

## KEY FINDINGS

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NATIONWIDE, MORE
THAN 650,000 TRULY
NEEDY INDIVIDUALS ARE
LANGUISHING ON
MEDICAID WAITING
LISTS



3

MEDICAID HAS LOST ITS
FOCUS, WITH MORE
THAN 28 MILLION
ABLE-BODIED ADULTS
NOW ENROLLED



2

AT LEAST 21,904 INDIVIDUALS ON

INDIVIDUALS ON MEDICAID WAITING LISTS HAVE DIED IN EXPANSION STATES SINCE OBAMACARE BEGAN



4

POLICYMAKERS MUST ACT SWIFTLY TO ROLL BACK OBAMACARE'S FAILED EXPANSION, INSTITUTE WORK REQUIREMENTS FOR ABLE-BODIED ADULTS, AND STOP WELFARE FRAUD TO PROTECT THE TRULY NEEDY

BOTTOM LINE: THE MEDICAID PROGRAM IS FAILING THOSE IT WAS DESIGNED TO SERVE.
MEDICAID NEEDS REFORM NOW.



## Who are America's forgotten waiting list enrollees?

In 1981, Congress created the home and community-based (HCBS) waiver program. These waivers allow states, if they choose, to extend home- and community-based Medicaid services to individuals who would otherwise qualify for care in a nursing home or institution. Essentially, these waivers allow truly needy individuals on Medicaid to receive additional care they need without being institutionalized.

The waiver programs are comprised of individuals with severe intellectual disabilities, traumatic brain injuries, spinal cord injuries, and mental illnesses, among other debilitating conditions.<sup>2</sup>

Benefits for these vulnerable individuals can include homemaker or home health aide services, personal care, adult day health care, habilitation, respite care, day treatment, psycho-social rehabilitation services, clinic services for individuals with chronic mental illness, and more.<sup>3</sup>

Most states currently operate at least one HCBS waiver program or provide HCBS services through their traditional Medicaid programs.<sup>4</sup> Because these programs are optional, states can limit enrollment. Once enrollment hits its cap, individuals are placed onto waiting lists.

As these individuals continue to wait for needed services—some for more than a decade—states are spending record amounts on Medicaid for able-bodied adults, with many states even expanding the program in recent years to cover even more non-disabled adults.

Every dollar spent on these able-bodied adults is a dollar that cannot go to help America's forgotten waiting list enrollees.

And so they wait. And wait. And wait.



### MEET SKYLAR

Skylar Overman and her family live just outside of Little Rock, Arkansas. Born with a rare neurological condition called Schizencephaly that requires round-the-clock care, 12 year-old Skylar spent more than 10 years on the state's Medicaid waiting list. While Skylar waited, the state enrolled more than 300,000 able-bodied adults in their ObamaCare Medicaid expansion.

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Nearly 250,000 of these individuals live in states that opted to expand Medicaid through ObamaCare to a new class of ablebodied adults.

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#### How bad is the problem?

Nationwide, there are more than 650,000 individuals on Medicaid waiting lists for needed home- and community-based services.<sup>5</sup> These are individuals with severe intellectual disabilities, spinal cord injuries, traumatic brain injuries, severe developmental disabilities, and more. In short, these are the individuals Medicaid was intended to help.

According to the most recent data, 38 states currently have Medicaid waiting lists. Nearly 250,000 of these individuals live in states that opted to expand Medicaid through ObamaCare to a new class of able-bodied adults.

# Nearly 250,000 truly needy individuals continue to wait in ObamaCare expansion states

Total waiting list enrollment as of 2016 in states that expanded Medicaid through ObamaCare

WAITING LIGH

STATE	WAITING LIST ENROLLMENT	
Alaska	535	
Arkansas	3,278	
California	4,088	
Colorado	3,194	
Connecticut	2,903	
Illinois	19,163	
Indiana	1,627	
lowa	8,928	
Kentucky	8,190	
Louisiana	73,929	
Maryland	36,156	
Michigan	3,311	
Minnesota	128	
Montana	1,309	
Nevada	1,372	
New Hampshire	260	
New Mexico	5,401	
North Dakota	3	
Ohio	62,118	
Oregon	134	
Pennsylvania	9,728	
West Virginia	1,540	
TOTAL	247,295	

Source: Kaiser Family Foundation

#### The waiting list death epidemic

The Foundation for Government Accountability has obtained new data from more than a dozen states regarding the death of individuals on Medicaid waiting lists. This information has been largely unavailable to the public until now.

