

***Enactment of the Rare ACCESS Act [PFLUGE 186; timestamped July 12, 2024 @ 1:28 p.m.] would ensure Medicaid access for individuals who require disease management and care coordination from a multi-disciplinary team of medical specialists, including those located in another state.***

**Five-year demonstration project:** The bill requires the Centers for Medicare & Medicaid Services to establish a five-year demonstration project for fiscal years 2025 through 2029 to support cross-state access to multi-disciplinary care teams for Medicaid beneficiaries with complex and debilitating rare conditions.

- **Demonstration project general scope:** The demonstration project would test the impact on federal and state budgets and on patient access, outcomes, and burden of illness from: (1) a comprehensive uniform Medicaid telehealth benefit; and (2) payment to states of a quarterly separate furnishing fee to offset costs of making providers whole for furnishing certain items and services, including telehealth and drugs administration, to out-of-state Medicaid beneficiaries.
  - ***Rationale:***
    - **Telehealth:** Telehealth benefits in Medicaid vary widely across the states, so the demonstration project should test the value of a uniform, robust benefit. Although CMS encourages states “to facilitate clinically appropriate care within the Medicaid program using telehealth technology to deliver services covered by the state,” the states have full autonomy regarding the “types of services to cover; where in the state it can be utilized; how it is implemented; what types of practitioners or providers may deliver services via telehealth...and reimbursement rates.”<sup>1</sup> This demonstration project is an opportunity to determine whether Congress should model the Medicaid telehealth benefit on the Medicaid prescription drug benefit, which is an *optional benefit with minimum federal obligations* for participating states.
    - **Payment:** Health care providers who specialize in treating rare genetic disorders are discouraged from providing services to Medicaid beneficiaries who reside outside their state because of burdensome provider enrollment processes and potentially lower reimbursement rates. State Medicaid plans are required to pay providers in another state for items and services rendered to an enrollee temporarily absent from that state.<sup>2</sup> Of most relevance to medically complex children and others with rare, genetic conditions, the implementing regulations specify that this reimbursement must occur if the state “determines that the needed medical services...are

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<sup>1</sup> CMS, STATE MEDICAID & CHIP TELEHEALTH TOOLKIT: POLICY CONSIDERATIONS FOR STATES EXPANDING USE OF TELEHEALTH COVID-19 VERSION at 4, <https://www.medicaid.gov/medicaid/benefits/downloads/medicaid-chip-telehealth-toolkit.pdf>.

<sup>2</sup> See 42 U.S.C.S. § 1396a(a)(16) (LexisNexis 2024).

more readily available in the other state,” among other conditions.<sup>3</sup> Such out-of-state providers are subject to the payment rates of the state where the Medicaid enrollee resides. Importantly, states have “broad flexibility” in determining payment rates for out-of-state providers.<sup>4</sup> This demonstration project will examine the viability of a payment mechanism that would ensure states are not financially harmed by making out-of-state providers whole.

- **Demonstration project eligible patients:** This provision specifies that Medicaid beneficiaries eligible for the demonstration project are:
  1. under age 21 and diagnosed with one or more multi-system chronic conditions that reduces cognition or physical function, a life limiting illness, or a rare pediatric condition;
  2. under age 65, blind or disabled, and receiving supplemental security income; or
  3. those diagnosed with a rare metabolic disorder, blood disorder, bleeding disorder, or nervous system disorder but who do not meet the other definitions.
  - ***Rationale:*** By limiting the scope of the demonstration project to Medicaid beneficiaries who are the most disabled or who have the potential to become disabled without proper disease management, it would appropriately solve the problem by capturing the Medicaid beneficiaries most likely to require travel to out-of-state providers for therapeutic intervention and other services or rely on telehealth services for management by the full range of medical specialists.
  
- **Demonstration project participating states:** The bill would require CMS to select a minimum of 15 states to participate in the demonstration project and allow for states that are not selected to opt-in within the first year. Among the 15 CMS selected participating states, it must include at least two states that meet the definition of a “rural state” and at least eight states that have the highest concentration, as determined by CMS, of medical facilities for the treatment of rare disorders, including metabolic clinics, hemophilia treatment centers, and “centers of excellence” expressly recognized by disease specific patient advocacy and research organizations.
  - ***Rationale:*** A minimum of 15 states should provide a large enough sample size to test the promise of a uniform telehealth benefit and the potential of a quarterly furnishing fee as a solution to underpayment of out-of-state providers. Requiring participation of two rural states and eight states with the most medical experts for rare disorders will ensure the demonstration features some of the most relevant

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<sup>3</sup> See 42 C.F.R. § 431.52 (LexisNexis 2024).

