



## **Triage Cancer's 2022 Legislative Priorities**

Triage Cancer is a national, nonprofit organization that provides free education on the legal and practical issues that may impact individuals diagnosed with cancer and their caregivers.

Cancer-related legal issues are any legal issues that arise as a result of a cancer diagnosis, including employment, insurance, government benefits, consumer rights, education, and estate planning. Many of these issues are not even thought of as legal issues by a lay audience, such as health insurance. However, the availability of health insurance coverage, consumer protections in the use of coverage, and the right to appeal denials of coverage are all routed in laws.

And, lack of awareness of the law and failure to recognize its power to help people has been a barrier to people getting their needs met. In the context of a cancer diagnosis, an understanding of your rights can mean the difference between losing your job, your health insurance, or even your home. And in its most extreme case, it can be the difference between getting access to care or losing your life.

Understanding how the law and proposed legislation may provide potential solutions to these issues is foundational to our work at Triage Cancer. Our staff have spent decades translating complex laws, programs, and legislative proposals for the cancer community.

This work has also highlighted the gaps in the law, ranging from health insurance issues, to paid family leave. Some of the issues are cancer-specific and some are much broader, such as challenges with accessing housing and government benefits.

**During 2022, Triage Cancer has identified the following issues as legislative priorities, but this list is not exhaustive:**

1. Expanding access to the FMLA and paid family and medical leave
2. Expanding access to Medicaid
3. Curbing non-ACA compliant health insurance plans (e.g., short-term, self-funded student, farm bureau, association, etc.)
4. Improving access to Social Security disability benefits and eliminating waiting periods
5. Improving oral chemotherapy parity
6. Curbing utilization management policies

This document provides an overview of these issues and potential legislative solutions.

Triage Cancer also believes that there are many legislative solutions related to lowering out-of-pocket medical costs and improving access to health care that could be pursued by the advocacy community, such as capping the out-of-pocket prescription drug costs for Medicare.

To see the latest legislative and policy proposals that we are tracking for their potential impact on the cancer community, or to learn how to get involved in cancer advocacy efforts, visit [TriageCancer.org/Advocacy](https://www.TriageCancer.org/Advocacy).

## 1. Expanding Access to the FMLA and Paid Family and Medical Leave

The federal Family and Medical Leave Act (FMLA) allows eligible employees to take a maximum of 12-weeks of unpaid, job-protected leave to care for their own serious health condition or as a caregiver for a family member. The FMLA restricts eligibility by limiting the definition of “family” and imposing rigid requirements.

- The FMLA defines “family member” as a spouse, child, or parent with a serious health condition. It does not include caregiving for parents-in-law, grandparents, grandchildren, siblings, or other family members. This limiting definition of protected caregivers ignores the reality of many cancer patients who depend on extended family for assistance during and after treatment.
- Other factors that restrict access to the FMLA include requirements that employees work:
  - for the government, or a private employer with 50 or more employees;
  - for an employer for at least 12 months; **and**
  - at least 1,250 hours in the past year.

### Today:

Only 56% of U.S. employees are eligible to take leave under the FMLA.<sup>1</sup>

- 6 in 10 Americans live with at least one chronic health condition that may need ongoing medical care and/or restrict daily activities that will require absence from work.<sup>2</sup>
  - Nearly 1 million Americans die of heart disease, stroke, or other cardiovascular diseases every year.<sup>3</sup>
  - 1.6 million people are diagnosed with cancer in the United States **every year**.<sup>4</sup>
  - More than 34 million Americans have diabetes, while another 88 million have prediabetes.<sup>5</sup>
- 53 million adults have provided care to an adult or child in the last 12 months.<sup>6</sup>
  - 61% of caregivers were employed while also caregiving.
  - 24% are caregiving for more than one person.
  - 23% find it difficult to take care of their own health and 23% report caregiving has made their own health worse.
  - 18% report high financial strain as a result of caregiving. 45% have experienced at least one financial impact as a result of their caregiving.
  - 61% of caregivers are women.
- In 2018, 56% of Americans believed that the FMLA covers more situations than it does (e.g., care for a sibling or grandchild).<sup>7</sup>

### Benefits for Employers:

- In 2018, 95% of worksites covered by the FMLA, report positive or neutral perceptions of the overall effect of the FMLA on their productivity, profitability, and employees.<sup>8</sup>

### Potential Improvements:

- Expand the definition of “family.”
  - Include siblings, in-laws, grandparents, grandchildren, and caregivers outside of immediate family.
- Provide 12 weeks of **paid** FMLA leave.

