Community Catalyst

CURBING MEDICAL DEBT TO ENSURE HEALTH AND ECONOMIC JUSTICE FOR LGBTQ+ PEOPLE

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Medical debt is personal debt a person incurs when they are unable to afford necessary health care services. While we know **medical debt is the most common type of debt reported on consumer credit records**, very little research has been conducted to understand how medical debt impacts LGBTQ+ people specifically. From the few available studies, it appears medical debt may impact LGBTQ+ people more than their cisgender and heterosexual peers, though more research and engagement with community members is necessary to draw concreate conclusions.

One of those few available studies comes from the Center for American Progress, which was published in 2013. It found that 4 in 10 uninsured LGBTQ+ adults reported carrying medical debt and 44% of all LGBTQ+ respondents reported delaying medical care because of high costs. This report also found that uninsured LGBTQ+ adults and LGBTQ+ adults with incomes below 139% of the Federal Poverty Level were even more likely to delay care due to costs, 60% and 58% respectively. The Kaiser Family Foundation found similar results in 2021, reporting LGBTQ+ are more likely to struggle to pay for medical expenses than their cisgender and heterosexual peers. Of those who struggled to afford care, 60% had to set up a payment plan and 59% were contacted by a collection agency regarding the unpaid medical debt.

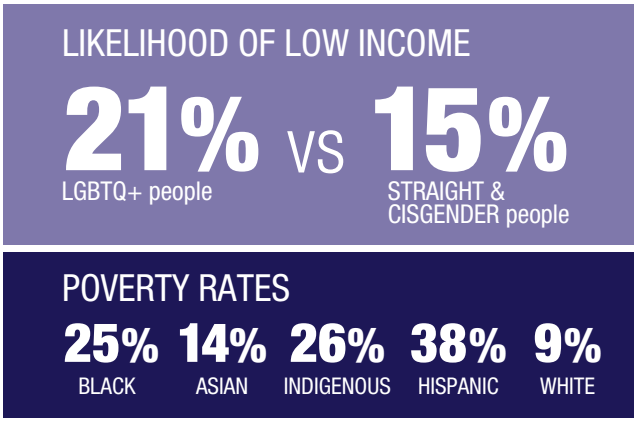
These studies suggest that medical debt is a significant issue for LGBTQ+ people, but the findings from the Center for American Progress are almost ten years old and we could only find one additional study on this topic. There is also a significant lack of sexual orientation and gender identity (SOGI) data in surveys, polls, and databases making it challenging to conduct an independent review of national trends of medical debt for the LGBTQ+ community. Without sufficient data collection or a robust body of research, we must turn to the

key drivers of medical debt to explore how those drivers might uniquely impact LGBTQ+ communities. As we will discuss in this policy brief, there are a significant number of indicators suggesting that LGBTQ+ people may be more vulnerable to medical debt than their cisgender and heterosexual peers. We believe this calls for additional advocacy and community engagement to bring LGBTQ+ people to the decision-making table to draft policy solutions that meet their needs.

MAIN DRIVERS OF MEDICAL DEBT

In December 2021, Community Catalyst released a policy brief identifying five main drivers of medical debt based on research with over a dozen state advocates fighting for medical debt protections. Each of these drivers have unique implications for the LGBTQ+ community, indicating a need for further research and community input on this issue. With further research and deep community engagement, we can begin pushing for stronger medical debt protections that appropriately address the unique needs of LGBTQ+ people and ensure our fight for health equity doesn't leave anyone behind.

1. Poor Health Status and Low Income



- LGBTQ+ adults are significantly more likely to have low-incomes than their straight and cisgender peers (21% vs 15%). Income disparities deepen for LGBTQ+ people of color, which can be seen through higher poverty rates among Black (25%), Asian (14%), Indigenous (26%), and Hispanic (38%) people compared to white (9%) people.

- Discrimination in the workplace leaves LGBTQ+ adults with smaller earnings and more job insecurity than their cisgender and heterosexual peers, making it harder to afford health care costs. According to the Williams Institute, one-in-ten LGBTQ+ workers experienced discrimination at work in the last year and 40% of LGBTQ+ workers report experiencing discrimination or harassment at work at some point in their lives. Some LGBTQ+ workers choose to leave workplaces due to discrimination but for those who stay, they are 1.5 times more likely to be laid off or fired than their peers (4.25% vs. 2.7%). LGBTQ+ adults are also more likely to be unemployed and looking for work (6.3%) than non-LGBTQ+ adults (3.5%).

