Jan. 13, 2023

Submitted to: dualeligibles@cassidy.senate.gov

The Honorable Bill Cassidy, MD
The Honorable Thomas R. Carper
The Honorable Tim Scott
The Honorable Mark R. Warner
The Honorable John Cornyn
The Honorable Robert Menendez

RE: **Improving Coverage for Individuals Dually-Eligible for Medicare and Medicaid – Request for Information**

Haystack Project appreciates the opportunity to respond to the Senators' November 22, 2022 Request for Information (RFI) seeking stakeholder input on reforms to improve health outcomes and efficiencies for individuals dually-eligible for Medicare and Medicaid.

Haystack Project is a 501(c)(3) non-profit organization enabling rare and ultra-rare disease advocacy organizations to highlight and address systemic access barriers to the therapies they desperately need. Our core mission is to evolve health care payment and delivery systems toward spurring innovation and quality in care toward effective, accessible treatment options for Americans living with rare or ultra-rare conditions. Haystack Project is committed to educating policymakers and other stakeholders about the unique circumstances of extremely rare conditions with respect to product development, commercialization, and fair access to care.

A significant proportion of Haystack Project's advocacy and education efforts focus on identifying and drawing attention to the unintended consequences our patient communities suffer when policy initiatives and process refinements fail to consider the unique challenges associated with rare and ultra-rare conditions. Haystack Project agrees that reforms for dually-eligible individuals should be informed and guided by "core principles," including diversity of patient needs, variable state capabilities to support care for this vulnerable patient group, and identification of incentives that might drive health system behaviors toward improved patient outcomes and efficiency. Our comments briefly summarize the unique challenges that rare and ultra-rare disease patients face, highlight considerations applicable to our patient communities within each of the core principles that should be part of any reform proposals, and provide our input and recommendations on specific questions within the RFI.

Background

Innovation in how disease mechanisms are understood and addressed has advanced at a pace that would have been unthinkable decades ago. The emergence of targeted cancer treatments, gene therapy and regenerative medicine, and immunologic approaches to rare, serious, and life-threatening conditions have given renewed hope to the millions of Americans affected by a rare disease. However, exceedingly small populations, long diagnostic journeys, and a limited natural history knowledge base for many rare diseases can make the treatment development and regulatory processes particularly challenging.

- Approximately 7,000 rare diseases have been identified to date
- 90-95% of identified rare diseases have no FDA-approved treatment.
- 80% of rare diseases are genetic and present throughout a person's life
- Approximately 50% of people affected by rare diseases are children
- 30% of children with a rare disease will not live to see their 5th birthday

Diversity of Needs

Haystack Project's advocacy work is grounded in our understanding that even the most well-meaning policies can have unintended consequences for rare disease patients. The preference for focusing on common conditions permeates our health system from provider education through the population-level priorities that drive health policy mechanisms and incentive frameworks. While this approach may appear pragmatic, it drives unduly-long diagnostic journeys for rare disease patients. In addition, reimbursement policies frequently exact unintended burdens on the health and lives of our patient communities.

While each rare disease, by definition, impacts a patient population of under 200,000, rare diseases cumulatively affect approximately 30,000,000 or 1 in 10 individuals in the U.S. The diagnostic journey for rare disease patients is particularly long and complex. A 2021 GAO Report to Congress entitled "RARE DISEASES: Although Limited, Available Evidence Suggests Medical and Other Costs Can Be Substantial" was compiled to assess the challenges and costs rare disease patients face accessing diagnostic and treatment services. The Report found that diagnostic delays place patients at high risk for compromised health outcomes, including disease progression, exposure to inappropriate interventions, emergence of comorbidities, and even death. These systemic barriers to appropriate care are also costly.

According to an economic study which included a survey of 1360 patients with 379 rare diseases cited to in the GAO Report, rare disease patients:

- Saw an average of 4.2 primary care physicians and 4.8 specialists for their diagnosis
- Made an average of 2.4 out-of-state trips related to their diagnosis
- Visited an emergency room an average of 3.7 times and

- Were hospitalized an average of 1.7 times for reasons related to their rare disease and prior to diagnosis.