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<sup>1</sup>[https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD\\_FMLA2018PB1WhoIsEligible\\_StudyBrief\\_Aug2020.pdf](https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD_FMLA2018PB1WhoIsEligible_StudyBrief_Aug2020.pdf)

<sup>2</sup><https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm>

<sup>3</sup><https://www.cdc.gov/chronicdisease/resources/publications/factsheets/heart-disease-stroke.htm>

<sup>4</sup><https://www.cdc.gov/chronicdisease/resources/publications/factsheets/cancer.htm>

<sup>5</sup><https://www.cdc.gov/chronicdisease/resources/publications/factsheets/diabetes-prediabetes.htm>

<sup>6</sup><https://www.caregiving.org/caregiving-in-the-us-2020/>

<sup>7</sup>[https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD\\_FMLA2018SurveyResults\\_FinalReport\\_Aug2020.pdf](https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD_FMLA2018SurveyResults_FinalReport_Aug2020.pdf)

<sup>8</sup>[https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD\\_FMLA2018SurveyResults\\_FinalReport\\_Aug2020.pdf](https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD_FMLA2018SurveyResults_FinalReport_Aug2020.pdf)

- Approximately one-half to one-third of eligible workers cannot afford to take unpaid leave, with the greatest impact falling on: low-wage workers, primarily women; racial/ethnic minorities; lower-educated workers; and blue-collar workers.
- Lower the requirement from 50 to 25 employees, to increase coverage in the private sector.
  - In 2018, only 10% private sector employers were covered by the FMLA, but they employed 59% of private sector employees.<sup>9</sup>
  - Reduce restrictions on length of employment and number of hours worked.
    - These changes would increase the number of workers eligible for leave.
  - Lengthen the time of protected leave.
    - Many cancer treatment protocols last longer than the 12 weeks allowed under FMLA.

## 2. Expanding Access to Medicaid

Medicaid is a federal program that provides health coverage to nearly 81 million individuals or 1 in 5 Americans. It is jointly funded by federal and state governments.<sup>10</sup>

- Medicaid is the single largest source of health coverage in the United States.<sup>11</sup>
  - 50% of all Medicaid enrollees are children, including Children’s Health Insurance Program (CHIP) participants, covering 83% of children living in poverty in the U.S.<sup>12, 13</sup>
  - During the COVID-19 public health emergency, nearly 16.7 million people enrolled in Medicaid between February 2020 and March 2022, a 23.5% increase in enrollment.<sup>14</sup>
  - More than 15% of Medicaid enrollees are seniors and people with disabilities.<sup>15</sup>
  - Medicaid covers nearly half of all births in the average state.<sup>16</sup>
- In 2019, 25% of the United States’ total annual budget went towards Medicare, Medicaid, CHIP, and Marketplace subsidies.<sup>17</sup>

### Medicaid Expansion:

The Patient Protection & Affordable Care Act of 2010 (ACA) created the opportunity for states to expand Medicaid to cover adults under age 65, with a household income up to 138% of the federal poverty level. The ACA provided significant federal funding to cover the expansion.<sup>18</sup>

- From 2020 on, the federal government pays 90% of the total costs of newly eligible enrollees.<sup>19</sup>
  - When states refuse expansion and deny coverage to those eligible, individuals without access to medical care are more likely to end up with serious medical conditions that are more expensive to treat, because they have been diagnosed late and/or gone untreated. Additionally, those individuals are more likely to eventually qualify for Medicaid due to having a disability, and the cost of their care is paid by the federal government at a much lower percentage than 90%, increasing the cost to states.
- The American Rescue Plan Act of 2021 offered further financial incentive for states to expand Medicaid.
  - In addition to the 90% federal payment for expansion, the 12 states that have not yet expanded would receive an additional 5% in federal matching for 2 years after they decide