Alarmingly, multiple states claimed to have no knowledge of deaths that have occurred amongst their waiting list members.<sup>8</sup> Some states provided only partial death totals.<sup>9-11</sup> As a result, the findings do not reflect the full magnitude of this crisis.

Data that was provided, however, paints a bleak picture: since ObamaCare expansion began, at least 21,904 individuals on Medicaid waiting lists have died in expansion states.<sup>12-30</sup>

While ObamaCare did not create these waiting lists, it is increasing the likelihood that truly needy individuals will never get the help they need by diverting billions of dollars to able-bodied adults.

In 2017 alone, taxpayers spent \$66.6 billion on ObamaCare Medicaid expansion.<sup>31</sup> States are now paying six percent of these costs—every penny of which could instead go to help the truly needy, including America's forgotten waiting list enrollees.<sup>32</sup>



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#### Since ObamaCare expansion began, at least 21,904 individuals on Medicaid waiting lists have died

ObamaCare expansion enrollment and total waiting list deaths since expansion began, by state

STATE	OBAMACARE EXPANSION ENROLLMENT	WAITING LIST DEATHS
Arkansas	289,428	74
California	3,828,401	384
Illinois	655,307	823
lowa	152,174	989
Kentucky	466,193	38
Louisiana	451,643	5,534
Maryland	291,044	8,495
Michigan	665,057	1,970
Minnesota	206,774	15
Nevada	220,582	304
New Mexico	259,537	2,031
Pennsylvania	705,911	154
West Virginia	181,105	1,093
TOTAL	8,084,097	21,904

The state of Maryland has the highest number of waiting list deaths since their ObamaCare Medicaid expansion began: a staggering 8,495 individuals on the state's waiting list for home- and community-based services have died. These individuals never got the care they needed, but even for individuals who eventually receive care, the wait can be grueling.

According to state officials, the average wait time for an individual to be approved for services is seven years and six months.<sup>33</sup>

What else happened over that same time period? The state enrolled nearly 300,000 able-bodied adults in their ObamaCare expansion, 103 percent more adults than were supposed to ever sign up.<sup>34</sup>This has led to significant cost overruns. In fact, taxpayers have wasted \$4.7 billion on Maryland's ObamaCare expansion, 219 percent more than promised.

While Maryland's expansion continues to spiral out of control, the truly needy are being left behind.



**8,495 DEATHS** 

AVERAGE WAIT TIME: UP TO 7.5 YEARS

When Louisiana Governor John Bel Edwards took office in January 2016, one of his first actions was to unilaterally expand ObamaCare. The expansion officially began on July 1, 2016 and, within the first five months, the state signed up 332,000 able-bodied adults, even though only 302,000 were ever supposed to enroll.<sup>35</sup> As of December 2017, more than 451,000 able-bodied adults are enrolled.<sup>36</sup>

The program is also grossly over budget. Despite promises that this new welfare program would cost just \$1.1 billion in its first year, actual costs have been more than twice that high, coming in at \$2.5 billion.<sup>37</sup>

But over that same time period, as billions were being spent on welfare for able-bodied adults, the Louisiana Department of Health reports that 5,534 individuals on the state's Medicaid waiting list died. The state also reports that individuals on the states' New Opportunities waiting list—individuals who have developmental disabilities—wait up to 2,377 days on average before receiving services. 38



**5,534 DEATHS** 

AVERAGE WAIT TIME: UP TO 6.5 YEARS

## NEW MEXICO

**2,031 DEATHS** 

AVERAGE WAIT TIME: UP TO 10.2 YEARS

New Mexico's ObamaCare expansion began on January 1, 2014. Since that time, the state has spent \$2.8 billion on welfare benefits for at least 259,537 able-bodied adults.<sup>39-40</sup> Both costs and enrollment have far exceeded projections.

But since the state's new welfare program began, at least 2,031 individuals on Medicaid waiting lists have died, never getting the services they needed. While the state was providing benefits for more than 259,000 able-bodied adults, these individuals with critical needs died before ever having those needs met. For individuals who do eventually get care, total waiting time averages 10.2 years, according to the state.

