Community Catalyst

July 2025

Tackling Medical Debt Together: A Community-Centered Toolkit

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Table of Contents

Key Definitions

Below are definitions of terms that we use throughout the toolkit:

- **Bias**: Positive or negative feelings for a trait, person, or group that are not based on reason or actual experiences.
- **Power**: The ability to direct or influence the course of events.
- **Equity**: Fair processes and outcomes in which everyone receives the support, resources, and access they need based on their identity, historical advantages or disadvantages and current circumstances.
- **Anti-Racism**: Actively opposing racism by advocating for changes in political, economic, and social life.
- **People/Communities most impacted by medical debt**: People and communities who because of bias, abuse of power, inequities, and/or systemic disadvantages experience medical debt at a higher rate and/or who medical debt impacts more significantly.

Toolkit Overview

This toolkit is here to help people who want to take action on medical debt, especially in ways that are equitable, inclusive, and centered on the needs of those most affected. It focuses on understanding the root causes of medical debt and finding community-driven solutions that support health equity and race justice.

This toolkit is made for both community advocates and community members. It can be used together with community members, by organizations themselves, or by small groups of staff. The goal is to give clear, useful strategies to reduce the causes and effects of medical debt while making sure that equity, inclusion, and community voice are part of all the work.

This toolkit can also help advocates plan both short-term and long-term goals.

What's Inside

To keep things simple, the toolkit is broken into sections:

- Assessing the Advocacy Landscape
- What's Behind Medical Debt in Our Communities?
- Community Voices, Clear Solutions
- What Stands in Our Way — and What Pushes Us Forward
- Making It Work: Group Decisions and Compromise
- From Ideas to Impact: Tracking Progress

Each section includes:

- Questions to help think and plan
- A real-life example of how to put the section into action
- A chance to reflect on the work with a few more questions

These sections may overlap a bit, but they're meant to make hard topics easier to understand. You can go through the whole toolkit from start to finish or just use the parts that are most helpful for your group and your time.

We've also included a shorter version at the beginning of the toolkit — one key question from each section. This can be useful if time is limited or to quickly find out what parts are most relevant to your work.

How This Toolkit Was Made

This toolkit is based on ideas and lessons learned from the work of our partner organizations and our work alongside them. We are grateful to have co-designed this toolkit with our partners across eleven states along with other national advocates. At the end, you'll find links to helpful resources from our partners working on medical debt and as well as resources not affiliated with this toolkit but that helped inform it.

