The Disability Law Center (DLC) appreciates the opportunity to offer feedback on the Utah Department of Health, Division of Medicaid and Health Financing’s proposed Section 1115 demonstration waiver, specifically Amendment 20. The DLC is designated by the governor as Utah’s Protection and Advocacy agency. Our mission is to enforce and strengthen laws that protect the opportunities, choices, and legal rights of the almost 300,000 Utahns with disabilities. These comments are submitted on behalf of our constituents, many of whom are PCN recipients, or would be eligible for the Medicaid expansion group. We have serious concerns about the potential consequences the proposals contained in the application could have for many of them.

**Demonstration Waiver Requirements**

At the outset, it is important to distinguish between proposed changes that meet the requirements of a Section 1115 Waiver and those the State may be interested in pursuing for other purposes, but which do not meet the requirements for approval under Section 1115. To be approved under Section 1115:

- The waiver must implement an “experimental, pilot, or demonstration” project;
- The waiver must be limited to Medicaid provisions in 42 U.S.C. § 1396a (Section 1902 of the Social Security Act);
- The experiment must be likely to promote Medicaid’s objectives; and
- The waiver of Medicaid’s requirements must be limited to the extent and period needed to carry out the experiment.\(^i\)

There are general criteria that CMS uses to determine whether Medicaid objectives are met.\(^ii\) These criteria include whether the demonstration will:

1. increase and strengthen overall coverage of low-income individuals in the state;
2. increase access to, stabilize, and strengthen providers and provider networks available to serve Medicaid and low-income populations in the state;
3. improve health outcomes for Medicaid and other low-income populations in the state; or
4. increase the efficiency and quality of care for Medicaid and other low-income populations through initiatives to transform service delivery networks.

With this background, we will address the proposed changes.

**Measurement and Evaluation**

In order to qualify under Section 1115, a waiver must propose an experiment, pilot, or demonstration project. Assessment of the results is key component to each of these designations. Unfortunately, we are forced to guess at how these proposals will be measured and evaluated. We are also left to wonder how their impact or effectiveness, in terms of increasing coverage or access, and improving quality, efficiency, or health outcomes, will be monitored and safeguarded.
Work Requirements

The waiver amendment seeks permission to impose work requirements as a condition of eligibility for PCN, and, potentially, adults without dependent children enrolled in Medicaid at a later date. We are left to believe the State is assuming that individuals from the target populations do not seek work because they have minimal health coverage. There is no data or evidence to suggest this is correct. Moreover, there is much evidence and data to suggest that the majority of these individuals work or are in working families.iii

The purpose of the Medicaid Act is to enable states to furnish medical assistance to low-income individuals who cannot afford the costs of medically necessary services, and to furnish “rehabilitation and other services to help [these individuals] attain or retain capability for independence and self-care.”iv Work requirements are neither medical assistance, nor a service provided to PCN/Medicaid beneficiaries. Further, according to the wording of the statute, independence and self-care are the desirable results of providing medical, rehabilitative, and related services. They are not the goals in and of themselves. Therefore, requests to add a work requirement have routinely been rejected in the past.v

Work requirements also ignore PCN/Medicaid's essential role as a safety net for people in need. PCN/Medicaid's enrollment fluctuates with the economy, increasing during downturns as jobs, and employer-sponsored insurance, are lost. Requiring work for health coverage has negative consequences. Among them, blocking access to necessary care that individuals need to be able to work in the first place. In Utah, the effectiveness of a similar requirement in the TANF program is questionable at best. In 2015, fewer than 14% of enrollees were employed in unsubsidized work, and less than 2% were engaged in education, job search, or other work-related activities.vi

This is likely a consequence of a lack of time or resources to follow up with a client or provide them with the type or intensity of support they need to be successful. Also, it is unclear whether the Department of Workforce Services tracks the type of job an individual who is employed gets, and whether it provides a living wage and affordable, quality health care coverage. Ultimately, rather than promoting work, such requirements often have the opposite effect, stymieing opportunities for self-reliance.