The challenges common to rare disease patients can be an overwhelming burden for dually-eligible individuals, people of color and other underserved populations, including rural communities. Communities of color face significant disparities in symptom severity, disease progression and mortality for rare diseases such as systemic lupus erythematosus and myasthenia gravis even though these conditions tend to occur across populations. Rare diseases such as sickle cell anemia, thalassemia, sarcoidosis disproportionately impact people of color. The growing number of beneficiaries with sickle cell disease (SCD) are primarily young, medically complex, and likely impacted by social determinants of health; ***over 70% of Medicare fee-for-service beneficiaries with SCD were dual-eligible.***

Medicare's SCD patients' experience within the opioid epidemic illustrates policy inequities as well as the high potential for unintended harms when new population-level initiatives are implemented. CMS' policy to curb the opioid abuse crisis was firmly grounded in public policy imperatives and proactively excluded cancer patients. SCD patients experienced access hurdles and denials of adequate pain management treatment until CMS recognized that "[t]he complex nature of SCD pain management may be exacerbated by ongoing efforts to address the opioid epidemic" and determined to exclude SCD patients from opioid restrictions. Unfortunately, Patients with other rare diseases also manifest with acute episodes of pain requiring opioids and yet remain without reliable access to the pain management care they need. The rarer the condition, the more likely policymakers will fail to recognize the unintended consequences of otherwise well-reasoned policies.

In addition, most rare disease patients have no FDA-approved treatment for their condition. These patients rely on off-label treatments within evolving standards of care. Although these treatments are needed to reduce the burden and/or progression of disease symptoms, their use in treating specific rare diseases are unlikely to be listed within CMS-accepted compendia and even less likely to be added to a treatment's label. These patients and their providers often face a labyrinth of barriers to care from disease-specific specialists as well as claim denials, prior authorization requirements, reconsiderations, and appeals to access the care they need. Access burdens are significantly greater for dually-eligible rare disease patients and their families and can be prohibitively burdensome for providers and too confusing for patients and their advocates to navigate. Patients changing plans or payers, particularly those who are dually-eligible, often have to re-navigate these processes to remain on their prescribed treatment regimen.

Range of States' capabilities in supporting the care of duals

Patients with extremely rare diseases often find that there are just a handful of disease-specific specialists in the entire country. Lack of local disease-specific specialists, combined with complexities associated with Medicaid patient access to out-of-state experts has been a longstanding barrier to timely diagnosis and appropriate care for individuals with rare diseases.

Prior to the Covid Public Health Emergency (PHE), states implemented a variety of requirements for out-of-state providers that, in some states, included full Medicaid enrollment, registration, and fee payment. Many states pay out-of-state providers at a lower rate than in-state providers receive.

The PHE introduced a streamlined approach to out-of-state Medicaid provider eligibility that should be a permanent pathway for Medicaid providers treating individuals with rare and ultra-rare conditions. Providers enrolled in their own state Medicaid program or participating in Medicare have established track records in patient care that should be recognized by all states. The rare and ultra-rare community needed these flexibilities long before Covid and will need them long after the PHE is over.

Financial incentives drive health system behaviors on outcomes and efficiency

While Haystack generally supports initiatives that incentivize clinicians and health systems to provide efficient, cost-effective, high-quality care, individuals with rare and ultra-rare diseases are particularly vulnerable to changes in how care is received as well as provider reimbursement for that care. Many CMS and private payer (including Medicare and Medicaid managed care organizations) implement incentive frameworks and policies that fail to consider the unique challenges involved in addressing rare diseases. This is especially true in the Medicare Shared Savings Program and the Quality Payment Program. Mechanisms that incentivize high-quality, cost-effective care in the general population can present strong disincentives to providing the testing, treatments, and provider oversight required to adequately manage rare and ultra-rare diseases.

