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## Threats to Medicaid and Health Equity Intersection

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## THREATS TO MEDICAID AND HEALTH EQUITY INTERSECTIONS

MARY CROSSLEY\*

### ABSTRACT

*The year 2017 proved politically tumultuous in the U.S. on many fronts, but perhaps none more so than health care. For enrollees in the Medicaid program, it was a “year of living precariously.” Long-promised Republican efforts to repeal the Affordable Care Act also took aim at Medicaid, with proposals to fundamentally restructure the program and drastically cut its federal funding. These proposals provoked pushback from multiple fronts, including formal opposition from groups representing people with disabilities and people of color and individual protesters. Opposition by these groups should not have surprised the proponents of “reforming” Medicaid. Both people of color and people with disabilities carry disproportionate burdens of ill health and face more significant barriers to accessing quality health care than other groups. As a consequence, the Medicaid program is particularly important to both groups.*

*Ultimately, defensive strategies by people with disabilities and people of color helped stymie both the efforts at “repeal and replace” and proposed changes to Medicaid. This successful advocacy raises a question about what other health-related concerns people with disabilities and people of color share. Considering these groups’ interests in contemporary Medicaid policy issues is a good place to start. To that end, this Article explores the relevance of race to states’ Medicaid expansion choices and the vulnerability of community-based services for people with disabilities in the event of funding cuts to Medicaid. I also suggest that marginalized groups may share similar concerns relating to Medicaid policy initiatives in two additional areas: growing interest in Medicaid work requirements and experiments with adopting value-based payment models for Medicaid providers. These are areas where collaborative advocacy may enhance the ability of people of color and people with disabilities to protect their common interests.*

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## I. INTRODUCTION

The year 2017 was politically tumultuous in the U.S. on many fronts, but perhaps none more so than health care. For enrollees in the Medicaid program and their advocates, it was a ‘year of living precariously.’ Long-promised Republican efforts to repeal the Affordable Care Act (ACA) also took aim at Medicaid, the joint federal-state health insurance program for persons with low incomes, with proposals to fundamentally restructure the program and drastically cut its federal funding.

These proposals provoked pushback from legislators and policy analysts and protests from activists.<sup>1</sup> The pushback and protests included formal opposition from groups representing people with disabilities and people of color.<sup>2</sup> They also included many individual protesters who raised their voices against the proposed cuts. Ultimately, threats to Medicaid prompted defensive strategies that stymied both the efforts at “repeal and replace” and proposed changes to Medicaid.<sup>3</sup>

This opposition should not have surprised the proponents of ‘reforming’ Medicaid.<sup>4</sup> Both people of color and people with disabilities carry disproportionate burdens of ill health and face more significant barriers to accessing quality health care than other groups.<sup>5</sup> In the parlance of health researchers, these groups experience health disparities and health care disparities. Although the causes of health disparities are multiple and complex

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1. Michelle Diamant, *Disability Advocates Arrested Protesting Medicaid Cuts*, DISABILITY SCOOP (Sept. 26, 2017), <https://www.disabilityscoop.com/2017/09/26/disability-advocates-arrest-cuts/24213/>.

2. See, e.g., *Statement of National ADAPT on the ACA Repeal Vote*, ADAPT, <https://adapt.org/statement-of-national-adapt-on-the-aca-repeal-vote/> (last visited Feb. 6, 2019); see also *Action Alert: Yet Another Threat to Health Care Coverage*, NAACP (Sept. 23, 2017), <https://www.naacp.org/latest/yet-another-threat-health-care-coverage/>.

3. Janni Lehrer-Stein, *ACA Repeal Round 2 – Disability Advocates Must be Heard*, HILL (Dec. 25, 2017), <https://thehill.com/opinion/healthcare/352268-aca-repeal-round-2-disability-advocates-must-be-heard>.

4. Frank J. Thompson, *Medicaid Rising: The Perils and Potential of Federalism*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE* 208 (Alan B. Cohen et al. eds., Oxford Univ. Press 2015) (noting historical precedent for advocacy groups to rally to Medicaid’s defense, along with service providers who rely on payments from the program); but cf. JAMILA MICHENER, *FRAGMENTED DEMOCRACY: MEDICAID, FEDERALISM, AND UNEQUAL POLITICS* 135 (Cambridge Univ. Press 2018) (noting that “Policy advocacy is rare.”).

5. *Disparities*, HEALTHY PEOPLE 2020 (Feb. 6, 2019), <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities#6>; *Disability and Health Overview*, HEALTHY PEOPLE 2020 (Feb. 6, 2019), <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>.

and effective remedies for racial and disability-based health disparities remain elusive,<sup>6</sup> the Medicaid program is particularly important to both groups.

The repeated thwarting of Republican attempts in 2017 to directly repeal the ACA and decimate Medicaid was in many ways a stunning and unexpected feat.<sup>7</sup> Political scientists in years to come will no doubt attempt to explain exactly what happened, but it seems beyond question that ongoing protests and the vocal advocacy for protecting the Medicaid program played a role in defeating “repeal and replace.” In short, the willingness of people of color and people with disabilities, along with others, to lay their bodies on the line to achieve a shared goal made a difference in preventing the dismemberment of the Medicaid program.

This example of successful advocacy left me wondering about other health-related concerns people with disabilities and people of color might share. Exploring the full range of parallel or shared concerns is a larger project than this Article permits, but considering Medicaid’s importance in responding to the health disparities experienced by both people with disabilities and people of color is a good place to start. That is the point of this Article. Greater understanding of the parallel and intersecting concerns that people with disabilities and people of color have regarding Medicaid holds value as an intellectual endeavor. It may also offer an underappreciated resource by encouraging persons who identify with different communities to recognize their common stake in Medicaid, and that recognition may enable more collaborative and effective advocacy to protect mutual interests in the program.

Part II of this Article will briefly recount the history of the Medicaid program, demonstrating how its coverage has expanded over time despite the program’s enduring vulnerability and (at least in some states) stinginess. In particular, it will describe how the ACA enlarged both Medicaid’s practical scope and its philosophical premise and how, by contrast, Republican proposals in 2017 sought a significant retrenchment of the program’s scope and the federal government’s role in it. Because Republicans controlled both houses of Congress and the White House, passing those proposals should have been easy, but those efforts failed, in part as the result of sustained protests and advocacy by people with disabilities and people of color. Part III explores why those groups have so much at stake in Medicaid, looking first to the health disparities that both groups experience. To explain how threats to Medicaid in 2017 provoked similar responses by people in both communities, Part III also

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6. Kendal Orgera and Samantha Artiga, *Disparities in Health and Health Care: Five Key Questions and Answers*, KAISER FAM. FOUND. 2–3 (2018), <https://www.kff.org/disparities-policy/issue-brief/disparities-in-health-and-health-care-five-key-questions-and-answers/>.

7. Dylan Scott, *Why Senate Republicans Couldn’t Repeal Obamacare*, VOX (July 28, 2017), <https://www.vox.com/policy-and-politics/2017/7/28/16054700/senate-obamacare-repeal-john-mccain-susan-collins-lisa-murkowski>.

considers the relevance of race to states' Medicaid expansion choices and the vulnerability of community-based services for people with disabilities if Medicaid's federal funding were drastically cut. Finally, Part IV will suggest two areas where current Medicaid policy initiatives signal particular importance for marginalized groups like people of color and people with disabilities. These include growing calls for Medicaid work requirements and experiments with adopting value-based payment models for Medicaid providers. These are additional areas where collaborative advocacy may enhance the ability of people of color and people with disabilities to protect their parallel interests.

## II. A MEMOIR OF MEDICAID AT MIDDLE AGE

Medicaid has been a politically vulnerable program since its creation in 1965.<sup>8</sup> It is a program for poor people and is dependent on state tax revenues for a portion of its funding.<sup>9</sup> One scholar suggests that it is “often viewed as a down-at-the-heels second cousin to Medicare.”<sup>10</sup> For these reasons, the political support of Medicaid has not historically been as widespread or deep as it has been for Medicare. The shortfalls in tax revenue that occur during economic downturns have often prompted states to cut Medicaid programs at the very time when their residents who have little means need the program the most.<sup>11</sup> As health law scholar Timothy Jost wrote in 2003: “a program for the poor will always be politically vulnerable, underfunded, and generally inadequate.”<sup>12</sup> Briefly reviewing Medicaid's evolution over the fifty-plus years since its creation, however, may help illuminate how Medicaid has become much more than a program of “welfare medicine” while retaining programmatic elements that mean it still provides coverage disproportionately for marginalized populations.<sup>13</sup>

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8. Judith D. Moore & David G. Smith, *Legislating Medicaid: Considering Medicaid and Its Origins*, 27 HEALTH CARE FINANCING REV. 45, 45 (2005).

9. *Medicaid*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/index.html> (last visited Feb. 6, 2019).

10. Thompson, *supra* note 4, at 191.

11. STAN DORN ET AL., KAISER COMMISSION ON MEDICAID AND THE UNINSURED, EXECUTIVE SUMMARY ON MEDICAID, SCHIP AND ECONOMIC DOWNTURN: POLICY CHALLENGES AND POLICY RESPONSES 5 (2008).

12. TIMOTHY JOST, *DISENTITLEMENT?: THE THREATS FACING OUR PUBLIC HEALTH-CARE PROGRAMS AND A RIGHTS-BASED RESPONSE* 178 (Oxford Univ. Press 2003).

13. *Medicaid: No Longer the Welfare Medicine Afterthought*, COLUMBIA U. MAILMAN SCH. PUB. HEALTH (July 9, 2015), <https://www.mailman.columbia.edu/public-health-now/news/medicaid-no-longer-welfare-medicine-afterthought>.

### A. *Medicaid's Birth and Growth*

To some extent, Medicaid is by definition a program for marginalized groups in U.S. society.<sup>14</sup> When Congress created Medicare and Medicaid in 1965, it understood the latter program as a descendant of the Elizabethan Poor Laws.<sup>15</sup> Medicaid was to provide for those “deserving poor” who could not be expected to contract health insurance through employment or otherwise.<sup>16</sup> In its initial incarnation, Medicaid covered persons who, by virtue of their poverty, were categorically eligible for cash assistance programs based on old age, blindness, or child dependency.<sup>17</sup> In 1972, the groups comprising the ‘categorically eligible’ grew to include persons with disabilities when Congress created Supplemental Security Income (SSI), a new, purely federal cash assistance program for the aged, blind, and disabled, and made receipt of SSI payments a basis for Medicaid eligibility.<sup>18</sup> The essential point is that Medicaid eligibility was firmly connected to the receipt of cash “welfare” benefits—hence the original conception of Medicaid as “welfare medicine.”<sup>19</sup>

Medicaid’s origin story also involved racial politics. Its predecessor program for “medically indigent” senior citizens, the Kerr-Mills “Medical Assistance for the Aged” program, was designed to be jointly funded by the federal and state governments but administered by the states.<sup>20</sup> Delegating implementation authority to the states permitted control by Southerners concerned about racial dynamics.<sup>21</sup> States’ responsibility to implement and administer was carried over to Medicaid.<sup>22</sup> This feature gives states substantial flexibility to adapt the program to state-level needs and values (taking a ‘glass-half-full’ perspective)

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14. *See Medicaid*, *supra* note 9.

15. David Orentlicher, *Medicaid at 50: No Longer Limited to the “Deserving” Poor?*, 15 *YALE J. HEALTH POL’Y, L., & ETHICS* 185, 185 (2015).

16. *Id.*

17. Jill Quadagno, *The Transformation of Medicaid from Poor Law Legacy to Middle Class Entitlement?*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE* 78 (Alan B. Cohen et al. eds., Oxford Univ. Press 2015) (listing programs).

18. Thompson, *supra* note 4, at 194.

19. *Id.* at 193.

20. Moore & Smith, *supra* note 8, at 45–46, 48.

21. Julian E. Zelizer, *The Contentious Origins of Medicare and Medicaid*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE* 3, 9 (Alan B. Cohen et al. eds., Oxford Univ. Press 2015). By contrast, some have argued that pressure from the civil rights movement contributed to the ultimate passage of the legislation that included both Medicare (a purely federal program) and Medicaid. *But cf.* David Barton Smith, *The Contentious Origins of Medicare and Medicaid*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE* 21, 26–27, 35 (Alan B. Cohen et al. eds., Oxford Univ. Press 2015) (suggesting that pressure from the civil rights movement contributed to the ultimate passage of the legislation that included both Medicare (a purely federal program) and Medicaid).

22. Moore & Smith, *supra* note 8, at 47–48.

and ideologies and prejudices (from a ‘glass-half-empty’ perspective). It explains why Medicaid programs—and recipients’ experience of Medicaid—can vary so greatly from state to state.<sup>23</sup>

Over time, Medicaid grew (via legislative amendment) to cover other groups like pregnant women, and the connection to receiving welfare benefits became more attenuated.<sup>24</sup> When Congress delinked Medicaid eligibility from the receipt of welfare benefits, the requirements of impoverishment became less stringent—at least for federal requirements.<sup>25</sup> By augmenting the flow of federal funds to permit states to insure low-income children and their uninsured parents, the creation of the State Children’s Health Insurance Program (CHIP) in 1997 further diluted the link between welfare programs and Medicaid, both programmatically and in the minds of the public.<sup>26</sup>

Beyond Congress’s incremental expansions of the groups eligible for Medicaid coverage, another important chapter in Medicaid’s evolution lies in the emergence of administrative waivers permitting states to deviate from Medicaid’s statutory rules.<sup>27</sup> In short, Congress delegated to the Secretary of Health and Human Services (HHS) authority to allow states to pursue initiatives in their own Medicaid programs that do not fit the federal statutory mold. The two most consequential types of waivers have been those permitting states to implement demonstration projects to test alternative ways to pursue Medicaid program objectives (§ 1115 waivers) and those allowing states to shift their Medicaid funding for long-term care away from institutional care and towards care provided in recipients’ homes or the community (§ 1915(c) waivers).<sup>28</sup> These waivers are relevant to discussions below, but for now the key point is that the waiver mechanism grants states significant flexibility in implementing the Medicaid program, subject to oversight by the executive branch.<sup>29</sup> As a result, many of the changes to the Medicaid program over the past three decades have occurred without congressional involvement.<sup>30</sup>

Despite incremental expansions in its first several decades, Medicaid retained some taint of welfarism and second-class status (particularly compared to its highly esteemed twin, Medicare). State budgetary concerns, mixed with lingering stigma attached to the program, produced aspects of state

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23. See generally MICHENER, *supra* note 4.

