July 30, 2026

The Honorable Robert F. Kennedy, Jr.
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dr. Mehmet Oz
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Submitted Electronically via regulations.gov

Re: Medicaid Program; Community Engagement Requirement for Certain Individuals; CMS-2454-IFC; 91 Fed. Reg. 33348

Dear Secretary Kennedy and Administrator Oz:

The undersigned organizations write to urge the Centers for Medicare & Medicaid Services (CMS) to make clear that individuals who suffer from organ failure and are on the waiting list for an organ transplant or were recently transplanted should be exempt from Medicaid community engagement requirements.

Americans in need of organ transplantation are battling advanced, and often life-threatening medical conditions. They have complex care needs including frequent medical testing, specialist appointments, medication management, hospital visits, hospitalization, dialysis or other life-sustaining treatment, and ongoing monitoring to make sure they remain healthy enough to receive a transplant when an organ becomes available.

For these patients, maintaining Medicaid coverage is important because it is essential to remain eligible for transplant. A loss of coverage, even for a short period of time, could lead to missed appointments, delayed treatment, or loss of life-saving therapy (including oxygen therapy), worsening health, or removal from active transplant consideration. For someone waiting for a lifesaving organ, that kind of disruption can have devastating consequences.

Patients that have received an organ transplant also have complex care needs including frequent laboratory testing and clinic visits all to ensure appropriate graft function, good patient recovery and correct use of multiple new prescribed medications. Loss of access to such care via lack of

Medicaid coverage could be catastrophic to patient recovery, including risk to both graft and patient survival.

CMS already recognizes in the interim final rule that individuals who are medically frail or who have special medical needs should be excluded from the community engagement requirement. CMS also recognizes that serious or complex medical conditions may include conditions that are life-threatening, require frequent monitoring, require advanced and sometimes invasive therapies, affect multiple organ systems, require coordination across multiple specialties, or carry a risk of serious complications. Patients actively listed for organ transplant and transplant recipients, specifically those within the first two years of transplant, both clearly fit within this framework.

However, without clear federal guidance, transplant candidates may be treated differently depending on the state where they live. Some patients could be forced to complete unnecessary paperwork, repeatedly prove the seriousness of their condition, or go through an appeal process simply to keep the coverage they need to remain prepared for transplant. That would place an unfair burden on patients who are already managing extremely difficult medical circumstances.

For that reason, CMS should expressly include organ transplant waitlist and recent organ recipient status as a qualifying basis for exclusion under the medically frail or special medical needs category. States should be required to treat current placement on the national organ transplant waiting list, or documentation from a transplant center or treating specialist, as sufficient proof that the individual is exempt from the community engagement requirement.

This clarification is necessary for several reasons:

First, Medicaid coverage plays a direct role in transplant readiness. Patients waiting for a transplant must stay connected to specialty care, regular monitoring (e.g. lab tests, imaging), medications, dialysis, oxygen therapy, or other treatment when needed. If coverage is interrupted, their health can decline quickly, and their ability to receive a transplant may be put at risk. For transplant recipients, close monitoring in the months following transplant are critical to identifying early signs of graft dysfunction and other myriad postoperative complications.

Second, transplant candidates and recent recipients often have medical needs that are unpredictable and time sensitive. They may need to attend appointments on short notice, travel to transplant centers, respond quickly when an organ becomes available, or manage complications that interfere with work or other required activities. These realities do not fit well into a monthly reporting system.

Third, the consequences of losing coverage are especially serious for this group. For many Medicaid beneficiaries, a coverage gap is harmful. For patients awaiting transplant or recovering from a recent transplant, it may be life-threatening. Patients without Medicaid or other insurance can be denied transplant. Even a temporary loss of coverage can lead to delays in care, avoidable hospitalization, and serious complications.

Fourth, a clear federal exemption would reduce confusion and administrative burden. State Medicaid agencies should not have to develop inconsistent processes for deciding whether transplant candidates qualify as medically frail. Patients should not have to repeatedly document the same condition when transplant waitlist status or a transplant-center attestation already provides clear evidence of their medical need.

This approach is also consistent with the purpose of the medically frail exclusion. CMS created that exclusion to protect people whose medical conditions make it unreasonable or inappropriate to subject them to community engagement requirements. People waiting for organ transplants are exactly the type of medically vulnerable population this protection is meant to cover.

To address this issue, CMS should add language substantially similar to the following:

"An individual suffering from organ failure who is undergoing evaluation for organ transplantation, currently listed for an organ transplant, or has received a transplant in the preceding 24 months, as documented by registration on the national organ transplant waiting list or by attestation from a transplant center or treating specialist, shall be considered to have special medical needs for purposes of the community engagement requirement and shall be excluded from the definition of an applicable individual."

CMS should also direct states to include organ transplant waitlist status in the lists of diseases, diagnoses, disorders, or other health conditions used to identify individuals who qualify for the medically frail or special medical needs exclusion. States should accept transplant-center documentation, provider attestation, or other reliable medical documentation without requiring unnecessary additional steps from the patient.

CMS should also make clear that transplant candidates are not able to rely only on short-term hardship exceptions. A hardship exception may help in a specific month when a patient is hospitalized, traveling for treatment, or dealing with an acute medical issue. But being on a transplant waiting list is not a short-term inconvenience. It reflects an ongoing and serious medical condition that requires stable access to care over months to years.

The requested clarification is narrow, reasonable, and medically necessary. It would protect patients, support transplant readiness, reduce administrative burden, and ensure the community engagement requirement does not unintentionally harm people who have recently been transplanted or are waiting for a lifesaving transplant.

We respectfully urge CMS to revise the rule and related guidance to expressly exempt individuals on an organ transplant waiting list from Medicaid community engagement requirements.

Sincerely,

American Liver Foundation
American Society for Histocompatibility and Immunogenetics
American Society of Nephrology
American Society of Transplantation
AvasHeart
Children's Organ Transplant Association and Transplant Families
Heart Brothers Foundation, Inc.
Heartfelt Help Foundation
Intestinal Rehab & Transplant Unwrapped
Kidney Solutions: A Network of Transplant Experience
Kidney Transplant Collaborative
Kidneys for Kids
The Mended Hearts, Inc.
National Kidney Foundation
North American Transplant Coordinators Organization
PKD Foundation
Renal Physicians Association
The Transplant Journey, Inc.
TRIO, the Transplant Recipients International Organization
Waitlist Zero