We are concerned that reimbursement and incentive mechanisms that, like the Shared Savings Program, shift risk to clinicians, could have unintended consequences to individuals with rare conditions for which benchmark costs are unavailable. Haystack Project continues to advocate for specific carve-outs applicable to rare disease patients as well as incentives to reward timely diagnosis, treatment planning, and care coordination. We believe that a carve-out is a pragmatic mechanism given that it is virtually impossible to reliably benchmark costs associated with treating Medicare beneficiaries with rare disorders, and even more so if the patient suffers from one or more additional chronic conditions. In addition, any reform efforts directed at provider incentives should consider and resolve the potential for unintended consequences for our patient communities by recognizing that:

- Diagnosing a patient with a rare disorder is usually a multi-year process involving a series of primary care clinicians, specialists, and diagnostic testing regimens – extreme rarity of a disorder compounds the resources required for diagnosis.
- The relatively small population size for many rare disorders precludes availability of clearly articulated, scientifically-validated treatment standards that would form the basis of a reliable benchmark.
- Patients with rare disorders may not have access to a specialist with experience in treating their condition, leaving their care to a set of providers in various specialties that

address specific disease symptoms. It is, therefore, difficult to assess which costs to assign to a specific clinician.

- Highly-specialized clinicians with expertise sufficient to manage the whole patient would appear to perform poorly when compared to clinicians managing more common conditions within the same specialty, even when their care is efficient, cost-effective and of the highest quality with respect to patient outcomes.
- The 2021 GAO report cited a number of relevant findings that complicate rare disease care within a value-based payment model that should inform the contours of any incentive-based reform to coverage for dually-eligible individuals:
    - **Overlap with other diseases.** Rare disease symptoms are often non-specific and overlap with more common diseases. Patients not only face long diagnostic journeys, but often receive costly and potentially toxic treatments due to misdiagnoses.
    - **Lack of clinician knowledge**. Because signs and symptoms of many rare diseases are not fully described or understood, patients and clinicians may fail to note significance of initial symptoms or discount patient/caregiver reports.
    - **Multiple disease presentations**. Many rare diseases are without a single set of symptoms and are associated with symptom variability on an individual level as well as over time. Other rare conditions can impact multiple organ systems leading to care from multiple specialists before a correct diagnosis is made.
    - **Comorbid conditions**. Comorbid conditions inject an additional layer of diagnostic complexity, particularly if the patient has two or more rare diseases. The GAO Report cited the example of acromegaly, a hormonal disease commonly accompanied by diabetes or cardiovascular disease. Acromegaly has a slow progression so that individuals are generally not correctly diagnosed until they present with advanced disease and multiple comorbidities.

Responses to Specific Questions

How would you separately define integrated care, care coordination, and aligned enrollment in the context of care for dually eligible beneficiaries? How are these terms similar and how are they different?

Haystack Project recommends that these terms be defined from a multi-stakeholder perspective:

Integrated Care (or "Integrated Health Services") – Health services that are funded and delivered with the intention and goal of ensuring that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care, and according

to their needs throughout the life course. Patients can plan and control their care to bring together services to achieve the outcomes that they view as important.

Care coordination – Deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care and the patient to achieve safer and more effective care.

Aligned enrollment – For individuals relying on coverage from two or more payers, aligned enrollment focuses on leveraging the total set of health care benefits available to the patient and their caregivers to achieve improved health outcomes while eliminating complexities associated with multiple payer decision makers driving access to or directing the care patients receive or when and where care is provided.

What are the shortcomings of the current system of care for dual eligibles? What specific policy recommendations do you have to improve coordination and integration between the Medicare and Medicaid programs?

Fully aligned care should be prioritized. Dual eligible, particularly those with rare and ultra-rare conditions, should not have to sort through multiple plans with divergent provider networks and coverage criteria to get care. Reforms directed toward promoting fully aligned care should make the process easier for policy makers, payers, patients and providers to navigate. Providers – especially small, independent clinics (which are more likely in rural and underserved areas) are hesitant to take on the complexities associated with dual eligible beneficiaries due to fears of not being paid, overly burdensome claims/appeals, and the fear that unintended errors in billing could result in penalties.

MACPAC's issue brief on plan enrollment for Duals, is based on 2011 data, but contains observations that remain relevant:

> In practice, the experience of dually eligible beneficiaries is more complex than having coverage from both Medicaid and Medicare. Both programs deliver services through fee for service (FFS) and managed care, and many beneficiaries receive services under both arrangements. For Medicaid services, many enrollees are enrolled in both a comprehensive plan for most medical services and a limited-benefit plan that provides oral health, behavioral health (including mental health and substance use services), LTSS, or transportation services. Each of these plans has its own set of providers, covered benefits, and processes that beneficiaries must understand and navigate.

