security Income (SSI). While SSI qualifies many for Medicaid, the application process can take years, leaving individuals with a waiting period before benefits begin. Medicaid expansion often fills this coverage gap, and the Rule as constructed could require some individuals living with an NMD in the Medicaid expansion population to lose coverage or be denied enrollment while waiting for an SSI determination due to the community engagement requirement, despite living with a serious health condition and/or disability. While SSI applicants enrolled in the expansion group will be subject to new requirements, applicants who meet the SSI criteria will not, although they will face difficulty proving a medical frailty exception while in the application process and still waiting for a disability determination. According to a recent analysis from the Kaiser Family Foundation, in 2023, 223,000 SSI applicants aged 19-64 received Medicaid while awaiting an SSI determination, with over 106,000 receiving coverage through Medicaid expansion.[15] These coverage gaps risk worsened health outcomes given that neuromuscular care requires ongoing treatment and comprehensive management.

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[10] Bordini BJ, Walsh RD, Basel D, Deshmukh T. Attaining Diagnostic Excellence: How the Structure and Function of a Rare Disease Service Contribute to Ending the Diagnostic Odyssey. Med Clin North Am. 2024 Jan;108(1):1-14. doi: 10.1016/j.mcna.2023.06.013. Epub 2023 Jul 26. PMID: 37951644.

[11] National Institutes of Health *What is the cost of genetic testing, and how long does it take to get the results,* para 1, https://medlineplus.gov/genetics/understanding/testing/costresults/

[12] Gunes D et al. Challenges in the clinical management of rare diseases and center-based multidisciplinary approach to creating solutions. Eur J Pediatr. 2025 Apr 5;184(5):281. doi: 10.1007/s00431-025-06101-z. PMID: 40186762; PMCID: PMC11972228.

[13] 42 C.F.R. § 435.556(a)(1))

[14]National Organization for Rare Disorders, "Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." 2020 (https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088Barriers30Yr-Survey-Report_FNL-2.pdf)

[15] https://www.kff.org/medicaid/what-could-medicaid-work-requicccrements-mean-for-ssi-applicants/?utm_campaign=KFF%3A%20Medicaid&utm_medium=email&_hsenc=p2ANqtz-_7Ir3Lc0cG9iC5vBsnVdvCGsseQqkV5As6vGslAvMI0ZH90O5uJVoaSFN7WowbKSjNWUwZwMmHqPUuoPSrrGXk6vKWqA&_hsmi=430652493&utm_content=430652493&utm_source=hs_email

Similar risks face individuals living with an NMD applying for or receiving Social Security Disability Insurance (SSDI). While people approved for SSI eventually may be eligible for Medicare and then excluded from the community engagement requirements, the vast majority of SSDI recipients under 65 must wait 24 months before they are eligible for Medicare benefits. Similar to SSI recipients, given the lack of affordable alternatives for coverage, Medicaid expansion plays an important stopgap role in providing coverage for SSDI recipients until they become fully eligible for Medicare. While such individuals would be widely recognized as medically frail, it is not clear that they would meet the exception due to an unclear definition of 'significant impairment', as the Rule is ambiguous about whether the substantial gainful activity standard used by SSI and SSDI is satisfactory for meeting the 'significant impairment' requirement. As constructed, the Rule does not provide a viable avenue for individuals living with an NMD and awaiting a decision by the Social Security Administration to seek a medical frailty exclusion. This poses serious risks to access to care for the neuromuscular community, given that disability determinations can take years[16].

Additionally, in order to qualify for a medical frailty exemption, the Rule declines to define an individual with a serious or complex medical condition, yet specifies that states must use lists of diseases, diagnoses, disorders, or other health conditions to define categories and identify individuals who may potentially qualify as medically frail. This poses a significant concern for families affected by neuromuscular conditions, especially rare and ultra-rare neuromuscular conditions, who continue to advocate for ICD-codes for their conditions. Only a small minority of NMDs have an ICD-10 diagnostic code specific to the disease. For everyone else, obtaining an ICD-10 diagnostic code is a long and arduous process. MDA and collaborators have successfully applied for ICD-10 codes for limb-girdle muscular dystrophies, but only after submitting extensive supporting evidence, hiring a consultant, and taking nearly two years to succeed. Making matters more difficult, the ICD-10 Coordination and Maintenance Committee recently announced a pause on accepting applications for new ICD-10 diagnostic codes for rare genetic diseases.[17] The Rule itself acknowledges that such lists will miss rare diseases during the initial implementation of the community engagement requirement.