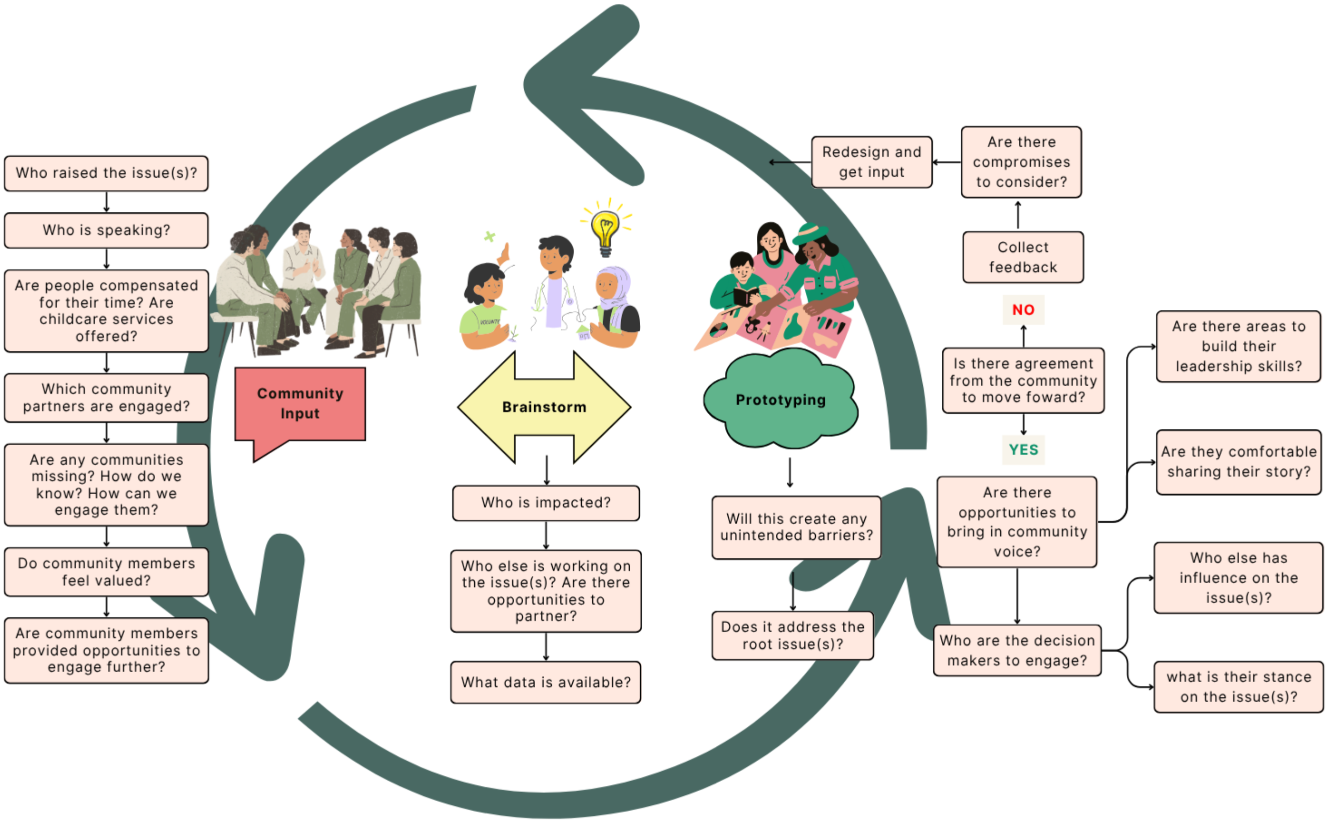
Before diving into the toolkit, below is a quick overview of how **Community Catalyst** works on medical debt and a visual guide to support the use of this toolkit.

Community Catalyst's Approach

At Community Catalyst, we work with people who have faced medical debt, as well as partner organizations across the country and other national groups advocating to prevent and end medical debt. We want people's stories to be heard and to help shape policies that reduce or eliminate medical debt.

Ending medical debt is part of our bigger goal to help communities make sure hospitals do the right thing — like offering financial help, stopping unfair bills, and keeping care available, especially in rural areas and communities that face the biggest challenges. Our work in this area includes pushing for lower health care costs and stopping unfair collection practices by hospitals.

Below is a visual which provides a quick guide for inclusive problem-solving that centers community voice, identifies root causes, and ensures a meaningful feedback loop with shared decision-making throughout the policy development process. Ideally the toolkit can also be used in this manner.



Shortened Toolkit

Assessing the Advocacy Landscape

How has medical debt come up as an issue? How are people talking about medical debt/asking about medical debt/organizing around medical debt/taking action to stop medical debt?

What's Behind Medical Debt in Our Communities?

How is medical debt understood and talked about in our state/communities? Does it depend on who is talking about it? Does it have to be a specific amount or not yet paid?

What causes medical debt? Pre-existing health conditions? Confusing medical bills? Not having insurance coverage? High out-of-pocket costs? Do these things impact certain groups differently? How?

Community Voices, Clear Solutions

If there are already solutions being proposed, who is proposing them and why? How were the solutions created? Does the community/people most impacted by medical debt support them? Will the issues that have come up in personal stories be resolved?

What Stands in Our Way—and What Pushes Us Forward

Who has power over the issue and why do they have power? Can we get them to support us? What unique perspective and expertise do we bring related to medical debt? What experiences and stories need to be at the forefront to change hearts and minds?

Making It Work: Group Decisions and Implementation

How do we make decisions as a group – especially around disagreement? How will communities and people most impacted by medical debt be included in these conversations? How do communities want to be involved and what do they need to engage (stipends, support, outreach, training, etc...)?

Reflection Points:

Before diving in…

- Related to Medical debt what are our goals and are those understood by everyone at our organization?
- Do we have practices in place to support and address the needs of storytellers? Can we train and support them to become advocates and leaders?