Lawmakers should consider mechanisms that would enable use of Medicaid premium payment programs in dually eligible populations.

Health care for individuals with rare and ultra-rare conditions can be relatively high-cost and often requires highly specialized clinicians to deliver quality care. Because a robust network of

providers is essential, rare disease patients are often good candidates for Medicaid premium payment programs (Medicaid pays the premium costs for commercial coverage as well as "wrap-around" coverage to ensure access to the full set of benefits available in Medicaid). The wrap-around benefits and cost-sharing protections are essential to ensure that Medicaid beneficiaries receiving private coverage will not have access to fewer benefits or pay higher out-of-pocket costs in the event that private coverage is lower than that in Medicaid or is associated with out-of-pocket costs to patients.
Unfortunately, implementation of premium payment programs is variable from state to state, patients are generally unaware of this alternative coverage mechanism, and available information is confusing for patients and their families. In addition, there are no mechanisms to facilitate coordination between Medicare and Medicaid that would enable use of premium payment programs for dually-eligible patients.

We expect that it may be helpful to ask that CMS collect data and other information on state implementation of premium assistance programs to assess:

- Use of this mechanism in both Medicaid expansion and non-expansion states
- How states identify high-cost Medicaid enrollees for premium assistance eligibility
- Written materials (online and print) available to patients that explain:
    - Wrap-around benefits
    - Cost-sharing protections
- Resources for patients enrolled in Medicaid premium assistance programs
- How much the state Medicaid program spends on wrap-around benefits and cost-sharing protections

In your view, which models have worked particularly well at integrating care for dual eligible, whether on the state level, federal level, or both? Please provide data, such as comparative analyses, including details on outcome measures and control group definitions, to support your response.

Dually-eligible individuals often have complex care needs that require the highest level of integration and alignment in care coordination and delivery. Haystack Project urges an approach that leverages the best characteristics of existing models while maintaining oversight to ensure that the for-profit entities operating plans in dual-eligible programs are not cutting care at the expense of patient outcomes. This is crucial for dual eligible with rare diseases as they are likely the most vulnerable patients in our health system.

As provided under section 1859(f)(7) of the Social Security Act, every SNP must have a Model of Care (MOC) approved by the National Committee for Quality Assurance (NCQA). The MOC provides the basic framework under which the SNP will meet the needs of each of its enrollees. Improving the MOC could have a significant impact on improving care coordination without substantial legislative changes.

A 2019 Rule set minimum standards for plan integration, including that they must offer:

- member assistance in obtaining Medicaid covered services and resolving grievances, requesting authorization of Medicaid services, and navigating the Medicaid appeals process
- integrated appeals for FIDE and HIDE SNPs (discussed below)
- notification to the state or its designee of hospital and skilled nursing facility admissions of plan members

We provide a brief overview below of existing models, together with links to informational sources.

Dual-eligible special needs plans (D-SNPs) (MACPAC Overview)

This type of Medicare Advantage (MA) plan can be distinguished from other MA plans in that the D-SNP must contract with the state. The level of integration/coordination plans offer is determined by the contract with the state, leading to varying levels of integration and coordination in D-SNPs.

Coordination Only D-SNPs (CO-D-SNPs) are sometimes referred to as "regular D-SNPs."

Highly integrated dual eligible special needs plans (HIDE SNPs) and Fully integrated dual eligible special needs plans (FIDE SNPs)

These integrated plans are available when an insurer has both Medicaid plans in the state and a D-SNP offering.

- In addition to Medicare benefits, **HIDE SNPs** must cover either behavioral health or long-term services and supports (LTSS).
- In addition to Medicare benefits, **FIDE SNPs** must cover both unless the state carves behavioral health services out of the capitation rate. However, all of the details are set by the contract with the state, so there is great variation across the country in terms of how these plans actually work and their quality.
- Both plans must have an integrated appeals process required – meaning plans must evaluate appeals under both Medicare and Medicaid criteria simultaneously
- FIDE SNPs with high population of frail patient can also get PACE frailty payments.