24. For example, in the 1980s Congress initially gave states the option of covering children and pregnant women with incomes too high to receive welfare benefits. Congress later proceeded to require states to cover those groups. Thompson, *supra* note 4, at 195.

25. Quadagno, *supra* note 17, at 79.

26. *Id.* at 80 (noting that CHIP “moved Medicaid even further beyond its poor law legacy”).

27. *About Section 1115 Demonstrations*, MEDICAID.GOV, <https://www.medicaid.gov/medicaid/section-1115-demo/about-1115/index.html> (last visited Feb. 6, 2019).

28. Thompson, *supra* note 4, at 197.

29. *About Section 1115 Demonstrations*, *supra* note 27.

30. See Thompson, *supra* note 4, at 197 (describing a pattern of “executive federalism”).

implementation that might appear as either fiscally responsible (from the perspective of conservatives and state budget directors) or downright stingy (from the perspective of liberals and Medicaid recipients). State income eligibility thresholds for low-income parents provide a prime example. Before the ACA expansion, many states imposed income thresholds well below the poverty level for parents.<sup>31</sup> For example, in Arkansas in 2009, the threshold was seventeen percent of the federal poverty level,<sup>32</sup> meaning that parents of a child covered by Medicaid, though theoretically eligible for Medicaid coverage, would earn too much to receive Medicaid coverage if they earned \$18,310 annually.<sup>33</sup>

Another manifestation of state stinginess is found in how states pay (or ‘reimburse’) the health care providers who treat Medicaid enrollees. Payment methods and levels are largely left up to the states, and the payment levels for the Medicaid program are notoriously low.<sup>34</sup> As a result, physicians may refuse to treat patients covered by Medicaid, leaving enrollees in some localities with few physicians willing to provide services.<sup>35</sup> Where they exist, community health centers offer a reliable source of care for Medicaid recipients. But concentrating beneficiaries in the practices of the subset of providers willing to treat Medicaid patients, coupled with the resentment that low payment rates provoke even among some of those providers, reinforce a perception of Medicaid as second-tier health care.<sup>36</sup>

In contrast to Medicare, whose coverage of senior citizens over time altered that group’s self-perception and led to its emergence as a center of political power with “a unitary social identity,”<sup>37</sup> Medicaid’s evolution has crafted more

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31. *Medicaid Income Eligibility Limits for Parents, 2002–2018*, KAISER FAM. FOUND., <https://www.kff.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-parents/?currentTimeframe=0&sortModel=%7B%22colId%22:%22January%202013%22,%22sort%22:%22asc%22%7D> (last visited Feb. 5, 2019).

32. *Id.*

33. *2009 HHS Poverty Guidelines*, U.S. DEP’T HEALTH & HUM. SERVS. (Dec. 1, 2009), <https://aspe.hhs.gov/2009-hhs-poverty-guidelines>.

34. Jayne O’Donnell & Laura Ungar, *Medicaid Turns 50 Mired in Controversy*, USA TODAY (July 15, 2017), <https://www.usatoday.com/story/news/2015/07/15/medicaid-expansion-effect-on-patients-taxpayers-states-hospitals/25612707/>.

35. *Id.*

36. Thompson, *supra* note 4, at 200–01; see also Nicole Huberfeld, *The Universality of Medicaid at Fifty*, 15 YALE J. HEALTH POL’Y, L., & ETHICS 67, 71 (2015) (referring to Medicaid’s “welfare-related stigma and such signifiers of lower status as the minimal reimbursement rates states paid to participating providers”).

37. Alan B. Cohen et al., *Introduction: Medicare, Medicaid, and the Moral Test of Government*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE* xvi (Alan B. Cohen et al. eds., Oxford Univ. Press 2015) (describing chapter written by Mark Schlesinger’s); see also Mark Schlesinger, *Medicare and the Social Transformations of American Elders*, in *MEDICARE AND MEDICAID AT 50: AMERICA’S*



of a patchwork quilt, covering groups who may not otherwise have much—other than their low incomes—in common. The largest number of Medicaid enrollees are low-income white children and their parents.<sup>38</sup> But because of the close connection in the U.S. between race and class, over time people of color have become disproportionately represented in Medicaid enrollment.<sup>39</sup> People with disabilities, who are disproportionately poor and are considered to be among the ‘deserving poor,’ also figure prominently in Medicaid policy discussions. In many instances, Medicaid recipients may share interests in the program regardless of their race or disability status. As this Article will demonstrate, however, in other instances the particular marginalization of people of color and people with disabilities at times gives them distinctive and shared concerns.

### B. *The ACA’s Medicaid Expansion*

Between the federal policies driving Medicaid’s growth and the devolution of implementation and policy authority to the states, the program’s first forty-five years were characterized by tensions between the program’s growth to cover more people and its hard-to-shake image as welfare medicine.<sup>40</sup> Despite these tensions, Medicaid grew to become an important “pillar in the American health care system.”<sup>41</sup> According to one scholar, the ACA “inaugurated a new era for Medicaid,”<sup>42</sup> which functioned as the health reform legislation’s “key mechanism to move toward universal coverage.”<sup>43</sup> In this “new era,” Medicaid appeared to finally attain the status of social insurance.<sup>44</sup> Any sense of Medicaid triumphalism proved premature, however, as the politics around Medicaid have been particularly contentious in the past decade since the ACA’s enactment.

The ACA, as enacted, required states to expand eligibility for their Medicaid programs to include all non-elderly adults with family income of up to 133% of the federal poverty level, regardless of whether they fell into one of the traditional coverage groups.<sup>45</sup> As a consequence, low-income, childless, non-disabled adults would become eligible to receive health coverage through Medicaid in all states. In addition, states whose pre-ACA income thresholds for

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ENTITLEMENT PROGRAMS IN THE AGE OF AFFORDABLE CARE 119, 122 (Alan B. Cohen et al. eds., Oxford Univ. Press 2015) (describing Medicare’s emergence as the new “third rail” in politics).

38. KAISER FAMILY FOUND., HEALTH COVERAGE BY RACE AND ETHNICITY: THE POTENTIAL IMPACT OF THE AFFORDABLE CARE ACT 6 (2013), <https://kaiserfamilyfoundation.files.wordpress.com/2014/07/8423-health-coverage-by-race-and-ethnicity.pdf>.

39. *Id.*

40. *See generally*, Thompson, *supra* note 4.

41. *Id.* at 207; Huberfeld, *supra* note 36, at 72 (noting that Medicaid, even prior to the ACA’s enactment, “financed the most health care of any payor, public or private. . .”).

42. Quadagno, *supra* note 17, at 81.

43. *Id.* at 78.

44. *Id.* at 81.

45. Huberfeld, *supra* note 36, at 72.

Medicaid had been particularly low for parents would have to raise their thresholds to the ACA-required level.<sup>46</sup> Beyond expanding the groups eligible for Medicaid and increasing income thresholds, the ACA also required states to include as covered services for the expansion population (*i.e.*, the persons newly eligible for Medicaid coverage) the ACA's ten categories of essential health benefits.<sup>47</sup> To make this strong medicine more palatable to the states, the federal government would assume a much larger share of the cost of covering the expansion population.<sup>48</sup>

A 2012 challenge to the constitutionality of the Medicaid expansion, however, disrupted the ACA's legislative plan. In *NFIB v. Sebelius*, the Supreme Court held unconstitutionally coercive the ACA's requirement that states expand their Medicaid program or risk losing federal matching funds for their entire Medicaid program.<sup>49</sup> The judicial disruption of the expansion was not complete, though. The Court did not strike down the ACA's expansion provision but instead recast it as optional rather than mandatory.<sup>50</sup> In short, post-*NFIB*, it has been up to states to decide whether to implement the Medicaid expansion.

Because *NFIB* left states free to expand their Medicaid programs or not, the Obama administration found itself in the position of trying to persuade some (typically conservative-leaning) states to expand so that the ACA's coverage goals might be achieved. That persuasion included a willingness to negotiate with states that proposed to expand Medicaid coverage in conjunction with a § 1115 waiver, even when those proposals included more conservative and market-oriented elements, like permitting the use of federal funds to help expansion enrollees to purchase private health insurance.<sup>51</sup> This connection of Medicaid to private health insurance markets may signal a "process of fundamental transformation"<sup>52</sup> of Medicaid, moving it further from its poor law

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46. *See id.*

47. *See* Patient Protection and Affordable Care Act § 1302, 42 U.S.C. § 18022 (2012).

48. *See Policy Basics: Introduction to Medicaid*, CTR. ON BUDGET & POL'Y PRIORITIES (Aug. 16, 2016), <https://www.cbpp.org/research/health/policy-basics-introduction-to-medicaid> (explaining that for the first three years of the expansion (2014–2016), the federal government will be responsible for 100% of the costs of Medicaid of newly eligible enrollees. After 2016, the federal share would decline to ninety percent in 2020. By contrast, the federal government pays a much smaller share of the Medicaid costs of traditional enrollees, paying seventy-three percent of Medicaid costs in the poorest states, with the national average of federal cost-share falling between fifty-seven percent and sixty percent.).

49. *See Nat'l Fed'n of Indep. Bus. v. Sebelius*, 567 U.S. 519, 689 (2012).

50. *Id.* at 523.

51. *See Premium Assistance in Medicaid and CHIP: An Overview of Current Options and Implications of the Affordable Care Act*, KAISER FAM. FOUND. 1 (2013), <https://kaiserfamilyfoundation.files.wordpress.com/2013/03/8422.pdf>; Quadagno, *supra* note 17, at 85; Thompson, *supra* note 4, at 206.

52. Quadagno, *supra* note 17, at 85.

roots. And the fact such changes are occurring in some states but not others augments the variability among state programs.<sup>53</sup>

States' expansion decisions are consequential—both to their low-income residents and to the health care providers who serve them. Expansion decisions are also consequential with regards to health care disparities. As of late 2018, thirty-seven states (including D.C.) have chosen to expand their Medicaid programs, and fourteen states have not.<sup>54</sup> Arguments against expanding Medicaid are often political and budgetary in nature. State leaders may be skeptical that the federal government will honor its legislative commitment to shoulder the vast majority of the costs of the expansion and may point to the budgetary impact on state coffers. Not surprisingly, the states that have so far refused to expand are 'red' states, with Republican-dominated statehouses and governors, and their decisions have tended to be highly partisan and ideological in nature.<sup>55</sup> They are also states where uninsured people living in or near poverty—the people who would benefit from expanding Medicaid—are disproportionately black and brown.<sup>56</sup> The racial dynamics of Medicaid expansion decisions are hard to miss, and, as discussed below in Part III, some scholars have begun exploring those dynamics.

In sum, by 2016, when the election put Republicans in control of Congress and the White House, the Medicaid program had evolved significantly from its 1965 “welfare medicine” origins toward something that resembled a social insurance program. That evolution, however, varied significantly from state to state in terms of pace and extent.

### C. *Republican Proposals to Contract and Restructure Medicaid*

The first major legislative target of the Republican-controlled Congress once President Trump took office was the ACA, including its Medicaid expansion.<sup>57</sup>

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53. See, e.g., *id.* (discussing the variations in Medicaid programs that state waivers have allowed in such states as Arkansas, Iowa, and Pennsylvania).

54. *Status of State Medicaid Expansion Decisions*, KAISER FAM. FOUND. (Jan. 23, 2019), <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.

55. See Thompson, *supra* note 4, at 204, 207 (describing the highly partisan and ideological nature of states' decisions whether to take up the Medicaid expansion, or what the author calls a “vertical partisan coalition in which state policymakers face pressure to act as loyal party members in the implementation process. The partisan identities of state policymakers drive their behavior more than pragmatic policy and administrative considerations about the advantages and disadvantages of a federal program for their jurisdictions.”).

56. See Rachel Garfield et al., *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid*, KAISER FAM. FOUND. 3 (2018), <https://www.kff.org/medicaid/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid/>.

57. Maggie Haberman & Robert Pear, *Trump Tells Congress to Repeal and Replace Health Care Law 'Very Quickly'*, N.Y. TIMES (Jan. 10, 2017), <https://www.nytimes.com/2017/01/10/us/repeal-affordable-care-act-donald-trump.html>.

After promising for years to repeal ‘Obamacare,’ the Republicans’ focus surprised no one. Only marginally less predictable was their attempt to fundamentally restructure Medicaid by turning over greater control of the program to the states and dramatically slashing future federal funding.<sup>58</sup> Republican efforts to transform Medicaid into a block grant program go back at least as far as the 1990s.<sup>59</sup> Although the precise details of the Medicaid-related provisions evolved as Congress debated health care bills over the spring, summer, and fall of 2017, the proposals shared key elements.

First, as might be expected in ACA repeal legislation, the proposals either cut federal financial support for the Medicaid expansion or terminated it altogether.<sup>60</sup> For example, the American Health Care Act, which the House passed in March 2017, would have eliminated the expansion option for states that had not yet taken up that option.<sup>61</sup> In addition, that bill called for ending the enhanced federal match. Starting in 2020, rather than paying ninety percent of costs for enrollees in the expansion population (as provided in the ACA), the federal government would pay only its regular federal Medicaid match for those enrollees.<sup>62</sup> Enacting this bill would have meant that states still considering expansion would lose that opportunity.<sup>63</sup> In addition, it would have forced states that already expanded their programs to cover millions of additional low-income persons either to shoulder far more of the cost or to contract program eligibility standards, leading to loss of coverage.<sup>64</sup>

The Republicans’ 2017 health care proposals went beyond ending the ACA’s Medicaid expansion and included provisions that would have fundamentally altered the federal government’s responsibility for the Medicaid program.<sup>65</sup> The motivating principle was to shift greater authority regarding Medicaid eligibility,

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58. See Shefali Luthra, *Everything You Need to Know About Block Grants—The Heart of GOP’s Medicaid Plans*, KAISER HEALTH NEWS (Jan. 24, 2017), <https://khn.org/news/block-grants-medicaid-faq/>.

59. See Thompson, *supra* note 4, at 196, 199 (discussing Republican efforts to transform Medicaid into a block grant program during the Clinton Administration and Republicans’ attempts following the 2010 midterms “to repeal the ACA, to derail its implementation, and to eviscerate funding for Medicaid.”).