<sup>4</sup> See MACPAC, ISSUE BRIEF: MEDICAID PAYMENT POLICY FOR OUT-OF-STATE HOSPITAL SERVICES at 1 (June 2020), <https://www.macpac.gov/wp-content/uploads/2020/01/Medicaid-Payment-Policy-for-Out-of-State-Hospital-Services.pdf> (emphasis added).

states for providers who typically treat patients who reside outside of their states. The opt-in provision will ensure interested states are not inadvertently excluded from the opportunity.

- **Demonstration project participating state medical licensure reciprocity:** The bill would require participating states to provide medical licensure reciprocity for “eligible telehealth providers” furnishing telehealth services covered under the demonstration project.
  - ***Rationale:*** Reciprocity for medical licensure as part of this demonstration project is necessary to allow out-of-state providers to practice medicine in the state of the patient through telehealth services. Generally, health care providers furnishing telehealth services “must abide by state licensure laws and state medical practice laws and requirements in the state where the patient is located.”<sup>5</sup> Although the recently established Interstate Medical Licensure Compact will simplify and expedite this process for providers seeking to practice across state lines, not all states participate.<sup>6</sup> Requiring reciprocity as one condition of participation will test a possible solution to another existing barrier for providing telehealth services to patients located in another state.
  
- **Demonstration project drug coverage restriction prohibition:** As a condition of eligibility for the quarterly furnishing fee under the demonstration project, a participating state shall not apply restrictive drug coverage policies, such as step therapy, to the physician administered drugs covered under such project unless the requirements or limitations are specified in the “Indications and Usage” section of the label of such drug.
  - ***Rationale:*** To best ensure that the implementation of a furnishing fee leads to patient access, it is necessary to condition eligibility for this fee to a prohibition against restricting or limiting payment for these physician-administered drugs in the project.
  
- **Demonstration project eligible drugs:** Drugs eligible for inclusion in the demonstration project are physician administered drugs (in both the outpatient and inpatient setting (if separately paid)) prescribed for a rare disease that is an approved use or an off-label use that is listed in specified compendia. In general, such drug must be more readily available for administration outside the state of the Medicaid beneficiary due to its complexity or the complexity of the rare disease or condition. If the drug is available within the state of the beneficiary, the out-of-state provider must be located a shorter distance from the primary residence of the Medicaid beneficiary than the in-state provider or is recognized by the

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<sup>5</sup> AM. MEDICAL ASS’N, LICENSURE & TELEHEALTH at 2, <https://www.ama-assn.org/system/files/issue-brief-licensure-telehealth.pdf>.

<sup>6</sup> See *id.* at 1.

patient advocacy and research organization representing the disease as having the necessary expertise to manage the condition.

- **Rationale:** Because rare diseases have limited numbers of centers of excellence and clinician experts throughout the country due to the complexity of the condition and low prevalence, it is common for rare disease patients to regularly travel long distances to receive infusions or to see the full team of specialists required to manage their condition.<sup>7</sup> For example, the Batten Disease Support and Research Association has identified Children’s Hospital Colorado in Aurora, CO, Children’s Hospital of Orange County in Orange, CA, Kennedy Krieger Institute in Baltimore, MD, Nationwide Children’s Hospital in Columbus, OH, and University of Rochester Batten Center in Rochester, NY as a Batten Disease Center of Excellence in the U.S.<sup>8</sup> Travel costs to centers of excellence and other clinician experts, such as those for Batten disease, as well as time away from school and work, are contributing significantly to the nearly \$1 trillion annual rare disease economic burden, according to a study commissioned by the EveryLife Foundation for Rare Diseases.<sup>9</sup> With respect to the CLN2 form of Batten disease, for example, it is also important to note that the sole FDA-approved therapy for is only available at a limited number of children’s hospitals in the U.S., so patients either must travel or permanently relocate for these bi-weekly enzyme replacement therapy infusions.<sup>10</sup> CLN2 and hundreds of other genetic disorders progress rapidly and are fatal without a therapeutic intervention, so creating a pathway through the demonstration project to help ensure therapy can be administered to Medicaid beneficiaries with these conditions is a necessity. This definition of an “eligible drug” captures the policy need and is aligned with existing CMS payment policy on when a state must pay for items and services rendered to a beneficiary outside their state.<sup>11</sup>

