



Elizabeth G. Taylor
Executive Director

Board of Directors

Ann Kappler
Chair
Prudential Financial, Inc.

William B. Schultz
Vice Chair
Zuckerman Spaeder LLP

Miriam Hartz
Secretary
Florida Health Justice Project

Nick Smirensky, CFA
Treasurer
New York State Health Foundation

L.D. Britt, MD, MPH
Eastern Virginia Medical School

Ian Heath Gershengorn
Jenner & Block

John R. Hellow
Hooper, Lundy & Bookman, PC (Ret.)

Michele Johnson
Tennessee Justice Center

Arian M. June
Debevoise & Plimpton LLP

Jane Preyer
Environmental Defense Fund (Ret.)

Lourdes A. Rivera
Center for Reproductive Rights

Shamina Sneed
Heitman LLC

Donald B. Verrilli, Jr.
Munger, Tolles & Olson

Ronald L. Wisor, Jr.
Hogan Lovells

Senior Advisor to the Board
Rep. Henry A. Waxman
Waxman Strategies

General Counsel
Marc Fleischaker
Arent Fox, LLP

October 20, 2021

The Honorable Xavier Becerra, Secretary
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Ave., S.W.
Washington, D.C. 20201

Re: Utah Primary Care Network Extension Request

Dear Secretary Becerra:

The National Health Law Program (NHeLP) is a public interest law firm working to advance access to quality health care and protect the legal rights of low-income and underserved people. We appreciate the opportunity to comment on Utah's request to extend the Primary Care Network project.

As Utah's application indicates, the Primary Care Network project started nearly 20 years ago as a way to expand coverage to population groups that were not described in the Medicaid Act at that time. That initial purpose has been lost. Currently, the project is a hodgepodge of features, many of which restrict coverage and access to care. For example, CMS has given Utah permission to only cover dental services for certain categories of beneficiaries and to provide a reduced package of benefits to adults who have children. These and other harmful features, described in more detail below, neither promote the objectives of the Medicaid Act nor serve a valid experimental purpose.

As a result, we recommend that CMS take the following steps in response to Utah's application: Where possible, CMS should require Utah to implement elements of the project through other

authorities (the state plan or non-demonstration waiver authorities). CMS should then evaluate the remaining elements of the project in accordance with section 1115.

HHS Authority Under Section 1115

For the Secretary to approve a project pursuant to section 1115, the project must:

- be an “experimental, pilot or demonstration” project;
- be likely to promote the objectives of the Medicaid Act;
- waive compliance only with requirements in 42 U.S.C. § 1396a; and
- be approved only to the extent and for the period necessary to carry out the experiment.

Discussing each of these limitations a bit further:

First, the state must propose to conduct an “experimental, pilot, or demonstration” project. This demands a “novel approach” to program administration.¹ To evaluate whether a proposed project is a valid experiment, the Secretary needs to know what will be tested and how, at the point in time when the project is being approved.

Second, the project must promote the Medicaid Act’s objectives. According to Congress, the purpose of Medicaid is to enable states “to furnish[] medical assistance” to individuals “whose income and resources are insufficient to meet the costs of necessary medical services” and to provide “rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care.”² Thus, the “central objective” of the Medicaid Act is “to provide medical assistance,” that is to provide health coverage.³

Third, the Secretary can only waive provisions set forth in section 1396a of the Medicaid Act. The Secretary cannot waive requirements contained in sections 1396b through 1396w-5.⁴ Once the Secretary has acted under section 1115(a)(1) to waive compliance with designated

¹ *Beno v. Shalala*, 30 F.3d 1057, 1069 (9th Cir. 1994).

² 42 U.S.C. § 1396-1; 1396d(a) (defining “medical assistance” as provision of, or payment for, specified health care and services).

³ *Stewart v. Azar*, 366 F. Supp. 3d 125, 138 (D.D.C. 2019); *id.* at 144 (rejecting “promoting health” as an independent objective because the Medicaid Act is “designed ... to address not health generally but the provision of care to needy populations” through a health insurance program).

⁴ See 42 U.S.C. § 1315(a)(1).



provisions in section 1396a, section 1115(a)(2) provides that the costs of “such project” are “regarded as expenditures under the State plan” and, thus, paid for under the same statutory formula that applies for a state’s expenditures under its state plan.⁵ Section 1115(a)(2) does not create an independent “expenditure authority” for the Secretary to allow a state to ignore provisions of the Medicaid Act outside of section 1396a or to rewrite the provisions in section 1396a or any other provision outside of section 1396a. To the contrary, it is a “clean-up” provision that merely provides the authorization necessary for federal reimbursement of expenditures for a project that has been approved under section 1115(a)(1).

Fourth, section 1115 allows approvals only “to the extent and for the period . . . necessary” to carry out the experiment.⁶ The Secretary cannot use section 1115 to permit states to make long-term policy changes.