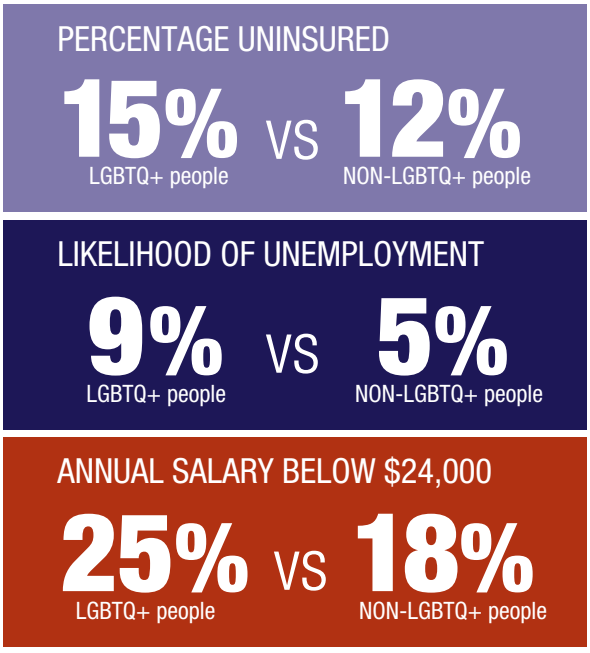
- Due to widespread transphobia in our culture that seeps into the medical system, transgender and nonbinary people have higher rates of mental and physical health conditions than their cisgender peers. For example, 39% of transgender adults report experiencing serious psychological distress in the past month compared to 5% of the general population, and 54% of transgender adults report at least one day of poor physical health in the past month compared to 36% of cisgender adults.

2. Unfair Billing and Collection Practices

- LGBTQ+ patients are continually billed for preexposure prophylaxis (PrEP) and its auxiliary services, a proven regimen to lower the risk of HIV infections. To receive a prescription, patients must complete initial lab work before starting medication and must then return every three months for a medical visit and additional lab work. Some patients are still billed for these services despite guidance from the Department of Labor requiring insurance companies to cover the costs of the medication and auxiliary services. With confusing formularies and medical bills, it's challenging for patients to push back on wrongful billing practices.

3. Lack of Health Insurance Coverage

- 15% of LGBTQ+ people in the U.S. are uninsured, compared to 12% of non-LGBTQ+ people, according to the Williams Institute. LGBTQ+ people are also more likely to be unemployed (9% vs. 5%) or have an annual salary below $24,000 (25% vs 18%) making it challenging to afford health insurance.



- Black, Indigenous, and other people of color in the LGBTQ+ community are more likely to be uninsured and have low-incomes than both their white-LGBTQ+ and non-LGBTQ+ peers.

- LGBTQ+ individuals often do not fall within "infertility" definitions that would qualify them for coverage of fertility services, as described in this issue brief from the Kaiser Foundation. Additionally, surrogacy, which is necessary for some LGBTQ+ couples to have children, is often not covered by insurance. Transgender and nonbinary people seeking gender-affirming care may also not meet criteria for "iatrogenic infertility" that would qualify them for coverage of fertility preservation. Even with new guidance from HHS that clarifies nondiscrimination protections for LGBTQ+ people in health care under Section 1557 of the ACA, patients can still be denied care under religious freedom laws.

- 40% of LGBTQ+ workers report experiencing discrimination at work at some point in their lives, and 8.9% of LGBTQ+ adults report being fired or not hired because of their sexual orientation or gender identity in the past year, according to the Williams Institute. Transgender people (48.8%) and people of color (33.2%) are even more likely to experience discrimination than their white (26.3%) and cisgender (27.8%) peers. This discrimination can lead to disruptions in health insurance coverage when a worker with employer-sponsored health plan is fired or needs to leave due to the unsafe working conditions.

- Covered benefits for gender affirming health care varies widely between states and between health insurance plan types – whether that be blanket bans for all forms of gender affirming care, or coverage

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options that only include a narrow scope of services. Even for states that prohibit arbitrary denials of gender-affirming health care, patients still struggle to receive care. A survey from the Center for American Progress in 2020 found that 43% of transgender respondents were denied surgery for their transition by their insurance and 52% of respondents who were transgender people of color said their insurance company denied them hormone therapy for their transition.