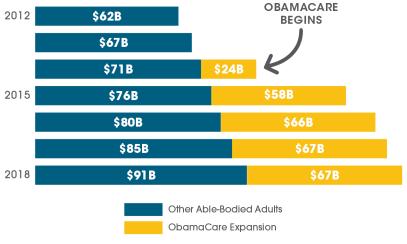
#### How did we get here?

The origins of these problems are not complex. Over time, Medicaid has expanded, losing its focus on the truly vulnerable and instead becoming a catch-all, openended welfare program. Not only have existing populations within Medicaid grown, but new populations have been added—populations that were never intended to be a part of the Medicaid program—leaving fewer and fewer dollars for those who truly need and deserve help.

Over the last two decades in particular, Medicaid spending and enrollment on non-disabled individuals has skyrocketed. In fact, since 2000 alone, spending on ablebodied adults has skyrocketed, now topping \$158 billion per year—an increase of more than 700 percent.<sup>41</sup>

Over that same time period, able-bodied adult enrollment has more than quadrupled, rising from just seven million to more than 28 million.<sup>42</sup>

### MEDICAID SPENDING ON ABLE-BODIED ADULTS MORE THAN DOUBLED AFTER OBAMACARE



Source: Centers for Medicare and Medicaid Services

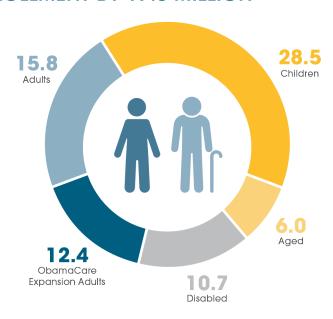
Taxpayers now spend more on Medicaid for able-bodied adults than for seniors or low-income children.<sup>43</sup>

In 2014, ObamaCare's Medicaid expansion to able-bodied, childless adults began and added even more fuel to this fire: states that accepted this expansion have added nearly 13 million new able-bodied adults to Medicaid.<sup>44</sup> There are now two and a half times as many able-bodied adults in Medicaid as there are individuals with disabilities.<sup>45</sup>

Thanks to the combination of these factors, Medicaid now consumes one out of every three dollars in state budgets, compared to just one in five in 2000.46

At the end of the day, the problem is simple: **Medicaid has** lost its focus as a safety net for the truly vulnerable and able-bodied adults are now consuming more and more resources.

## ABLE-BODIED ADULT MEDICAID ENROLLMENT NOW EXCEEDS DISABLED ENROLLMENT BY 17.5 MILLION





Medicaid now consumes 1 out of every 3 dollars in state budgets.

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## THREE STEPS TO FIXING A BROKEN MEDICAID SYSTEM

The challenge policymakers face is straightforward: Medicaid is broken and bloated. While able-bodied adults continue to enroll and receive benefits—with no time limits or work requirements in place—the truly needy are being pushed to the back of the line. Fixing Medicaid should be a top priority for every policymaker in the country and there are three simple things that can be done immediately to right the ship.



#### 5.5 MILLION

able-bodied adults would be freed from welfare within the first year if every expansion state implemented an enrollment freeze.



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## Stop ObamaCare's Medicaid expansion

First and foremost, states that have expanded Medicaid through ObamaCare should immediately begin unwinding these programs through enrollment freezes. Every dollar states spend on Medicaid expansion is a dollar that cannot be spent on individuals like Skylar and others on the waiting list.

Rolling back Medicaid expansion requires one simple step: stopping enrollment. Simply closing the front door in this way would allow existing enrollees to remain on the program until their incomes rise and they exit the program, just as they would anyway. But with enrollment closed, new enrollees would not be able to sign up, and enrollment would immediately begin to decline.

If every expansion state implemented an enrollment freeze, nearly 5.5 million able-bodied adults would be freed from welfare within the first year alone and taxpayers would save at least \$581 billion over ten years—all money that would immediately be freed up for the truly needy.<sup>47-48</sup>

Several states are now pursuing expansion rollbacks. In 2017, the Arkansas House passed a bill to freeze enrollment. Shortly thereafter, the Ohio legislature passed an enrollment freeze and sent it to Governor John Kasich's desk. Other states are now considering freezing enrollment in order to unwind expansion and protect the truly needy.