A recent study from the Kaiser Family Foundation found that more than 40% of non-SSI adult Medicaid enrollees are working full-time, with another 18% working part-time. It is reasonable to assume a fair percentage of the part-timers would prefer to be working full-time, and that many are probably working somewhere close to the 30-hour threshold already (if this is the case, a possible explanation may be that, if an employer offers benefits, an employee often becomes eligible if he or she works 30 or more hours per week). The same analysis found that 35 percent of unemployed adults receiving Medicaid, but not receiving Disability/SSI, reported illness or disability as their primary reason for not working.vi In fact, the 11 exemptions in Utah’s proposal are a tacit acknowledgment that most low-income enrollees who are not already working have a good reason not to be employed.viii A work requirement would only add to enrollees already considerable burdens by requiring verification of their compliance or exemption.

This, in turn, would require new systems to apply different requirements based on length of enrollment, accurate tracking and documentation of employment and/or caregiving hours, and an effective screening process for disability and temporary conditions, all on an individual level. For instance, Indiana says its work search program would cost $90/month to administer and run per enrolled member.ix The with-waiver estimated monthly cost to cover an adult in Indiana’s new adult group is $567 in Demonstration year 5, meaning that work search would constitute close to 16% of the coverage cost for enrolled members.x The state does not specify how much
would be spent on training and employment supports relative to the cost of administering and enforcing the requirement. In short, this would require tremendous investment of resources and administrative costs and, as CMS has previously concluded, would create dangerous barriers to enrollment and care.

People with chronic conditions that impact their ability to work but do not qualify them for disability benefits will be at high risk of losing access to care. Chronic conditions are, by definition, not time-limited and can be episodic or impact individuals for extended periods. While the amendment states that work requirements will not apply to beneficiaries who are physically or mentally unable to work, the evidence from other programs with similar requirements is that individuals with disabilities are often not exempted and are more likely to lose benefits.

For example, one study from Franklin County, OH, found that 33% of the individuals referred to a SNAP employment program in order to keep their benefits reported a physical or mental limitation, and 25% of them indicated that the condition limited their daily activities. Additionally, nearly 20% of the individuals had filed for SSI or SSDI within the previous 2 years.\textsuperscript{x}\textsuperscript{i} Between April 1, 2015 and March 31, 2017, approximately only 18,299 Wisconsin FSET participants gained employment. This number includes both the Food Share recipients who are required to participate in the program and voluntary enrollees.\textsuperscript{x}\textsuperscript{i}\textsuperscript{i} Over the same time period, the work requirement and time limit for childless adults caused more than three times the number of participants - over 70,000 individuals - to lose access to critical food assistance.\textsuperscript{x}\textsuperscript{i}\textsuperscript{ii} These losses occurred despite the fact the SNAP law contains an explicit provision exempting those from the 3-month time limit who are “mentally or physically unfit for employment…”\textsuperscript{x}\textsuperscript{i}\textsuperscript{iv}

Similarly, repeated studies of TANF programs have found that clients with physical and mental health issues are disproportionately likely to be sanctioned for not completing the work requirements.\textsuperscript{x}\textsuperscript{v} Such clients may not understand what is required of them, or may find it difficult to complete paperwork or travel to appointments to be assessed for exemptions. Work requirements and time limits most often serve as a mechanism to take away crucial support for low-income individuals. Similar findings are no less likely in Utah since a significant share of eligibility determinations are made online or by phone, with little opportunity to interact with or assess the capacities or abilities of an applicant face-to-face.