As noted above, several features of Utah’s proposed project exceed one or more of these limitations and harm Medicaid beneficiaries.

Imposing Work Requirements

The initial application posted for comment included a work requirement for individuals in the expansion population, noting that Utah currently has approval for a “community engagement requirement” and asking for “continued approval of this requirement” with no changes. That was incorrect. On August 10, 2021, CMS withdrew its approval of the Utah work requirements, finding that they are not likely to promote the objectives of the Medicaid Act.⁷ On October 19, 2021, we became aware of a change in the application. Although the date of the application

⁵ *Id.* § 1315(a)(2).

⁶ *Id.* § 1315(a); *see also id.* §§ 1315(e)(2), (f)(6) (limiting the extension of “state-wide, comprehensive demonstration projects” to one initial extension of up to 3 years (5 years, for a waiver involving Medicare-Medicaid eligible individuals) and one subsequent extension not to exceed to 3 years (5 years, for Medicare-Medicaid waivers). In 2017, a CMS Informational Bulletin announced the intent “[w]here possible, . . . [to] approve the extension of *routine, successful, non-complex*” section 1115(a) waivers for a period up to 10 years. Ctr. for Medicaid & CHIP Servs., CMS, CMCS Informational Bulletin 3 (Nov. 6, 2017) (emphasis added). The Bulletin should be disregarded because it conflicts with, among other things, section 1115’s limitation of approvals to experimental, pilot, or demonstration projects (not for “routine” projects) and only for the period necessary to carry out the experiment (not to maintain a successful experiment as an ongoing policy).

⁷ Letter from Chiquita Brooks-LaSure, Admin., Ctrs. for Medicare & Medicaid Servs., to Emma Chacon, Interim Dir., Div. of Medicaid & Health Fin., Utah Dep’t of Health (Aug. 10, 2021), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ut-primary-care-network-state-ltr-08102021.pdf> (discussing the existing research on work requirements and noting the impact of the COVID pandemic).



submission remains the same, the proposal now states: “the State is not requesting a renewal of this [work] requirement.”⁸ Thus, at the time of this comment submission, Utah has withdrawn its request to impose a work requirement. As a result, we will not be submitting comments summarizing the extensive evidence establishing that work requirements are harmful and reduce Medicaid coverage. However, if during the review of this request, CMS or the State should seek to impose a work requirement, we believe that would be a substantive change requiring an additional public notice and comment period.

Reducing Benefits for Parents

Utah proposes to continue providing a reduced benefits package to individuals who are in the (1) parent/caretaker population; or (2) expansion population and happen to have dependent children. Eliminating coverage of critical benefits for parents is completely arbitrary and is contrary to the objectives of the Medicaid program. There is nothing experimental about it.⁹ In its application, Utah concedes that the reduced benefits package is not experimental, explaining that the only reason for it is to enable the State to achieve budget neutrality.¹⁰ The interim evaluation further confirms that the State is not conducting an experiment, as the evaluation does not examine the effects of the reduced benefits package on enrollees.¹¹

Eliminating NEMT

One of the benefits that Utah seeks to continue to withhold from parents is non-emergency medical transportation (NEMT).¹² Aside from the fact that the application is not altogether clear about which populations are affected by this waiver, the Medicaid Act now requires states to

⁸ Utah Dep’t of Health, Utah 1115 Demonstration Waiver Renewal Request 2022-2027, at 18 (2021), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ut-primary-care-network-pa15.pdf> [hereinafter “Application”].

⁹ See *Beno v. Shalala*, 30 F.3d 1057, 1069 (9th Cir. 1994) (finding that a “simple benefits cut, which might save money, but has no research or experimental goal, would not satisfy” the experimental requirement in section 1115).

¹⁰ Application at Attachment 6.

¹¹ See Application at Attachment 1. The interim evaluation purports to test the hypothesis that the decline in benefits and increase in cost-sharing for the “current eligibles” population will not adversely affect the health of those enrollees by focusing on changes in rates of hypertension diagnosis and use of prescription medications. *Id.* at 15, 32-36. But the hypothesis is untethered from the benefits Utah proposes to withhold. That data has no bearing on the question of how eliminating coverage of the services described in Table 2 of the application impacts the health of current eligibles, as those services are not related to receiving a hypertension diagnosis or use of prescription drugs.

¹² Application at 15.



cover necessary NEMT for all Medicaid enrollees to and from Medicaid services.¹³ Specifically, in 2020, Congress amended the Medicaid Act to make coverage of transportation services explicit.¹⁴ Congress amended 42 U.S.C. § 1396u-7(a)(1)(F) – a provision outside of section 1396a – to require states to ensure that individuals enrolled in alternative benefit plans receive NEMT services.¹⁵ With these changes, Congress expressed its clear intent that states cover NEMT, including for the expansion population.

What is more, eliminating NEMT is a simple benefits cut with no experimental or demonstration purpose. It also runs counter to the objectives of the Medicaid Act, as it will reduce access to medically necessary services for adults with dependent children.