The Rule also requires states to review their lists to determine if health conditions should be removed from their list due to advances in treatment. While research breakthroughs are leading to better treatments and longer lives for many individuals living with a neuromuscular condition, that does not necessarily mean the individual does not experience fluctuating symptoms or have a disability that precludes their ability to meet the community engagement requirement. We urge CMS to require states seeking to remove a condition from their list to solicit and consider public comment prior to removal. We also ask that states be required to provide clear, accessible, and user-friendly processes for individuals to request consideration of a condition to be added to the state's lists, with the requirement for the state to respond to such requests in a timely manner.

[16] Social Security Administration. (2026, June 9). *Social Security performance*. https://www.ssa.gov/ssa-performance

[17] https://www.cdc.gov/nchs/icd/icd-10-maintenance/guidance.html

The Burden of Redetermination and Documentation on Community Members and Their Healthcare Teams:

A consequence of the flawed medical frailty definition, and requirements therein, under the Rule is the burden placed upon NMD community members and their healthcare teams to document their conditions and their impact onto work as to show exception from the Rule. The six-month verification requirement carries with it a significant chance for members of the NMD community to fall through the cracks and lose coverage, placing families at risk for catastrophic medical debt given the high costs of neuromuscular condition management. Even temporary loss of coverage interrupts personal care, skilled nursing, therapy, medical supplies, and other services that allow people living with NMDs to remain safely in their communities. We do not have to wonder about whether this will happen: we need look no further than Arkansas's attempt to implement a work requirement in 2018, where more than 18,000 people lost access to coverage largely due to procedural issues, not a lack of eligibility.[18] Given the restrictive definitions adopted and the onerous requirements of the Rule, it is highly likely that we will see catastrophic coverage losses as a result. The Urban Institute estimates 8.2 million people will lose coverage due to the advanced restrictions in the Rule.[19] The need to recertify compliance with the Rule on a six-month basis is incredibly burdensome for members of the community in general, if for no other reason than for the emotional experience of having to rehash their own lived realities.[20] Due to potential difficulties for states to use ex-parte renewals (see below), it also creates infinitely more opportunities for people to lose coverage due to any number of administrative issues. A community member could move and forget to update their address, be hospitalized due to their condition and unable to respond to mail, have a disability that precludes them from physically accessing their mail, or a member of their healthcare team could phrase medical reasoning somewhat differently which then runs afoul of a state reviewer, thus requiring an appeal process, or any number of other procedural issues.

The paperwork burdens of the Rule predominantly fall to already overworked healthcare teams. Since MDA was founded in 1950, life expectancy and quality of life have vastly improved for people living with NMDs due in large part to the best-in-class, comprehensive care provided by a wide variety of healthcare specialists at MDA Care Centers. As mentioned above, the Rule requires community members to come in to see their healthcare teams at MDA Care Centers to obtain documentation for an exemption which will require both community members and their healthcare teams to know enough about the federal and state requirements to document their needs appropriately. This then effectively transforms healthcare providers into quasi-Medicaid administrators, a role which they have no training to play, and warps the patient-provider

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[18] Wagner and Schubel, CENTER FOR BUDGET AND POLICY PRIORITIES "States' Experiences Confirm Harmful Effects of Medicaid Work Requirements" Nov. 18, 2020. https://www.cbpp.org/research/health/states-experiences-confirm-harmful-effects-of-medicaid-work-requirements#:~:text=In%20Arkansas%2C%20more%20than%2018%2C000,course%20of%20just%20seven%20months.

[19] Karpman et al. URBAN INSTITUTE, " State-by-State Estimates of Medicaid Expansion Coverage Losses under a Federal Work Requirement" https://www.urban.org/sites/default/files/2025-04/State-by-State-Estimates-of-Medicaid-Expansion-Coverage-Losses-under-a-Federal-Work-Requirement.pdf?utm_source=themorninggrind.beehiiv.com&utm_medium=newsletter&utm_campaign=cutters-restrictors-investors

[20] https://www.youtube.com/watch?v=DfEfxswtUNM&t=11s

relationship which would otherwise, and as shown from the clinician's perspective below, be focused on care. For the NMD community, this burden will largely fall on neurologists already strained by workforce shortages,[21] who may then need to coordinate with other members of the care team such as cardiologists, pulmonologists, physical and occupational therapists, and others. This will tax MDA Care Centers which are already stretched thin with additional paperwork responsibilities that siphon resources from patient care.

