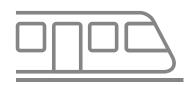
# ISSUE BRIEF

April 2019

# Non-Emergency Medical Transportation:

PAST, PRESENT, AND FUTURE OF A CRITICAL SERVICE









# PART III:

# NON-EMERGENCY MEDICAL TRANSPORTATION AND 1115 WAIVERS - A TOOLKIT

#### About the Authors:

The Center for Health Law and Policy Innovation of Harvard Law School (CHLPI) advocates for legal, regulatory, and policy reforms to improve the health of underserved populations, with a focus on the needs of low-income people living with chronic illnesses and disabilities. CHLPI works with consumers, advocates, community-based organizations, health and social services professionals, food providers and producers, government officials, and others to expand access to high-quality health care and nutritious, affordable food; to reduce health disparities; to develop community advocacy capacity; and to promote more equitable and effective health care and food systems. CHLPI is a clinical teaching program of Harvard Law School and mentors students to become skilled, innovative, and thoughtful practitioners as well as leaders in health, public health, and food law and policy.

**Lung Cancer Alliance** serves and listens to those living with and at risk for lung cancer to reduce stigma, improve quality of life and increase survival. Lung Cancer Alliance empowers its community by helping people navigate the paths of early detection, diagnosis and treatment. Insights allow Lung Cancer Alliance to improve care, amplify awareness, drive advocacy and lead research with the vision of tripling the number of survivors in the next decade.







## I. Introduction

For millions of Americans, Non-Emergency Medical Transportation (NEMT) serves as a critical bridge to care. NEMT allows patients to receive the screening, treatment, and monitoring they need, thereby helping to improve health outcomes and control health care costs. Recognizing the important role that transportation plays in ensuring access to care, the federal government has required states to provide NEMT services as part of their Medicaid benefit package for almost the entire history of the Medicaid program.

However, recent budgetary and political pressures have led many states to reexamine their Medicaid programs and explore new ways to contain costs. To do so, some states are exploring innovative new partnerships, payment structures, and benefits that have the potential to improve program efficiency and/or reduce utilization of high-cost services. Others are instead focusing on changes that would cut costs by restricting Medicaid eligibility or cutting key benefits. In some cases, these changes include reducing or eliminating access to NEMT services for certain populations, an approach that poses a threat to both access to care and, ultimately, patient health outcomes.

States that want to implement these types of widespread restrictions in their Medicaid program must get approval from the federal government under a **Medicaid Section 1115 Demonstration Waiver**. The good news for patients and advocates is that federal laws and regulations create a series of opportunities for stakeholders to get involved in the Waiver process and voice any concerns that they may have. This issue brief, **Part III** in our NEMT series, will therefore take a close look at Medicaid Section 1115 Demonstration Waivers and how stakeholders can leverage the legal requirements of the Waiver process to protect NEMT benefits in their state.

### II. What are Medicaid Waivers?

States have two basic mechanisms for operating their Medicaid programs: (1) State Plans and (2) Waivers.

- 1. State Plans: All states have a State Plan. A State Plan is the document that describes the overall structure of a state's Medicaid program, including details on items such as eligibility, covered benefits, and provider payments. Although State Plans vary widely between states, all State Plans must follow the basic rules for state Medicaid programs established in the Social Security Act and federal Medicaid regulations. If a state wishes to make changes to its State Plan, it can do so by submitting a State Plan Amendment to the Centers for Medicare & Medicaid Services (CMS).
- 2. Waivers: In contrast, if a state wants to make a change to the structure of its Medicaid program that would violate federal Medicaid requirements (as is the case where a state is seeking to reduce or eliminate coverage of NEMT), it must apply for a waiver. Each type of waiver is referred to by the section of the Social Security Act in which it appears and has its own legal requirements and limitations. States can use different types of waivers to achieve different goals in their Medicaid programs, but those who want to curtail NEMT will likely request a Section 1115 Demonstration Waiver.

## III. Medicaid Section 1115 Waivers - A Deeper Dive

Section 1115 Waivers are the most flexible category of Medicaid waivers, giving states significant latitude to explore new approaches to delivering and paying for Medicaid services. Under the Section 1115 Waiver authority, the Secretary of Health and Human Services has the discretion to approve waivers of the provisions of Section 1902 of the Social Security Act<sup>2</sup>—a section that includes many core Medicaid requirements—as well as to provide federal funds to pay for services and populations that would not otherwise be covered under Medicaid rules.<sup>3</sup> As a result, states can use 1115 Waivers both very broadly to restructure their Medicaid programs and very narrowly to provide targeted services to specific populations.