We have been working with state Medicaid advocates and directly with Medicaid beneficiaries for five decades. In our experience, NEMT is essential Medicaid coverage. Many people who live in poverty simply do not have the means to access medically necessary services on their own. Access to private vehicles is lower and transportation barriers are higher among lower-income populations, and Medicaid beneficiaries in particular.¹⁶ Public transportation (if available) is often too expensive, too limited, and/or too infrequent to use. Friends or family may be unable or unwilling to take off work to drive an enrollee to an appointment. In addition, domestic violence survivors or young adults may need confidential access to a provider and depend on NEMT to help get them to the appointment. In one study, more than 7% of Medicaid beneficiaries reported that transportation was a primary barrier to accessing timely

¹³ See 42 U.S.C. § 1396a(a)(4); 42 C.F.R. § 431.53.

¹⁴ See Consolidated Appropriations Act, 2021, Pub. L. No. 116-260, § 209(a) (2020) (amending 42 U.S.C. §§ 1396a(a)(4), 1396b(i)).

¹⁵ See 42 U.S.C. § 1396u-7(a)(1)(F) (“...a State may not provide medical assistance through [an alternative benefit plan] unless . . . the benchmark benefit package or benchmark equivalent coverage (or the State) (i) ensures necessary transportation for individuals enrolled under such package or coverage to and from providers; and (ii) provides a description of the methods that will be used to ensure such transportation.”)

¹⁶ Samina T. Syed et al., *Traveling Towards Disease: Transportation Barriers to Health Care Access*, 38 J. COMMUNITY HEALTH 976, 989 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4265215/>; Sarah Rosenbaum et al., George Washington Univ. School of Pub. Health & Health Servs., *Medicaid’s Medical Transportation Assurance: Origins, Evolution, Current Trends, and Implications for Health Reform* (2009), https://hsrc.himmelfarb.gwu.edu/sphhs_policy_briefs/34/. See also Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Evaluation of the Iowa Health and Wellness Plan: Member Experiences in the First Year*, 27 (April 2015), http://ppc.uiowa.edu/sites/default/files/ihawp_survey_interactive.pdf (Fig. 3.18 shows lower income Medicaid expansion beneficiaries are more than twice as likely to require transportation help and three times as likely to have an unmet transportation need).



primary care. In contrast, less than 1% of privately insured individuals reported the same problem.¹⁷

Data from Kentucky confirm that Medicaid enrollees rely on NEMT to access health care appointments. From June 2014 to June 2015, individuals in the Kentucky expansion population used over 140,000 NEMT trips.¹⁸ Similarly, data from Indiana and Iowa, which received permission to eliminate NEMT for the expansion population, further demonstrate that many enrollees cannot access care without NEMT.¹⁹ It must be noted that Iowa's and Indiana's evaluations were deeply flawed, principally because they: (1) used inappropriate and dissimilar comparison groups; and (2) had poor survey response rates (in Indiana) and potential response bias. However, even with these limitations, Iowa's evaluation shows that a significant subset (13%) of Medicaid expansion adults reported an unmet health care need due to lack of adequate transportation.²⁰ The percentage was higher (15%) among enrollees with income below 100% of FPL.²¹ Roughly one-quarter of all Iowa Medicaid enrollees worried some or a lot about the cost of transportation to providers, and again, enrollees with lower incomes reported significantly more concerns.²² Indiana's most recent evaluation likewise shows that lack of transportation caused enrollees in the expansion population to forgo medically necessary care.²³

Notably, data from Iowa also indicate that women, people of color, and younger people are significantly more likely to report a transportation barrier.²⁴ In addition, people in relatively

¹⁷ Paul T. Cheung et al., *National Study of Barriers to Timely Primary Care and Emergency Department Utilization Among Medicaid Beneficiaries*, 60 ANNALS EMERGENCY MED. 4e2 (July 2012), [http://www.annemergmed.com/article/S0196-0644\(12\)00125-4/fulltext](http://www.annemergmed.com/article/S0196-0644(12)00125-4/fulltext).

¹⁸ Commonwealth of Kentucky, *Kentucky HEALTH: Helping to Engage and Achieve Long Term Health*, 45 (2016), <https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ky/ky-health-pa.pdf>.

¹⁹ See Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Evaluation of the Iowa Health and Wellness Plan: Member Experiences in the First Year*, 27 (April 2015), http://ppc.uiowa.edu/sites/default/files/ihawp_survey_interactive.pdf.

²⁰ *Id.*

²¹ *Id.*

²² *Id.*

²³ The Lewin Group, *Indiana HIP 2.0: Evaluation of Non-Emergency Medical Transportation (NEMT) Waiver* (Nov. 2016), <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> (finding that among enrollees who scheduled and missed an appointment and did not have NEMT, 80% reported lack of transportation as one of the reasons for missing their appointment, and 20% reported lack of transportation as the sole reason for missing their appointment).