In almost any system in which eligibility is conditioned on or attached to work requirements, these requirements will hit individuals with chronic and disabling conditions hardest. Thus, work requirements implicate the civil rights protections contained in the Americans with Disabilities Act (ADA) and section 504 of the Rehabilitation Act, laws which make it illegal for states to take actions that have a discriminatory impact on people with disabilities.\textsuperscript{x}\textsuperscript{vi} Section 1115 does not authorize the Secretary of HHS to waive these laws.\textsuperscript{x}\textsuperscript{vii}

The end result of this policy may be less people with PCN/Medicaid coverage and more people seeking uncompensated care in our hospitals. There will be more gaps in coverage, leading to more expensive treatment when eligibility is eventually regained. Hospitals will suffer financially as they are expected to treat more people with chronic or acute illness with less funding.

Simply, work requirements go against Medicaid’s purpose of increasing coverage, as well as the positive health outcomes that depend it.
Time Limit on Eligibility

The proposed amendment also places a 60-month lifetime cap on the PCN and Medicaid adults without dependent children populations. The State appears to indicate it is in an effort to help individuals find work by saying they expect these individuals will “do everything they can” to help themselves before they lose coverage. However, occupations commonly held by this low-income population, in child care, construction, retail, and food service, etc. often lack an employer-sponsored health insurance benefit. Additionally, large employer-sponsored plans are not required to offer mental health or substance use disorder services, and some private plans exempt court-ordered services from coverage. As stated in the previous section, the data and evidence does not support the State’s contention that individuals choose to receive Medicaid because they do not want to work.

Nationally, there are many reasons adults on PCN/Medicaid, and not receiving Disability/SSI, are unemployed. These individuals take care of their families (28%), go to school (18%), and are retired (8%). But the greatest number of them do not work due to illness or disability (35%). These populations will be at great risk of losing access to care. Their health and safety will be at great risk because the State has made a poor assumption about the work ethic of tens of thousands of Utahns.

Additionally, two years ago, the Legislature passed the Justice Reinvestment Initiative, which aims to keep a person from entering or returning to jail or prison by providing him or her with community-based mental health and/or substance use treatment. This past session, they made a $6 million down payment on that commitment. They also devoted over $11 million to treating more Medicaid-eligible individuals in the community. Sadly, the waiver request represents a significant retreat from these proactive commitments. If it is approved and implemented, much of the taxpayers' recent substantial investment will have been wasted.

Frankly, the vast majority of Medicaid recipients are out of work for reasons beyond their control. Capping the number of months an individual can be eligible for benefits is not an experiment based on evidence or data. Moreover, the time limit does not promote the objectives of the Medicaid Act. In fact, it will lead to reduced coverage and poorer health outcomes.

Elimination of Presumptive and Retroactive Eligibility

The proposed amendment seeks to eliminate presumptive and retroactive eligibility. Presumptive eligibility means hospitals and other providers can enroll a patient immediately based on what he or she tells them about his or her financial situation. The determination is later reviewed for accuracy. Retroactive eligibility is provided for under 42 U.S.C. 1396a(a)(34) (Section 1902), which permits retroactive coverage, up to three months prior to the month of application provided that the individual otherwise meets the eligibility requirements during the month(s) and has incurred medical expenses. As stated by Utah’s Medicaid director, Nate Checketts, at the June 22, 2017 public hearing, the two proposed eligibility changes are designed to make Medicaid more like private insurance coverage, i.e. have providers determine insurance status at the time of delivering the service to encourage people to enroll early to receive preventative care. Unfortunately, this rationale does not hold up under scrutiny. It is crucial for relatively healthy individuals to enroll in private coverage early so their premiums help cover the cost of relatively sicker enrollees. However, PCN and Medicaid do not, and cannot, operate like private insurance because, after housing, food, and other basic expenses, enrollees with income between $0-955 a month are highly unlikely to be able to afford out-of-pocket costs of any nontrivial amount.
The reality is not that people purposefully delay seeking care or coverage. Rather, elimination of presumptive eligibility, as well as retroactive eligibility, places providers, such as hospitals, ambulance services, and nursing homes at financial risk. Without the ability to determine a patient presumptively eligible or retroactively claim for care provided to Medicaid-eligible individuals, providers will see an increase in uncompensated care, making it challenging for them to keep their doors open to serve our most vulnerable citizens. For example, a hospital that treats a stroke victim on or towards the last day of the month is put at financial risk when the patient (who may be incapable of submitting an application) does not submit a Medicaid application until the next month, perhaps just a day or two away. As such, the hospital, although legally (and morally) obligated to provide treatment will not be paid for treating the stroke. An ambulance that transports a patient to a hospital will likely not be paid – either by a hospital or Medicaid – since the ambulance has no control over when a Medicaid application may be submitted, and will not and cannot refuse to transport a person due to lack of insurance coverage. And, a nursing facility that is treating a private pay patient who is spending down their resources will not know precisely when that spenddown is met and is likely to miss submitting a timely application.