<sup>9</sup>[https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD\\_FMLA2018SurveyResults\\_FinalReport\\_Aug2020.pdf](https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/WHD_FMLA2018SurveyResults_FinalReport_Aug2020.pdf)

<sup>10</sup> <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>

<sup>11</sup> <https://www.medicaid.gov/medicaid/eligibility/index.html>

<sup>12</sup> <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/>

<sup>13</sup> <https://www.hhs.gov/about/news/2021/06/21/new-medicaid-and-chip-enrollment-snapshot-shows-almost-10-million-americans-enrolled.html>

<sup>14</sup> <https://www.kff.org/coronavirus-covid-19/issue-brief/analysis-of-recent-national-trends-in-medicaid-and-chip-enrollment/>

<sup>15</sup> <https://www.medicaid.gov/medicaid/eligibility/seniors-medicare-and-medicaid-enrollees/index.html>

<sup>16</sup> <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/>

<sup>17</sup> <https://www.cbpp.org/research/federal-budget/where-do-our-federal-tax-dollars-go>

<sup>18</sup> <https://www.medicaid.gov/medicaid/eligibility/index.html>

<sup>19</sup> <https://www.commonwealthfund.org/blog/2019/fiscal-case-medicaid-expansion>

to expand.<sup>20</sup> This is expected to more than offset a state's cost of expansion, but all 12 states have declined to expand Medicaid, to date.<sup>21</sup>

- Eligibility criteria vary from state to state, but generally a person qualifies for Medicaid based on having a low income and resource level, in addition to meeting other requirements, such as having a disability, being pregnant, or being a senior. In states with expanded Medicaid coverage, low income is the *only* qualifier, which improves access to coverage and care.<sup>22</sup>
- In some states, an individual's income may exceed Medicaid limits, but because they have high medical bills, they may be able to qualify through the Medicaid Medically Needy pathway. The individual would "spend down" the "excess income" on medical costs, which then allows them to become eligible for Medicaid.<sup>23</sup>

### Today:

In states that have not expanded access to Medicaid, there is a significant gap in coverage for those who are under the income limit for financial assistance through the Health Insurance Marketplace, but cannot meet the other eligibility requirements for Medicaid. Of the 12 states that have not expanded Medicaid, in 6 of these states 10% or more of their total population is uninsured, while most states that have expanded Medicaid have uninsured numbers at about half that rate.<sup>24</sup>

- In Alabama, 49% of the uninsured population would become Medicaid eligible through expansion.<sup>25</sup>
- Texas has the highest rate of uninsured individuals in the country at 17.5%. Through Medicaid expansion, more than 1.4 million people would become eligible for Medicaid coverage.<sup>26</sup>
- If Medicaid expansion were adopted by the 12 remaining states, nearly 4 million uninsured adults would become eligible for coverage.<sup>27</sup>

### Costs of Not Expanding:

- Between 2013 and 2022, unexpanded states have missed out on more than \$305 billion of federal funding.<sup>28</sup>
- From 2013 to 2022, \$152 billion in federal taxes will be collected from residents of unexpanded states that will be directed to fund other states' Medicaid expansion.<sup>29</sup>
- From 2013 to 2017, expanded states experienced a 45% drop in uninsured rates while unexpanded states only experienced a 2% drop.<sup>30</sup>
- Similarly, from 2013-2017, the gap in uninsured rates between White and Black adults shrank by 51% in expansion states, compared to 33% in non-expansion states, and the gap in uninsured rates between White and Hispanic adults shrank by 45% in expansion states compared to 27% in non-expansion states.<sup>31</sup>
- Hospitals in states that have not yet expanded Medicaid are more likely to experience hospital closures due to the financial constraints of uncompensated care, while hospitals in expansion states have been less likely to close after expansion.<sup>32</sup>