²⁴ Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan*, 26 (Mar. 2016), <https://ppc.uiowa.edu/publications/non-emergency-medical->



poorer health (58% higher odds), with multiple physical ailments (63%), or who have any functional deficit (245%) were all much more likely to report unmet transportation needs.²⁵ Eliminating NEMT for adults with dependent children will disproportionately harm these populations, likely exacerbating existing health care disparities.

Significantly, evaluators in Indiana and Iowa found ongoing unmet transportation needs among enrollees that on paper had access to NEMT. The persistence of those unmet needs suggests an ineffective or poorly publicized NEMT benefit in those states. In fact, Indiana's most recent survey revealed that the overwhelming majority of Medicaid enrollees did not know if they had access to NEMT services or incorrectly identified whether or not their plan provided NEMT.²⁶ Iowa's evaluators did call for further research to understand "the causes of unmet NEMT need, how to better promote access to NEMT, and how barriers to transportation affect access to needed health care services."²⁷ However, Utah is not proposing to investigate these legitimate research questions. Rather, it is simply seeking to extend the elimination of NEMT without any explanation.

Not surprisingly, research demonstrates that effective NEMT services improve access to health care. For example, research shows that transportation barriers can reduce adherence to medications.²⁸ Studies also indicate that individuals with common chronic conditions like asthma or diabetes are more likely to complete the recommended care management visits when they have access to effective NEMT.²⁹ Better adherence to medications and care

[transportation-and-iowa-health-and-wellness-plan](#) (finding that women were 24% more likely to report an unmet transportation need, and Black enrollees had 83% higher odds of reporting a transportation barrier). See also Alina Salganicoff et al., Kaiser Family Found., *Women and Health Care in the Early Years of the Affordable Care Act: Key Findings from the 2013 Kaiser Women's Health Survey* (2014), <https://www.kff.org/womens-health-policy/report/women-and-health-care-in-the-early-years-of-the-aca-key-findings-from-the-2013-kaiser-womens-health-survey/> (finding that prior to Medicaid expansion, nearly one in five low-income women nationwide (18%) cited transportation problems as a reason for forgoing medical care).

²⁵ Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan*, 26 (Mar. 2016), <https://ppc.uiowa.edu/publications/non-emergency-medical-transportation-and-iowa-health-and-wellness-plan>.

²⁶ The Lewin Group, *Indiana HIP 2.0: Evaluation of Non-Emergency Medical Transportation (NEMT) Waiver*, 28-31 (Nov. 2016).

²⁷ Suzanne Bentler et al., Univ. of Iowa Pub. Policy Ctr., *Report in Brief: Non-Emergency Medical Transportation and the Iowa Health and Wellness Plan*, 1 (Aug. 2016), http://ppc.uiowa.edu/sites/default/files/nemt_brief.pdf.

²⁸ Timothy E. Welty et al., *Effect of Limited Transportation on Medication Adherence in Patients with Epilepsy*, 50 J. AM. PHARM. ASSOC. 698 (2010) (attached); Ramzi G. Salloum et al., *Factors Associated with Adherence to Chemotherapy Guidelines in Patients with Non-small Cell Lung Cancer*, 75 LUNG CANCER 255 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3210900/>.

²⁹ See, e.g., Jinkyung Kim et al., *Transportation Brokerage Services and Medicaid Beneficiaries' Access to Care*, 44 HEALTH SERVS. RES. 145 (2009), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2669622/>; Leela V. Thomas &



management visits can improve control of chronic conditions, reducing costly hospitalizations or emergency department visits. In fact, research shows that NEMT is cost effective for states.³⁰

In sum, there is simply no basis to conclude that eliminating NEMT for adults with dependent children in Utah will yield any useful information or promote the objectives of the Medicaid program. Instead, it will only reduce access to medically necessary care. To achieve its stated goal of improving participant health, Utah should be exploring innovative methods of providing NEMT, not proposing to eliminate the benefit.³¹

Eliminating EPSDT

Utah is seeking permission to continue its waiver of EPSDT services for individuals ages 19 and 20 who are in the parent/caretaker eligibility group. Since adding EPSDT to the Medicaid Act in 1967, Congress has amended the EPSDT provisions on numerous occasions, each time adding more detail as to how it expects EPSDT to be covered by the states and consistently requiring EPSDT coverage for all individuals under age 21. Most recently, in 2010 Congress provided that coverage for the expansion population would consist of the coverage listed in 42 U.S.C. § 1396u-7. Notably, 42 U.S.C. § 1396u-7(a)(1)(A)(ii) – a provision outside of section 1396a – requires this coverage to consist of EPSDT for individuals under the age of 21. Because Congress placed the EPSDT coverage requirement outside of 1396a and also repeatedly made its intent with respect to EPSDT coverage abundantly clear, the Secretary does not have the authority to waive the requirement.