The chart below, and contained within the provided link, advances a set of recommended refinements to improve HIDE SNPs. https://www.arnoldventures.org/stories/fixing-the-fide-snp-redefining-fully-integrated

Changes to Existing Requirements: The following are proposed changes to the FIDE-SNP definition.		
FIDE-SNP Attribute(s) [iii] [iv]	**Summary of the Issue**	**Recommended Improvements and Impact**
Legal Entity Requirement	CMS' clarified interpretation in 2019 that FIDE-SNPs must be on the same *legal* entity license as the organization's Medicaid product. This has little impact on the experience of a dual eligible individual. While a FIDE-SNP should not be made up of two separate organizations or (sometimes internally competing) entities, the addition of "legal" to the entity requirement is not meaningful in practice. Within a Medicaid organization, legal entity is a matter of internal administration, not enrollee experience.	This requirement should follow federal regulation that a FIDE-SNP must offer Medicaid and Medicare benefits "under a single entity" rather than the same *legal* entity.[v] CMS' revised interpretation of this language requiring a single "legal" entity created an unnecessary barrier to entry for organizations otherwise able to provide an integrated experience for enrollees. Clarifying the requirement would reduce these roadblocks to entry while preserving meaningful integration.
Minimum 180 days of Nursing Facility Service	Regulations and CMS guidance address the spirit of including LTSS broadly in the Medicaid capitation associated with a FIDE-SNP, but the only explicit form of LTSS stated in regulation is 180 days of nursing facility services per year. The Administration has a stated goal of moving LTSS into the home and community when it's possible and consistent with peoples' wishes. The fact that a FIDE-SNP doesn't have to have these services in their Medicaid contracts hinders this broader goal.	A significant opportunity and need for integration occurs when a dual eligible individual is receiving HCBS. CMS could improve the FIDE-SNP model with more explicit regulatory requirements of minimally required HCBS. Additionally, CMS could document the states with Medicaid LTSS programs that could meet this minimum requirement.
Coordinate health care and LTSS using aligned care management and specialty care network methods	The terms "aligned" and "specialty care network methods" are difficult to understand and enforce from a state perspective. Concrete definitions of these terms could improve beneficiary's care experience and help states ensure that plans are complying with standards.	CMS should define these terms to assist states in setting FIDE-SNP standards and promote a more seamless beneficiary experience. For example, this might include: - One care manager responsible for Medicare and Medicaid benefits and services - A single electronic care management platform or mechanism to connect platforms in a way that allows care managers to see the "whole person" - A single health risk assessment - A specified percentage of overlap of key providers that the FIDE-SNP must contract with across Medicare and Medicaid to promote continuity
Coordinate or integrate enrollment, member materials, communications, grievance and appeals, and quality improvement	The difference between "coordination" and "integration" is unclear, especially when applied to concepts like quality improvement and member materials. This creates substandard attempts at integration. For example, sending two separate Medicaid and Medicare beneficiary communications materials in one envelope could be compliant with FIDE-SNP "coordination."	CMS should clarify what is intended with the terms "coordinate" or "integrate," including defining what is *not* permissible. Additionally, because much of the burden around this requirement falls to a state to come into alignment with Medicare requirements, CMS should provide technical support and tip sheets specific to the differences in state requirements and Medicare requirements. For example: - CMS should ensure states understand Medicare enrollment policies and time frames, and how to leverage Medicaid enrollment policies (like auto-assignment) to maximize aligned enrollment. - At a minimum, FIDE-SNPs should be required to provide aligned beneficiaries with a single integrated Evidence of Coverage (EOC) document, identification card, formulary, and provider directory. - FIDE-SNPs should have a single customer service portal/ phone line and should consolidate any overlapping Medicaid/Medicare communications

D-SNPs affiliated with managed long-term services and supports (MLTSS)

This option is available for states seeking to better align their LTSS plans. States typically require issuers to offer both a D-SNP and an MLTSS plan to ensure that all of the plans in the state are "aligned." MLTSS plans meet all the requirements of a HIDE SNP.

Haystack Project recommends that reform initiatives ensure that dual-eligible individuals have sufficient enrollment alternatives to "regular" MA plan enrollment.