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<sup>20</sup> <https://www.kff.org/medicaid/issue-brief/medicaid-provisions-in-the-american-rescue-plan-act/>

<sup>21</sup> <https://www.kff.org/medicaid/issue-brief/medicaid-provisions-in-the-american-rescue-plan-act/>

<sup>22</sup> <https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/>

<sup>23</sup> <https://www.medicaidplanningassistance.org/medicaid-spend-down/>

<sup>24</sup> <https://www.kff.org/other/state-indicator/health-insurance-coverage-of-the-total-population-cps>

<sup>25</sup> <https://www.kff.org/other/state-indicator/health-insurance-coverage-of-the-total-population-cps>

<sup>26</sup> <https://www.kff.org/medicaid/fact-sheet/uninsured-adults-in-states-that-did-not-expand-who-would-become-eligible-for-medicaid-under-expansion/>

<sup>27</sup> <https://www.kff.org/medicaid/fact-sheet/uninsured-adults-in-states-that-did-not-expand-who-would-become-eligible-for-medicaid-under-expansion/>

<sup>28</sup> <https://www.healthinsurance.org/medicaid/>

<sup>37</sup> <https://www.healthinsurance.org/medicaid/>

<sup>30</sup> <https://www.cbpp.org/research/health/chart-book-the-far-reaching-benefits-of-the-affordable-care-acts-medicaid-expansion#5>

<sup>31</sup> <https://www.cbpp.org/research/health/chart-book-the-far-reaching-benefits-of-the-affordable-care-acts-medicaid-expansion#5>

<sup>32</sup> <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2017.0976>

- From 2013-2020, 101 rural hospitals shut down, 71% of which were located in the South.<sup>33</sup>
  - Studies show expansion states experience a significant improvement in rural hospitals' operating margins and financial performance.<sup>34</sup>
  - Rural hospitals' median operating margins are -0.3% in states that have not expanded Medicaid and are 0.8% in states that have expanded Medicaid.<sup>35</sup>
  - Hospitals located in a Medicaid expansion state experienced a 62% decrease in the risk of a rural hospital closing.<sup>36</sup> Rural hospitals have higher dollar values of unrecoverable debt and charity care in non-expansion states than rural hospitals in expansion states, which can leave these rural hospitals at greater risk of closing. Increased hospital closures leave rural residents without emergency and/or hospital care.<sup>37</sup>

### Benefits of Expanding:

- Between 2014 to 2017, Medicaid expansion saved the lives of 19,200 adults ages 55 to 64 or 4,800 lives per year.<sup>38</sup>
  - In unexpanded states, more than 15,600 older adults died prematurely.<sup>39</sup>
  - Medicaid expansion led to 12 fewer deaths per 100,000 people each year and an overall 3.8% decrease in adult deaths per year.<sup>40</sup>
- Studies show the fiscal impact of Medicaid expansion leads to state budget savings and significant revenue increases by 4.4-4.7% between 2014-2017.<sup>41</sup>
- Expansion improves access to health care, resulting in residents receiving treatment previously unobtainable and increasing overall self-reported health status, decrease in depression, and fewer premature deaths.<sup>42</sup>
- Expansion led to increases in regular check-ups, early-stage cancer diagnoses, prescriptions filled for heart disease and diabetes, and surgical care.<sup>43</sup>
- Expansion led to decreases in skipping medications due to cost, one-year mortality in end-stage renal disease, and people without a primary care physician or center.<sup>44</sup>
- Evictions fell 20% in Medicaid expansion states.<sup>45</sup>
  - When there are fewer evictions, it saves state governments money spent on housing, decreases strain on homeless shelters, and fewer people end up living on the streets.
- Medicaid expansion enrollees report coverage helps them work more and find work quicker than without coverage due to improved health outcomes, which reduces state unemployment expenses.<sup>46</sup>
- By reducing unpaid medical bills, expansion improves enrollees' credit and leads to an increase in home buying and lower-interest mortgages, auto, and credit card loans, which ultimately improves the housing market and stimulates the economy.<sup>47</sup>