However, there are limits to 1115 Waiver authority. In order to approve an 1115 Waiver, the Secretary must determine that the proposed changes are part of an "experimental, pilot, or demonstration project which, in the judgment of the Secretary, is likely to assist in promoting the objectives of [the Medicaid program]." Thus, advocates have emphasized that the Secretary should not approve any waivers that will not test a hypothesis/evaluate outcomes or which will not reasonably advance the Medicaid program's goals of providing medical and long-term services. Additionally, Section 1115 Waivers must meet a series of transparency requirements (described in more detail below) and be budget neutral for the federal government. This means that the federal government cannot be expected to pay more to support the state's Medicaid program under the proposed Waiver than it would if the Waiver did not exist.<sup>6</sup>

# IV. How are Medicaid Section 1115 Waivers Being Used to Restrict NEMT?

Historically, states have used 1115 Waivers to achieve a wide variety of goals. These goals have often focused on *expanding* access to Medicaid by providing coverage to additional populations (e.g., adults, people living with HIV, or individuals coping with natural disasters or other emergency situations).<sup>7</sup> Additionally, some states have also used 1115 Waivers to alter their approach to Medicaid delivery and payment systems in order to better incentivize health care providers to provide efficient, high-quality care.<sup>8</sup>

**1115** Waivers and Transportation Innovation: Some states are continuing to use 1115 Waivers to expand access to transportation in innovative ways. Under its latest 1115 Waiver, the Massachusetts Medicaid program will provide "flexible services" funding that Accountable Care Organizations (ACOs) can use to address health-related social needs in their member populations. ACOs will use this funding to provide certain Medicaid members with services that otherwise would not be covered by Medicaid. For example, ACOs may use "flexible services" funding to provide transportation to and from housing and nutrition support services.

Similarly, under its new 1115 Waiver, North Carolina's Medicaid program will launch "Healthy Opportunity Pilots" that will address non-medical issues including transportation insecurity.

However, in response to recent political and budgetary pressures, a number of states have adopted a more restrictive approach to 1115 Waivers. Rather than looking to increase Medicaid coverage, these states have applied for 1115 Waivers that would reduce overall eligibility for the Medicaid program by establishing work requirements, eligibility time limits, and/or lock-out periods. Additionally, several states have used 1115 Waivers to limit or eliminate access to NEMT services for certain populations. 10

The table below provides a summary of the states that have recently requested to limit access to NEMT services as part of an 1115 Waiver. The details of these waivers, including key terms and trends, are explained in more detail below.

Table 1: Status of 1115 Waiver Requests Regarding NEMT as of March 2019

State	Waiver Status	Population(s) Affected	Exemption for Medically Frail?	Notes
Arizona <sup>11</sup>	Pending	Certain able-bodied adults with income equal to 100 – 138% of federal poverty level, living in urban areas	Yes	Arizona does not appear to have formally requested this Waiver yet. Instead, it has noted an interest in pursuing a Waiver in a November 2017 letter to CMS. <sup>12</sup>
Indiana <sup>13</sup>	Approved	Expansion population	Yes	
lowa <sup>14</sup>	Approved	Expansion population	Yes <sup>15</sup>	
Kentucky <sup>16</sup>	Pending	Expansion population (eliminates NEMT for all services)  Non-expansion population (eliminates NEMT for methadone services only)	Expansion population Waiver: Yes Non-expansion population Waiver (methadone): No	Kentucky's 1115 Waiver has been approved twice by CMS, but subsequently rejected by a federal court. It is now once again pending. <sup>17</sup>
Massachusetts <sup>18</sup>	Pending	Expansion population (eliminates NEMT for all services <b>except</b> Substance Use Disorder treatment)	Yes	

A few of these efforts pre-date the Trump Administration, and even the Affordable Care Act.<sup>19</sup> However, the Trump Administration has shown *particular* interest in approving and even encouraging states to waive NEMT services,<sup>20</sup> suggesting that such Waivers may become more widespread over the next few years.

Current approved and pending Waivers appear to follow certain trends, including:

- **1. Focus on Expansion Population:** These Waivers focus primarily on elimination of NEMT services for the Medicaid expansion population—that is, the population of adults with incomes up to 138% of federal poverty level (FPL) that became newly eligible for Medicaid coverage under the Affordable Care Act.<sup>21</sup> This trend is troubling for a number of reasons:
  - Need for Services: First, 2015 data gathered by the Kaiser Family Foundation from Logisticare, one of the nation's largest NEMT brokers, indicates that there is a real and potentially growing need for NEMT in the expansion population. Specifically, the Foundation found that in examining two sample states (New Jersey and Nevada) expansion adults' use of NEMT services rose over the course of a year from roughly 2 to 5%, potentially due to beneficiaries learning about these services over time.<sup>22</sup>
  - **Undermining Policy Goals:** Second, this same data indicated that expansion adults were roughly 50% more likely to use NEMT to access preventive services than other Medicaid enrollees.<sup>23</sup> Encouraging the use of preventive services to avoid later need for more intensive, costly care is a core goal of health care reform efforts. Reducing access to NEMT services may therefore undermine this policy goal by preventing expansion adults from receiving preventive care.
- 2. Differing Approaches on Behavioral Health: Two states that have applied for 1115 Waivers to exclude NEMT services—Massachusetts and Kentucky—have also taken distinctly different approaches when deciding how the Waiver will impact access to Substance Use Disorder (SUD) treatment services. While Massachusetts's proposed Waiver amendment contains an exception that would allow enrollees to continue to use NEMT to access SUD treatment, Kentucky's Waiver would prevent enrollees from using NEMT to access methadone treatment. Kentucky's limitation on NEMT in the context of methadone services is significant because it would apply to both its expansion population and its broader Medicaid population. This limitation is particularly concerning, as accessing behavioral health services (including SUD treatment) is one of the most common uses of NEMT.<sup>24</sup>
- 3. Medical Frailty: Almost all approved or pending NEMT Waivers provide an exception for individuals who are deemed medically frail. Federal regulations provide a broad baseline definition of medically frail that includes individuals with "disabling mental disorders," "chronic substance use disorders," "serious and complex medical conditions," and certain disabilities. States have considerable flexibility in applying this definition. States can determine the severity and types of conditions that fall within the federal categories or even adopt a more protective standard. States also have flexibility in determining how to identify individuals who are medically frail (e.g., using claims data vs. self-attestation vs. case-by-case determinations). As a result, this exception may be more or less robust, depending upon the state involved.
  - Exception: Kentucky: Notably, though, Kentucky's Waiver, which would broadly prevent use of NEMT to access methadone services, does not include an exception for medically frail individuals (or any similar category of individuals). As a result, even individuals with significant disabilities or chronic conditions would not be able to access NEMT in association with methadone treatment.