In your analyses of data on dual eligible, did you consider continuity of enrollment status or consistency of full and partial dual eligible status during a year?

CMS has recently proposed to require that States apply the same Medicaid renewal procedures for MAGI and non-MAGI beneficiaries. Currently, streamlined processes that make it easier for eligible individuals to apply and remain enrolled in Medicaid and CHIP are only available for populations who are eligible for Medicaid based on MAGI. In many states, this has led to a more burdensome process for beneficiaries who qualify for Medicaid on a non-MAGI basis, such as being age 65 or older or having blindness or a disability.

Haystack supports this approach to ensure equitable treatment of Medicaid beneficiaries regardless of the statutory basis on which they qualify for the program. Individuals who are Medicaid eligible based on age, blindness or disability are likely dually-eligible and may experience additional barriers related to document retention, communication (for example, limited English proficiency and low health literacy), technology (for example, printing costs, access to a computer or internet) and access to transportation, among others.

How does geography play a role in dual coverage? Are there certain coverage and care management strategies that are more effective in urban areas as compared to rural areas?

Haystack Project recommends reforms to streamline access to out-of-state providers (discussed above) and improve access to effective remote care opportunities for dually-eligible individuals.

The GAO discussed previously in this response noted that rare disease patients are frequently unable to access specialists due to geography or failure to receive a referral for follow-up care at initial symptoms, and often progress to more severe disease states by the time they receive an accurate diagnosis. The impact on health outcomes is significant. Forty-one percent of rare disease patients also receive at least one misdiagnosis, and many are treated for a condition they did not have. Approximately 7 percent of rare disease patients reported that they were given a false psychological/psychiatric diagnosis that further impeded and delayed their treatment. Making access to appropriate experts through telemedicine and by streamlining access to out-of-state providers could make a meaningful difference in addressing some of these findings.

Haystack has also heard from patients and caregivers regarding the barriers individuals with hearing and/or visual impairments face in seeking care. Usher Syndrome, for example, is a very rare (approximately 25,000 US patients) inherited disease that causes combined hearing loss and vision loss from retinitis pigmentosa. For these patients, it is essential that remote care includes access to an ASL interpreter if they have sufficient remaining vision, or a tactile sign interpreter if they do not. Providers treating dually-eligible patients should be incentivized and sufficiently reimbursed for offering telemedicine services that are accessible for hearing and vision impaired patients.

Lack of reliable broadband wireless technologies and/or devices with data and video capabilities have also made it difficult for dual-eligible individuals, particularly those in rural areas to take advantage of the expanded availability of telemedicine other than through telephone-only visits.

Haystack Project recommends reforms that facilitate:

- Increased access to and use of telehealth within the patient's home. For rare disease patients subtle changes in disease symptoms and/or progression could have profound impacts on longer-term outcomes. Use of wearables, monitors, and access to layperson-friendly medical equipment would enhance remote monitoring capabilities and provide key patient information that may not be ascertained from periodic in-person visits.
- Providing patients with mobile devices and bandwidth (5G or 4G access) that are capable of delivering high-quality video resolution so that remote visits are as helpful to both clinician and patients as they can be.
- Ensuring that many patients and their families have sufficient education, training, and support to identify and utilize technologies that could improve day-to-day care burden and health outcomes.

Haystack Project expects that the value to patients in terms of improved outcomes and fewer acute events would outweigh the costs of wearable devices, improved video within remote visits, and other resources that can improve information available to patients, clinicians, and payers. Dually-eligible patients are not only the patient population most likely to experience improved health outcomes from use of these technologies, but are the least likely to be able to afford them. Unless there is a level playing field on access to emerging technologies, a family's financial resources will enable or limit the impact that technology can have on improving patient outcomes.

Conclusion

Haystack Project appreciates the opportunity to provide contextual information on the challenges faced by dually-eligible individuals with rare and ultra-rare disease, and recommendations to improve care integration, coordination, and resultant health outcomes. We look forward to a continuing dialogue on this important initiative that impacts a significant

proportion of our patient community. Please contact Haystack Project's policy consultant, Saira Sultan at 202-360-9985 or saira.sultan@connect4strategies.com with any questions or if you need further information from Haystack Project or our patient advocacy organization members.


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