Kenneth R. Wedel, *Nonemergency Medical Transportation and Health Care Visits among Chronically Ill Urban and Rural Medicaid Beneficiaries*, 29 SOC. WORK IN PUB. HEALTH 629 (2014) (attached); P. Hughes-Cromwick et al., Transportation Research Board, *Cost Benefit Analysis of Providing Non-Emergency Medical Transportation* (Oct. 2005), https://altarum.org/sites/default/files/uploaded-publication-files/05_project_report_hsd_cost_benefit_analysis.pdf [hereinafter P. Hughes-Cromwick et al.].

³⁰ P. Hughes-Cromwick et al.; J. Joseph Cronin, Jr., et al., Florida State Univ., *Florida Transportation Disadvantaged Programs Return on Investment Study* (2008); Medical Transportation Access Coalition, *Non-Emergency Medical Transportation: Findings from a Return on Investment Study* (2018), <https://mtacoalition.org/wp-content/uploads/2018/07/NEMT-ROI-Methodology-Paper.pdf>; The Stephen Group, *Recommendations to the Ark. Health Reform Task Force* (2015), <https://www.stephengroupinc.com/images/engagements/Final-Report-Volume-II.pdf>.

³¹ See, e.g., Nat'l Org. of State Offices of Rural Health and Ass'n of State & Territorial Health Officials, *Social Determinants of Health: A Quick Reference Guide for State Offices of Rural Health and State and Territorial Health Officials* (2017), <https://astho.org/Clinical-to-Community-Connections/Cross-Sector-Partnerships-to-Address-Social-Determinants-of-Health/SDH-Quick-Reference-Guide/> (recognizing transportation as a critical social determinant of health for individuals living in rural areas).



In addition, eliminating EPSDT is inconsistent with the objectives of the Medicaid Act. As noted above, Congress has included EPSDT in the Medicaid Act as a detailed, comprehensive program to cover preventive and treatment services for individuals under age 21. EPSDT entitles these individuals to receive comprehensive screening services, as well as any of the services listed in the Medicaid Act when necessary to “correct or ameliorate” illnesses and conditions discovered during a screening.³² Since 1967, Congress has targeted the EPSDT coverage standards to meet the particular health care needs that face low-income individuals under age 21.

Waiving ESPDT will leave 19- and 20-year-old parents without access to a range of important treatment services, including comprehensive dental, vision, and hearing services, which will lead to worse overall health outcomes.³³ As a U.S. Surgeon General report explains, oral health is essential to overall health.³⁴ Untreated oral health problems often lead individuals to seek care in the emergency room. In 2009, preventable dental conditions were the cause of 830,000 emergency room visits nationwide, and hospital care for dental conditions is nearly ten times as expensive as preventive dental care.³⁵ Emergency room visits for dental conditions cost about \$1.6 billion nationwide.³⁶

Similarly, the CDC has declared vision loss a serious public health problem, as “people with vision loss are more likely to report depression, diabetes, hearing impairment, stroke, falls, cognitive decline, and premature death,” as well as “substantially compromis[ed] quality of life.”³⁷ Further, the cost of vision loss is estimated to exceed \$35 billion.³⁸ Notably, untreated dental, vision, or hearing problems can make it more difficult for individuals to get and/or keep

³² 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).

³³ See Application at 15 (indicating that vision care is limited to one eye examination every 12 months and does not include eye glasses; speech and hearing services are limited to hearing evaluations or assessments as well as hearing aids if hearing loss is congenital; dental services are not covered, with unspecified exceptions).

³⁴ Dep’t of Health & Human Servs., U.S. Pub. Health Serv., *Oral Health in America: A Report of the Surgeon General* (2000), <https://www.nidcr.nih.gov/sites/default/files/2017-10/hck1ocv.%40www.surgeon.fullrpt.pdf>.

³⁵ Pew Ctr. on the States, *A Costly Dental Destination: Hospital Care Means States Pay Dearly* 1, 3 (2012), <http://www.pewtrusts.org/-/media/assets/2012/01/16/a-costly-dental-destination.pdf>.

³⁶ Cassandra Yarbrough et al., *Estimating the Cost of Introducing a Medicaid Adult Dental Benefit in 22 States*, *Am. Dental Ass’n* 2 (2016),

http://www.ada.org/~media/ADA/Science%20and%20Research/HPI/Files/HPIBrief_0316_1.ashx.

³⁷ *Why is Vision Loss a Public Health Problem?*, Ctrs. for Disease Control & Prevention, https://www.cdc.gov/visionhealth/basic_information/vision_loss.htm (last reviewed June 12, 2020).

³⁸ *Id.*



a job. With respect to dental services, nearly 30% of low-income adults say the appearance of their mouth and teeth affects their ability to interview for a job.³⁹

Finally, eliminating EPSDT has no valid experimental purpose. The policy is nothing more than a benefits cut. The State will not test an innovative approach to health care delivery by preventing 19- and 20-year-old parents from receiving medically necessary services. What is more, HHS has been permitting Utah to waive EPSDT since 2002. Even assuming that the waiver was experimental at that time (which it was not), it is impossible to continue to construe it as experimental.