<sup>33</sup> <https://www.gao.gov/assets/gao-21-93.pdf>

<sup>34</sup> <https://www.kff.org/medicaid/report/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review/>

<sup>35</sup> <https://ccf.georgetown.edu/2020/05/12/expanding-medicaid-would-help-keep-rural-hospitals-open-in-14-non-expansion-states/>

<sup>36</sup> <https://www.vox.com/policy-and-politics/2020/2/18/21142650/rural-hospitals-closing-medicaid-expansion-states>

<sup>37</sup> <https://www.healthaffairs.org/doi/10.1377/hlthaff.2014.1340>

<sup>38</sup> [https://www.nber.org/system/files/working\\_papers/w26081/w26081.pdf](https://www.nber.org/system/files/working_papers/w26081/w26081.pdf)

<sup>39</sup> <https://www.cbpp.org/research/health/chart-book-the-far-reaching-benefits-of-the-affordable-care-acts-medicaid-expansion#4>

<sup>40</sup> [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(21\)00252-8/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00252-8/fulltext)

<sup>41</sup> <https://www.commonwealthfund.org/publications/issue-briefs/2020/may/impact-medicaid-expansion-states-budgets#2>

<sup>42</sup> [https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#\\_ftn2](https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#_ftn2)

<sup>43</sup> [https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#\\_ftn2](https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#_ftn2)

<sup>44</sup> [https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#\\_ftn2](https://www.cbpp.org/research/health/states-that-have-expanded-medicaid-are-better-positioned-to-address-covid-19-and#_ftn2)

<sup>45</sup> <https://www.cbpp.org/evictions-fell-sharply-in-medicaid-expansion-states>

<sup>46</sup> <https://www.cbpp.org/medicaid-expansion-enrollees-report-coverage-helps-them-work-and-look-for-work-5>

<sup>47</sup> <https://www.cbpp.org/studies-medicaid-coverage-improves-financial-security-0>

### 3. Elimination of Short-Term Health Insurance Plans

Originally intended only for people who were between jobs or needed temporary coverage for other reasons, short-term health insurance plans only provide coverage for a certain period of time and can mislead consumers into purchasing subpar health insurance with their low premiums. Short-term health insurance plans have significant limitations compared to the protections seen with the ACA-compliant health insurance plans, and can leave patients without health care coverage and access to certain services.

- Key excluded limitations and protections include:
  - Denial or higher premiums for pre-existing conditions or health history
  - Lack of prescription drug coverage
  - Lack of mental health care
  - Lack of substance abuse treatment
  - Lack of maternity care
  - Higher premiums based upon gender and age<sup>48</sup>
- Short-term plans are not required to have an out-of-pocket maximum and have significant benefit limitations. This means people with serious medical conditions, like a cancer, will pay significantly more for their medical expenses.<sup>49</sup>

#### Today:

- In 2019, 3 million Americans had short-term insurance, which is a 27% increase from 2018.<sup>50</sup>
  - The growth in enrollment can likely be attributed to a Trump administration final rule that extended the maximum duration of these plans and allowed them to be sold alongside other plans that comply with the ACA's consumer protections.<sup>51</sup>
  - This decision also encouraged consumers to use private brokers when searching for Marketplace plans on [www.healthcare.gov](http://www.healthcare.gov), the Marketplace site used by 36 states.
  - This website includes a tab for short-term health insurance and a number to reach a broker to purchase a plan.
  - These plans typically have lower monthly premiums and appear attractive to consumers on their face.
  - Because [www.healthcare.gov](http://www.healthcare.gov) plans are supposed to comply with ACA consumer protections, many purchasers accidentally chose a plan **not** required to comply because they are linked on the site.
- These short-term plans are sold through misleading marketing tactics and even through straight up lies.
  - Results of covert testing revealed health insurance brokers use deceptive tactics, including making false or misleading statements that the ACA non-compliant plan covered pre-existing conditions it did not or omitting relevant information.<sup>52</sup>
  - These practices lead consumers to purchasing inadequate health coverage under the impression that the coverage is as comprehensive as ACA compliant plans.
  - Brokers for these plans can make 10-times the amount for these short-term health insurance plans than ACA-compliant plans.<sup>53</sup>