These proposals fail to meet the basic requirements for a Section 1115 waiver. Making Medicaid consistent with private coverage is not evidence that such a proposal promotes the objectives of the Medicaid program. Nor does requiring hospitals and other providers to determine insurance status prior to delivering services promote the objectives of the Medicaid Act. Furthermore, failing to pay providers for giving care to a person made ineligible for coverage under this proposal would only weaken the Utah Medicaid program’s ability to maintain an adequate network of providers, as required by federal law, and will increase uncompensated care, thus undermining the stability of provider system and its ability to treat our most vulnerable residents.

As stated above, a Section 1115 waiver is required to seek to implement an “experiment, pilot or demonstration” that promotes the objectives of the Medicaid Act. CMS measures this requirement in part by the extent to which the pilot will “strengthen providers and provider networks available to serve Medicaid and low income populations in the state...”. Certainly, we can expect to see more people subject to debt collection or declaring bankruptcy due to medical debt, more hospitals and other providers suffering financial losses serving uninsured individuals, and more people denied appropriate treatment, only to need more expensive treatment later. It is hard to see what acceptable experimental purpose is being measured by this proposal and how the inevitable outcomes will promote the objectives of the Medicaid Act.

**Copays for Non-Emergent Use of the Emergency Department**

The Medicaid Act contains specific and detailed waiver requirements for states that seek to impose increased copayments. These protections cannot be ignored. They are not waivable through a Section 1115 waiver because the authority to impose co-payments, and the limitations therein, do not appear in Section 1396a.

Even if the Department could seek a waiver under Section 1396o (Section 1916) of co-payments, such a waiver cannot be given to impose higher co-payments for the appropriate use of the hospital ED. The proposed amendment suggests that the State seeks “to encourage the appropriate use of services by charging higher co-pays for non-emergent use of the ED.” Because the State does not define “non-emergent services,” we are left unclear on whether a person could be charged a co-pay for emergency services.

Under Section 1396o(a)(2)(D), no cost-sharing may be imposed for “emergency services as defined by the Secretary.” The term “emergency services” is defined in the cost-sharing
regulations at 42 CFR §447.51, which reference the Secretary’s definition at 42 CFR §438.114. That regulation defines “emergency services” as:

“Emergency services means covered inpatient and outpatient services that are as follows:
(i) Furnished by a provider that is qualified to furnish these services under this Title.
(ii) Needed to evaluate or stabilize an emergency medical condition.”

The regulations further define “emergency medical condition” as:

“Emergency medical condition means a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) that a prudent layperson, who possesses an average knowledge of health and medicine, could reasonably expect the absence of immediate medical attention to result in the following:
(i) Placing the health of the individual (or, for a pregnant woman, the health of the woman or her unborn child) in serious jeopardy.
(ii) Serious impairment to bodily functions.
(iii) Serious dysfunction of any bodily organ or part.”

Therefore, if a person with an emergency medical condition presents at the ED, it is unlawful to charge a co-payment. So, even if the State could seek a waiver under 1396o, it is not entirely clear that a co-payment in these circumstances would not violate the Medicaid Act.