60. EDWIN PARK ET AL., CTR. ON BUDGET & POL’Y PRIORITIES, HOUSE REPUBLICAN PROPOSALS TO RADICALLY OVERHAUL MEDICAID WOULD SHIFT COSTS, RISKS TO STATES 1 (2017), <https://www.cbpp.org/sites/default/files/atoms/files/2-24-17health2.pdf>.

61. H.R. 1628, 115th Cong. (2017).

62. See Julia Paradise, *Restructuring Medicaid in the American Health Care Act: Five Key Considerations*, KAISER FAM. FOUND. 2 (2017), <https://www.kff.org/medicaid/issue-brief/restructuring-medicaid-in-the-american-health-care-act-five-key-considerations/>.

63. MATT BROADDUS & EDWIN PARK, CTR. ON BUDGET AND POL’Y PRIORITIES, HOUSE REPUBLICAN HEALTH BILL WOULD EFFECTIVELY END ACA MEDICAID EXPANSION 1 (2017), <https://www.cbpp.org/sites/default/files/atoms/files/6-6-17health.pdf>.

64. *Id.* at 1–2.

65. Paradise, *supra* note 62, at 1.

coverage, and operations to the states, while limiting the federal government's financial obligations. A component common to the proposals was the capping of federal funding for each state's Medicaid program, a sharp departure from the existing model where the federal government matches (according to a formula) each state's spending on Medicaid without any pre-determined limit.<sup>66</sup> To illustrate, imagine federal funding as a water supply for Medicaid. Since Medicaid's creation in 1965, federal Medicaid funding has been a spigot that continues to flow as long as the state continues to spend on Medicaid recipients' needs in accordance with federal conditions. By contrast, federal funding under the Republican proposals could be visualized as buckets of water for each state that—once emptied—would remain dry until the delivery of the next year's bucket. And, to continue the metaphor, the gap between the states' water needs and federal water supplies would have increased over time. Proposals varied regarding whether federal funding would be established on a capped per enrollee basis or as a block grant to the state, but they consistently limited the growth in federal funding provided to a predetermined inflation rate, leaving the gulf between funding and need growing over time. The effect would be \$834 billion less in federal Medicaid spending from 2017 to 2026 according to a Congressional Budget Office projection.<sup>67</sup>

Advocates highlighted that, under the proposals, states would enjoy greater leeway in structuring their Medicaid programs with respect to benefits, payment, and eligibility.<sup>68</sup> Republican bills would have trimmed back conditions on states' receipt of Medicaid funding and increased states' ability to impose work requirements or drug testing on recipients.<sup>69</sup> In short, going forward, states' funding would be capped but would have fewer strings attached. Critics of the proposals, however, worried about how funding caps would limit states' capacity to adapt to changing needs, such as the increased demands for treatment associated with the opioid addiction epidemic, natural disasters, or an aging population.<sup>70</sup> Enacting the proposed legislation should have been a straightforward task given Republicans' control of both houses of Congress and the White House. Yet repeated attempts at passage failed.<sup>71</sup> Many factors were

66. PARK ET AL., *supra* note 60, at 5.

67. CONG. BUDGET OFFICE, COST ESTIMATE H.R. 1628 AMERICAN HEALTH CARE ACT OF 2017 tbl.3 (2017), <https://www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/hr1628aspassed.pdf>

68. Gary Claxton et al., *State Flexibility to Address Health Insurance Challenges Under the American Health Care Act, H.R. 1628*, KAISER FAM. FOUND. 1–3 (2017), <https://www.kff.org/health-reform/issue-brief/state-flexibility-to-address-health-insurance-challenges-under-the-american-health-care-act-h-r-1628/>.

69. H.R. 1628, 115th Cong. (2017).

70. Haeyoun Park, *Republicans' Changes to Medicaid Could Have Larger Impact Than Their Changes to Obamacare*, N.Y. TIMES (Mar. 7, 2017), <https://www.nytimes.com/interactive/2017/03/07/us/politics/medicaid-reform-impact-on-states.html?auth=login-smartlock>.

71. See also PARK ET AL., *supra* note 60, at 7.

at play, but the sustained and vocal protests by people with disabilities, people of color, and others doubtless played a role. Why was preserving Medicaid so important to those groups? The next Part explores that question.

### III. HEALTH DISPARITIES AND MEDICAID

To be sure, proposed Republican cuts to Medicaid threatened harm to all persons enrolled in or eligible for Medicaid.<sup>72</sup> Recipients who were disabled or members of a minority group feared the same potential harms that any Medicaid recipient might. Decreased federal funding and an end to the open-ended federal match of state Medicaid spending would leave all enrollees vulnerable to predicted cuts in covered benefits and heightened challenges in accessing providers if states reduced reimbursement.<sup>73</sup> These concerns, while broadly shared by Medicaid enrollees, loomed especially large for people of color and people with disabilities because of those groups' disproportionate representation among Medicaid enrollees.<sup>74</sup> Moreover, black Americans were

72. Julie Rovner, *Timeline: Despite GOP's Failure To Repeal Obamacare, The ACA Has Changed*, KAISER HEALTH NEWS (Apr. 5, 2018), <https://khn.org/news/timeline-roadblocks-to-affordable-care-act-enrollment/>.

73. BROADDUS & PARK, *supra* note 63, at 1 n.1.

74. Although whites constitute the largest group of Medicaid enrollees, the Medicaid program is of particular importance to people with disabilities and racial and ethnic minority groups, both of which are disproportionately represented in the Medicaid population. Although Blacks and Hispanics made up twelve percent and eighteen percent, respectively, of the U.S. population in 2016, they represented eighteen percent and thirty percent of non-elderly enrollees in Medicaid in the same time period. *Population Distribution by Race/Ethnicity*, KAISER FAM. FOUND., <https://www.kff.org/other/state-indicator/distribution-by-raceethnicity/?currentTimeframe=0&selectedDistributions=white—black—hispanic&selectedRows=%7B%22wrapups%22:%7B%22united-states%22:%7B%7D%7D%7D&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (last visited on Feb. 9, 2019); *Distribution of the Nonelderly with Medicaid by Race/Ethnicity*, KAISER FAM. FOUND., <https://www.kff.org/medicaid/state-indicator/distribution-by-raceethnicity-4/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (last visited on Feb. 9, 2019). In 2013, the respective percentages of the entire Medicaid population were twenty-one percent and twenty-five percent. *Medicaid Enrollment by Race/Ethnicity*, KAISER FAM. FOUND., <https://www.kff.org/medicaid/state-indicator/medicaid-enrollment-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (last visited on Feb. 9, 2019).

Because of the lack of consistent data collection regarding recipients' disability and Medicaid's multiple eligibility pathways, it is more challenging to state with confidence the precise number or percentage of Medicaid enrollees who have a disability. In 2015, more than ten million non-elderly persons with disabilities qualified for Medicaid coverage based on their disability, constituting about fifteen percent of beneficiaries. The program, however, also covers many disabled people who qualified for coverage based on their poverty. For example, elderly persons living in poverty qualify for Medicaid based on their age and poverty, but they may also be living with a disability. See MOLLY O'MALLEY WATTS ET AL., KAISER FAM. FOUND., *MEDICAID FINANCIAL ELIGIBILITY FOR SENIORS AND PEOPLE WITH DISABILITIES IN 2015* 1, 10 (2016), <http://files.kff.org/attachment/report-medicaid-financial-eligibility-for-seniors-and-people-with->

disproportionately represented in states that, for a combination of reasons, were less equipped to handle Medicaid funding cuts.<sup>75</sup>

Medicaid cuts also threatened to exacerbate the health-related inequity already experienced by persons in these groups. Medicaid covers a broader range of benefits and services than other forms of health insurance, and some of those benefits may help address social determinants of health and vulnerabilities that contribute to the health disparities described below. In addition, the health disadvantages experienced by people with disabilities and people of color translate into higher levels of need for the medical services that Medicaid funds.<sup>76</sup> Thus, public funding of Medicaid is particularly important to people of color and people with disabilities. Fully appreciating why that is requires an understanding of the health disparities experienced by people of color, by people with disabilities, as well as the under-examined intersection of the two.

#### A. *Health Disparities*

The phrase ‘health disparities’ refers to differences in health existing between different groups of people but does not encompass all possible differences. Instead, the term has come to mean differences associated with socioeconomic disadvantages experienced by groups who have historically

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disabilities-in-2015; *Health Care Experiences of Adults with Disabilities Enrolled in Medicaid Only: Findings from a 2014–2015 Nationwide Survey of Medicaid Beneficiaries*, MEDICAID.GOV 1–2, 14 (2017), <https://www.medicaid.gov/medicaid/quality-of-care/downloads/performance-measurement/namcahpsdisabilitybrief.pdf>; cf. L. KRAUSE ET AL., REHAB. RESEARCH & TRAINING CTR. ON DISABILITY STATISTICS & DEMOGRAPHICS, 2017 DISABILITY STATISTICS ANNUAL REPORT 2 (2018), [https://disabilitycompendium.org/sites/default/files/user-uploads/2017\\_AnnualReport\\_2017\\_FINAL.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/2017_AnnualReport_2017_FINAL.pdf) (finding that 35.2% of persons aged sixty-five or older had a disability in 2017). Similarly, estimates of the percentage of the U.S. population with disabilities vary widely, from 12.6% to nearly 20%. Kristen Bialik, *7 Facts About Americans with Disabilities*, PEW RES. CTR. (July 27, 2017), <http://www.pewresearch.org/fact-tank/2017/07/27/7-facts-about-americans-with-disabilities/>; see MATTHEW W. BRAULT, U.S. DEP’T OF COMMERCE, AMERICANS WITH DISABILITIES: 2010 4 (2012), <https://www.census.gov/library/publications/2012/demo/p70-131.html>. Regardless of the precise numbers, the range of health-related services that Medicaid covers makes the program particularly valuable in meeting the broad-ranging needs of many people with disabilities. In comparison to private health insurance plans, Medicaid covers a broader swath of services that are particularly valuable to the functioning and independence of people with disabilities. Robin Rudowitz & Rachel Garfield, *10 Things About Medicaid: Setting the Facts Straight*, KAISER FAM. FOUND. 4–5 (2018), <http://files.kff.org/attachment/Issue-Brief-10-Things-to-Know-about-Medicaid-Setting-the-Facts-Straight>.

75. Lola Fadulu, *The Republicans’ Medicaid Cuts, if They Pass, will Disproportionately Hurt Black Americans*, QUARTZ (June 29, 2017), <https://qz.com/1016185/bcra-health-care-reform-the-republicans-medicaid-cuts-would-disproportionately-hurt-black-americans/> (relying on Kaiser Family Foundation study that identified eleven “high risk” states and asserting that of those eleven states, five were among the ten states with the highest percentage of black residents).

76. Michael R. Ulrich, *Challenges for People with Disabilities Within the Health Care Safety Net*, HEALTH AFF. (Nov. 18, 2014), <https://www.healthaffairs.org/doi/10.1377/hblog20141118.042813/full/>.

suffered discrimination or exclusion.<sup>77</sup> Thus, health disparities raise social justice concerns; they reflect inequity relating to health and health care.<sup>78</sup>

The field of public health increasingly has understood health disparities and health equity as among its central concerns. In short, public health not only seeks to raise the level of the population's health overall; it also works to address imbalances in the distribution of good health among different populations.<sup>79</sup> Eliminating health disparities has also emerged as a significant health policy goal in the U.S., consistently appearing among the objectives of HHS's Healthy People plans.<sup>80</sup>

### 1. Racial Health Disparities

Racial health disparities<sup>81</sup> first came to the federal government's attention in the mid 1980s when a report shone a light on their existence. In the following decades, policy makers, researchers, and health care professionals have devoted increasing focus, energy, and resources to understanding and addressing racial health disparities.<sup>82</sup> Researchers have documented these disparities, probed their

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77. Paula Braveman, *What are Health Disparities and Health Equity? We Need to be Clear*, 129 PUB. HEALTH REP. 5, 6 (2014).

78. *Id.* at 6. The scope of what the phrase "health disparities" encompasses may vary somewhat by context, but the term generally refers broadly to population level differences between demographic groups in measurements of health status, particular health outcomes, and the access to, utilization of, and quality of care. See Olivia Carter-Pokras & Claudia Baquet, *What is a "Health Disparity"?*, 117 PUB. HEALTH REP. 426, 431 (2002). "Health care disparities," by contrast, refer to differences in access to health care, the level and type of health care received, and insurance coverage. Thus, health care disparities are a subset of the broader category of health disparities. For example, differences in the percentage of patients with breast cancer receiving breast-conserving surgery would be a health care disparity, while differences in mortality rates for persons with breast cancer would be a health disparity. For brevity's sake, I will generally use the term "health disparities" to comprise both concepts unless specific reference to health care disparities is important.

79. *Disparities*, *supra* note 5.

80. *Health Objectives for the Nation Healthy People 2000: National Health Promotion and Disease Prevention Objectives for the Year 2000*, 39 CTRS. FOR DISEASE CONTROL & PREVENTION MORBIDITY MORTALITY WKLY. REP. 689, 695-97 (1990), <https://www.cdc.gov/mmwr/preview/mmwrhtml/00001788.htm>; *Healthy People 2020*, CTRS. FOR DISEASE CONTROL & PREVENTION, [https://www.cdc.gov/nchs/healthy\\_people/hp2020.htm](https://www.cdc.gov/nchs/healthy_people/hp2020.htm) (last visited Feb. 13, 2019) (identifying "eliminat[ing] health disparities" as one of "two overarching goals"); *Disparities*, *supra* note 5 (stating that Healthy People 2020's goal has expanded "to achieve health equity, eliminate disparities, and improve the health of all groups.").

81. MARGARET M. HECKLER, REPORT OF THE SECRETARY'S TASK FORCE ON BLACK AND MINORITY HEALTH 82 (1985), <http://health-equity.lib.umd.edu/3005/1/ANDERSON.pdf>.

82. See POVERTY & RACE RESEARCH ACTION COUNCIL, ORGANIZING TO ADDRESS MINORITY HEALTH DISPARITIES: A DIRECTOR OF STATE AND LOCAL INITIATIVES 25, 27 (2008), <https://prrac.org/pdf/HealthDirectory.pdf>.



causes, and traced their trajectories.<sup>83</sup> Yet the efforts have produced only limited progress in actually reducing disparities.