Looking ahead…

- What lessons did we learn about doing this work moving forward? What went well and where can we improve? Knowing what we know now, what are our long-term goals for change?

Assessing the Advocacy Environment

How does medical debt affect the communities you work with? What's already being done about it and how can your group help fill those gaps or bring in new voices?

- ☐ How is medical debt affecting people in our communities?
  - ○ Are people struggling to pay for care or for medical bills?
  - ○ Have people paid medical bills when they should have gotten free or lower-cost care (charity care/financial assistance)?
  - ○ Are people only being offered payment plans or medical credit cards?
  - ○ Are underinsured people being left without payment options?
  - ○ Are people getting wrong or confusing information — or not getting info in their preferred language — about help like charity care/financial assistance?
  - ○ Is there something else happening?
- ☐ Are the people most impacted by medical debt:
  - ☐ Talking about it?
  - ☐ Asking us about it?
  - ☐ Organizing or taking action to stop it
- ☐ What are other groups or organizations in our community or state doing about medical debt?
- ☐ Are there gaps in how medical debt is being addressed? Is there a way we can help?
- ☐ What strengths do our community leaders and partners bring to this work?
- ☐ Is there any knowledge, experience, or perspective missing that we need to include?

Reflection Point: Think about your group's goals and capacity:
Before you get started, take a moment to think about how ready you are to do this work. Ask yourselves:

- What are our goals when it comes to medical debt? Does everyone in our group understand them?
- What is our commitment to equity? Are there things we want to do better as we work on medical debt?
- Do we have the time, money, and support to make sure equity is a real part of this work?

Case Study:
The Pennsylvania Health Access Network (PHAN) regularly conducts focus groups in collaboration with trusted community-based organizations directly serving communities of color. Partnerships are critical for engaging honest feedback, as community-based organizations are often the sole source for many communities to get support and resources on navigating various challenges they may encounter. The focus groups educate community members and engage in Q&A on topics such as health insurance coverage, hospital financial assistance, and opportunities to join advocacy efforts. Focus groups have become essential to helping PHAN better understand how medical debt impacts the community and learn about what improvements the community would like to see to address their medical debt burdens. Questions and stories shared from individuals may differ between communities and allow PHAN to evaluate the nuances of how medical debt is perceived.

What's Behind Medical Debt in Our Communities?

Do we understand what is causing medical debt? Is that true for everyone involved? How do we know? What do we need to understand better?

Questions	Notes
History of Medical Debt: What is the history of medical debt in the communities we support? What has changed? What is the same?	
How People Talk About Medical Debt: How is medical debt usually talked about in our state and communities? What words do people use when they talk about medical debt? Does the message change depending on who's talking — like a community member, policymaker, or advocate?	
Inequities: How does medical debt impact different groups of people? Think about: ● Race, ethnicity, or culture ● Gender identity and sexual orientation ● Immigration status ● Income or financial situation ● Disability ● Age or generation ● Where people live (rural or urban)	

• People who primarily speak languages other than English • Uninsured and underinsured	
Understanding Bias and Gaps: What facts, stories, or data do we have about medical debt? Does this information tell the full story and capture community members' experiences? Are some voices or experiences missing that we can help to bring forward?	
Lifting Up Voices: What personal stories about medical debt haven't been shared — but should be?	

Reflection Point: Are we being equitable and inclusive?

As you plan, check in on how you're showing up for all communities. Ask yourselves:

- Are we leaving out any groups because the data says they aren't impacted — even though they may still be struggling?
- What are community leaders telling us about medical debt and equity? Are we really listening?