**Evaluating the Impact of NEMT Waivers – Iowa and Indiana:** As a condition of their 1115 Waivers, CMS required both Iowa and Indiana to evaluate the impact of waiving NEMT services. Both states concluded that that the elimination of NEMT services did not significantly impact access to care. However, the data underlying these conclusions remains concerning:

Indiana: Indiana conducted an evaluation that compared surveys from two groups of Medicaid enrollees: (1) enrollees covered by the Waiver who did not have access to NEMT benefits and (2) enrollees covered by the Waiver who did have access to NEMT benefits because their Medicaid managed care plan voluntarily covered these services.<sup>26</sup> The surveys indicated that 4.7% of Waiver enrollees without NEMT benefits missed appointments due to transportation-related issues.<sup>27</sup> While this number was not significantly different from the percentage of Waiver enrollees with NEMT that missed appointments due to transportation (4.1%),<sup>28</sup> it does indicate that a substantial number of Waiver enrollees had an unmet need that could be met through NEMT services. Additionally, the surveys indicated that this need was particularly high for individuals with lower

incomes (5.1% for individuals below federal poverty level) and for individuals with complex health care needs (6.6%).<sup>29</sup>

**lowa:** lowa conducted an evaluation that compared surveys of three groups of Medicaid enrollees: (1) Waiver enrollees below 100% FPL (no NEMT); (2) Waiver enrollees with incomes between 101-133% FPL (no NEMT); and (3) Medicaid State Plan enrollees (NEMT).<sup>30</sup> These surveys found that 13% of Waiver enrollees with incomes below 100% FPL and 6% Waiver enrollees with incomes between 101-133% FPL had an unmet need for NEMT services.<sup>31</sup> While these percentages were lower than those for State Plan enrollees (16%),<sup>32</sup> they again indicate a substantial need for transportation that could have been addressed through NEMT.

# V. How Can Stakeholders Get Involved in the Section 1115 Waiver Process?

As noted earlier, federal law and regulations establish transparency requirements that generally must be met before CMS can approve a new 1115 Waiver or Waiver renewal.<sup>33</sup> These requirements create a series of opportunities for stakeholders, such as Medicaid participants, health care providers, and advocacy organizations, to place public pressure on state and federal policymakers to change or eliminate potentially harmful provisions from the proposed Waiver before it is approved.

- 1. State-Level Requirements: Federal regulations require states to provide stakeholders with an opportunity to comment on any application to create or extend an 1115 Waiver demonstration project. Specifically, stakeholders must have the opportunity to review the 1115 Waiver application, submit written comments, and participate in public hearings before the state submits the application to CMS.
  - **Public Hearings:** States must hold **at least two public hearings** to seek input on the 1115 Waiver application.<sup>34</sup> Interested stakeholders can attend these hearings and provide oral testimony explaining why they support or oppose the policies in the proposed Waiver.
    - Timing: The hearings must be held at least 20 days before the state submits the Waiver application to CMS.<sup>35</sup>
    - Accessibility: The hearings must be held on two separate dates and in two separate locations.
       The state must allow stakeholders to participate via phone or web conference for at least one of the hearings or otherwise demonstrate that the hearings were accessible to stakeholders throughout the state.<sup>36</sup>
  - Written Comment Period: States must also provide an opportunity for stakeholders to submit written comments on the 1115 Waiver application. The state must accept written comments for a period of at least 30 days and must allow comments to be submitted in a hard copy or electronic format.<sup>37</sup>

**How Do I Find Information Regarding State-Level Hearings and Comment Periods?:** The state must publicize information about the 1115 Waiver application and the opportunities for stakeholder input in a couple of ways.