Waiving the IMD Exclusion for Mental Health

Utah requests authority to continue receiving federal financial participation (FFP) for residential and inpatient treatment services for individuals with serious mental illness in institutions for mental diseases (IMDs).⁴⁰ For the same reasons we objected to Utah's original request, we oppose Utah's request for an extension of this authority. First, because the IMD exclusion lies outside of 42 U.S.C. § 1396a, it cannot be waived. Second, Utah has not explained how obtaining FFP for services rendered at IMDs constitutes a valid experiment under the Medicaid Act. Third, the majority of changes that Utah proposes do not require waiver of the IMD exclusion. And fourth, the waiver runs the serious risk of diverting funds from community-based mental health services and supports into institutional services, undermining community integration and the *Olmstead* mandate.

The Secretary Does Not Have Authority to Waive the IMD Exclusion.

As noted above, the Secretary can only waive provisions set forth in 42 U.S.C. § 1396a of the Medicaid Act. The IMD exclusion is contained in 42 U.S.C. § 1396d, which specifically excludes from the definition of medical assistance “any such payments with respect to care or

³⁹ Am. Dental Ass'n, Health Policy Inst., *Oral Health and Well-Being in the United States* (2015), <https://www.ada.org/~media/ADA/Science%20and%20Research/HPI/OralHealthWell-Being-StateFacts/US-Oral-Health-Well-Being.pdf?la=en>.

⁴⁰ Because of the unique and long history of mental health IMD waivers, we are focusing these comments on Utah's request for FFP for residential and inpatient treatment services for individuals with serious mental illness in IMDs. However, Utah is also requesting a waiver of the IMD exclusion for residential substance use disorder (SUD) services. This too is an impermissible use of Section 1115, for many of the same reasons that Utah's request for FFP for enrollees in MH IMDs is impermissible. See, e.g. Cathren Cohen et al., Nat'l Health Law Program, *Medicaid Section 1115 Waivers for Substance Use Disorders: A Review* 8-11 (June 8, 2021), <https://healthlaw.org/resource/medicaid-section-1115-waivers-for-substance-use-disorders-a-review/>.



services for any individual who has not attained 65 years of age and who is a patient in an institution for mental diseases...⁴¹ Because the IMD exclusion lies outside of section 1396a, it cannot be waived. Moreover, as noted above, section 1115(a)(2) does not create an independent “expenditure authority” for the Secretary to allow a state to ignore provisions of the Medicaid Act outside of section 1396a.

FFP for IMDs is Not an Experiment.

As noted above, a section 1115 request must propose a genuine experiment of some kind. An experiment must have stated goals, a hypothesis, and a way to measure that hypothesis. According to Congress, “States can apply to HHS for a waiver of existing law to test a unique approach to the delivery and financing of services to Medicaid beneficiaries . . . contingent upon development of a detailed research methodology and comprehensive evaluation for the demonstration.”⁴² Providing FFP for mental health services in IMDs is not an experiment. CMS first permitted states to waive the IMD exclusion in 1993, and by the early 2000s, nine states had waivers to fund IMDs for psychiatric treatment: Arizona, Delaware, Maryland, Massachusetts, New York, Oregon, Rhode Island, Tennessee, and Vermont.⁴³ Some of these states only covered individuals at certain hospitals or for a set number of days; others offered broader coverage. As of 2009, CMS had phased out all but one of these projects, precisely because they were no longer “innovative or experimental.”⁴⁴

Although CMS has recently encouraged states to apply for mental health-related section 1115 waivers that would allow for FFP for services provided in IMDs, CMS has not provided any justification for its change in position.⁴⁵ With almost 30 years of waivers, it is no longer plausible to claim that providing FFP for services to individuals residing in IMDs is a bona fide experiment, demonstration, or pilot. Section 1115 does not offer HHS a “back door” to provide funding for settings that Congress explicitly carved out of Medicaid.

⁴¹ 42 U.S.C. § 1396d(a)(31)(B).

⁴² H.R. Rep. No. 3892, pt. 2, at 307-08 (1981).

⁴³ U.S. Gov. Accounting Office, *States Fund Services for Adults in Institutions for Mental Disease Using a Variety of Strategies* 29 (2017), <https://www.gao.gov/assets/690/686456.pdf>.

⁴⁴ *Id.*

⁴⁵ CMS, *Dear State Medicaid Director Letter* (Nov. 13, 2018) (SMD #18-011) (Opportunities to Design Innovative Service Delivery Systems for Adults with a Serious Mental Illness or Children with a Serious Emotional Disturbance), <https://www.medicaid.gov/federal-policy-guidance/downloads/smd18011.pdf> [hereinafter “SMD #18-011”].