Case Study:

In 2021, when working to advance improved hospital financial assistance policies, the Colorado Center on Law and Policy (CCLP) realized the way medical debt was described by public data sources in CO did not capture the full experiences of many community members. To have an effective solution, CCLP recognized community voices were key in understanding what was going wrong - especially those most impacted by medical debt. To address this issue, CCLP partnered with groups like the Center for Health Progress, Colorado Consumer Health Initiative's Consumer Assistance Program, and the Summit Family and Intercultural Resource Center; organizations deeply involved in community organizing and helping community members fight exorbitant hospital bills. CCLP and partners recognized that for community members connected to these organizations to engage in policy-making spaces, childcare, technology support for virtual participation, transportation, language access, and compensation for people's time would be required. After struggling to secure enough funds to support these needs, the groups pivoted to using the funding they did raise to compile stories of peoples' experiences with medical debt and better support the community organizations to engage in policy processes. Ultimately, this process led to prioritizing affordability, consumer protections, screening and simplification of applications, and strong enforcement mechanisms – issues which were identified in close collaboration with partners and community members. To learn more about this process and, ultimately, the passage of legislation which achieved these priorities, check out our report here.

Community Voices, Clear Solutions

What does change that centers equity and voices of the people most impacted by medical debt look like?

Questions	Notes
Goals: What does success and progress look like for us? What are our short-term and long-term goals? Do we agree on the goals?	
Proposed Solutions: Are there already ideas or solutions being shared? Who came up with them and why? How were they created? Do the people most impacted support them? Do we support them? Do they actually get at the root causes of medical debt?	
Connecting Stories to Solutions: Will the problems shared in people's stories be fixed by our goals or the solutions others are suggesting?	
Involving the Community: Have the people most impacted by medical debt helped shape solutions? Did it happen in a way that felt fair and respectful to them? If not, what can we do to fix that?	
Checking for Equity: How does the solution impact people from different backgrounds and identities (like race, gender, income, or language)? Are some groups left out or treated unfairly? If yes, how can we include them?	
Building Community Power: Will the solutions and the process help give more power to the people most impacted by medical debt? Will they see real changes in their lives and their medical debt situations?	

***Reflection Point**: **Supporting storytelling and building leaders**.*
Medical debt is often framed as a personal fault, instead of a problem with the health care system. That's why it's important to support people as they share their stories and help them grow to become advocates. Ask yourselves:

- *Do we have ways to support and address the needs of storytellers? (i.e. policies on protecting individual privacy, consent forms, etc.)*
- *Do we have ways to train and support storytellers to become advocates and leaders?*

Case Study:
At the Maine Access Immigrant Network (MAIN), community members grew frustrated at not seeing their own voices accurately reflected in hospital-led Community Health Needs Assessments (CHNA). MAIN works directly with the state’s immigrant and refugee communities to bridge access to health and social services. However, there has historically been limited opportunities for community engagement and pre-determined issues presented at hospital convened local forums. Inspired by a model led by the Wabanaki tribal community to create their own Waponahki Health Needs Assessment (WHNA), MAIN is looking to spearhead a CHNA run entirely by immigrant- and refugee-led organizations. The WHNA helped the Wabanaki community tell their own story on community needs and revealed chronic diseases impacting their communities that were never reflected in hospital reported data. Access to affordable health care has been a significant crisis facing the immigrant and refugee community, but the community challenges have not fit into the confines of a rigid, hospital-led CHNA process. A community-based participatory research model aims to allow community members to use lived experience and culturally appropriate survey methods to lead to the development of effective solutions. Learn more about the WHNA here.

Tribal Members Aged 18–24, if you received an invitation to the Wabanaki Health Needs Assessment (WHNA), please fill it out before March 31, 2023.

Your participation in the WHNA helps to create a healthier future for every generation of our indigenous communities.

Photo courtesy of Wabanaki Public Health & Wellness

What Stands in Our Way—and What Pushes Us Forward

What’s getting in the way of our goals? Who supports us?