**State Agency Website:** First, the state must publish information regarding the application, hearings, and comment process either on the main page of the public website of the state agency responsible for the application (likely the state Medicaid agency), or provide a "readily identifiable" link on its main page to a separate page about the application.<sup>38</sup>

**State Administrative Record or Popular Newspapers:** The state must also publish a public notice of the application in the state's administrative record or in widely circulated newspapers.<sup>39</sup>

Mailing Lists and Additional Mechanisms: Finally, the state must "utilize additional mechanisms, such as an electronic mailing list, to notify interested parties of the demonstration application(s)." To learn more about signing up for Medicaid mailing lists in your state, visit the website of the state agency responsible for your Medicaid program and/or contact the state agency directly using their publicly available contact information (e.g., email or phone number). Local health care advocacy organizations or coalitions may also be able to provide guidance on accessing any relevant mailing lists.

- 2. Federal-Level Requirements: Once the state has met the requirements described above, it can submit the 1115 Waiver application to CMS for approval. When submitting the application, the state must describe the concerns raised by stakeholders during the comment period and how the state considered those concerns in the application submitted to CMS.<sup>41</sup> Federal regulations then require CMS to provide stakeholders with a second opportunity to review the application materials and provide written input.
  - Written Comments: CMS must provide an opportunity for stakeholders to submit written comments on the 1115 Waiver application. Similar to states, CMS must accept written comments for a period of 30 days and must allow comments to be submitted in a hard copy or electronic format.<sup>42</sup> CMS must then publish these comments online and review and consider all comments submitted within the comment period when determining whether to approve the application.<sup>43</sup>

**How Do I Find Information Regarding the Federal-Level Comment Period?:** Like states, CMS must publicize information about the 1115 Waiver application and the opportunities for stakeholder input in several ways:

**CMS Website:** CMS must publish the state's 1115 Waiver application materials and information on the process for submitting written comments on the CMS website. 44 Specifically, to learn more about pending waivers, visit the State Waivers List section of the Medicaid.gov website, found here: <a href="https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html">https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html</a>.

Mailing Lists and Additional Mechanisms: CMS must also notify "interested parties through a mechanism, such as an electronic mailing list, that CMS will create for this purpose." To sign up for relevant mailing lists, visit the CMS Email Updates page of CMS.gov, found here: <a href="https://www.cms.gov/About-CMS/Agency-Information/Aboutwebsite/EmailUpdates.html">https://www.cms.gov/About-CMS/Agency-Information/Aboutwebsite/EmailUpdates.html</a>.

## VI. Tips, Tools, and Resources

This section provides an overview of helpful tips, tools, and resources that you can use as you look to leverage the 1115 Waiver transparency requirements described above to protect access to NEMT services in your state.

- 1. Public Hearings: As noted above, you will generally have at least **two** opportunities to attend a public hearing about your state's proposed 1115 Waiver. These public hearings can be a valuable opportunity to learn about the Waiver and to raise any questions, concerns, or suggestions that you might have. When preparing for these hearings, consider the following tips and strategies:
  - Educate Yourself in Advance: While the state Medicaid agency may provide information on the Waiver at the hearing itself, it will be helpful to learn as much as you can in advance so that you can come to the hearing prepared to respond to the proposal. To prepare yourself, review the Waiver materials on the state's website.
  - Develop Your Talking Points: The state hearings should provide you with an opportunity to ask questions or provide oral testimony regarding the proposal. When developing your talking points, consider the

#### following:

- Introduce Yourself and Your Connection to the Issue: At the start of your testimony be sure to introduce not only yourself, but also how you, your organization, or your work is connected to the issues in the Waiver or the Medicaid program more generally. For example, do you work with populations that will be particularly impacted by the proposed NEMT restrictions? Highlighting this connection will give additional weight to your comments.
- Be Prepared to Be Brief: Hearing organizers may limit the amount of time that each individual has to speak. Therefore you should be ready to cover your key talking points quickly.
- Highlight Potential Harms Associated with the Waiver: Key talking points could include: (1) how the NEMT Waiver will limit access to care; (2) how the NEMT Waiver will impact health care outcomes and costs; and (3) how the NEMT Waiver could undermine any other state policy priorities.
- Use Compelling Data or Examples: Where possible, support your arguments with compelling data or examples. Table 2 at the end of this section provides an overview of several studies on the impact of NEMT on health outcomes and costs. If you work with particular populations, you can also research whether studies are available on the specific impact or need for NEMT services for that group.
- Consider Submitting a Written Version of Your Testimony: If the hearing is particularly well-attended or time limits are placed on oral testimony, you may not be able to present all of your talking points inperson. If that is the case, you can consider submitting a written version of your testimony (e.g., in the form of a letter) to meeting organizers or the leadership of your state Medicaid agency.
- Encourage Others to Attend Hearings: If you are familiar with other individuals or organizations that will be affected by the proposed NEMT restrictions, encourage them to attend the hearing and to share their stories and concerns. Testimony from individuals who actually use and depend upon NEMT services can be particularly persuasive, and engaging multiple voices will make the overall message more powerful.