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<sup>7</sup> See, e.g., NAT’L ORG. FOR RARE DISORDERS (“NORD”), ENSURING ACCESS TO TELEHEALTH FOR RARE DISEASE (2020), <https://rarediseases.org/wp-content/uploads/2020/10/NRD-2098-RareInsights-Telehealth-Report.pdf> (describing the burden rare disease patients face in accessing their providers). According to the NORD survey, “[t]hirty-nine percent of patients travel at least 60 miles to receive medical care. The burden of travel is so great that 17 percent have moved (or are considering relocation) to be closer to treatment to manage their rare diseases over the long-term.” *Id.* at 4.

<sup>8</sup> See Batten Disease Support & Research Ass’n, Centers of Excellence, <https://bdsrafoundation.org/batten-disease-centers-of-excellence/>.

<sup>9</sup> See Grace Yang et al., *The National Economic Burden of Rare Disease in the United States in 2019*, 17 ORPHANET J. OF RARE DISEASES 163 (2022).

<sup>10</sup> Data on file with the author.

<sup>11</sup> See 42 C.F.R. § 431.52.

- **Demonstration project telehealth benefit:**
  - **Eligible telehealth providers:** The bill expressly includes as an “eligible telehealth provider” the full range of medical specialists who would likely be part of a multi-discipline care management team for most rare disorders, including those disorders treated at disease specific clinics or centers of excellence: physicians, psychologists, neuropsychologists, genetic counselors, social workers, nurse practitioners, case managers, dietitians, behavior therapists, speech therapists, audiologists, physical therapists, occupational therapists, or any other providers determined by CMS. Such providers are required to have a full unrestricted license in their primary jurisdiction without a documented history of drug and alcohol abuse, criminal behavior, or non-compliance with CME.
    - ***Rationale:*** Access to multidiscipline care teams through telehealth has led to better patient outcomes by alleviating geographic and capacity barriers at metabolic clinics.<sup>12</sup> PKU and Hunter syndrome are examples of rare metabolic disorders that require such disease management. A physician, dietitian, genetic counselor, social worker, case manager, behavioral therapist, and a psychologist or neuropsychologist comprise the team that manages PKU,<sup>13</sup> while Hunter syndrome patients generally interface with a physician, audiologist, speech therapist, physical therapist, occupational therapist, and behavioral therapist.<sup>14</sup> According to published peer-reviewed medical literature, more than 50 percent of adults diagnosed with PKU, however, are *not* receiving appropriate long-term care.<sup>15</sup> Among the reasons identified for these patients becoming “lost to follow-up” is the lack of *adult* PKU clinics and overall poor foundation to facilitate the transition of pediatric patients to adult care.<sup>16</sup> The need for a seamless transition to adult

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<sup>12</sup> See, e.g., Tanyel Zubarioglu et al, *The Impact of Telemedicine for Monitoring and Treatment of Phenylketonuria Patients on Metabolic Outcome During Coronavirus Disease-19 Outbreak*, 28 TELEMEDICINE AND E-HEALTH 123, 258 (Feb. 2022) (illustrating the success of telehealth for approximately 100 PKU patients during the COVID-19 pandemic as evidenced by better phenylalanine control), <https://www.liebertpub.com/doi/epdf/10.1089/tmj.2020.0569>.

<sup>13</sup> See Janet Thomas, MD et al., *Strategies for Successful Long-Term Engagement of Adults with Phenylalanine Hydroxylase Deficiency Returning to the Clinic*, 5 J. OF INBORN ERRORS OF METABOLISM & SCREENING 1, 2 (Sept. 2017).

<sup>14</sup> See Joseph Muenzer et al, *Multidisciplinary Management of Hunter Syndrome*, 124(6) PEDIATRICS e1228 (2009).