Research by physicians, epidemiologists, sociologists, and others into racial health disparities has found its way into the legal literature, with numerous books, law review articles, and reports addressing various aspects of the problem.<sup>84</sup> Without attempting to summarize that large and growing literature, several points are worth briefly noting. As I have written elsewhere, racial health disparities have proven themselves to be pervasive, pernicious, pricey, and persistent.<sup>85</sup>

Researchers writing in the *Journal of the American Medical Association* in 2015 succinctly captured how pervasive those disparities are: “In the United States, compared with white individuals, black individuals have earlier onset of multiple illnesses, greater severity and more rapid progression of diseases, higher levels of comorbidity and impairment through the life course, and increased mortality rates.”<sup>86</sup> Although researchers are still working to understand the precise causes of racial health disparities, pernicious causes doubtless play some role. Because of the history of institutional and structural racism in the U.S., blacks experience greater disadvantages compared to whites on social determinants of health like education, employment, and income.<sup>87</sup> The disproportionate incarceration of black persons negatively affects the health of black communities.<sup>88</sup> And racism and discrimination—both found in members of society generally and specifically in the health professions—also contribute to the injustices that blacks face with respect to their health.<sup>89</sup>

These pervasive racial health disparities lead to troubling results. The human toll of disproportionate rates of morbidity and mortality is severe. According to an estimate by former U.S. Surgeon General David Satcher, eliminating the mortality gap between whites and blacks would prevent more than 83,000 premature black deaths annually.<sup>90</sup> The mortality gap dilutes the political influence of blacks and decreases the return they collectively reap on their contributions to the Social Security system.<sup>91</sup> Poor health and barriers to access

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83. *See id.* at 30, 42.

84. *See id.* at 43, 45, 58.

85. *See* Mary Crossley, *Black Health Matters: Disparities, Community Health, and Interest Convergence*, 22 MICH. J. RACE & L. 53, 59–60 (2016).

86. David R. Williams & Ronald Wyatt, *Racial Bias in Health Care and Health: Challenges and Opportunities*, 314 J. AM. MED. ASS'N 555, 555 (2015).

87. David R. Williams et al., *Understanding Association Among Race, Socioeconomic Status, and Health: Patterns and Prospects*, 35 HEALTH PSYCHOL. 407, 409 (2016).

88. Crossley, *supra* note 85, at 62.

89. *Id.* at 61–62.

90. David Satcher et al., *What if We Were Equal? A Comparison of the Black-White Mortality Gap in 1960 and 2000*, 24 HEALTH AFF. 459, 460 (2005).

91. Crossley, *supra* note 85, at 64.

present challenges to educational attainment and employment for individual blacks and can contribute to social unrest in communities.<sup>92</sup>

Beyond these social justice implications, racial health disparities carry a hefty price tag for society. Studies have sought to quantify the societal cost. According to one, eliminating racial health disparities would have translated into a \$229.4 billion decrease in direct medical expenditures over the three-year period from 2003–2006, with the figure rising to more than one trillion dollars when indirect costs associated with lost work productivity, illness, and premature death were included.<sup>93</sup> Another study estimated that in a single year the disparities experienced by Medicare and Medicaid enrollees alone cost the federal government seventeen billion dollars.<sup>94</sup>

All the attention that researchers and policy makers have paid to racial health disparities over the past several decades has produced limited success. The report accompanying the 2018 County Health Rankings conducted by the University of Wisconsin Population Health Institute found that meaningful health gaps based on race and ethnicity persist.<sup>95</sup> It also draws a connection between place-based and race-based disparities, explaining that ongoing residential segregation means that communities of color are less likely to enjoy social investments to support strong schools, healthy and affordable housing, and other health-promoting opportunities.<sup>96</sup>

## 2. Health Disparities for People with Disabilities

In comparison to racial health disparities, which have received federal attention for more than three decades, the idea that people with disabilities may, as a demographic group, experience health disparities is much newer. While typically viewing people with disabilities as less healthy than people without disabilities, physicians and health researchers have tended to understand disability as a negative health outcome or consequence of aging, rather than as a demographic trait in its own right.<sup>97</sup> This traditional understanding aligns with a medical model of disability, which views disability as a defect located in a person's body and views medical treatment as the appropriate response.<sup>98</sup>

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92. *Id.* at 64, 70.

93. Thomas LaVeist et al., *Estimating the Economic Burden of Racial Health Inequalities in the United States*, 41 INT'L J. HEALTH SERVS. 231, 233–34 (2011).

94. TIMOTHY WAIDMAN, ESTIMATING THE COST OF RACIAL AND ETHNIC HEALTH DISPARITIES 1 (Urban Inst. 2009).

95. UNIV. OF WIS. POPULATION HEALTH INST., COUNTY HEALTH RANKINGS KEY FINDINGS 2018 2 (2018).

96. *Id.* at 8.

97. Tawara D. Goode et al., *Parallel Tracks: Reflections on the Need for Collaborative Health Disparities Research on Race/Ethnicity and Disability*, 52 MED. CARE S3, S5 (Supp. III 2014).

98. The World Health Organization (WHO) offers the following description of the medical model:

Viewing disability through a medical model suggests that any social and health disadvantages that people with disabilities experience are the “natural and direct consequences of disability.”<sup>99</sup> In this view, even if people with disabilities, as a group, are shown to have worse health outcomes or poorer access to care, those unfortunate results may be deemed the inevitable results of their bodily defects and not the sort of avoidable (and thus unjust) differences that fall into the category of health disparities.<sup>100</sup>

By contrast, most contemporary thinking about disability incorporates a social model. The social model of disability recognizes that the disadvantages associated with being disabled are, to a large degree, the product of social, institutional, and physical environments that (whether intentionally or not) exclude people with impairments from full participation in society.<sup>101</sup> These barriers to fully including people with disabilities cause much of the harm they experience. Consequently, removing those barriers improves the lot of people with disabilities.<sup>102</sup> From this perspective, many of the health and social disadvantages that people with disabilities experience might be mitigated or eliminated by policies attending to barrier removal.

In reports published in the past fifteen years, medical and public health bodies began paying closer attention to the poor health status and unmet health

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The *medical model* views disability as a problem of the person, directly caused by disease, trauma, or other health condition, which requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual's adjustment and behavior change. Medical care is viewed as the main issue, and at the political level the principal response is that of modifying or reforming health care policy.

WORLD HEALTH ORG., INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH 20 (2001).

99. SILVIA YEE ET AL., COMPOUNDED DISPARITIES: HEALTH EQUITY AT THE INTERSECTION OF DISABILITY, RACE, AND ETHNICITY 6 (2016).

100. See *Disabilities supra*, text accompanying note 80, for the meaning of the phrase “health disparities.”

101. The WHO describes the social model as follows:

The *social model* of disability. . . sees the issue mainly as a socially created problem, and basically as a matter of the full integration of individuals into society. Disability is not an attribute of an individual but rather a complex collection of conditions, many of which are created by the social environment. Hence the management of the problem requires social action, and it is a collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life. The issue is therefore an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights. For this model disability is a political issue.

WORLD HEALTH ORG., *supra* note 98, at 20.

102. *Disability and Health*, HEALTHYPEOPLE.GOV, <http://www.healthypeople.gov/2020/top-ics-objectives/topic/disability-and-health> (last visited Feb. 20, 2019).

needs of many people with disabilities.<sup>103</sup> Recognizing barriers to the receipt of quality care and the achievement of optimal health, these reports incorporated the social model of disability.<sup>104</sup> And in publishing Healthy People 2020, its decennial blueprint for the nation's public health, HHS explicitly included disability as a distinct basis for health disparities for the first time.<sup>105</sup>

Thus, policymakers and researchers increasingly recognize that people with disabilities represent a population that experiences health and health care differences and disparities.<sup>106</sup> Because the legal literature has yet to pay much attention to disability health disparities, briefly noting some of the research may be helpful. Researchers have begun documenting differences in the health status, social determinants of health, and receipt of care by people with disabilities. In terms of health status, people with disabilities are far more likely than non-disabled people to report that they are in fair or poor health.<sup>107</sup> They also report higher rates of risk factors (like smoking, obesity, and physical inactivity) that increase their risk of becoming sick.<sup>108</sup> People with disabilities face a heightened risk of both unintentional and violent injury, with persons with cognitive disabilities facing the highest risk.<sup>109</sup> Moreover, people with disabilities are more likely to be disadvantaged when it comes to social determinants of health like education, employment, income, and transportation.<sup>110</sup>

Although it is not captured by typical approaches to health disparities research, segregation is another important aspect of the health-related injustice suffered by people with disabilities. Historically, the absence of community-based supports for independent living forced many people with disabilities to live in institutions in order to receive needed health services and supports.<sup>111</sup>

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103. See, e.g., U.S. SURGEON GEN., U.S. DEP'T HEALTH & HUM. SERVS., THE SURGEON GENERAL'S CALL TO ACTION TO IMPROVE THE HEALTH AND WELLNESS OF PERSONS WITH DISABILITIES (2005); *Disability and Health*, *supra* note 102; WORLD HEALTH ORG., WORLD REPORT ON DISABILITY 57 (2011). In addition, in 2009 the National Council on Disability published a report on health care for people with disabilities, which catalogued numerous shortcomings in the health care and medical treatment that the group receives. NAT'L COUNCIL ON DISABILITY, THE CURRENT STATE OF HEALTH CARE FOR PEOPLE WITH DISABILITIES 12 (2009).

104. U.S. SURGEON GEN., *supra* note 103; *Disability and Health*, *supra* note 102; WORLD HEALTH ORG., *supra* note 103.

105. *Disparities*, *supra* note 5.

106. Amy M. Kilbourne et al., *Advancing Health Disparities Research Within the Health Care System: A Conceptual Framework*, 96 AM. J. PUB. HEALTH 2113, 2115–16 (2006).

107. Lisa I. Iezzoni, *Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities*, 30 HEALTH AFF. 1947, 1949–50 (2011).

108. *Id.* at 1950.

109. Gloria L. Krahn et al., *Persons with Disabilities as an Unrecognized Health Disparity Population*, 105 AM. J. PUB. HEALTH S198, S201 (Supp. II 2015).

110. *Id.* at S202; Iezzoni, *supra* note 107, at 1947.

111. NAT'L COUNCIL ON DISABILITY, *supra* note 103; Julie Bershadsky et al., *Place of Residence and Preventive Health Care for Intellectual and Developmental Disabilities Services Recipients in 20 States*, 127 PUB. HEALTH REP. 475, 476 (2012).

Confinement in institutions deprived people with disabilities of opportunities for education, employment, social interaction, and civic engagement.<sup>112</sup> Only in 1999 did the U.S. Supreme Court recognize that, for people who could live in the community with support, segregation in institutions was a form of discrimination violating the Americans with Disabilities Act.<sup>113</sup>

Research has also documented differences in access to care and the quality of care received by people with disabilities. Although they have roughly comparable rates of insurance coverage as non-disabled people, people with disabilities are more likely to be covered by a public insurance program.<sup>114</sup> Even with coverage, they may still face financial barriers to accessing care. Disabled adults are 2.5 times more likely than non-disabled adults to say they have delayed or skipped health care because of cost.<sup>115</sup> They also report a lower likelihood of receiving preventive care, even though they have significantly higher rates of chronic diseases than the general population.<sup>116</sup>

To be sure, concluding that identified health differences are avoidable health disparities for people with disabilities can be tricky. “Within a disability context, determining disparities is complex, in that it requires considering which observed differences in health status are avoidable, and which may be unavoidable because they related directly to the underlying health condition that led to the disability.”<sup>117</sup> In other words, the close connection between some health conditions and disabling effects (for some but not all persons with disabilities) may make it challenging to tease out the element of avoidability and injustice in the health outcomes of persons with disabilities.<sup>118</sup> Additional factors complicating research into disability-based disparities flow from the varying definitions of disability used by government agencies and health

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112. Angela Dugar et al., *Disability, Health, Community Living and Human Rights*, in HEALTH AND HUMAN RIGHTS RESOURCE GUIDE 9.1, 9.16 (FXB Ctr. for Health and Human Rights ed., 2013), <https://cdn2.sph.harvard.edu/wp-content/uploads/sites/25/2014/03/HHRRG-master.pdf>.

113. *Olmstead v. L.C.*, 527 U.S. 581, 583 (1999). In his concurring opinion in *Olmstead*, Justice Kennedy explained how proof of unjustified institutionalization could even support a more conventionally understood discrimination claim. “If [plaintiffs] could show that persons needing psychiatric or other medical services to treat a mental disability are subject to a more onerous condition than are persons eligible for other existing state medical services ... then the beginnings of a discrimination case would be established.” *Id.* at 612 (Kennedy, J., concurring).

114. Krahn et al., *supra* note 109, at S202.

115. *Id.* at S201.

116. *Id.*; Iezzoni, *supra* note 107, at 1950–51 (finding that women with disabilities have much lower rates of Pap tests and screening mammography than do nondisabled women, and disabled persons with breast cancer and non-small-cell lung cancer are significantly less likely to receive surgery and are more likely to die from their cancers).

117. Krahn et al., *supra* note 109, at S198.

118. *See id.* at S202 (noting that health differences for people with disabilities are “complexly determined” and require a “closer look...to identify those differences that are preventable and unjust.”).

organizations<sup>119</sup> and the heterogeneity of the disability population itself.<sup>120</sup> Despite these challenges, researchers and policymakers increasingly recognize that at least some of the health and health care differences experienced by people with disabilities are preventable and therefore unjust.<sup>121</sup>

Research into disability-related disparities still has far to go in identifying the extent, nature, and precise causes of the health disparities experienced by people with disabilities. Along with physical barriers to accessing appropriate care, a prime suspect believed to contribute to disparities is the negative attitudes of health care professionals, attributable in part to their inadequate education regarding the lived experience of people with disabilities and their health needs.<sup>122</sup> A lack of funding has also hampered research into disability-related disparities, as federal funding for health disparities research is explicitly focused on racial and ethnic disparities.<sup>123</sup> As the following part points out, however, race/ethnicity and disability often intersect in producing disparities.<sup>124</sup>

### 3. Disparities at the Intersection of Race and Disability

Even as recognition of disability as a basis for health disparities accelerated, research exploring how the interaction of race and disability affects health care access or health outcomes lagged.<sup>125</sup> As one pair of researchers noted in 2014, the literature on disability health disparities “has given scant attention to the diversity of the population of people with disabilities” and research on racial and ethnic disparities “has rarely considered or included the potential compounding or interaction effects of having a disability.”<sup>126</sup> The succeeding five years, however, have seen an uptick in the volume of research looking at health-related

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119. *See id.* at S199 (noting that, in 2003, federal statutes contained at least sixty-seven definitions of disability).