Federal policymakers have a role to play as well: by stopping new expansions or simply eliminating the enhanced funding that encourages states to cut from the truly needy, Congress can ensure the truly needy in non-

expansion states are protected once and for all.49

If Congress fails to act and all additional non-expansion states opt to expand ObamaCare, annual Medicaid spending on able-bodied adults will surpass spending on the disabled.<sup>50</sup>

## Pursue work for all able-bodied enrollees

The best way to help able-bodied adults get out of welfare and back on their feet is through work requirements. Research has shown that, after work requirements are put into effect, able-bodied adults go back to work in more than 600 different industries and their incomes more than double on average. 51-52

Prior presidential administrations never allowed states to adopt commonsense work requirements, despite their proven success in food stamps and cash welfare.<sup>53</sup> The Trump administration changed that: in January 2018, the Centers for Medicare and Medicaid Services released guidance that allow states to use Medicaid waivers to require able-bodied adults to work, train, or volunteer. Since then, the Administration has approved Medicaid work requirements in Kentucky and Indiana.

More states—expansion and non-expansion states alike—are moving in the same direction, with several states seeking to apply work requirements to virtually all ablebodied adults on Medicaid, not just expansion enrollees.<sup>54</sup>

Medicaid work requirements can help move millions of able-bodied adults from welfare to work. States should continue pursuing them, but Congress should also make it easier for states by cementing Medicaid work requirements into federal law.

### Attack welfare fraud

Waste, fraud, and abuse robs taxpayers and the truly needy of billions of dollars every year. According to the U.S. Department of Health and Human Services, most improper payments in the Medicaid program stem from eligibility errors—individuals enrolled in Medicaid even though they

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may no longer qualify or perhaps never did.55

An Obama-era regulation makes this problem worse, limiting how frequently states can check eligibility and requiring them to automatically re-enroll individuals in many cases. <sup>56</sup> But life changes that effect welfare eligibility—like getting married, changing jobs, moving out of state, or working more hours—do not happen on a yearly calendar. By checking eligibility more frequently and utilizing data they already have—such as wage reports and death records—states can catch welfare fraud much sooner, before it costs taxpayers and the truly needy billions of dollars.

States should do all they can to check eligibility more frequently and with better data. But the Trump administration has the opportunity to make fighting fraud easier by fixing this rule and empowering states to go after bad actors. This would immediately free up more resources for those who truly need help, including individuals trapped on Medicaid waiting lists.

Congress can and should also give states the expressed authority to check eligibility as often as they would like.

# BOTTOM LINE: IT IS TIME TO FIX MEDICAID.

Medicaid has lost sight of its core purpose as a safety net for the truly vulnerable. Over the last few decades in particular, the program has become bloated, enrolling a record number of able-bodied adults who are consuming limited resources. As these adults consume more and more resources, the truly needy are being left behind, many of them dying before ever getting the additional services they need.

In order to restore Medicaid, policymakers must reprioritize and refocus the program on the truly needy. They can do this by stopping ObamaCare's failed Medicaid expansion, empowering individuals through work requirements, and cracking down on welfare fraud. It is time to fix Medicaid.