Utah’s primary impetus for requesting a waiver of the IMD exclusion is to obtain FFP for psychiatric IMD beds.⁴⁶ Utah hypothesizes that the SMI/IMD waiver is to “reduce[] utilization of emergency department’s (EDs) among Medicaid individuals with SMI/SED while awaiting mental health treatment in specialized settings.”⁴⁷ However, this hypothesis was already explicitly tested and found to be unsupported by the federally authorized Medicaid Emergency Psychiatric Demonstration (MEPD) program, a three-year IMD demonstration authorized by the Section 2707 of the Affordable Care Act.⁴⁸ The MEPD evaluation found that in those states that had sufficient data to draw conclusions, “[t]he results do not support our hypothesis that ER visits would decrease as a result of MEPD.”⁴⁹ The MEPD evaluation also found that the MEPD did not reduce psychiatric admissions to non-psychiatric beds, often called “scatter-bed” admissions.⁵⁰ So, this has been studied – through legal demonstrations – and the answers are known. There is no need for section 1115 in this context.

Because Utah’s request to waive the IMD exclusion does not propose a novel experiment, with stated goals, a reasonable hypothesis, and evaluation measures, the Secretary should not approve this demonstration request.

Utah Can Make the Additional Proposed Changes Via State Plan Authority.

As noted above, Utah’s request is specially for an extension of purported “expenditure authority” for “services furnished to eligible individuals ages 21 through 64 who receive treatment for a SMI and who are short-term residents in facilities that meet the definition of an IMD.”⁵¹ However, CMS requires any state that seeks FFP for services in IMDs to “also . . . commit to taking a number of actions to improve community-based mental health care.”⁵² Thus, Utah has agreed to take steps to reduce preventable readmissions to acute care, improve availability of crisis stabilization services, improve access to community based services, and improve care coordination in the community following episodes of acute care. To

⁴⁶ Utah Dep’t of Health, Utah 1115 Primary Care Network Demonstration Waiver Amendment Request, Behavioral Health Services for Adults with Serious Mental Illness 2 (Jul. 31, 2020), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ut-primary-care-network-pa11.pdf>.

⁴⁷ Application at 22.

⁴⁸ Crystal Blyer et al., Mathematica Policy Research, *Medicaid Emergency Psychiatric Services Demonstration Evaluation, Final Report*, (Aug. 18, 2016), <https://innovation.cms.gov/Files/reports/mepd-finalrpt.pdf> [hereinafter “MEPD Evaluation”].

⁴⁹ MEPD Evaluation at 49.

⁵⁰ *Id.* at 41.

⁵¹ Application at 26.

⁵² SMD #18-011 at 13.



achieve these reforms, the State describes a number of modifications to its behavioral health system.⁵³ These reforms include changes to managed care contracts to require follow up with all ED and inpatient discharges within 72 hours, new legislative investments in crisis services, and the establishment of a statewide crisis line.⁵⁴

While these reforms are laudable, Utah does not need to waive the IMD exclusion to make these changes. These reforms can already and easily be achieved via amendments to managed care contracts and/or state plan amendments. To put it another way, the reforms are immaterial to Utah's request for FFP for services provided to residents of IMDs. Waiving the IMD/FFP exclusion should not be a reward for the State making improvements to behavioral health services that it can already make through existing authorities.

Utah's Proposal Risks Diverting Resources Away from Community-Based Services and Undermining Community-Integration.

Even with the reforms referred to in the previous section, Utah still woefully underfunds community-based services. It currently ranks 48th in Mental Health America's state adult rankings, indicating that it has a high prevalence of need and a low rate of access to care.⁵⁵ Recent data collected by the Substance Abuse and Mental Health Services Administration suggests the State fails to provide the types of community-based services that individuals need when leaving acute care settings, such as Assertive Community Treatment (ACT). Only 0.9% of individuals with SMI receive ACT in Utah, compared with a national utilization rate of 1.8%.⁵⁶ Experts estimate that the need is actually much greater.⁵⁷

A 2019 Report from the Gardner Policy Institute paints a dire picture.⁵⁸ The report finds that 17.5 % of adults in Utah experience poor mental health, and that 32.1% of Utahns whose

⁵³ SMI Implementation Plan, <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ut-pcn-impl-plan-aprvl-smi-imd-imp-plan-combnd.pdf>.

⁵⁴ *Id.*

⁵⁵ *Adult Ranking 2022*, Mental Health America, <https://www.mhanational.org/issues/2022/ranking-states> (last visited Oct. 18, 2021).

⁵⁶ SAMHSA, *Utah 2020 Mental Health National Outcome Measures (NOMS)*, <https://www.samhsa.gov/data/sites/default/files/reports/rpt35277/Utah.pdf>

⁵⁷ Gary S. Cuddeback et al., *How Many Assertive Community Treatment Teams Do We Need?*, 57 PSYCHIATRIC SERVS. 1803 (2006), <https://ps.psychiatryonline.org/doi/full/10.1176/ps.2006.57.12.1803>.