Table 2: NEMT Studies and Resources (full citations/links in endnotes)

Author(s)	Title	Description
P. Hughes- Cromwick et al. <sup>46</sup>	Cost Benefit Analysis of Providing Non-Emergency Medical Transportation	2005 analysis that provides data on (1) populations likely to experience transportation barriers to medical care and (2) cost-effectiveness of NEMT for specific health conditions
Richard Wallace et al. <sup>47</sup>	Access to Health Care and Nonemergency Medical Transportation: Two Missing Links	2005 analysis that provides data on populations likely to experience transportation barriers to medical care
J. Joseph Cronin <sup>48</sup>	Florida Transportation Disadvantaged Programs: Return on Investment Study	2008 analysis by Florida State University finding that if 1% of medical trips result in avoidance of a hospital stay, return on investment to Florida is 1108% or \$11.08 for every \$1 invested in the transportation program
MaryBeth Musumeci & Robin Rudowitz <sup>49</sup>	Medicaid Non-Emergency Medical Transportation: Overview and Key Issues in Medicaid Expansion Waivers	2016 analysis of NEMT in 1115 Waivers that includes data from Logisticare, a large NEMT broker, on frequently cited reasons for using NEMT and use of NEMT in the expansion population
U.S. Gov't Accountability Office (GAO) <sup>50</sup>	Efforts to Exclude Nonemergency Transportation Not Widespread, but Raise Issues for Expanded Coverage	2016 analysis of state approaches to NEMT in the expansion population and potential implications of waiving NEMT coverage
Michael Adelberg et al. <sup>51</sup>	The Value of Medicaid's Transportation Benefit: Results of a Return on Investment Study	2018 analysis commissioned by the Medical Transportation Access Coalition finding a substantial return on investment for NEMT when used to access dialysis and diabetic wound care
Erskine et al. <sup>52</sup>	Barriers to Healthcare Access and Long-Term Survival After an Acute Coronary Syndrome	2018 analysis finding that transportation barriers to medical care were associated with a higher post-discharge risk of mortality for patient survivors of acute coronary syndrome

Author(s)	Title	Description	
Starbird et al. <sup>53</sup>	A Systematic Review of Interventions to Minimize Transportation Barriers Among People with Chronic Diseases	2018 compilation and analysis of intervention studies, which found that transportation support is associated with overall improvements in patient health outcomes	
Thomas et al. <sup>54</sup>	Access to Transportation and Health Care Visits for Medicaid Enrollees with Diabetes	2018 analysis showing that the use of NEMT is a significant predictor of diabetes care visits	
Rochlin et al. <sup>55</sup>	Economic Benefit of "Modern" Nonemergency Medical Transportation That Utilizes Digital Transportation Networks	2019 analysis showing that "traditional" NEMT and "modern" NEMT (i.e., Lyft and Uber) are both cost-effective. The analysis also found that "modern" NEMT has the potential to yield greater cost savings and improve overall patient experience	

- 2. Submitting Written Comments: You will also have **two** opportunities to submit written comments on the proposed waiver—once to the state agency that is preparing the Waiver and once to CMS as it considers whether to approve the Waiver. It is important for stakeholders to submit comments at **both** the state and federal level. When developing your comments, consider the following tips and strategies:
  - Formatting Your Comments: Comments can be submitted in the form of a letter. The letter can be addressed to the relevant agency (i.e., your state Medicaid agency or CMS) or the leadership of that agency.
  - **Developing Your Comments:** Many of the same strategies that apply to developing your talking points for state Waiver hearings apply in the context of written comments.
    - Introduce Yourself and Your Connection to the Issue: Again, it is helpful to begin your comment letter by introducing yourself or organization and how you are connected to the Waiver and/or Medicaid program more generally.
    - Summarize Key Takeaways at the Outset: If your comment letter will be longer than a page or two, it can be helpful to summarize your key recommendations/takeaways in a paragraph or several bullets in your introduction.
    - Lay out Arguments Methodically, Using Headers to Highlight Key Takeaways: Be aware that
      agency officials will be reviewing numerous comments and may be reading quickly. Therefore, it
      can be helpful to separate out each of your core arguments and use bold headers at the start of
      each new section to highlight key takeaways.
    - Highlight Potential Harms Associated with the Waiver: As with your talking points for a state hearing, arguments in your comment letter could include: (1) how the NEMT Waiver will limit access to care; (2) how the NEMT Waiver will impact health care outcomes and costs; and (3) how the NEMT Waiver could undermine any other state or federal policy priorities.
    - Propose Alternatives, if Appropriate: As discussed in Part II of this series, there are a variety of ways that states can improve delivery of NEMT without limiting access to services. If these strategies seem relevant to your state, you could consider highlighting them as potential alternatives to the NEMT Waiver, especially in comment letters directed to your state Medicaid agency.
    - Use Compelling Data or Examples: Again, be sure to support your arguments with compelling data or examples wherever possible. As a starting point, see Table 2 above for an overview of several studies that provide helpful data on NEMT. When using data in your written comments, include footnotes with citations and active hyperlinks to encourage agency officials to review these additional resources on the benefits of NEMT.
  - Encourage Sign-ons or Additional Comment Submissions: To strengthen the impact of your comments, consider asking other organizations to sign on to your letter to show that they agree with your recommendation to protect NEMT benefits. You can also encourage other individuals or organizations to

submit their own comment letters to further reinforce this message.