<sup>15</sup> *Id.*

<sup>16</sup> See Jennifer Beazer et al., *Strategies to Engage Lost to Follow-Up Patients with Phenylketonuria in the United States: Best Practice Recommendations*, 23 MOLECULAR GENETICS & METABOLISM REPORTS 2 (June 2020) (pointing to the “unavailability of adult PKU clinics”.) (emphasis added); Barbara Burton et al., *Management of Adolescents and*

care is emerging as an issue for other rare metabolic disorders like Hunter syndrome with such individuals now surviving *beyond the age of 20* due to advances in diagnostics, disease management, and therapeutic interventions.<sup>17</sup> Notwithstanding this need to transition such patients from multidisciplinary teams of pediatric experts to those teams that specialize in adults with rare metabolic disorders “in order to minimize negative health effects and to sustain patients' quality of life,”<sup>18</sup> many metabolic clinics are not equipped to manage the influx of adult patients.<sup>19</sup> Telehealth is not only a recommended but also a proven strategy for overcoming such barriers, which will lead to optimal long-term disease management in patients with rare metabolic disorders like PKU.<sup>20</sup> A recent study revealed that telehealth visits with the team of specialists resulted in better phenylalanine control for PKU patients and recommended that it be used for monitoring and follow-up.<sup>21</sup> Including this variety of specialists in this demonstration project will assess the impact of a robust telehealth benefit on disease management of complex conditions.

- **Eligible telehealth services:** The bill would define an eligible telehealth service as an audio and video encounter with a health care provider located at a distant site for the purpose of:
  1. diagnosis, treatment, or care management;
  2. peer-to-peer consult (including such consults commencing following the transmission of patient’s medical information, such as an electronic health

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*Young Adults with Phenylketonuria: Development of International Best Practice Recommendations Using a Modified Delphi Approach*, 137 MOLECULAR GENETICS & METABOLISM 114, 115 (July 2022).

<sup>17</sup> See Karolina M. Stepien et al., *Challenges in Transition From Childhood to Adulthood Care in Rare Metabolic Diseases: Results From the First Multi-Center European Survey*, FRONTIERS IN MEDICINE (Feb. 2021) (emphasis added).

<sup>18</sup> *Id.*

<sup>19</sup> See Cynthia Freehauf et al., *Impact of Geographic Access to Care on Compliance and Metabolic Control in Phenylketonuria*, 108 MOLECULAR GENETICS & METABOLISM 13, (2013) (describing the limited number of metabolic clinics, especially in rural areas); Burton, *supra*, note 83 (underscoring that the success of transition to adult care depends on the capacity of the metabolic clinic).

<sup>20</sup> See Burton, *supra*, note 16, at 121 (discussing the improved disease management of PKU patients due to the use of telehealth during the COVID-19 pandemic); Zubarioglu, *supra* note 79, at 264-265 (recommending, based on its success during the COVID-19 pandemic, continued use of telehealth services for successful management of PKU patients); Beazer, *supra* note 16, at 4 (suggesting that clinics embrace telehealth to reach PKU patients who are lost to follow-up).

<sup>21</sup> See Zubarioglu, *supra* note 12, at 259-260 (detailing that PKU patients would draw a blood sample at home to measure phenylalanine levels, transport it to the lab for analysis, and submit journal details of diet, weight, and any therapeutic intervention electronically, after which the distant provider would meet with patient and assess the data, modifying diet and medicine as necessary).

- record, diagnostic image, or provider report, from an originating site to a distant site without the presence of the patient at either site);
3. patient education, including REMS required education for prescription drug use; and
  4. patient monitoring, including any monitoring required following the administration of a gene therapy.
- **Rationale:** Coordinated care through telehealth is an opportunity to improve quality of life for the affected individuals and their families. For example, peer-to-peer telehealth consults are necessary for efficient care coordination in multi-system rare disorders like cystinosis and Friedreich’s ataxia.<sup>22</sup> On one hand, Colorado offers a generous telehealth benefit that provides payment for all providers in a peer-to-peer telehealth consult, and pays for services furnished by speech therapists, physical therapists, occupational therapists, and behavioral therapists.<sup>23</sup> In contrast, Washington is more restrictive, seemingly only paying for peer-to-peer consults in the event the patient is located with one of the providers during such a consult.<sup>24</sup> Telehealth can also reduce the burden on patients and caregivers in complying with requisite monitoring following the administration of a gene therapy.<sup>25</sup> Patients who receive gene therapy are generally obligated to undergo multi-year post-administration monitoring to allow physicians to not only evaluate its efficacy and durability, but also observe and mitigate any adverse events.<sup>26</sup> For example, gene therapy for hemophilia A and B is expected to be part of a hub and spoke treatment model in which gene therapy would be administered at a “regional hub” hemophilia treatment center (HTC) with post-administration monitoring

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<sup>22</sup> See Rupesh Raina et al., *Structured Transition Protocol for Children with Cystinosis*, 5 FRONTIERS IN PEDIATRICS (2017); Louise A Corben et al., *Consensus Clinical Management Guidelines for Friedreich Ataxia*, 9 ORPHANET J. OF RARE DISEASE 184 (2014).