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- 9. Total waiting list deaths were calculated by adding deaths across multiple waiting lists in some cases. These numbers likely understate the total number of waiting list deaths. For example, the state of Kentucky provided information about six separate waiting lists. The state provided waiting list death total for five of the six categories. The total deaths for the five waiting lists provided were summed for a total of 38 deaths.
- 10. California and Kentucky provided death totals for only some waiting lists.
- 11. While average wait times were requested, not all states supplied this data. Some states provided total average waiting times across all waiting lists. Others provided waiting list times by list. Additionally, some states provided average wait times for some waiting lists and not others. The data from these states is incomplete and does not fully reflect waiting list times. States provided average wait times in a variety of increments, including months and years.
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- 13. Only states that reported waiting list deaths are reflected in the table.
- Alaska's ObamaCare expansion began on September 1, 2015. State officials report that they do not track waiting list deaths.
- 15. Arkansas waiting list deaths reflect total deaths from January 1, 2014, the day the state's ObamaCare expansion began, through March 30, 2016. As a result, total deaths since expansion began are likely understated. Waiting list deaths were provided through Arkansas Legislative Audit.
- 16. California waiting list deaths were reported from January 1, 2014, the day the state's ObamaCare expansion began, through March 31, 2017. Total waiting list deaths were provided for only the Nursing Facility / Acute Hospital Waiver, for a total of 384. California maintains at least two other waivers. The state did not supply death data for its MSSP waiver and reported no deaths as of March 22, 2017 for its Assisted Living Waiver.
- 17. Colorado's ObamaCare expansion began on January 1, 2014. State officials report that they do not maintain data on waiting list deaths. Officials indicated that the state closes cases when an individual passes away, but declined to provide the total number of closures due to death. Colorado did report total waiting list enrollment of 2,592 as of December 2013. As of March 2017, total waiting list enrollment reached 3,193, a net increase of 601 individuals.
- 18. Connecticut's ObamaCare expansion began on January 1, 2014. Connecticut did not supply any information about waiting list deaths in response to a data request.
- 19. Iowa waiting list deaths were reported from January 1, 2014, the date the state's ObamaCare expansion began, to March 22, 2017. The state reported deaths for five waiver waiting lists: brain injury, children's mental health, health and disability, intellectual disability, and physical disability. For the state's children's mental health waiver, the state reported deaths of "less than five." Since an exact number was not given, these deaths were not included in the 989 total deaths for lowa. The state also noted in their response that some individuals who died may have been on multiple waiting lists, which could result in duplicate counting of their deaths.
- 20. Illinois waiting list deaths reflect author's calculations for total deaths from January 9, 2014, the month state's ObamaCare expansion began, to February 9, 2018. Data was provided by the Illinois Department of Human Services. Because the state began tracking waiting list deaths prior to ObamaCare expansion, deaths that had occurred prior to January 2014 were subtracted from the February 2018 total to determine deaths since the month ObamaCare expansion began.
- 21. Kentucky waiting list deaths reflect total deaths since January 1, 2014, when the state's ObamaCare expansion began, to February 2, 2017. The state provided waiting list death totals for three of its four waiting lists. As a result, total waiting list deaths for Kentucky may be understated.
- 22. Louisiana waiting list deaths reflect total deaths since July 1, 2016, when the state's ObamaCare expansion began, to December 31, 2017. The state provided death totals for four waiting lists.
- 23. Maryland waiting list deaths reflect total deaths since January 1, 2014, when the state's ObamaCare expansion began, to February 17, 2017.
- 24. Michigan waiting list deaths reflect total deaths since April 1, 2014, when the state's ObamaCare expansion began, to

- February 2, 2017.
- 25. Minnesota waiting list deaths reflect total deaths since December 1, 2015 to April 1, 2017. While the state's ObamaCare expansion began on January 1, 2014, state officials indicated that they changed the "method of managing home and community-based services waiver waiting lists on December 1, 2015." As a result, total deaths were supplied since December 1, 2015 and are likely understated.
- 26. Nevada waiting list deaths reflect total deaths from January 1, 2014, when the state's ObamaCare expansion began, to March 2017.
- 27. New Mexico waiting list deaths reflect total deaths from January 2014, when the state's ObamaCare expansion began, to February 22, 2017. The state reported an average waiting time of 10.2 years.
- 28. The Ohio Department of Developmental Disabilities declined to provide a number of waiting list deaths.
- 29. Pennsylvania waiting list deaths reflect total deaths from January 1, 2015, when the state's ObamaCare expansion began, to June 7, 2017 when the state supplied the requested totals.
- 30. West Virginia waiting list deaths reflect total deaths for two of the state's three waiting lists from fiscal year 2014, when the state's ObamaCare expansion began, through fiscal year 2016. West Virginia's fiscal year begins on July 1. As a result, the state's death totals may include additional deaths that occurred between July 1, 2013 and January 1, 2014 when the state's ObamaCare expansion officially began.
- 31. Nicholas Horton and Jonathan Ingram, "The future of Medicaid reform: Empowering individuals through work," Foundation for Government Accountability (2017), https://thefga.org/wp-content/uploads/2017/11/The-Future-of-Medicaid-Reform-Empowering-Individuals-Through-Work.pdf.
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