⁵⁸ Laura Summers et al., Kem C. Gardner Policy Inst., *Utah's Mental Health System*, 6 (August 2019), <https://gardner.utah.edu/wp-content/uploads/MentalHealthReportAug2019.pdf>



incomes are between zero and \$25,000 per year experience poor mental health.⁵⁹ The report estimates that in 2015 the majority of adult Utahns with a mental illness did not receive any mental health treatment or counseling.⁶⁰

Utah's demonstration risks exacerbating current gaps in services by creating more incentives to increase institutional capacity instead of developing community-based resources. This in turn could worsen shortages and continue a negative cycle of viewing institutional settings as the solution to SMI treatment needs. This is particularly concerning given the evidence of the risk of "bed elasticity," a phenomenon where supply drives demand.⁶¹ That is, if beds are available, they are filled, siphoning resources from community-based services, but when beds are not available, other options adequately meet individuals' needs. When states have limited resources, spending money on costlier institutional settings results in less available funding for more cost-effective community-based programs, making community-based services harder to access. Historically, the IMD exclusion has provided important incentives to states to develop community-based alternatives and to rebalance spending towards more integrated settings. Community-based treatment is often more effective and frequently more cost-effective than inpatient or residential care.⁶²

While the current Special Terms and Conditions (STCs) require Utah to "ensure the on-going maintenance of effort (MOE) on funding outpatient community-based services to ensure that resources are not disproportionality drawn into increasing access to treatment in inpatient and residential settings at the expense of community-based services," an MOE is cold comfort when the current levels of community-based services are substantially insufficient to meet the needs of enrollees.⁶³ While the STCs require the State to increase crisis and community-based services, the STCs do not specify the size of the increase, nor does it require a rate of growth in investment in community-based services sufficient to ensure that FFP for IMDs does not incentivize overuse of institutional settings.⁶⁴

⁵⁹ *Id.* at 4-6, 22.

⁶⁰ *Id.* at 4-6.

⁶¹ Martha Shumway et al., *Impact of Capacity Reductions in Acute Public-Sector Inpatient Psychiatric Services*, 63 PSYCH. SERVS. 135 (2012), <https://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.201000145>.

⁶² See Barbara Dickey et al., *The Cost and Outcomes of Community-Based Care for the Seriously Mentally Ill*, 32 HEALTH SERV. RES. 599 (1997), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1070217/>.

⁶³ Utah Primary Care Network, Special Terms and Conditions 62 (amendment approved July 23, 2021), <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/ut-primary-care-network-cms-appvl-07232021.pdf>.

⁶⁴ *Id.*



Finally, providing FFP for services provided in IMDs could undermine hard-won civil rights for people with disabilities and decades of federal policy initiatives stressing the importance of increasing community integration.⁶⁵ IMDs are by definition institutional settings where individuals with disabilities receive services, and decisions regarding funding for services in IMDs will inevitably have an impact on where people with disabilities receive services. In passing the Americans with Disabilities Act, Congress found that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”⁶⁶ Providing FFP for large institutional settings could reify discriminatory presumptions about the ability of individuals with disabilities to receive services in community-based settings, and undermining the integration mandate articulated by the Supreme Court in *Olmstead v. LC*. In short, this request promotes the segregation of people with mental illnesses.

Because Utah’s request risks diverting resources from community-based services and undermining the civil rights of people with disabilities, the Secretary should not approve this demonstration request.

In Vitro Fertilization and Genetic Testing for Qualified Conditions

Utah is requesting approval of its 2021 amendment request regarding coverage of IVF services and PGD. We are incorporating here our previous comments urging CMS to reject that request.⁶⁷

Conclusion

While NHeLP supports the use of section 1115 to implement experimental projects that are likely to promote the objectives of the Medicaid Act, we strongly object to any efforts to use this law to skirt essential provisions that Congress has placed in the Medicaid Act to protect Medicaid beneficiaries and ensure that the program operates in their best interests. As

⁶⁵ President’s New Freedom Comm’n on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America* (2003), <https://govinfo.library.unt.edu/mentalhealthcommission/reports/FinalReport/FullReport.htm>.

⁶⁶ 42 U.S.C. § 12101(a)(2).

⁶⁷ Letter from Jennifer Lav and Catherine McKee, Nat’l Health Law Program, to Ctrs. for Medicare & Medicaid Servs. (Feb. 12, 2021) (attached).



demonstrated above, Utah's proposed project is inconsistent with the standards of section 1115.

We have included numerous citations to supporting research, including direct links to the research. We direct CMS to each of the materials we have cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal administrative record for purposes of the Administrative Procedure Act. If CMS is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.

Thank you for the opportunity to comment on Utah's application. If you have further questions, please contact Jane Perkins, perkins@healthlaw.org, Jennifer Lav, lav@healthlaw.org, or me, mckee@healthlaw.org.

Sincerely,



Catherine McKee
Senior Attorney