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<sup>48</sup> <https://www.cbpp.org/research/health/key-flaws-of-short-term-health-plans-pose-risks-to-consumers>

<sup>49</sup> <https://energycommerce.house.gov/newsroom/press-releases/ec-investigation-finds-millions-of-americans-enrolled-in-junk-health>

<sup>50</sup> <https://energycommerce.house.gov/newsroom/press-releases/ec-investigation-finds-millions-of-americans-enrolled-in-junk-health>

<sup>51</sup> <https://energycommerce.house.gov/newsroom/press-releases/ec-investigation-finds-millions-of-americans-enrolled-in-junk-health>

<sup>52</sup> <https://www.gao.gov/products/gao-20-634r>

<sup>53</sup> <https://energycommerce.house.gov/newsroom/press-releases/ec-investigation-finds-millions-of-americans-enrolled-in-junk-health>

- Because of the potential dangers of short-term plans, 11 states do not offer these options either due to an outright ban or the implementation of very strict requirements that disincentivize these plans.<sup>54</sup>
  - Each state has its own rules with regard to how long a short-term health insurance plan lasts, whether it is renewable, the maximum number of renewals, and any other state-specific rules.<sup>55</sup>

Potential Improvements:

- Limit the availability of short-term plans at the federal level, as well as curb other non-ACA compliant health insurance plans, such as self-funded student plans, farm bureau plans, and association health plans. Alternatively, require these plans to offer the same consumer protections as ACA compliant health plans.

#### **4. Improving Access to Social Security Disability Benefits and Eliminating Waiting Periods Related to Social Security Disability Insurance (SSDI)**

SSDI is a federal program that provides cash benefits to eligible employees with disabilities who are unable to work.

Today:

The eligibility for SSDI process is extremely complicated due to the restrictive requirements of minimum work “credits” and the narrow definition of disability.

- To be eligible for SSDI benefits,<sup>56</sup> the employee must:
  - 1. Have worked long enough to earn enough credits and worked in a job recently where they paid into the Social Security retirement system**
    - The number of works credits needed to qualify for disability benefits depends on age. Work credits are based on your total yearly wages or self-employment income. You can earn up to 4 credits per year.
    - Generally needed: 40 credits with at least 20 credits earned in the last 10 years ending with the year the disability began.
  - 2. Have a medical condition that meets the SSDI’s strict definition of disability**
    - The disability has lasted or is expected to last for at least a year or to result in death.
    - Their medical condition prevents the employee from completing the same work as done before the disability.
    - The employee cannot adjust to other work because of the medical condition.

**This strict application process results in 65-70% of all applicants being denied, leaving many Americans with disabilities and who are unable to work, without benefits.**<sup>57</sup>

- More than 61 million adults live with a disability in America.<sup>58</sup>
- That’s 1 in 4 adults (approximately 26%) living with some type of disability that could prevent them from working, including:
  - 13.7% of adults with disabilities have serious difficulty with walking and mobility.<sup>59</sup>
  - 10.8% have cognitive impairments that impact the ability to concentrate, remember, and make decisions.<sup>60</sup>

<sup>54</sup> <https://www.healthinsurance.org/wp-content/uploads/2022/01/state-by-state-short-term-health-insurance.pdf>

<sup>55</sup> <https://www.healthinsurance.org/wp-content/uploads/2022/01/state-by-state-short-term-health-insurance.pdf>

<sup>56</sup> <https://www.ssa.gov/benefits/disability/qualify.html>

<sup>57</sup> <https://www.disability-benefits-help.org/disability-tips/dont-panic-if-your-disability-claim-denied#:~:text=Approximately%2065%2D70%25%20of%20all,decision%20and%20improve%20your%20claim.>

<sup>58</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>59</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>60</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