120. Goode et al., *supra* note 97, at S5.

121. *Id.*

122. Iezzoni, *supra* note 107, at 1948; Goode et al., *supra* note 97, at S4–5.

123. Goode et al., *supra* note 97, at S3.

124. *Id.* at S6.

125. *See* Willi Horner-Johnson et al., *Promoting a New Research Agenda: Health Disparities Research at the Intersection of Disability, Race, and Ethnicity*, 52 MED. CARE S1, S1 (Supp. III 2014) (noting that the “understanding of the intersection of disability with race and ethnicity in health care is very limited”); Jana J. Peterson-Besse et al., *Barriers to Health Care Among People with Disabilities Who are Members of Underserved Racial/Ethnic Groups: A Scoping Review of the Literature*, 52 MED. CARE S51, S60 (Supp. III 2014) (noting a “critical gap in the literature” regarding barriers to health care access for people with disabilities who also belong to underserved racial or ethnic groups); Goode et al., *supra* note 97, at S3 (calling for merging previously parallel lines of research regarding racial/ethnic disparities and disability disparities).

126. Horner-Johnson et al., *supra* note 125, at S1–S2 (introducing a special issue of the journal *Medical Care* on the intersection of disability, race, and ethnicity and noting the complexity of varying definitions and characterizations of disability used by researchers beginning to study these intersections).

intersections and connections between race and disability.<sup>127</sup> Appearing primarily in the public health literature, these studies explore how various permutations of race, disability, and other socio-demographic factors interact in the populations studied.<sup>128</sup>

Their findings suggest the need for researchers, policy makers, and activists to adopt an intersectional perspective on race, disability, and health.<sup>129</sup> In the late 1980s, legal scholar Kimberlé Crenshaw coined the term “intersectionality” to describe the challenges African-American women faced when bringing employment discrimination claims.<sup>130</sup> Crenshaw described how the law, by engaging in “single-axis thinking,” failed to recognize the compounded discrimination experienced by workers who were both African American and women.<sup>131</sup> Since then, intersectionality’s “insistence on examining the dynamics of difference and sameness has played a major role in facilitating consideration of gender, race, and other axes of power in a wide range of political discussions and academic disciplines.”<sup>132</sup> Originally used to describe the experiences of African-American women, the concept applies as well to others with multiple marginalized identities.<sup>133</sup>

Emerging research examines how living at the intersection of belonging to a racial/ethnic minority group and being disabled affects health status and the use of health care. For example, one study found that among people with less severe disabilities, racial and ethnic disparities existed in overall health, total annual health care visits, and the percentage reporting no visit to a doctor during the year.<sup>134</sup> Some researchers have focused more narrowly on racial and ethnic health disparities among people with particular disabilities.<sup>135</sup> Others have found

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127. See, e.g., *id.* at S1; Peterson-Besse et al., *supra* note 125, at S52 (providing examples of research literature on intersectionality).

128. See, e.g., Horner-Johnson et al., *supra* note 125, at S2; Peterson-Besse et al., *supra* note 125, at S52 (describing factors studied in recent research).

129. Horner-Johnson et al., *supra* note 125, at S2; Peterson-Besse et al., *supra* note 125, at S61; Goode et al., *supra* note 97, at S6.

130. Kimberlé Crenshaw, *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*, U. CHI. LEGAL FORUM 139, 140 (1989).

131. *Id.*

132. Sumi Cho et al., *Toward a Field of Intersectionality Studies: Theory, Applications, and Praxis*, 38 SIGNS 785, 787 (2013).

133. See, e.g., Camara P. Jones, *Systems of Power, Axes of Inequity: Parallels, Intersections, Braiding the Strands*, 52 MED. CARE S71, S74–75 (Supp. III 2014).

134. Stephen P. Gulley et al., *Difference, Disparity & Disability: A Comparison of Health, Insurance Coverage and Health Service Use on the Basis of Race/Ethnicity Among U.S. Adults with Disabilities, 2006-2008* 52 MED. CARE S9 (Supp. III 2014). These researchers found fewer racial/ethnic disparities among persons with more severe disabilities.

135. Sandra Magana et al., *Racial and Ethnic Disparities in Quality of Health Care Among Children with Autism and Other Developmental Disabilities*, 50 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 287, 287–88 (2012) (indicating that that families of black and

that both disability and racial/ethnic minority status lead to poorer health outcomes.<sup>136</sup> For example, a study by Parish et al. found both that Latino and black adults with intellectual and developmental disabilities (IDD) had worse health outcomes compared to white adults with IDD, and that Latino and black adults with IDD experienced worse health outcomes compared to non-disabled adults from the same racial and ethnic group.<sup>137</sup> In short, persons at the intersection of both having an intellectual disability and being black or Latino had worse outcomes than persons with only one of those statuses. These early findings notwithstanding, research regarding the compounded effects of being both disabled and a member of a marginalized racial/ethnic group remains in its infancy, and research into *how* specifically the dual disparities produce compounded effects is “virtually nonexistent.”<sup>138</sup>

Departing from a focus on disability and race/ethnicity intersectionality, researchers have also analyzed variations in disability prevalence among different racial and ethnic groups. A 2017 report commissioned by the Health and Medicine Division of the National Academies of Sciences, Engineering & Medicine provides an overview of analyses of available data regarding the prevalence of different types of disabilities.<sup>139</sup> Although a single generalization cannot capture the varying prevalence of different kinds of impairments, these analyses support some overarching general points. First, disability is more prevalent among African-American and American Indian/Alaska Native populations than among white non-Hispanic, Hispanic/Latino populations, and Asian populations.<sup>140</sup> Across racial/ethnic demographic groups, women are more likely to experience disability, and the prevalence of disability increases with age.<sup>141</sup>

Interestingly, the connection between aging and physical disability appears to accelerate for African Americans, according to one set of researchers. “In fact, the prevalence of physical disability for African Americans/blacks in any given age group was similar to the prevalence for non-Hispanic whites who were 10

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Latino children with autism face greater challenges in accessing health quality care than families of white children).

136. RACHEL BLICK ET. AL., OHIO DISABILITY & HEALTH PROGRAM, THE DOUBLE BURDEN: HEALTH DISPARITIES AMONG PEOPLE OF COLOR LIVING WITH DISABILITIES 1 (2015).

137. Sandra Magaña et al., *Racial and Ethnic Health Disparities Among People with Intellectual and Developmental Disabilities*, 54 INTELLECTUAL & DEVELOPMENTAL DISABILITIES 161, 168 (2016).

138. YEE ET AL., *supra* note 99, at 72.

139. *See id.* at 10.

140. *Id.* at 10–19. This statement holds true with respect to physical disability, vision trouble, and intellectual disability but not for hearing trouble or mental illness, where the prevalence is higher among whites.

141. David F. Warner & Tyson H. Brown, *Understanding How Race/Ethnicity and Gender Define Age-Trajectories of Disability: An Intersectionality Approach*, 72 SOC. SCI. & MED. 1236, 1238 (2011).



years older.”<sup>142</sup> This finding aligns with an intriguing and disturbing line of research suggesting that blacks face an increased risk of disablement over time, as compared to whites.<sup>143</sup> This elevated risk of becoming disabled likely flows from social, rather than biological, factors. Several studies reinforce the concept of social determinants of disability.<sup>144</sup> Having a low economic status or low educational status and being exposed to stressful or dangerous workplace conditions appear to make it more likely that a person will experience disability, especially as he ages.<sup>145</sup> And blacks disproportionately experience the social determinants identified as contributing to disablement.<sup>146</sup> Moreover, to the extent that blacks who receive medical care experience worse outcomes than whites, a plausible conclusion is that the receipt of lower quality medical care

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142. YEE ET AL., *supra* note 99, at 16. At the opposite end of the age spectrum the same is true: researchers have found that disability is more prevalent among African American children than non-Hispanic whites and Hispanic/Latino children. *Id.* at 18–19.

143. Carlos F. Mendes de Leon et al., *Black-White Differences in Risk of Becoming Disabled and Recovering from Disability in Old Age: A Longitudinal Analysis of Two EPESE Populations*, 145 AM. J. EPIDEMIOLOGY 488, 495 (1997).

144. *See generally* Regina Fiorati & Valeria Meirelles Carril Elui, *Social Determinants of Health, Inequality and Social Inclusion Among People with Disabilities*, 23 REVISTA LATINO-AM. ENFERMAGEM 329 (2015); Gregor Wolbring, *People with Disabilities and Social Determinants of Health Discourses*, 102 CAN. J. PUB. HEALTH 317 (2011).

145. Gopal K. Singh & Sue C. Lin, *Marked Ethnic, Nativity, and Socioeconomic Disparities in Disability and Health Insurance Among US Children and Adults: The 2008-2010 American Community Survey*, 2013 BIOMED RES. INT’L 1–2 (2013) (finding that socioeconomic differences accounted for 60.2% of racial/ethnic variations in disability among children and 89.7% among adults).

146. *Id.* at 12; Seth A. Seabury et al., *Racial and Ethnic Differences in the Frequency of Workplace Injuries and the Prevalence of Work-Related Disability*, 36 HEALTH AFF. 266, 271 (2017) (suggesting that disparities in economic opportunities expose members of minority groups to increased risk of workplace injury and disability); Warner & Brown, *supra* note 141, at 1 (finding that Black women experience a “trajectory of accelerated disablement” compared to other groups); Kenzie Latham, *Progressive and Accelerated Disability Onset by Race/Ethnicity and Education Among Late Midlife and Older Adults*, 24 J. AGING HEALTH 1320, 1323 (2012) (identifying low educational attainment as a strong predictor of accelerated disability onset and race/ethnicity as important predictors of progressive disability onset); T. Brown & R. Thorpe, *Race/Ethnicity, Stress, Mobility Limitations and Disability Among Older Men*, 56 GERONTOLOGIST 591 (Supp. III 2016) (finding that “racial/ethnic differences in SES, stressors, discrimination and chronic conditions — individually and collectively—account for a substantial proportion of racial/ethnic disparities in functional mobility and disability.”); *cf.* Carlos Siordia, *Disability Prevalence According to a Class, Race, and Sex (CSR) Hypothesis*, 2 J. RACIAL ETHNIC HEALTH DISPARITIES 303, 304 (2015) (examining a “Class, Race, Sex hypothesis” that disadvantages associated with low educational attainment, racial minority status, and being female will compound to affect the risks of becoming disabled); Roland J. Thorpe et al., *Racial Disparities in Disability among Older Adults: Findings from the Exploring Health Disparities in Integrated Communities Study*, 26 J. AGING HEALTH 1261, 1261 (Dec. 2014) (“persistent and consistently observed racial disparities in physical functioning likely stem from racial differences in social resources and environmental conditions”).

may make disability more likely.<sup>147</sup> Given findings regarding the interaction of socioeconomic factors, quality of care, and disablement, it is not surprising that blacks experience higher rates of disabilities than whites.<sup>148</sup>

Even as findings regarding disparities in disability prevalence are emerging, scholars are theorizing their meaning. Scholars have used the phrase “emergent disability” to describe the growing number of disabilities found in communities experiencing poverty and disadvantage.<sup>149</sup> Beth Ribet has described these disabilities as arising from “injuries and deprivations rooted in racial and class oppression.”<sup>150</sup> For example, a person whose only employment options (because of poor schooling and low social capital) lie in workplaces with high levels of physical injury may acquire an emergent disability. So too may an African-American child who, after years of living in segregated housing sited near an environmental hazard, suffers aggravated asthma. From this perspective, being non-white (a status disproportionately associated with socioeconomic deprivation) looks like a risk factor for becoming disabled. Moreover, the inequitable distribution of that risk is not a matter of happenstance, but connects to larger questions of social justice for people of color.<sup>151</sup> Ribet describes the phenomenon in theoretical terms: “disability is not simply racially charged, but often racially generated.”<sup>152</sup>

#### *B. Disability and Race Concerns in Preserving Medicaid*

Recognizing the extent of health disparities experienced by people of color and people with disabilities adds a dimension to our understanding of how changes to Medicaid coverage and funding could negatively affect the wellbeing of those groups. As noted earlier, people with disabilities and people of color shared basic concerns with other Medicaid enrollees about what would happen to their health care if the Republicans’ 2017 proposals to restructure Medicaid passed. The foregoing discussion of race- and disability-related health disparities, however, lays the groundwork for exploring the distinctive concerns that Republican proposals provoked for each group.

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147. Cf. DAVID A. ANSELL, *THE DEATH GAP: HOW INEQUALITY KILLS* 130–31 (Univ. of Chi. Press 2017).

148. See Rashmi Goyat et al., *Racial/Ethnic Disparities in Disability Prevalence*, 3 J. RACIAL & ETHNIC HEALTH DISPARITIES 635, 642 (2017) (finding that non-Hispanic African Americans were more likely to have severe disability than were non-Hispanic whites, but that adjusting for socioeconomic status eliminated the disparity).

149. Beth Ribet, *Surfacing Disability Through a Critical Race Theoretical Paradigm*, 2 GEO. J. L. & MOD. CRITICAL RACE PERSPECTIVES 209, 211 (2010).

150. *Id.*

151. Jennifer Pokempner & Dorothy E. Roberts, *Poverty Welfare Reform, and the Meaning of Disability*, 62 OHIO ST. L. J. 425, 457–58 (2001) (“Recognizing that disabilities are often caused by inequitable allocations of wealth and power implicates the state in creating disability, not just reacting to impairments in ways that disable.”).