4. Complicated and confusing Insurance Adjudication Process

- Complex billing processes around gender affirming surgery make it challenging for patient's to clearly understand the cost of surgery and their payment options. As this story from NPR explains, the difference between the cash price and insurance cost-sharing can vary widely and if there is a billing error during adjudication it can result in exorbitant bills a patient didn't agree to.
- Transgender and nonbinary patients can face a range of denials for health care services during the adjudication process. This can include billing errors tied to mismatching gender markers for sex-specific health care, and insurance plans failing to recognize certain gender affirming care as medically necessary.
- Errors tied to mismatching gender markers are automatically generated by insurance companies for services like gynecological visits or prostate exams to prevent fraud. This automation assumes that a person's gender marker on their insurance record indicates their anatomy, but the assumptions made in this process don't hold true for some transgender, nonbinary, and intersex people. Some states create modifier codes for providers to enter that circumvent these errors, but if these codes are entered incorrectly a patient will have to follow-up with their insurance company or health care provider to explain what happened and try to resolve the issue.
- When it comes to medical necessity, insurance plan might cover hormone replacement therapy but not cover gender affirming surgeries despite both services falling under standards of care for transgender and nonbinary people. To receive coverage for these denied services, patients must challenge the denial and demonstrate that the service is recognized as a medically necessary treatment for gender dysphoria, and in some cases go a step further and prove the service is also medically necessary for them as an individual.

There often is not a single website or form patients can access that clearly outlines the sequencing and required documentation needed to receive coverage for gender affirming surgeries.

5. High Out-of-Pocket Cost Sharing

- Not all transgender and nonbinary people need or want gender affirming surgeries, but for those who do, costs can not only be high, but the range in price between providers can make it challenging to plan for. According to one estimate from the Philadelphia Center for Transgender Surgery, costs can range from $10,000 to $70,000 depending on the surgery. These costs are clearly extraordinarily high for people who pay out of pocket but even for patients who can receive coverage through their health insurance, high deductibles can mean people must delay necessary surgery until/if they meet that deductible.

- The above estimates don't include the cost of behavioral health and medical visits needed to qualify for surgery or follow-up care. Health plans generally require patients to obtain a series of letters from their medical team confirming that gender affirming surgery is medically necessary before scheduling a procedure with a surgeon. While requirements vary between states and health plans, this can include letters from the patient, their primary care provider, and one or two mental health providers – all of whom will need to work with the patient for a year while they outwardly express their gender. In addition, patients may then need to seek a referral from their primary care provider to the selected surgeon. This is not only time consuming, but confusing as this information is often not readily available from health insurance plans. There often is not a single website or form patients can access that clearly outlines the sequencing and required documentation needed to receive coverage for gender affirming surgeries.

RECOMMENDATIONS

Based on these findings, it is clear LGBTQ+ are more vulnerable to medical debt than their cisgender and heterosexual peers. Community Catalyst always seeks to empower those directly impacted by health systems and policy decisions. We believe through further community engagement we could pursue the following recommendations and secure significant protections against medical debt for LGBTQ+ people.

- **Secure coverage for Gender Affirming Care** under Medicaid, Medicare, Marketplace, and private insurance through administrative and legislative action. Services must be covered with little to no cost-sharing and include all services within existing standards of care for transgender and nonbinary people – such as those outlined by the World Professional Association for Transgender Health (WPATH).
- **Identify national health and economic surveys** missing comprehensive and culturally appropriate sexual orientation and gender identity (SOGI), race, and ethnicity data. Improving data collection will allow advocates to better assess current impacts of medical debt for LGBTQ+ people and track changes over time to ensure policy measures are appropriately addressing the issue. It is important that data collection efforts not only include SOGI data but race and ethnicity as well so advocates can better understand how intersectional identities impact health outcomes and access to care. Direct input from LGBTQ+ individuals is critical for success as these demographic questions can be viewed as invasive without proper introductory language and clear messaging as to how data will be used and stored.

- **Include LGBTQ+ voices** in Community Health Needs Assessments to identify solutions at the local level aimed at addressing the high cost of gender affirming care and other health needs identified by community members. This could include expanding financial assistance programs to cover gender affirming health care and behavioral health care costs, developing action plans to address LGBTQ+ cultural competency and discrimination, or creating hardship provisions for LGBTQ+ patients with medical bills exceeding a set percentage of household income.

Community Catalyst is a leading non-profit national health advocacy organization dedicated to advancing a movement for health equity and justice. Learn more about our work at communitycatalyst.org