• **Submitting Your Comments:** For information on **where/how** to submit your comment letter, review the instructions available on the website for your state Medicaid agency or CMS.

#### **Example: Federal Comment Letter (Abbreviated)**

Below is an abbreviated example of how you might format and compose a **federal comment letter** in response to an 1115 Waiver proposal that would eliminate NEMT services for the Medicaid expansion population in your state. As you can see, the letter incorporates many of the **key themes** and **data points** emphasized throughout this series. In your own comment letters, be sure to include data, examples, or arguments that are specific to your state's proposal and the populations most relevant to your work.

For additional ideas, talking points, and examples, consult the websites of other national and local health advocacy organizations that are likely to be tracking and responding to 1115 Waiver proposals. For example, **Families USA** has created a number of resources on 1115 Waivers—and NEMT specifically—that you may find helpful. These materials can be found at: <a href="https://familiesusa.org/">https://familiesusa.org/</a>.

[Date]

Submitted via the Federal Medicaid.gov Portal

Centers for Medicare & Medicaid Services Department of Health and Human Services P.O. Box 8016 Baltimore, MD 21244-8016

Re: Comments for [State Waiver Title] Application

To Whom It May Concern:

We are writing on behalf of [Organization]. For the past [#] years, [Organization] has worked both locally and on a national level to promote policies to improve the health of the roughly 117 million Americans<sup>56</sup> living with disability and/or chronic health conditions such as cancer, HIV, and diabetes. As part of our work, we partner with communities, nonprofits, and advocates across the country to expand access to care for these vulnerable populations.

We appreciate the opportunity to submit comments on [State's] recent Section 1115 Waiver Demonstration Application. [Organization] is deeply concerned that the waiver of NEMT services proposed in the Application would substantially decrease meaningful access to care for low-income individuals living with chronic illnesses and disabilities. For the reasons described below, we therefore oppose the Waiver Application and urge the Centers for Medicare & Medicaid Services (CMS) to reject it.

# [State's] Proposal to Eliminate NEMT for the Expansion Population Would Undermine the Objectives of the Medicaid Program

Section 1115(a) of the Social Security Act, codified at 42 U.S.C. § 1315(a), allows a federal waiver to facilitate a State's "experimental, pilot, or demonstration project" that, "in the judgment of the Secretary, is likely to assist in promoting the objectives" of the Medicaid program. One of the primary objectives of Medicaid, as explained by § 1901 of the Social Security Act, is to enable each State to furnish "medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services." <sup>57</sup>

[State's] proposal to eliminate NEMT services would directly undermine this overarching goal of furnishing medical assistance, as it would prevent, rather than promote, access to necessary care. Each year, roughly 3.6 million Americans miss or delay essential medical care due to transportation-related difficulties.<sup>58</sup> Low-income adults are

particularly likely to encounter these types of transportation barriers. NEMT therefore serves as a critical bridge to medical care for all Medicaid enrollees, including individuals in the Medicaid expansion population. For example, a recent analysis indicated that the use of NEMT more than doubled (from  $^{2}$ % to  $^{5}$ %) among expansion adults in New Jersey and Nevada from spring 2014 - 2015.

Without NEMT, many of these individuals would lose meaningful access to medical care. Thus the proposed waiver of NEMT services would allow the state to avoid, rather than fulfill, its commitment to furnishing medical assistance. CMS should therefore reject [State's] proposal to waive NEMT for failing to promote the objectives of the Medicaid program.

#### [State's] Proposal to Eliminate NEMT for the Expansion Population Would Worsen Health Outcomes

By decreasing access to care, [State's] proposal to eliminate coverage of NEMT would also undermine one of the core goals of health care reform: the need to improve individual and population health outcomes. Rather than promoting this goal, [State's] proposal would worsen health outcomes both generally for the expansion population and more specifically for those members of the expansion population living with chronic illnesses.

Recent data from one of the nation's largest NEMT providers indicates that expansion adults are roughly 50% more likely to use NEMT to access preventive services than other Medicaid enrollees. By accessing preventive services, these enrollees can reduce their likelihood of developing serious acute or chronic illnesses, thereby improving their health outcomes. Without access to NEMT, these enrollees may instead forgo preventive services, resulting in a sicker, more costly Medicaid population in the long-term.

Eliminating access to NEMT services will also have a serious and disproportionate impact on health outcomes for expansion enrollees living with chronic conditions. Individuals with chronic conditions are particularly likely to miss appointments or delay care due to transportation barriers. <sup>62</sup> Because chronic diseases require ongoing management to prevent the escalation of symptoms, this trend can have a negative impact on patient health outcomes. <sup>63</sup> For example, poor access to transportation has been shown to be associated with underuse of chemotherapy among lung cancer patients, <sup>64</sup> and a number of studies have indicated that greater travel burdens (i.e., distance or time to care) are associated with later diagnosis, less appropriate treatment, and worse health outcomes for cancer patients more broadly. <sup>65</sup>

Given the potential negative impact on both short and long-term health outcomes, CMS should deny [State's] request to waive NEMT services.