152. Ribet, *supra* note 149, at 241.

### 1. Disability Concerns

In addition to broadly shared concerns about cuts to Medicaid, people with disabilities perceived proposed federal cuts as particularly threatening state funding of home and community-based services (HCBS) programs.<sup>153</sup> Examples of HCBS include personal attendant services, habilitation services, transportation support, case management, and respite services. States' funding of HCBS as part of their Medicaid programs responds to the preference of many disabled people for receiving needed services in their homes or community settings rather than in nursing homes or other institutions.<sup>154</sup> The Medicaid program, however, includes a structural preference for institutional care.<sup>155</sup> Under the federal Medicaid statute, participating states are required to cover services provided to enrollees in nursing homes.<sup>156</sup> HCBS, by contrast, are optional benefits; states can choose to cover them as part of their Medicaid program but are not obligated to do so.<sup>157</sup> Over the past few decades, all states have chosen to provide coverage for at least some HCBS for at least some groups of Medicaid enrollees, but the demand for Medicaid-funded HCBS continues to outstrip the supply in most states.<sup>158</sup>

The growth of Medicaid-funded HCBS has helped make some inroads on the segregation of people with disabilities in institutions. That progress has resulted largely from the confluence of two forces. First, the *Olmstead* decision signaled to states that their failure to provide services to disabled persons in the community could violate the ADA.<sup>159</sup> Second, the greater availability of Medicaid waivers has permitted states to devote funding to HCBS for disabled beneficiaries rather than institution-based services.<sup>160</sup> Thus, states increasingly have had both the legal motive (*Olmstead*) and the

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153. See JUDITH SOLOMON & JESSICA SCHUBEL, CTR. ON BUDGET AND POL'Y PRIORITIES, MEDICAID CUTS IN HOUSE ACA REPEAL BILL WOULD LIMIT AVAILABILITY OF HOME- AND COMMUNITY-BASED SERVICES 1 (2017), <https://www.cbpp.org/sites/default/files/atoms/files/5-18-17health.pdf>; Mary Crossley, *Community Integration of People with Disabilities: Can Olmstead Protect Against Retrenchment?*, LAWS, 2017, at 2.

154. *Id.* at 5, 6.

155. Sidney D. Watson, *From Almshouses to Nursing Homes and Community Care: Lessons from Medicaid's History*, 26 GA. ST. U. L. REV. 937, 938–39 (2010).

156. *Id.* at 938.

157. See generally Marshall B. Kapp, *Home and Community-Based Long-Term Services and Supports: Health Reform's Most Enduring Legacy?*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 9, 14 (2014).

158. Laura D. Hermer, *Rationalizing Home and Community-Based Services under Medicaid*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 61, 80 (2014).

159. *Id.* at 70.

160. *Id.* at 70–71.

financial means (Medicaid funding) to support greater community integration for their disabled citizens.<sup>161</sup>

Republican proposals raised the concern that, if the federal government were to make bone-deep cuts to its Medicaid funding,<sup>162</sup> cash-strapped states might drastically cut or even eliminate their coverage of optional HCBS programs in order to preserve the ability to pay for mandatory services, like nursing home care.<sup>163</sup> Doing so would threaten disabled Medicaid recipients living in the community with having to move into an institution to receive needed care and make it harder for disabled Medicaid recipients already in an institution to transition into a community setting.<sup>164</sup> As a result, people with disabilities and progressive analysts decried the proposals as “risk[ing] a return to widespread institutionalization.”<sup>165</sup> Thus, beyond concerns that the Republican proposals would threaten coverage of needed health services, people with disabilities recognized a threat to their hard-fought gains in independence and community integration.

## 2. Race-related Concerns

People of color, by contrast, had particularly high stakes in maintaining the Medicaid expansion in the states that had already chosen to expand and in preserving other states’ ability to pursue future expansion with generous federal support. Ever since *NFIB v. Sebelius* presented states with the decision whether to expand their Medicaid programs to extend coverage to more low-income residents,<sup>166</sup> the racial equity implications have been apparent. A majority of people who stood to benefit from the expansion were people of color. Across the U.S., people of color were disproportionately likely to be uninsured and to have low incomes. As states decided whether to expand, the variable impact by state

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161. See Sarah Rosenbaum et al., *Olmstead v. L.C.: Implications for Medicaid and Other Publicly Funded Health Services*, 12 HEALTH MATRIX 93, 137 (2002).

162. The Congressional Budget Office estimated that the proposal would reduce federal Medicaid spending by \$880 billion over a decade. CONG. BUDGET OFFICE, *supra* note 67.

163. Robin Rudowitz, *Data Note: Review of CBO Medicaid Estimates of the American Health Care Act*, KAISER FAM. FOUND. (June 14, 2017), <http://files.kff.org/attachment/Data-Note-Review-of-CBO-Medicaid-Estimates-of-the-American-Health-Care-Act>.

164. Disabled persons who are also members of a racial or ethnic minority are more likely than white disabled persons to live in an institution. YEE ET AL., *supra* note 99, at 75. Thus, white disabled Medicaid recipients were more likely than non-white disabled Medicaid recipients to lose highly valued HCBS. By contrast, the threatened cuts would leave non-white disabled Medicaid recipients even less likely to receive HCBS at all.

165. Rebecca Vallas et al., *5 Ways President Trump’s Agenda Is a Disaster for People with Disabilities*, CTR. AM. PROGRESS (Mar. 8, 2017), <https://www.americanprogress.org/issues/poverty/news/2017/03/08/427629/5-ways-president-trumps-agenda-disaster-people-disabilities>.

166. Nat’l Fed’n of Indep. Bus. v. Sebelius, 567 U.S. 519, 575 (2012).

on people of color was notable.<sup>167</sup> Among blacks who stood to gain insurance from the Medicaid expansion, almost six in ten lived in states that chose not to move forward with the expansion,<sup>168</sup> meaning that blacks were disproportionately left behind when the Medicaid expansion became optional for states rather than mandatory.

The experience in states that have expanded Medicaid confirms the value of the expansion for people of color. One study examined the impact of the ACA coverage expansions (including both the Medicaid expansion and financial subsidies to assist low-income persons in buying private insurance) on health disparities by comparing data from 2013 and 2015 for white, black, and Hispanic adults with respect to three measures of health care access.<sup>169</sup> Examining national averages, the study found decreases in the uninsured rate among all three groups but found steeper declines for blacks and Hispanics than for whites, which produced a narrowing of the gaps in coverage rates among these groups.<sup>170</sup>

But even as they experienced improvements overall in insurance levels, people of color in states that chose not to expand disproportionately fell into a “coverage gap” where they were bereft of any of the coverage-related benefits of the ACA.<sup>171</sup> The term “coverage gap” describes the situation of low-income persons who cannot enroll in Medicaid because their state has not expanded and who also are ineligible for the federal subsidies for purchasing private insurance (popularly known as Obamacare) *because their incomes are too low*.<sup>172</sup> As enacted, the ACA contemplated that all states would expand Medicaid to cover

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167. *The Impact of Current State Medicaid Expansion Decisions on Coverage by Race and Ethnicity*, KAISER FAM. FOUND. 2 (2013), <https://kaiserfamilyfoundatiok.files.wordpress.com/2013/00/8450-the-impact-of-current-state-medicaid-expansion-decisions.pdf>.

168. *Id.* at 3.

169. Susan L. Hayes et al., *Reducing Racial and Ethnic Disparities in Access to Care: Has the Affordable Care Act Made a Difference?*, COMMONWEALTH FUND 3 (2017), [https://www.commonwealthfund.org/sites/default/files/documents/\\_\\_\\_media\\_files\\_publications\\_issue\\_brief\\_2017\\_au\\_hayes\\_racial\\_ethnic\\_disparities\\_after\\_aca\\_ib.pdf](https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_issue_brief_2017_au_hayes_racial_ethnic_disparities_after_aca_ib.pdf).

170. *Id.* The study also found narrowing of the racial disparities in the percentage of people who reported skipping needed care because of costs and lacking a usual source of care. *Id.* at 3. When focusing on expansion states as compared to non-expansion states, the study found that racial disparities in these access-related measures were smaller in states that chose to expand. *Id.* at 4. Discerning the impact of a state’s expansion of Medicaid, as compared to that of expanded coverage via Obamacare subsidies or other factors present in a state, is challenging. Even before the Medicaid expansion, indicators for all three access measures were lower (better) for all three racial groups and racial and ethnic disparities were narrower in the states that chose to expand, and racial and ethnic disparities were narrower in the states that chose to expand, reflecting that these states had more generous eligibility standards even before the ACA. *Id.* In these states, expansion seemed to offer the greatest benefit for Hispanics, in terms of the narrowing of disparities between 2013 and 2015. Susan L. Hayes et al., *supra* note 169, at 4.

171. Garfield et al., *supra* note 56 at 3–4.

172. *Id.* at 1–2.

persons with household incomes up to 138% of the federal poverty level (FPL).<sup>173</sup> The legislation also made federal subsidies for purchasing private plans available to persons with household incomes of 100–400% of FPL.<sup>174</sup> Uninsured people with incomes below the federal poverty level in non-expansion states therefore are shut out from both avenues to coverage, even though they may pay taxes to support subsidies for others who earn more. Uninsured black adults were more than twice as likely to fall into this unenviable category as compared to both whites and Hispanics.<sup>175</sup> This disproportionate representation of blacks in the coverage gap results from the decisions of many Southern states with large populations of uninsured blacks not to expand.<sup>176</sup> By contrast, several states with large populations of uninsured Hispanics, including California, New York, and Arizona, decided to expand Medicaid.<sup>177</sup>

The recognition that people of color stand to particularly benefit from Medicaid expansion and be particularly disadvantaged by non-expansion decisions has prompted consideration of whether race may have influenced states' expansion decisions. Professor Mark Hall critically examined justifications that non-expanding states have proffered for choosing to leave untapped millions of dollars of federal funding to provide health coverage for their uninsured low-income residents.<sup>178</sup> Concluding that “[t]he evidence entirely fails to support policy arguments that Medicaid is worse than having no insurance or that expansion would cost states tremendous amounts of money,” Hall found that “aside from crass political motivation (that some might think is racially tinged), obstinate ideology is the only other possible justification” that could explain states' “stubborn refusal.”<sup>179</sup> Researchers from the University of Chicago analyzed public opinion in non-expanding states to identify the role of state-level public support for expansion in states' decisions.<sup>180</sup> They found evidence that public support for the expansion was racialized and that states' decisions tended to reflect white support (or nonsupport) for expansion and not nonwhites' support.<sup>181</sup> Moreover, they posited that higher nonwhite populations

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173. *See id.*

174. *Id.* at fig.1.

175. Samantha Artiga et al., *The Impact of the Coverage Gap for Adults in States Not Expanding Medicaid by Race and Ethnicity*, KAISER FAM. FOUND. 3 (2015), <http://files.kff.org/attachment/issue-brief-the-impact-of-the-coverage-gap-for-adults-in-states-not-expanding-medicaid-by-race-and-ethnicity>.

176. *Id.* at 4.

177. *Id.* at 3.

178. *See* Mark A. Hall, *States' Decisions Not to Expand Medicaid*, 92 N.C. L. REV. 1459, 1461, 1466 (2014).

179. *Id.* at 1477–78.

180. Colleen M. Grogan & Sunggeun (Ethan) Park, *The Racial Divide in State Medicaid Expansions*, 42 J. HEALTH POL., POL'Y & L. 539, 540 (2017).

181. *See id.* at 560.

combined with low white support in some states may have created “racialized backlash.”<sup>182</sup>

Thus, as the foregoing discussion demonstrates, people with disabilities and people of color had both common and distinctive reasons for turning out to protest changes to the Medicaid program and the repeal of the ACA. Including fundamental restructuring of Medicaid in legislation to repeal and replace the ACA was one of several tactical mistakes by Republicans that may have doomed their repeal efforts in the spring, summer, and fall of 2017.<sup>183</sup> That tactical error prompted people of color and people with disabilities to find common cause and to raise their voices together in effective activism to preserve Medicaid.<sup>184</sup> Might this example of shared activism suggest the possibility of future cooperation or collaboration between these two groups regarding other aspects of Medicaid policy? Part IV considers the potential for shared interests regarding two aspects of Medicaid policy.

#### IV. INTO THE FRAY ONCE MORE? NEW FRONTS FOR MEDICAID ACTIVISM

The 2018 midterm election’s return of control of the House of Representatives to Democrats means that the threat of fundamental legislative restructuring of Medicaid is off the table for at least two years.<sup>185</sup> Policy debates about how best to promote the quality of care received by Medicaid enrollees while containing the program’s cost and the extent of state flexibility in remaking Medicaid, however, continue unabated and remain ripe for administrative action. Two areas of policy debate and innovation in particular may present fertile ground for people with disabilities and people of color to raise related concerns in activism. The first is the move by a growing number of states to use Medicaid waivers to impose work requirements on a subset of

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182. *Id.* at 558; cf. Paul Krugman, *States of Cruelty*, N.Y. TIMES, Aug. 28, 2016, at A17 (noting that “opposition to [the Medicaid expansion] is concentrated in states where voters in local elections don’t like the idea of helping neighbors who don’t look like them.”).

183. See Gregory Krieg, *Why the Republican Health Care Message is Floundering*, CNN: POLITICS (July 8, 2017), <https://www.cnn.com/2017/07/08/politics/republicans-health-care-messaging/index.html> (predicting that a failure to pass the Republican health care bill would be the result of “repeated tactical blunders . . . .”); Philip Bump, *As Long as the Republican Bill Cuts Medicaid Coverage, It’s Likely to Be Unpopular*, WASH. POST (July 13, 2017), [https://www.washingtonpost.com/news/politics/wp/2017/07/13/as-long-as-the-republican-bill-cuts-medicaid-coverage-its-likely-to-be-unpopular/?noredirect=on&utm\\_term=.7cb7b9401720](https://www.washingtonpost.com/news/politics/wp/2017/07/13/as-long-as-the-republican-bill-cuts-medicaid-coverage-its-likely-to-be-unpopular/?noredirect=on&utm_term=.7cb7b9401720).

184. See Jennifer Flynn, *In the Fight to Save Health Care, the Heroes Ride on Wheelchairs—and Wear Pink*, NATION (Oct. 23, 2017), <https://www.thenation.com/article/in-the-fight-to-save-healthcare-the-heroes-ride-on-wheelchairs-and-wear-pink/>.