<sup>23</sup>See *Telemedicine - Provider Information*, COLORADO DEP’T OF HEALTH CARE POLICY & FINANCING, <https://hcpf.colorado.gov/provider-telemedicine>.

<sup>24</sup> See WASH. APPLE HEALTH (MEDICAID), WASH STATE HEALTH CARE AUTH., PHYSICIAN-RELATED SERVICES/HEALTH CARE PROFESSIONAL SERVICES (Aug. 2022), <https://www.hca.wa.gov/assets/billers-and-providers/Physician-related-services-guide-20220801.pdf>.

<sup>25</sup> See Anita Nosratieh and Rachel Tunis, FasterCures, *Cures for Life: Long-Term Follow-Up Data Collection for Cell and Gene Therapies* at 12 (2020), [https://milkeninstitute.org/sites/default/files/reports-pdf/cures-for-life-7-15-20\\_0.pdf](https://milkeninstitute.org/sites/default/files/reports-pdf/cures-for-life-7-15-20_0.pdf).

<sup>26</sup> See FDA, LONG TERM FOLLOW-UP AFTER ADMINISTRATION OF HUMAN GENE THERAPY PRODUCTS: GUIDANCE FOR INDUSTRY at 26-27 (2020), <https://www.fda.gov/media/113768/download>.

occurring at the patient’s local HTC.<sup>27</sup> Leveraging telehealth within this care model will foster active patient engagement for data collection and facilitate peer-to-peer consults necessary for optimal patient management. This is especially critical considering by 2030, FDA is likely to approve 30 gene therapies for rare genetic disorders.<sup>28</sup>

- **Demonstration project payment from participating states to providers:** In the case of an out-of-state Medicaid beneficiary receiving telehealth services at any location, a physician administered drug, or a service that is consistent with the standard of care and furnished on the same day and at the same site of service as the drug administration, the bill would require participating states to pay no less than the payment rate of the provider’s state for such items and services (including, in the case of telehealth, both providers in a peer-to-peer consult and an originating site fee).
  - ***Rationale:*** Paying no less than the reimbursement rates that the out-of-state Medicaid provider would be entitled to under its state plan for drugs and their administration as well as telehealth services will remove a significant barrier to providers treating Medicaid beneficiaries who reside in other states. According to MACPAC, as of November 2018, a significant majority of states paid less to out-of-state providers than to in-state providers for both inpatient and outpatient hospital services.<sup>29</sup> Lower payment rates force out-of-state providers to bill the Medicaid beneficiary or absorb the costs as uncompensated care, which is unsustainable in the long run, especially as more therapeutic interventions are approved for conditions that currently lack an FDA-approved therapy.
- **Demonstration project CMS quarterly furnishing fee to participating states:** Under certain conditions, CMS shall provide a quarterly furnishing fee payment to offset any excess payments made by the state to out-of-state providers for items and services furnished under the demonstration project.
  - ***Rationale:*** A quarterly furnishing fee to reimburse states for making providers whole for furnishing telehealth and physician administered drugs to patients

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<sup>27</sup> See, e.g., Steven Pipe et al., *Gene Therapy: Practical Aspects of Implementation*, 28(Suppl 4) HAEMOPHILIA 44, 47 (2022); Wolfgang Miesbach et al., *Delivery of AAV-Based Gene Therapy Through Haemophilia Centres—A Need for Re-evaluation of Infrastructure and Comprehensive Care: A Joint Publication of EAHAD and EHC*, 27 HAEMOPHILIA 967, 970 (2021).

<sup>28</sup> See MASS. INST. OF TECH., NEW DRUG DEVELOPMENT PARADIGMS INITIATIVE, UPDATE PROJECTION OF US DURABLE CELL AND GENE THERAPIES PRODUCT-INDICATION APPROVALS BASED ON DECEMBER 2019 DEVELOPMENT PIPELINE 3 (table 2) (2020), <https://newdigs.tuftsmedicalcenter.org/wp-content/uploads/2022/06/NEWDIGS-Research-Brief-2020F207v51-PipelineAnalysis.pdf>.