Similarly, we have heard healthcare providers that are planning for their role under the Rule express concerns over needing to cite more ancillary impacts of a neuromuscular condition that nonetheless have a profound impact on one's ability to work. For example, subjective symptoms such as fatigue, pain, and discomfort are difficult to measure, and healthcare providers need to help patients define those symptoms and their impact. As a more specific example, consider the perspective of a healthcare provider in one of MDA's clinics, who shared:

> "These requirements will place a large burden on health care providers who care for people with disabilities. The main problem for my team in clinic will be the requirement to provide certification regarding the ability of our patients to work. This will be an unfunded mandate to complete excessive paperwork. This requirement for certification will tax my clinic with new responsibilities that have nothing to do with caring for our patients. Finally, patients with disabilities will face the risk of losing Medicaid coverage due to this unnecessary requirement."

As one can see in this one example, the documentation healthcare teams and patients are asked to produce under the framework of this rule is incredibly onerous and rife with potential pitfalls as far as obtaining exceptions. All of this exists against the backdrop that healthcare providers and teams are already massively overburdened by documentation requirements in general.[22]

Definition of Family Caregiver:

Similar to the definitional issue with medical frailty, the Rule's definition of family caregiver once again exceeds the language of PL 119-21, which takes the definition of family caregiver from the RAISE Family Caregivers Act (PL 115-119) to define family caregivers as: "an adult family member or other individual who has a significant relationship with, and provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation"[23]. The Rule, however, limits the exemption only to caregivers with a familial relation or who live with the individual.[24] If they do not meet this additional criteria, they must find a way to document 80 hours of caregiving, despite the fact that caregiving is often informal and very rarely do formal records exist – or risk losing the coverage that keeps them healthy enough to provide care. The RAISE Act definition adopted by Congress when instituting work requirements intentionally provides a modern, more expansive view of who constitutes a caregiver by purposefully including the many different individuals who can assume the role of caregiver, such as close friends and neighbors, rather than the direct familial and co-residential

[21] https://neurologytoday.aan.com/doi/10.1097/01.wnt.0001192524.55082.8c
[22] *Id.*
[23] Pub. L, No. 115-119, 132 Stat. 23 (2018)
[24] P.L. 119-21 § 71119(a)(xx)(9)(A)(ii)(III)

ties the Rule demands. We ask CMS to withdraw their definition of family caregiver and revert back to the definition provided in statute.

Family Caregiving and the Neuromuscular Disease Community:

Access to Medicaid is vital for family caregivers themselves to be able to provide care for their loved ones. While many of those living with an NMD receive coverage through "traditional" Medicaid, many family caregivers rely on expanded Medicaid to receive access to care. By jeopardizing access to coverage for family caregivers, the Rule places the care of those living with an NMD in jeopardy, because if a family caregiver cannot receive coverage themselves, it draws into question whether they can provide the care our community relies upon. Such a position endangers the lives and health of community members and places community members at greater risk of costly, avoidable (and thus, potentially illegal) institutionalization. We urge CMS to bring the Rule in line with the standard set out in the RAISE Act, and PL 119-21.

Issues with the Application of 1115 Waivers to the Rule:

PL 119-21 mandates community engagement requirements for applicable individuals enrolled in Medicaid expansion (i.e., Group VIII coverage) or in a Section 1115(a)(2) demonstration waiver providing minimum essential coverage to adults 19-64 who are ineligible for Medicare, Medicaid under the state plan, or are pregnant. The Rule affirms these individuals must meet community engagement requirements, while also noting the variability among 1115 waiver populations across states, necessitating a systemic review to determine who in those populations may be required to meet community engagement requirements. Some Section 1115 waivers were created by states without Medicaid expansion to cover the same group with additional restrictions, while other states who have expanded Medicaid use the waivers to include individuals otherwise excluded from community engagement requirements, including individuals enrolled in SNAP or TANF and subject to those programs' requirements. States already faced a heavy lift in implementing community engagement requirements for the Medicaid expansion population alone, while now expansion and non-expansion states will face the additional lift of needing to implement the requirements for Section 1115 populations as well.

Given this Herculean task, we request that CMS expedites their review of 1115 waiver populations and communicates the results clearly with states and MDA so we can properly prepare the NMD community to comply with the requirements. We urge CMS to grant good-faith exceptions or additional time for states to implement community engagement requirements, especially for 1115 waiver populations.

For individuals affected by NMD receiving services through a 1915(c) waiver, the Rule affirms they are not required to meet community engagement requirements. However, we urge CMS to confirm that this exception also applies to individuals receiving home and community-based services through 1915(i), 1915(j), and 1915(k) waiver authorities. States must also receive guidance to ensure that any HCBS enrollees who do not receive MEC from expansion or an 1115 waiver must not be required to prove an exception, and that those who do receive MEC and HCBS through 1115 waivers are explicitly excluded from the community engagement requirements due to medical frailty.