#### [State's] Proposal to Eliminate NEMT Would Sacrifice Cost-Effective and/or Cost-Saving Care

By connecting patients to the services they need to prevent or manage serious conditions, NEMT also plays an important role in controlling health care costs. Research has shown that NEMT services are cost-saving when used to connect patients to care for a number of common chronic conditions, including asthma, heart disease, and diabetes. Additionally, even when NEMT is not directly cost-saving, it is often cost-effective, considering the improved health outcomes experienced by patients when they have consistent access to necessary care. Should therefore deny [State's] request in recognition of the importance of promoting both improved health outcomes and cost-effective and cost-saving care.

[Organization] thanks you for this opportunity to provide input on [State's] Section 1115 Waiver Demonstration Application. For all of the reasons stated above, we urge CMS to reject the Application, as it will undermine, rather than promote, access to care for thousands of chronically ill individuals in [State]. Should you have any questions, please contact [Organization representative] at [email address].

Sincerely, [Organization Representative]



# VII. Additional Threats - 2019 and 2020 Budget Proposals

Up to this point, NEMT services have been designated as a mandatory Medicaid benefit. As a result, states have been required to seek a Waiver to eliminate or restrict NEMT. As described above, the Waiver process can be an important source of transparency and protection for NEMT services, as it creates multiple opportunities for stakeholders to publicly voice their opposition to these changes. Additionally, Waivers of NEMT services have generally been limited to specific populations (e.g., expansion populations) or services.

However, the Trump Administration recently signaled that it may attempt to take administrative action that would make it far easier for states to eliminate the NEMT benefit across their entire Medicaid population without the need for a Waiver.<sup>68</sup> In its fiscal year 2019 and 2020 budget proposals for the Department of Health and Human Services, the Administration stated that "[t]he Budget commits to using regulatory authority to change provision of [NEMT] from mandatory to optional."<sup>69</sup> HHS has also announced that it intends to release a proposed rule in May 2019 that will "reexamine current regulations under[] which States are required to assure NEMT for all Medicaid beneficiaries when they have no other means of accessing medical services."<sup>70</sup>

If the Trump Administration were to alter Medicaid regulations to make NEMT an optional benefit, states would still be required to use the Waiver process to limit NEMT benefits within specific populations or regions. However, they would be able to use State Plan Amendments, rather than Waivers, if they decided to eliminate NEMT benefits across their *entire* Medicaid population. States differ in their requirements for approving State Plan Amendments (e.g., some states require legislative approval), but, in general, stakeholders have far fewer opportunities to comment on or influence State Plan Amendments, as they are not subject to the same federal transparency requirements as 1115 Waivers.

Therefore, in addition to monitoring 1115 Waivers, stakeholders interested in protecting access to NEMT should watch for and respond to any proposals to alter federal regulations to make NEMT an optional benefit.

**How Do I Watch for and Respond to Proposals to Change Federal Regulations?:** Changes to federal regulations must generally go through a federal notice and comment process. This means that the federal government must alert the public to the proposed change and allow stakeholders to submit comments in response.

• Watching for Proposed Changes: Proposed changes to federal regulations will generally be posted in a Notice of Proposed Rulemaking (NPRM) in the Federal Register. These NPRMs can be found on the

website for the Federal Register: <a href="https://www.federalregister.gov/">https://www.federalregister.gov/</a>. It may also be helpful to join **mailing lists** for health care provider or advocacy groups that are interested in NEMT, as they may distribute helpful alerts and advice regarding relevant proposals.

• Responding to Proposed Changes: The NPRM will contain information regarding how to submit comments on the proposed changes. In drafting a comment a letter, you can use many of the same strategies and talking points that you would in responding to an 1115 Waiver proposal (described above).

#### VIII. Conclusion

Despite growing evidence regarding the impact that access to transportation can have in improving health outcomes and controlling costs, a number of state and federal policymakers are currently looking to restrict access to NEMT services. As described in this issue brief, health care providers, advocacy organizations, and other stakeholders can play an important role in protecting NEMT services. By leveraging opportunities to publicly respond to proposals to restrict access to NEMT, stakeholders can alert decision-makers to the importance of NEMT services and urge them to pursue innovative, rather than restrictive, solutions.

Stakeholders should remember, though, that NEMT is only one strategy for overcoming the barriers that prevent patients from accessing necessary care. To more holistically address these barriers, stakeholders can also encourage policymakers to step back and develop a comprehensive plan to address state and local transportation barriers. Therefore, the final resource in this series will examine the broader landscape of policies and programs that can be used in conjunction with NEMT to better connect patients to care.