The copayments also conflict with non-waivable provisions of the Medicaid Act regarding copayments. In provisions located outside of § 1396a, the Medicaid Act provides states with flexibility to establish copayments, but it also includes beneficiary protections.xx Among these are limits on the copayment amount and requirements that emergency room cost sharing be tied only to non-emergency services furnished to an individual in the hospital ED, only if the following conditions are met: (1) the individual has an actually available and accessible alternative to the ED for the service, and the hospital informs the individual, after conducting the EMTALA screen, of the copayment and the name and location of alternative service providers, along with a referral.xxx These protections are not built into this waiver, and, therefore, it should be denied.

Besides the legal prohibition on imposition of copayments as set forth in the waiver document, the proposed waiver application is not likely to promote the objectives of Medicaid. It is also unclear how ‘areas with insufficient urgent care access’ will be defined and the criteria used to develop these definitions, especially given that the Department has yet to establish current network adequacy standards for managed care service areas.

Over the last 40-years, cost sharing has been one of the most heavily studied aspects of the Medicaid program and these studies have produced a consistent finding: copayments harm low-income people by causing them to forego medically necessary care.xxii While studies show that Medicaid recipients use the emergency department more than persons with other insurance, studies also show they are in poorer health and that most visits are appropriate.xxiii Moreover, studies of Medicaid and CHIP nonemergency ED copayments have repeatedly demonstrated that they are ineffective at reducing nonemergency ED use.xxiv
It is hard to see how discouraging people from appropriate use of the ED is a worthwhile experiment, especially when the state does not yet have a fully functioning system of alternatives for affordable and convenient off-hours care, such as health homes, integrated physical and mental health care, or easily accessible urgent care. In fact, it is counter to everything the DOH has tried to reduce inappropriate use of the ED.xxv

**Conclusion**

The proposed amendment contains a number of proposals that are prohibited by law, including a provision that clearly is not waivable, and that research has shown to be inconsistent with the purposes of the Medicaid program. This waiver, if adopted, would not promote the beneficial purposes of the Medicaid Act. It would not increase or strengthen overall coverage., As we have shown, proposals such as the work requirement, time limit, and unaffordable cost-sharing would have the effect of reducing coverage of the very individuals and families that the Act was enacted to assist. It would also destabilize access to providers through proposals like the elimination of retroactive coverage and hospital presumptive eligibility, which would inevitably lead to an increase in uncompensated care. Finally, it would worsen, not improve, health outcomes, as thousands of needy Utahns would lose coverage, through no fault of their own, as a direct consequence of these punitive measures.

Thank you for your time and consideration of our input. If you have questions or would like more information, please do not hesitate to contact us.
By contrast, as far back as the 1970s, states obtained section 1115 waivers to test work requirements for the AFDC population (which, in contrast to Medicaid, does have work promotion as a purpose of the program). These waivers required states to conduct “rigorous evaluations of the impact,” typically requiring the random assignment of one group to a program operating under traditional rules and another to the more restrictive waiver rules. United States Dep’t of Health & Human Services, State Welfare Waivers: An Overview, http://aspe.hhs.gov/hsp/isp/waiver2/waivers.htm.


Garfield et al., supra note 3.


Rober M. Damler et al., MILLIMAN, 1115 Waiver – Healthy Indiana Plan, 4 (May 24, 2017), attached to HIP 2.0 application. It is not clear if this statement refers to $90 per member enrolled in the Gateway program or per member enrolled in HIP 2.0.

Id.


Id.

7 CFR 273.24


See Burns-Vidlak v. Chandler, 939 F. Supp. 765, 772 (D. Haw. 1996) (finding Rehabilitation Act and ADA are not included in section 1396a and “none of the statutes for which § 1315 authorizes waivers contain anti-discrimination provisions.”). See generally Alexander v. Choute, 469 U.S. 287, 301 (1985) (“[T]he otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers. The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled [.]”) (emphasis added).