<sup>29</sup> See MACPAC, *supra* note 4, at 1.



requiring specialists outside their state for such services is worth testing through the demonstration project as a potential solution to this impediment for patient access to out-of-state providers in Medicaid.

- **Demonstration project payment rate stabilization:** As a condition of eligibility for the quarterly furnishing fee under the demonstration project, following selection by CMS as a participating state or election to become a participating state, such state shall not lower their payment rates for the items and services included in the project and if such state has lowered such rates in the 12 months prior to selection or election, the payment rate on which the furnishing fee is based shall not be lower than the Medicaid national three-year average for such items and services.
  - **Rationale:** A moratorium on state payment rate reductions on the items and services included in the demonstration project is essential to prevent states from inappropriately shifting expenditures to the federal government.

**Streamlined Medicaid Provider Enrollment:** The bill requires a state plan to immediately recognize an out-of-state provider furnishing in-person or telehealth services as a participating provider in their state upon a simple attestation through a new national web-based portal of possessing medical expertise in the patient’s disease and the medical necessity of the service following the submission of a diagnosis code or description of symptoms.

- **Rationale:** Streamlined enrollment as an out-of-state Medicaid provider would alleviate significant provider burden and improve patient outcomes. An out-of-state provider is required to enroll as a participating provider in the Medicaid program in the state of the beneficiary receiving the service to receive payment.<sup>30</sup> Because rare diseases have limited numbers of centers of excellence and clinician experts throughout the country, it is common for rare disease patients to regularly travel long distances to receive infusions or to see the full team of specialists required to manage their condition.<sup>31</sup> Such patients are also increasingly using telehealth to see these specialists.<sup>32</sup> Notwithstanding CMS guidance that encourages automatic reciprocity by allowing state Medicaid plans to “rely on the results of screening performed by Medicare contractors, other State Medicaid agencies or other CHIP

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<sup>30</sup> See 42 U.S.C.S. § 1396a(kk)(7)(A) (LexisNexis 2024) (codified at 42 C.F.R. § 455.410 (LexisNexis 2024)).

<sup>31</sup> See, e.g., *NORD, supra note 7*, at 3 (describing the burden rare disease patients face in accessing their providers).

<sup>32</sup> See, e.g., Jessica F. Scherr et al, *Utilizing Telehealth to Create a Clinical Model of Care for Patients with Batten Disease and Other Rare Diseases*, 2 THERAPEUTIC ADVANCES IN RARE DISEASES (Aug. 2021) (promoting the ability for telehealth to not only enhance and expand service delivery between a Batten disease patient and their physician at a center of excellence, but also improve peer-to-peer collaboration between physicians treating the rare disorder).

programs,”<sup>33</sup> most states require their own, often duplicative or more burdensome process.<sup>34</sup> For example, physicians at Boston Children’s Hospital have provided several examples of absurd enrollment processes required by other states to treat their Medicaid patients, which has had a direct negative impact on patient care.<sup>35</sup> California, however, *does not* require separate screening for out-of-state providers and has established an *express* enrollment process for such providers.<sup>36</sup> A national web-based Medicaid provider enrollment portal with a uniform, streamlined submission process will remove a growing barrier to Medicaid patient access.

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<sup>33</sup> See Center for Medicaid and CHIP Services, CMCS Informational Bulletin: Medicaid/CHIP Provider Screening and Enrollment (Dec. 23, 2011).

<sup>34</sup> See HIGHMARK, MEDICAID PROVIDER ENROLLMENT REQUIREMENTS BY STATE (Jan. 26, 2021), <https://content.highmarkprc.com/Files/InterPlanProg/bc-medicaid-prov-enroll-requirements.pdf>.

<sup>35</sup> See Nick Manetto et al., *Medicaid’s Unnecessary Barriers Delay Care for Children with Complex Needs*, STAT NEWS (May 1, 2018), <https://www.statnews.com/2018/05/01/medicaid-barriers-delay-care-children-complex-needs/>.

<sup>36</sup> See, e.g., MACPAC, *supra* note 4, at 4 (emphasis added).