#### **Endnotes**

- For example, Section 1915(b) Waivers can be used to establish mandatory Medicaid managed care programs, while Section 1915(c) Waivers can be used to provide "home and community-based services" to help certain enrollees remain in a community setting who would otherwise require institutional care (i.e., care in a nursing home or hospital). See 42 U.S.C. § 1396n(b); 42 U.S.C. § 1396n(c); "At-a-Glance" Guide to Federal Medicaid Authorities Useful in Restructuring Medicaid Health Care Delivery or Payment, Integrated Resource Center (Apr. 2012).
- <sup>2</sup> 42 U.S.C. § 1315(a)(1).
- <sup>3</sup> 42 U.S.C. § 1315(a)(2)(A).
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- 5 See Section 1115 Waivers: Limits and Overreach, Families USA (Aug. 2017), https://familiesusa.org/product/section-1115-waivers-limits-and-overreach.
- This budget neutrality requirement is not actually established via law or regulation, but is instead a traditional part of CMS's approach to 1115 waiver policy. See e.g., MaryBeth Musumeci et al., Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers, Kaiser Family Foundation, 2 (Mar. 2018).
- <sup>7</sup> See MaryBeth Musumeci et al., Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers, Kaiser Family Foundation, 10 (Mar. 2018).
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- See MaryBeth Musumeci et al., Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers, Kaiser Family Foundation, 1, 3, 5 (Mar. 2018).
- A few states have also used the Expenditure Authority under Section 1115(a)(2) to withhold NEMT benefits for certain demonstration programs. The Expenditure Authority allows the Secretary to authorize costs that would not otherwise be eligible for federal funding. 42 U.S.C.S. § 1315. Pursuant to this authority, some states have expanded health coverage and delivery system reforms while simultaneously denying NEMT benefits to these programs. See, e.g., Demonstration Approval, Oklahoma SoonerCare, Ctrs. For Medicare & Medicaid Srvcs., 9 (Aug. 31, 2018), available at https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ok/ok-soonercare-ca.pdf.
- See Letter to Seema Verma, Administrator, CMS, and Brian Neale, Director, Center for Medicaid and CHIP Services, from Thomas J. Betlach, Director, Arizona Health Care Cost Containment System (Nov. 17, 2017), available at https://www.azahcccs.gov/shared/Downloads/News/FlexibilitiesLetterFinal 11172017.pdf.
- Arizona also appears to have requested a one-year waiver of NEMT services for the Medicaid expansion population when seeking to extend its 1115 Waiver in 2015. See Arizona's Application for a New Section 1115 Demonstration, Arizona Health Care Cost Containment System, 35, 44 (Sept. 2015), available at https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/az/Health-Care-Cost-Containment-System/az-hccc-ext-app-10152015.pdf. However, CMS does not appear to have responded to or approved this request when approving the extension in September 2016. See AHCCS 1115 Demonstration Extension, Ctrs. for Medicare & Medicaid Srvcs. (Sept. 2016), available at https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/az/Health-Care-Cost-Containment-System/az-hccc-demo-ext-09302016.pdf.
- See Demonstration Approval, Healthy Indiana Plan, Ctrs. for Medicare & Medicaid Srvcs., 12 (Feb. 1, 2018), available at https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-ca.pdf.
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- See Efforts to Exclude Nonemergency Transportation Not Widespread, but Raise Issues for Expanded Coverage, U.S. Gov't

- Accountability Office, 7-8 (Jan. 2016) (noting that Indiana and Iowa waived NEMT benefits when expanding Medicaid coverage to certain populations prior to the Affordable Care Act).
- See, e.g., Letter from Seema Verma, CMS Administrator, and Tom Price, Health and Human Services Secretary, to State Governors (Mar. 14., 2017) (suggesting that states consider ways to create greater alignment between Medicaid benefit design and commercial insurance for non-disabled adults, including waivers of NEMT).
- As with the traditional Medicaid population, federal regulations require coverage of NEMT for individuals covered by Medicaid expansion. *See* 42 C.F.R. § 440.390.
- MaryBeth Musumeci & Robin Rudowitz, *Medicaid Non-Emergency Medical Transportation: Overview and Key Issues in Medicaid Expansion Waivers*, Kaiser Family Foundation, 3 (Feb. 2016).
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- <sup>25</sup> 42 C.F.R. § 440.315(f).
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- <sup>27</sup> Indiana HIP 2.0: Evaluation of Non-Emergency Medical Transportation (NEMT) Waiver, The Lewin Group, Inc., ES-3 (Nov. 2016), available at https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/in/Healthy-Indiana-Plan-2/in-healthy-indiana-plan-support-20-nemt-final-evl-rpt-11022016.pdf.
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- <sup>34</sup> 42 C.F.R. § 431.408(a)(1)(iv).
- <sup>35</sup> 42 C.F.R. § 431.408(a)(3).
- <sup>36</sup> 42 C.F.R. § 431.408(a)(3).
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- <sup>39</sup> 42 C.F.R. § 431.408(a)(2)(ii).
- <sup>40</sup> 42 C.F.R. § 431.408(a)(2)(iii) (emphasis added).
- <sup>41</sup> 42 C.F.R. § 431.412(a)(1)(viii), (c)(2)(vii).
- <sup>42</sup> 42 C.F.R. § 431.416(b)(1)(iv).
- <sup>43</sup> 42 C.F.R. § 431.416(d)(1), (d)(2).
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