185. If the *Texas Children’s Hosp. v. Azar* case is upheld, it could result in the invalidation of the entire ACA including the Medicaid expansion. See *Tex. Children’s Hosp. v. Azar*, 315 F. Supp. 3d 322 (D.D.C. 2018); Chas Roades, *What the 2018 Midterms Mean for Healthcare*, GIST HEALTHCARE: BLOG (Nov. 7, 2018), <https://gisthealthcare.com/2018-midterms-mean-healthcare/>.

Medicaid enrollees,<sup>186</sup> and the second is states' consideration of value-based methods of provider reimbursement for their Medicaid programs.<sup>187</sup>

#### A. Medicaid Work Requirements

##### 1. Generally

Conservatives have long endorsed the concept of establishing employment-related conditions for recipients of welfare programs in the U.S., and 'welfare reform' legislation enacted in 1996 imposed work requirements for cash welfare payments for participants in the Temporary Aid to Needy Families (TANF) program.<sup>188</sup> Similarly, governors of a number of states have long sought to impose similar requirements in Medicaid, but prior to the Trump administration, the Centers for Medicare and Medicaid Services (CMS) had rebuffed states' attempts to obtain waivers permitting the implementation of work requirements.<sup>189</sup> It was not until 2018, however, that Kentucky became the first state to receive a waiver from the federal government permitting it to impose "community engagement" requirements on Medicaid recipients as a condition of Medicaid eligibility.<sup>190</sup> After the Trump administration first signaled in 2017 its willingness to allow states to impose them, in January 2018, CMS communicated to states that it would approve waiver applications seeking authority to impose work requirements.<sup>191</sup> As of this writing, five states have received work requirement waivers, and an additional ten have waiver applications pending. Litigation over Kentucky's waiver is ongoing,<sup>192</sup> as is a nationwide challenge to the Trump administration's stance.<sup>193</sup>

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186. See MaryBeth Musumeci et al., *Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers*, KAISER FAM. FOUND. 3 (2018), <https://www.kff.org/medicaid/issue-brief/section-1115-medicare-demonstration-waivers-the-current-landscape-of-approved-and-pending-waivers/>.

187. See *Value-Based Purchasing*, MEDICAID & CHIP PAYMENT & ACCESS COMM'N, <https://www.macpac.gov/subtopic/value-based-purchasing/> (last visited Feb. 1, 2019).

188. See HEATHER HAHN ET AL., WORK REQUIREMENTS IN SOCIAL SAFETY NET PROGRAMS 5 (Urban Inst. ed., 2017), [https://www.urban.org/sites/default/files/publication/95566/work-requirements-social-safety-net-programs\\_4.pdf](https://www.urban.org/sites/default/files/publication/95566/work-requirements-social-safety-net-programs_4.pdf).

189. *Id.* at 16–17.

190. Benjy Sarlin, *First-in-Nation Medicaid Work Requirements Approved for Kentucky*, NBC NEWS (Jan. 12, 2018), <https://www.nbcnews.com/politics/white-house/first-nation-medicare-work-requirements-approved-white-house-kentucky-n837281>.

191. Brian Neale, Dir., Ctrs. for Medicare & Medicaid Servs., Letter to State Medicaid Directors on Opportunities to Promote Work and Community Engagement Among Medicaid Beneficiaries (Jan 11, 2018), <https://www.medicare.gov/federal-policy-guidance/downloads/smd18002.pdf>.

192. See *Stewart v. Azar*, 313 F. Supp. 3d 327 (D.D.C. 2018).

193. Amy Goldstein, *New Lawsuit Challenges Trump Administration's Support for Medicaid Work Requirements*, WASH. POST (Aug. 14, 2018), <https://www.washingtonpost.com/national/health-science/new-lawsuit-challenges-trump-administrations-support-for-medicare-work-require>



In announcing the policy shift to State Medicaid Directors, CMS described its decision to support work requirements as assisting states' "efforts to improve Medicaid enrollee health and well-being through incentivizing work and community engagement" by developing programs that are "designed to promote better mental, physical, and emotional health . . . [and] to help individuals and families rise out of poverty and attain independence."<sup>194</sup> Experience with TANF work requirements, however, fuels skepticism about whether conditioning Medicaid eligibility on satisfying work requirements will accomplish those policy goals. As a basic matter, work requirements may have a negligible impact on increasing employment levels among Medicaid enrollees, because many of them are already working, and most of those who are not report that either a major impediment (such as a physical health condition, addiction, or limited education) or a family-related responsibility keeps them from holding a job. Persons facing such barriers to employment are unlikely to succeed in sustaining employment without the assistance of supportive services, which state Medicaid agencies are not prepared to offer.<sup>195</sup>

Moreover, even if some people do pursue and gain employment in the wake of a work requirement, their employment is unlikely to translate to reduced Medicaid rolls, since the types of jobs that Medicaid enrollees typically hold do not offer health insurance.<sup>196</sup> If anything, work requirements may cost states money as a result of the new administrative costs of implementing those requirements.<sup>197</sup> Most fundamentally, however, is the concern that many people receiving Medicaid rely on it to maintain a level of health sufficient to permit their employment.<sup>198</sup> Losing Medicaid eligibility as a result of their failure to achieve employment or—as likely—their failure to meet reporting requirements could actually decrease their employability.<sup>199</sup>

Beyond these general concerns regarding the impact of work requirements on Medicaid-eligible citizens, a state's adoption of work requirements may pose particular threats to the coverage and well-being of people with disabilities and racial/ethnic minorities. Although the nature and seriousness of these threats depend somewhat on how a state goes about implementing work requirements,

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ments/2018/08/14/dde88462-9ff0-11e8-8e87-c869fe70a721\_story.html?utm\_term=.4672bcbdd89d3.

194. Neale, *supra* note 191, at 1.

195. Mary Beth Musumeci & Julia Zur, *Medicaid Enrollees and Work Requirements: Lessons from the TANF Experience*, KAISER FAM. FOUND. 3 (2017), <https://www.kff.org/medicaid/issue-brief/medicaid-enrollees-and-work-requirements-lessons-from-the-tanf-experience/>.

196. *Id.* at 5.

197. *Id.* at 8.

198. *Id.* at 6; HANNAH KATCH, ET AL., CTR. ON BUDGET & POL'Y. PRIORITIES, TAKING MEDICAID COVERAGE AWAY FROM PEOPLE NOT MEETING WORK REQUIREMENTS WILL REDUCE LOW-INCOME FAMILIES' ACCESS TO CARE AND WORSEN HEALTH OUTCOMES (2018), <https://www.cbpp.org/sites/default/files/atoms/files/2-8-18health2.pdf>.

199. *See* Musumeci & Zur, *supra* note 195 at 9; KATCH, ET AL., *supra* note 198.

in particular what exemptions from work requirements it recognizes, several areas of concern exist.

## 2. People with Disabilities and Work Requirements

Advocates for imposing work requirements as a condition of receiving Medicaid typically describe those requirements as targeting “able-bodied” adults, while exempting people with disabilities, senior citizens, and pregnant women.<sup>200</sup> The January 2018 CMS letter to State Medicaid Directors explicitly states that persons who are eligible for Medicaid by virtue of their eligibility for SSI (eligibility that flows from a determination of permanent and total disability) cannot be subjected to work requirements.<sup>201</sup> That guidance also directs states to include exemptions for persons determined to be “medically frail” but does not specify how medical frailty should be determined and by whom.<sup>202</sup>

As noted above, many current Medicaid enrollees who are not working cite some physical or mental impediment to employment, but they may not be eligible for SSI. Their impairments may not rise to the level of a total and permanent disability or may not have persisted long enough to meet SSI’s two-year duration requirement. Thus, a person may experience significant functional limitations making it difficult to get a job without meeting the exacting standard for SSI eligibility. A related concern is that states may turn to physicians as gatekeepers for the medical frailty exemption.<sup>203</sup> Such reliance would be troubling on multiple levels. It would once again place physicians in a position of power over people with disabilities, giving physicians authority to control the access that people with disabilities have to needed benefits.<sup>204</sup> Giving physicians the ‘keys’ to Medicaid eligibility would be particularly cruel in the cases of persons who are forced off Medicaid because of their failure to report employment. Without Medicaid coverage, those persons may find themselves unable to find a doctor willing to see them and document their medical frailty.<sup>205</sup>

Persons with mental illness or intellectual disabilities are likely to face particular challenges in achieving stable employment, even if their impairment does not qualify them for SSI and an automatic exemption from work

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200. Robert Pear, *Trump Administration Says States May Impose Work Requirements for Medicaid*, N.Y. TIMES (Jan. 11, 2018), <https://www.nytimes.com/2018/01/11/us/politics/medicaid-work-requirements.html>.

201. Neale, *supra* note 191, at 6.

202. *Id.* at 5.

203. See Milton C. Weinstein, *Should Physicians be Gatekeepers of Medical Resources?*, 27 J. MED. ETHICS 268, 269 (2001).

204. John Z. Ayanian et al., *Mitigating the Risks of Medicaid Work Requirements*, 379 N. ENG. J. MED. 803, 804 (2018).

205. CTR. ON BUDGET POL’Y. & PRIORITIES, *TAKING AWAY MEDICAID FOR NOT MEETING WORK REQUIREMENTS HARMS PEOPLE WITH DISABILITIES 2* (2018), <https://www.cbpp.org/sites/default/files/atoms/files/1-26-18health.pdf>.

requirements. Employers may be ill equipped to accommodate the fluctuating symptoms of mental illness, and Medicaid programs are unlikely to provide the kinds of intensive employment supports that make employment viable for persons with mental illnesses or impairments. People with mental illness or cognitive impairments are also disproportionately likely to have been involved with the criminal justice system, a factor further diminishing their employability.<sup>206</sup>

### 3. African Americans and Work Requirements

Like people with disabilities, African Americans may face particularly high barriers to employment and thus be disproportionately disadvantaged by imposing work requirements as a condition of Medicaid coverage. In fact, some of these barriers are similar to those experienced by people with disabilities. For example, African-American men are over-represented among incarcerated persons in the U.S. and thus face significant barriers to employment post-incarceration.<sup>207</sup> Beyond high incarceration rates, health and educational disparities based on race and the persistence of employment discrimination contribute to continuing gaps in the employment rates of whites and blacks.<sup>208</sup>

Beyond these structural barriers to achieving employment permitting them to maintain Medicaid coverage in states imposing work requirements, states' implementation of work requirements may disproportionately disadvantage African Americans. In applying for work requirement waivers, several states proposed exemptions based on county unemployment rates.<sup>209</sup> Analyses of these exemptions reveal that, if implemented, they would differentially impact Black people.<sup>210</sup>

For example, in its original waiver proposal, Michigan planned to exempt from the work requirement any enrollee living in a county with an unemployment rate higher than 8.5%.<sup>211</sup> The stated goal was to protect rural

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206. *Id.*

207. Michael Massoglia, *Incarceration, Health, and Racial Disparities in Health*, 42 L. & SOC'Y. REV. 275, 276–78 (2008).

208. Janelle Jones, *Black Unemployment is at Least Twice as High as White Unemployment at the National Level and in 12 States and D.C.*, ECON. POL'Y. INST. (Oct. 30, 2018), [https://www.epi.org/publication/2018q3\\_unemployment\\_state\\_race\\_ethnicity/](https://www.epi.org/publication/2018q3_unemployment_state_race_ethnicity/).

209. Rachel Garfield et al., *Implications of Work Requirements in Medicaid: What Does the Data Say?* KAISER FAM. FOUND. 11 (2018), <https://www.kff.org/medicaid/issue-brief/implications-of-work-requirements-in-medicaid-what-does-the-data-say/>.

210. *Id.*

211. Dylan Scott, *How Medicaid Work Requirements Can Exempt Rural Whites but not Urban Blacks*, VOX (May 3, 2018), <https://www.vox.com/policy-and-politics/2018/5/3/17315382/medicaid-work-requirements-michigan-race>. Michigan also proposed a similar exemption [hereinafter Scott, *Medicaid Work Requirements*]. Jeff Stein & Andrew Van Dam, *Michigan's GOP has a Plan to Shield Some People from Medicaid Work Requirements*, WASH. POST (May 11, 2018), <https://www.washingtonpost.com/news/wonk/wp/2018/05/11/michigans-gop-has-a-plan-to-shield>

counties, where fewer jobs are available and transportation poses particular challenges.<sup>212</sup> Those counties, however, are also whiter than the more densely populated counties whose residents would remain subject to the work requirement.<sup>213</sup> Recent census data show the populations of all Michigan counties with an unemployment rate above ten percent are seventy-five to ninety percent white.<sup>214</sup> Were the proposed exemption implemented, only 1.2% of the people benefiting the unemployment exemption would be black, even though 23% of Medicaid enrollees in Michigan are black.<sup>215</sup> After the racial implications of the proposed unemployment exemption were publicized, Michigan amended its proposal to remove that exemption.<sup>216</sup>

Whether or not the exemptions for high-unemployment counties move forward, the imposition of work requirements is likely to have an outsized and negative effect on people of color, as well as people with disabilities. At least in the short term, we are likely to see the federal government continuing to support efforts by some states to pursue work requirements for Medicaid and the courts continuing to assess the legitimacy of those requirements. Medicaid work requirements thus represent an important area of Medicaid policy in which people of color and people with disabilities have overlapping and parallel interests that could support collaborative advocacy and activism.

#### B. Value-Based Reimbursement Methods and Vulnerable Populations

Another policy innovation that state Medicaid programs are contemplating is changing how they pay providers who render services to Medicaid enrollees to incorporate value-based reimbursement methods.<sup>217</sup> Medicaid originally paid

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-some-people-from-medicaid-work-requirements-theyre-overwhelmingly-white/?noredirect=on&utm\_term=.d26920d27fa0.

212. Dylan Scott, *The Trump Administration's Plan for Medicaid Work Requirements, Explained*, VOX (Jan. 12, 2018), <https://www.vox.com/policy-and-politics/2018/1/11/16877916/medicaid-work-requirements-trump-guidance>.

213. Scott, *Medicaid Work Requirements*, *supra* note 211; Scott, *supra* note 212.

214. Scott, *Medicaid Work Requirements*, *supra* note 211.

215. In comparison, whites constitute fifty-seven percent of Medicaid beneficiaries in Michigan, but would make up eighty-five percent of persons benefiting from the exemption. Alice Ollstein, *Trump Admin Poised to Give Rural Whites a Carve-Out on Medicaid Work Rules*, TALKING POINTS MEMO (May 14, 2018), <https://talkingpointsmemo.com/dc/trump-admin-poised-to-give-rural-whites-a-carve-out-on-medicaid-work-rules>.