See, UDOH, supra note 8, p. 1, #2

See, Garfield et al., supra note 3.

See 42 U.S.C. §§ 1396o, 1396o-1.

Id. § 1396o-1(e).


Ellyn Boukkus and Emily Carrier, Dispelling Myths about the Emergency Department Use: Majority of Medicaid Visits Are for Urgent or More Serious Symptoms, Center for Studying Health System Change, HSC Research Brief, No. 23

Mona Siddiqui et al., The Effect of Emergency Department Copayments for Medicaid Beneficiaries Following the Deficit Reduction Act of 2005, 175 JAMA INTERNAL MED. 393 (2015); Karoline Mortensen, Copayments Did Not Reduce Medicaid Enrollees’ Nonemergency Use of Emergency Departments, 29 HEALTH AFFAIRS 1643 (2010); David J. Becker et al., Co-payments and the Use of Emergency Department Services in the Children’s Health Insurance Program, 70 MED. CARE RES. REV. 514 (2013).

“In SFY 2007, efforts to educate all Medicaid enrollees, not just those covered through the 1115 Waiver, about appropriate emergency department use increased; likewise the overall number of ED claims decreased as did the incidence of non-emergent claims. This trend for the appropriate use of ED services continued through SFY2011 and shows that education campaigns can be effective.” (Emphasis added). (Utah Department of Health, Attachment 2 - 1115 Demonstration Waiver (2016), available at http://health.utah.gov/MedicaidExpansion/pdfs/Utah1115_Waiver_Amendments_Extension7-16.pdf.

1 42 U.S.C. § 1315(a) (codification of section 1115).


v By contrast, as far back as the 1970s, states obtained section 1115 waivers to test work requirements for the AFDC population (which, in contrast to Medicaid, does have work promotion as a purpose of the program). These waivers required states to conduct “rigorous evaluations of the impact,” typically requiring the random assignment of one group to a program operating under traditional rules and another to the more restrictive waiver rules. United States Dep’t of Health & Human Services, State Welfare Waivers: An Overview, http://aspe.hhs.gov/hsp/isp/waiver2/waivers.htm.


viii Rober M. Damler et al., MILLIMAN, 1115 Waiver – Healthy Indiana Plan, 4 (May 24, 2017), attached to HIP 2.0 application. It is not clear if this statement refers to $90 per member enrolled in the Gateway program or per member enrolled in HIP 2.0.

ix Id.


xii Id.

xiii 7 CFR 273.24


xvi See Burns-Vidlak v. Chandler, 939 F. Supp. 765, 772 (D. Haw. 1996) (finding Rehabilitation Act and ADA are not included in section 1396a and “none of the statutes for which § 1315 authorizes waivers contain anti-discrimination provisions.”). See generally Alexander v. Choute, 469 U.S. 287, 301 (1985) (“[T]he otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers. The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are entitled [.]”) (emphasis added).

xvii See, UDOH, supra note 8, p. 1, #2

xviii See, Garfield et al., supra note 3.

xix See 42 U.S.C. §§ 1396o, 1396o-1.

xx Id. § 1396o-1(e).


xxii Ellyn Boukkus and Emily Carrier, Dispelling Myths about the Emergency Department Use: Majority of Medicaid Visits Are for Urgent or More Serious Symptoms, Center for Studying Health System Change, HSC Research Brief, No. 23

xxiii Mona Siddiqui et al., The Effect of Emergency Department Copayments for Medicaid Beneficiaries Following the Deficit Reduction Act of 2005, 175 JAMA INTERNAL MED. 393 (2015); Karoline Mortensen, Copayments Did Not Reduce Medicaid Enrollees’ Nonemergency Use of Emergency Departments, 29 HEALTH AFFAIRS 1643 (2010); David J. Becker et al., Co-payments and the Use of Emergency Department Services in the Children’s Health Insurance Program, 70 MED. CARE RES. REV. 514 (2013).

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