- 5.9% have hearing impairments and 4.6% have vision impairments.<sup>61</sup>
- 6.8% have difficulty with independent living and 3.7% have difficulty with self-care.<sup>62</sup>
- 11.8% of all SSDI applications approved in 2018, were related to a cancer diagnosis.<sup>63</sup>

Communities disproportionately impacted:

- 1 in 4 women have a disability.<sup>64</sup>
- 2 in 5 American Indians/ Alaskan natives have a disability.<sup>65</sup>
- 2 in 5 adults over 65 have a disability.<sup>66</sup>

In addition to the application process being restrictive, once someone is approved for SSDI benefits, there is a full five-month waiting period that someone must endure, before cash benefits begin, leaving someone who is unable to work due to their medical condition, without any financial assistance. The current five-month waiting period for SSDI is an enormous burden on individuals' relying on these lifeline funds for housing, food, and other basic needs.

- In 2017, more than 10,000 Americans died while waiting for SSDI benefits to begin, which can significantly affect individuals with cancer who desperately need these SSDI benefits.<sup>67</sup>

In addition to the waiting for SSDI benefits to begin, there is also a 24-month waiting period before someone who is receiving SSDI benefits to become eligible for Medicare.

#### Potential Improvements:

- Streamline the application process.
- Expand the narrow definition of a disability, especially with regard to a cancer diagnosis.
- Eliminate the 5-month waiting period for SSDI payments to be paid out upon approval for SSDI.
- Phase out the 24-month waiting period for access to health insurance coverage through Medicare.

Eliminating the waiting periods for Medicare and the five-month waiting period for SSDI would reduce the financial burden of a cancer diagnosis, and save lives.

## **5. Improving Oral Chemotherapy Parity**

Oral chemotherapy parity laws address the issue of inequitable insurance coverage between oral chemo medications and traditional intravenous delivery of chemotherapy treatment for cancer patients.

- Oral parity laws require health insurance plans to ensure that cancer patients do not pay more out-of-pocket for oral chemo medication than IV chemo medication.<sup>68</sup>

#### Today:

- Intravenous chemotherapy is typically covered under a health plan's medical benefits, which may result in a lower out-of-pocket cost to a patient.
- But, oral anti-cancer medications are usually covered by a health plan's prescription drug benefit which may require a patient to cover a percentage of the drug's overall cost, resulting in a higher out-of-pocket cost to a patient.<sup>69</sup>

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<sup>61</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>62</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>63</sup> <https://www.alperinlaw.com/library/ssdi-benefits-for-cancer-patients.cfm>

<sup>64</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>65</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>66</sup> <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>67</sup> <https://www.brown.senate.gov/newsroom/press/release/brown-introduces-bill-to-eliminate-the-waiting-period-for-social-security-disability-benefits>

<sup>68</sup> <https://www.myeloma.org/article/imf-applauds-oral-parity-legislation>

<sup>69</sup> <https://www.ils.org/advocate/oral-parity>

- Oral chemotherapy can be beneficial to a patient for a number of reasons, including ease of access, a lower need to take time off work to attend medical appointments, and lower transportation or childcare costs to attend in-person medical appointments.
  - However, due to the high price of cancer medications, this cost-sharing method results in expensive out-of-pocket costs that prevents many patients from accessing oral chemotherapy.<sup>70</sup>
  - Pill medications directly attack the cancer cells and often have fewer side effects than traditional methods,<sup>71</sup> yet the lack of federal oral parity laws allow an unnecessary barrier to exist.