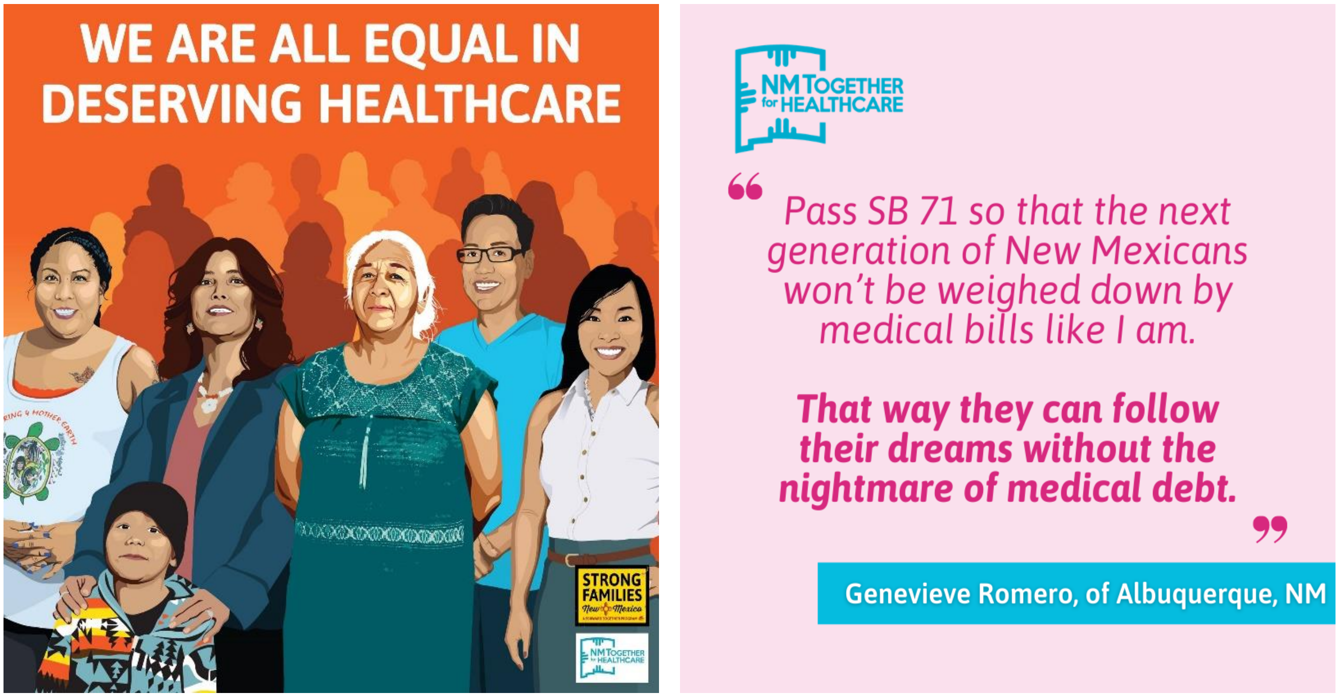
To make real change, we need to know what will help us move forward — and what might hold us back. A simple way to do this is by using a **SWOT Analysis***:* **S***trengths,* **W***eaknesses,* ***O****pportunities, and* ***T****hreats.*

Questions to Guide Thinking:

- What groups or people have power in this issue? Where do they stand?
- What’s happening in the world or our community that affects this work (like politics or social issues)?
- What do policymakers or decision makers think about this issue?

Strengths ● What strengths/power do we have when we work together? ● What knowledge or experience do we bring around medical debt?	***Weaknesses*** ● Are there competing priorities at the organization or coalition? ● What are we short on: time, money, and/or people?
Opportunities ● Who do we need to influence to make change? ● What stories or experiences can help change minds and build support?	***Threats*** ● Is there strong opposition to our ideas? ● Are other big issues making it harder for medical debt to get attention?

Case Study:
In 2021, when working to pass the Patients’ Debt Collection Protection Act, a coalition of organizations in New Mexico, including the New Mexico Center on Law and Poverty, Strong Families New Mexico (Forward Together), and Casa de Salud dug into the beliefs and talking points of their opposition. Some legislators thought the protections would incentivize middle- and high-income to take advantage of the system. Some provider and hospital groups claimed they did not send medical debt into collections while also opposing the legislation from prohibiting such action – asserting it would hurt their bottom line and impose administrative costs. To counteract this, the coalition uplifted the voices of health workers and clinicians within their group, who were able to explain proper screening for coverage options increases reimbursement. The coalition also used storytelling through social media to highlight the impacts the protections would have on people who need them most. To learn more about their campaign's successes and challenges, visit here.



“Pass SB 71 so that the next generation of New Mexicans won’t be weighed down by medical bills like I am.

That way they can follow their dreams without the nightmare of medical debt.”