Issues with Self Attestation and the Burden on States:

Here, we largely echo the comments of our colleagues at the Partnership to Protect Coverage. "The Rule implements an impermissible and harmful standard with respect to sworn attestations. Under PL 119-21, states have the option of using sworn attestations alone to verify various exceptions and exclusions.[25] The Rule, however, allows sworn attestation generally only until the end of 2027, and for medical frailty only adds a one-time attestation allowed starting in 2028. In all cases, states lose the option to have on-going sworn attestations. This policy directly contravenes the flexibility explicitly granted in PL 119-21.

Since at least Fall 2025, CMS had been telling states they would be able to use clinical diagnostic codes to identify exclusions.[26] In reasonable reliance of this guidance, states have built definitions, policies, and infrastructure to implement this policy. Changing the definition only seven months before implementation must begin will result in financial losses and inefficiency for states, and leaves states with an impossible implementation landscape ahead. The IFR contains ambiguous policies and leaves states with many unanswered questions."

The definition of medical frailty and limitation on self-attestation also subverts the entire design of Congress's exclusion process by undermining the ability of states to use data driven identification. PL 119-21 requires states to use data to assess eligibility, including the use of clinical data to assess eligibility for exclusions. Using such data, states could efficiently identify exclusions based on data sources, without having to resort to burdensome and error-prone processes such as manual verification of documentation sent by mail. By adding a layer of significant impairment assessment onto the clinical eligibility criteria, the IFR makes it much harder or impossible for states to automate their processes. As a result, states, individuals, and providers will experience heavy burdens to document medical frailty.

Given the accelerated implementation timeline, it is likely the exception process will fail and many individuals Congress intended to exempt will lose their health coverage. In addition to violating the statute, the policy will be very harmful to individuals in the NMD community as it will further burden states and cause advanced timelines for implementation, causing more people to fall through the cracks. Congress included the sworn attestation flexibility because many types of exclusions will be impossible to prove through data-driven methods or by documentation. For example, multi-disciplinary care,[27] the gold standard for treating neuromuscular diseases, typically runs on six-month appointment cycles which will make it very difficult to line up appointments with verifying claims data. Similarly, often the procedures relied upon for the

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[25] Brooks et al. GEORGETOWN UNIVERSITY CENTER FOR CHILDREN AND FAMILIES, "New Federal Medicaid Work Reporting Requirements Rule Threatens Coverage for Vulnerable Americans: An Explainer of the Interim Final Rule", July 16 2026. https://ccf.georgetown.edu/2026/07/16/new-federal-medicaid-work-reporting-requirements-rule-threatens-coverage-for-vulnerable-americans-an-explainer-of-the-interim-final-rule/

[26] *Id.*

[27] multidisciplinary care is characterized by comprised of a variety of medical providers and allied health professionals who work in tandem to provide all-encompassing care for specific conditions. Clinic personnel depends on the disease of interest; however, common roles include physicians, nurses, medical assistants, and advanced practice providers. Additional specialists in MDCs are occupational and physical therapists, psychologists, social workers, dieticians, and research teams.

kinds of claims which could prove an exclusion are not necessarily obvious on their face, requiring more burden and input from a healthcare team.

We support CMS's generalized requirement for states to pursue ex-parte information and maximize data sources before requesting information from enrollees. We urge CMS to take a proactive approach in enforcing these requirements, to ensure that states make efforts and investments to use potentially available data sources. However, it is also *vitally* important that CMS and states both do not exclusively rely on data sources such as ICD-10 codes to drive ex-parte reviews. As CMS notes specifically in the Rule, the muscular dystrophies are prone to being left off such lists due to their rarity.[28]

Conclusion:

The Rule as constructed risks serious disruptions in coverage for the neuromuscular community, which in turn risks delayed care, worsened health outcomes, and further strain on overwhelmed health care systems. For the forgoing reasons, we urge CMS to recognize the illegality of the Rule as it currently exists and to rescind the above provisions to ensure members of the neuromuscular community and their caregivers can maintain access to vital care. We are grateful for the opportunity to comment on the Medicaid Community Engagement Requirement. For questions regarding MDA or the above comments, please contact me at jcartner@mdausa.org.

Sincerely,

Joel Cartner

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Shannon Wood

Shannon Wood
Director, Disability Policy
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[28] Medicaid Program; Community Engagement Requirement for Certain Individuals, 91 Fed. Reg. 33375