216. Amanda Michelle Gomez, *Michigan Scrapped Its Racist Medicaid Work Exemption. But It's Still Happening Elsewhere.*, THINKPROGRESS (May 24, 2018), <https://thinkprogress.org/michigan-scrapped-its-racist-medicaid-work-exemption-but-its-still-happening-elsewhere-9a044d4ed9b2/>.

217. Tricia Leddy et al., *Value-Based Payments in Medicaid Managed Care: An Overview of State Approaches*, CTR. HEALTH CARE STRATEGIES 1–3 (2016), <https://xiyeg3kibip1m7w6b1hmkozg-wpengine.netdna-ssl.com/wp-content/uploads/2017/02/MAC-eBook-Pre-Reads-09-25-17-1.pdf>.

providers on a fee-for-service basis, but over the past several decades, states increasingly have moved enrollees into managed care settings in order to provide limits to and greater predictability in state Medicaid spending.<sup>218</sup> That shift continues,<sup>219</sup> but in addition, some states today are considering incorporating value-based payment models into Medicaid. Medicare has been experimenting with value-based reimbursement initiatives (also referred to as “pay for performance” or P4P) for years.<sup>220</sup> States are taking notice and beginning to consider reimbursement innovations designed to simultaneously improve the quality of care enrollees receive while also containing costs.

The concept of giving providers incentives to provide high value care (meaning care that simultaneously is of high quality and efficiently delivered) is laudable on its face. Implementing value-based reimbursement methods, however, may pose significant risks to medically complex or particularly disadvantaged Medicaid enrollees, groups that disproportionately include people with disabilities and people of color.<sup>221</sup> While calibrating potential risks and benefits associated with P4P is complex, two types of risks that could unduly affect people with disabilities and people of color merit description.

A common thread running through P4P approaches to reimbursement is valuing the extent to which patients’ health responds to providers’ interventions, with financial rewards given to providers whose care improves patient health and penalties imposed on providers whose care is followed by undesirable

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218. SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., MEDICAID HANDBOOK: INTERFACE WITH BEHAVIORAL HEALTH SERVICES 5-1 (2013), [https://store.samhsa.gov/system/files/sma13-4773\\_mod10.pdf](https://store.samhsa.gov/system/files/sma13-4773_mod10.pdf).

219. Diane Rowland & Kristina Hanson, *Medicaid: Moving to Managed Care*, 15 HEALTH AFF. 150, 150 (1996). States generally moved low-income children and their parents into managed care plans first. Marsha Gold & Jessica Mittler, *Medicaid’s Complex Goals: Challenges for Managed Care and Behavioral Health*, HEALTH CARE FINANCING REV., 2000, at 85, 86. States are adopting this approach because managed care plans offer control over costs, provide greater accountability for outcomes, and improve care for patients. *Managed Care*, MACPAC, <https://www.macpac.gov/subtopic/managed-care/> (last visited Feb. 17, 2019). In recent years, states have increasingly sought to move Medicaid enrollees with disabilities or who are medically frail into managed care. John Connolly & Julia Paradise, *People with Disabilities and Medicaid Managed Care: Key Issues to Consider*, KAISER FAM. FOUND. 1 (2012), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8278.pdf>. Those moves have raised concerns about accessibility and the adequacy of networks to meet the complex medical and social needs of those persons. *See generally id.*

220. Value-based reimbursement falls within the broader category of “alternative payment models” (APMs) that includes a range of payment methods that depart from traditional fee-for-service. Bailit Health, *Categorizing Value-Based Payment Models According to the LAN Alternative Payment Model Framework: Examples of Payment Models by Category*, STATE HEALTH & VALUE STRATEGIES 1, 3 (2018), [https://shvs.org/wp-content/uploads/2018/02/SHVS\\_APM-Categorization\\_Brief-Final.pdf](https://shvs.org/wp-content/uploads/2018/02/SHVS_APM-Categorization_Brief-Final.pdf).

221. Karen E. Joynt Maddox, *Financial Incentives and Vulnerable Populations – Will Alternative Payment Models Help or Hurt?*, 378 NEW ENG. J. MED. 977, 977, 978 (2018).

outcomes. Applying P4P across a large number of patients requires employing a limited number of objectively measurable markers of good outcomes (for example, achieving a certain degree of control for blood sugar levels in persons with diabetes) or poor outcomes (for example, death within ninety days of undergoing a particular surgery).

Using an absolute, invariable performance measure as the basis for financial rewards and penalties, however, incentivizes providers to take easy cases (patients who seem likely to achieve the positive performance measure) and avoid the hard cases (patients who seem unlikely to achieve it).<sup>222</sup> From a population health perspective, people with disabilities and people of color suffer higher baseline levels of medically complicating conditions and are more likely to be socioeconomically disadvantaged than non-disabled and white patients.<sup>223</sup> As a consequence, providers whose incomes depend in part on their patients achieving quality care benchmarks may view persons in those groups as undesirable patients because their prospects of achieving those benchmarks is lower.<sup>224</sup> Thus, one basic concern with basing provider reimbursement on quality measures is that doing so will negatively affect access and care for people with disabilities and people of color, along with other disadvantaged groups.<sup>225</sup>

This problem is easy to recognize but challenging to address. The standard response is to employ risk adjustment measures, which seek to remove from payment calculations differences in patient health and other risk factors that can affect outcomes but that are not under the provider's control. Risk adjustment measures are meant to allow more accurate performance comparisons across providers who treat patients across the range of clinical complexity and

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222. *Id.*

223. See INST. OF MED. OF THE NAT'L ACADEMIES, *THE FUTURE OF THE PUBLIC'S HEALTH IN THE 21ST CENTURY* 57–58, 61 (Jennifer Bitticks et al. eds., 2002).

224. Tim Doran et al., *Impact of Provider Incentives on Quality and Value of Health Care*, ANN. REV. PUB. HEALTH, 2017, at 453–54. Baseline health status and environmental factors—neither of which lies within a provider's control—may play substantial roles in whether a particular patient achieves a good health outcome. Maddox, *supra* note 221, at 977; see CTRS. FOR MEDICARE & MEDICAID SERVS., *OUTCOME-BASED QUALITY IMPROVEMENT MANUAL A-3* (2010), <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/downloads/HHQIOBQIManual.pdf>; SEAN P. CLARKE & NANCY E. DONALDSON, *AGENCY FOR HEALTHCARE RES. & QUALITY, PATIENT SAFETY AND QUALITY: AN EVIDENCE-BASED HANDBOOK FOR NURSES 2-121* (2008). The higher statistical likelihood of poor outcomes may also interact with provider perceptions that patients from a particular group are less likely to comply with the provider's directions and with a provider's implicit or explicit bias regarding group members. William J. Hall et al., *Implicit Racial/Ethnic Bias Among Health Care Professionals and Its Influence on Health Care Outcomes: A Systematic Review*, 105 AM. J. PUB. HEALTH 2588, 2599–600 (2015).

225. See Maddox, *supra* note 221, at 977, 978 (noting incentives for clinicians to avoid groups “who are at risk for high costs or poor outcomes in part because of factors beyond clinicians' control”).

socioeconomic challenge.<sup>226</sup> Risk adjustment methods have become an integral part of P4P approaches. They attempt to eliminate the penalty that providers whose patient mix includes persons with multiple chronic conditions or who experience environmental challenges to good health would otherwise face.<sup>227</sup> Creating risk adjustment methods that accomplish these ends has proven complex and expensive. It remains to be seen whether entirely satisfactory methods can be developed.<sup>228</sup>

The concern about unsatisfactory risk adjustment often is framed as a concern about how the use of P4P might negatively affect access to care by patients with complex health conditions or socioeconomic challenges.<sup>229</sup> Of equal concern is the impact that P4P measures could have on the providers who have tended to serve more disadvantaged populations. To a significant degree, minority and low-income patients are geographically concentrated around providers that have limited resources and are rated more poorly on quality measures.<sup>230</sup> Instituting value-based reimbursement for Medicaid enrollees could easily lead to the phenomenon of resource-rich providers growing richer and resource-poor providers growing poorer. That is because federal P4P programs have to date tended to be zero-sum games that “requir[e] penalties and bonuses to offset.”<sup>231</sup> By consequence, the provider that is successful at meeting quality benchmarks is rewarded at the expense of providers that fail to do so.<sup>232</sup> Achieving those benchmarks may require providers to ramp up investments in health information technology, case management, and other services—investments that simply may be beyond the means of providers traditionally caring for Medicaid enrollees and other under-served groups.<sup>233</sup> The challenges that traditional Medicaid providers may face in adapting to a P4P environment in Medicaid could thus lead to a “reverse Robin Hood effect”<sup>234</sup> in which under-

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226. See CTRS. FOR MEDICARE & MEDICAID SERVS., RISK ADJUSTMENT FACT SHEET 1–2 (2015), <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeedbackProgram/Downloads/Risk-Adjustment-Fact-Sheet.pdf>.

227. See Maddox, *supra* note 221, at 977–78.

228. *Id.* at 978 (asserting that “[c]urrent risk-adjustment methods are not sophisticated enough to reliably distinguish poor-quality care from high medical and social risk”).

229. Chris Fleming, *Quality: P4P and Quality Incentives Can Hurt Poor, Minority Patients*, HEALTH AFF. (Apr. 13, 2017), <https://www.healthaffairs.org/doi/10.1377/hblog20070413.000182/full/>.

230. See Rita Rubin, *How Value-Based Medicare Payments Exacerbate Health Care Disparities*, 319 J. AM. MED. ASS’N 968, 968 (2018).

231. *Id.*; Eric T. Roberts et al., *The Value-Based Payment Modifier: Program Outcomes and Implications for Disparities*, 168 ANNALS INTERNAL MED. 255, 256 (2018).

232. See Roberts et al., *supra* note 231 at 256; Rubin, *supra* note 230, at 968.

233. Steven Landers et al., *The Future of Home Health Care: A Strategic Framework for Optimizing Value*, 28 HOME HEALTH CARE MGMT. & PRAC. 262, 274 (2016).

234. Austin B. Frakt & Ashish K. Jha, *Face the Facts: We Need to Change the Way We Do Pay for Performance*, 168 ANNALS INTERNAL MED. 237, 291 (2018).

resourced providers, because they are ill-equipped to meet benchmarks, are financially penalized, with those penalties funding the rewards that go to richer institutions that can adapt to P4P expectations.

These unintended consequences of value-based reimbursement—whether for low-income, minority, or disabled persons or for the providers that have traditionally served them—are not necessarily insurmountable problems. Without getting too far into the weeds of program design, we can imagine several adaptations that state Medicaid programs could pursue to address the concerns described above.<sup>235</sup> Policymakers could focus on devising benchmarks that incentivize the improvement of individual patients' health, rather than the achievement of an absolute standard. Under an improvement-based standard, providers might find patients in poorer health attractive because they have more room to improve.<sup>236</sup> The same philosophy might be deployed on a population level, by rewarding providers financially if they are able to narrow health disparities experienced by disadvantaged groups.<sup>237</sup> Another adaptation would be for P4P programs to avoid the “reverse Robin Hood effect” by making comparisons only between peer institutions with similar patient mixes.<sup>238</sup> Moreover, if state Medicaid programs consider adopting value-based payment models, they should consciously address particular obstacles to achieving good outcomes that people of color and people with disabilities face. For people of color, these obstacles include language barriers, lingering effects of structural racism and segregation, and physician bias. For people with disabilities, payment models should address heightened need for long-term, integrated, and specialized care<sup>239</sup> and the lack of accessible providers and medical technology.

In short, research to date suggests that substantial work will be needed before state Medicaid programs' use of value-based reimbursement methods could be seen as a step towards diminishing disparities rather than exacerbating them.<sup>240</sup> Devising ways to adjust for medical and social risks, patient mix, and provider resources are all important and integrally related. As suggested above, the adjustments of particular importance for people of color and for disabled people may vary somewhat. But, while the specifics may differ, the two groups

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235. For a more complete listing of approaches, see Lawrence P. Casalino et al., *Will Pay-For-Performance and Quality Reporting Affect Health Care Disparities?*, 26 HEALTH AFF. w405, w409–11 (Web Exclusive 2007).

236. Maddox, *supra* note 221, at 979.

237. Casalino et al., *supra* note 235, at w410–11.

238. Frakt & Jha, *supra* note 234, at 291–92.

239. See Erin Taylor et al., *State Strategies: Value-Based Payment for Medicaid Populations with Complex Care Needs*, ST. HEALTH & VALUE STRATEGIES 1, 4 (2017), [https://www.shvs.org/wp-content/uploads/2017/04/Value-Based-Payment-Models\\_4.10.pdf](https://www.shvs.org/wp-content/uploads/2017/04/Value-Based-Payment-Models_4.10.pdf) (suggesting payment models adopted by several states to improve care for people with disabilities).

240. Sara S. Bachman et al., *Statement of the Problem: Health Reform, Value-Based Purchasing, Alternative Payment Strategies, and Children and Youth with Special Health Care Needs*, 139 PEDIATRICS S89, S96–97 (2017).



share similar core concerns about Medicaid's adoption of P4P. I do not suggest that accomplishing these changes to P4P methods will be easy, from either a technical or political perspective. But no one thought in 2017 that defeating proposals to repeal the ACA and restructure Medicaid would be easy either.

#### V. CONCLUSION

Advocacy and activism by people with disabilities and people of color played a role in the failure to repeal the ACA and fundamentally restructure Medicaid. Their actions were motivated by strong interests—shared and distinctive—that both groups had in preserving and strengthening Medicaid so it could continue to provide access to needed care and help narrow health disparities those groups experience. The preservation of the ACA and the Medicaid program demonstrates the power of advocacy and activism by these groups. Further changes to Medicaid policy, such as the imposition of work requirements and the adoption of value-based reimbursement methods, also pose threats to access to care for Medicaid enrollees in these groups. Identifying the similarity of these threats gives Medicaid enrollees who have disabilities or are members of a minority group a chance to find common ground in pursuing advocacy and activism to ensure that Medicaid functions to narrow health disparities rather than exacerbating them.