***Potential Improvement:***

A federal law requiring private health insurance plans to cover injectable cancer medications to also cover oral cancer medications at no less favorable cost sharing.<sup>72</sup> Oral cancer medication makes up 35% of pharmaceutical companies' research and development pipeline and it is increasingly becoming the standard of care for certain cancers.<sup>73</sup>

- This requirement should apply to 1) FDA-approved medications, 2) medications that are medically necessary for cancer treatment, and 3) medications that are clinically appropriate with regards to type, frequency, and duration.
- To be deemed in compliance, health insurance plans should not be allowed to change or replace benefits to increase out-of-pocket costs, 2) reclassify benefits to increase costs, or 3) apply more restrictive limitations to oral anticancer medications compared to injectable anticancer medications.
- We strongly believe this would help to relieve the financial toxicity of a cancer diagnosis, by holding insurance companies accountable for unbalanced out-of-pocket costs.
- The option to receive medications that can be self-administered outside of a hospital, in one's own home or even at work, could exponentially increase quality of life and decrease other burden such as; loss of employment income, transportation, cost of hospital stays, and more.

**6. Curbing Utilization Management Policies**

Current health insurance utilization management policies delay patient care and can have potential negative effects on a patient's health outcomes and quality of life. Some of the most common types of utilization management are:

- **Formulary restrictions:** Formularies view drugs within a certain class or indication as therapeutically interchangeable.
  - Therapeutic equivalency may not be established in cancer care as it is in other diseases and treatment choices.
  - Even though there might be similarities in some class of medications, toxicities can be vastly different, which could limit use of certain medications deemed to be "similar."
- **Step therapy:** Patients must fail or not be able to tolerate a lower-cost therapy before being approved for a higher cost therapy.
  - It is not always reasonable to allow a cancer patient to fail a treatment option before a potentially more-appropriate medication because could put the patient in a life-or-death situation.
  - It is not ethical to make a patient use step therapy and then pay higher out-of-pocket costs for the medication that is on a higher premium tier.

<sup>70</sup><http://www.nnecos.org/Resources/Documents/Oral%20Oncology%20Parity%20Laws%20Fact%20Sheet%20AUG%202014.pdf>

<sup>71</sup><http://www.nnecos.org/Resources/Documents/Oral%20Oncology%20Parity%20Laws%20Fact%20Sheet%20AUG%202014.pdf>

<sup>72</sup>[https://www.congress.gov/bill/117th-congress/senate-bill/3080#:~:text=Introduced%20in%20Senate%20\(10%2F27%2F2021\)&text=This%20bill%20requires%20group%20health,for%20patient%2Dadministered%20anticancer%20medications](https://www.congress.gov/bill/117th-congress/senate-bill/3080#:~:text=Introduced%20in%20Senate%20(10%2F27%2F2021)&text=This%20bill%20requires%20group%20health,for%20patient%2Dadministered%20anticancer%20medications)

<sup>73</sup><https://bilirakis.house.gov/media/press-releases/bilirakis-fights-ensure-cancer-patients-have-equivalent-access-oral>

- **Prior authorization:** Payers require patients to get pre-approval before receiving care or they will deny coverage for that care.
  - Sometimes the people conducting the prior authorization review have limited oncology experience and are simply following an algorithm.
  - The period of time to complete a prior authorization has significantly increased, from several days to possibly over a week.

In 2019, ACS conducted a nationwide study detailing the negative effects insurance utilization management policies have had on patient care.<sup>74</sup>

- 1 in 3 cancer patients reported having to wait for an insurance plan to approve a cancer treatment, test, or prescription drug.<sup>75</sup>
- 56% of doctors reported the same issue.<sup>76</sup>
- 2 of the most common and harmful policies at that time were:
  - Prior authorization
  - Step therapy
- Patients & caregivers reported that these policies and requirements “delayed their care, increased their stress and frustration, contributed to worse outcomes and cost them more out of pocket.”
- 60% of patients & 84% of doctors oppose prior authorizations.<sup>77</sup>
- 68% of patients & 78% of doctors oppose step therapy.<sup>78</sup>

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<sup>74</sup> <https://www.fightcancer.org/releases/new-survey-utilization-management-delays-cancer-care-leads-more-stress-and-contributes>

<sup>75</sup> <https://www.fightcancer.org/releases/new-survey-utilization-management-delays-cancer-care-leads-more-stress-and-contributes>

<sup>76</sup> <https://www.fightcancer.org/releases/new-survey-utilization-management-delays-cancer-care-leads-more-stress-and-contributes>

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