Genevieve Romero, of Albuquerque, NM

Photos courtesy of NM Together 4 Healthcare

Making It Work: Group Decisions and Compromise

How do we make decisions as a group – especially around compromises?
How will we make sure the voices of people most impacted by medical debt are included when tough choices are made?

Questions	Notes
What decision-making process do we use? Is it different for urgent vs. non-urgent decisions? Are community voices included – and how?	
How do we decide if the comprise is okay? What areas can we be flexible on – and what things are non-negotiable? How do we know what the impacts of decisions are?	
How will we handle disagreements between partners and allies- especially when they have different views on equity?	

Case Study: In Colorado, a coalition of organizations working together to support legislation advancing equitable health coverage decided that no one organization was able to make decisions alone. Together they developed a clear decision-making protocol and process. This included a steering committee made up of impacted community members, a policy committee made up of all core coalition organizations, and a rapid decision-making team comprised of members of both committees. The steering and policy committee developed shared values to guide decisions, and both met weekly to discuss updates and issues. For non-urgent decisions, the policy committee would develop a proposal which would then be sent to the steering committee to accept or respond with a counter proposal. For urgent decisions, the ad-hoc rapid response team would coordinate over text to gain consensus. In both situations, when consensus was difficult the group used a voting system. All decisions were communicated to the full coalition via e-mail or at meetings.

From Ideas to Impact: Tracking Progress

How can we make sure our solutions stand the test of time and remain true to the spirit of what we wanted them to look like?

Questions	**Notes**
How will everyone – especially advocates and community members – know how things are going? What are the key steps or goals along the way? How do people give or get feedback?	
How can people most impacted by medical debt help carry out solutions? What support (like money, outreach, training, etc...) do they need to be part of it? How do they want to be engaged?	
How will we know if solutions are working and what needs to change? Will there be evaluations and do they measure the right things? Is anything missing that we should also track?	
What ways do community members have to share feedback? Are those methods working well and meeting their needs?	
How will we track whether the solutions reduce inequities or cause any unexpected problems?	
In the end, who will benefit most from this work - in terms of impact, reputation, social capital or money?	

Reflection Point: Looking Back and Moving Forward

Take time to reflect on what you've done, what you've learned, and what comes next:

- *What did we achieve? Did our work help get at the root causes of medical debt?*
- *What goals did we not reach? What compromises were made - and who did they impact the most?*
- *What did we learn about doing this work? What went well and where can we do better next time?*
- *Now that we know more, what are our long-term goals to change the system?*

Case Study:

The Illinois Coalition for Immigrant and Refugee Rights (ICIRR) is dedicated to building power with immigrant and refugee communities across Illinois. ICIRR members encompass multiethnic community-based organizations across the state. Together, they develop their annual policy agenda and help shape the coalition-wide strategy. While issues that stray from the policy agenda may arise throughout the year, ICIRR remains intentional in seeking feedback and input from their members before making any decisions. ICIRR hosts an annual People's Congress event for members with focused breakouts to engage input on commonly encountered issue areas. All members are asked to check in with their communities on issues to prioritize, and challenges such as affordable health care access has remained a focus area members have elevated as a priority. ICIRR utilizes member feedback to help develop tools to tackle concerns such as how to conduct a community listening session, tackling misinformation, and protecting communities from deportations.

Case Study:
At the Center for Health Progress, their mission is to build a powerful movement to unite against corporate greed in the health system. Meaningful and equitable access to affordable health care is a core part of their work. CHP’s structure ensures community members actively participate in decision-making, informing priorities, and driving activities. CHP’s community leaders across the state are deeply valued; each member is provided voting power on who should be elected to their Board as well as voting power on organizational priorities. This incredibly empowering model allows community leaders opportunities to join the organization’s board of directors and recognizes the importance of transparency by ensuring leadership and organizational direction are truly representative of their local communities. At CHP, every month around 20 individual volunteers gather around a horseshoe table to discuss updates to organizing campaigns. Honoring their commitment to language justice, all non-bilingual participants are given a headset as active interpretation in English and Spanish occurred, allowing everyone “to speak in the language of their heart.” A community leader is compensated for their ability to provide simultaneous interpretation during the meeting.

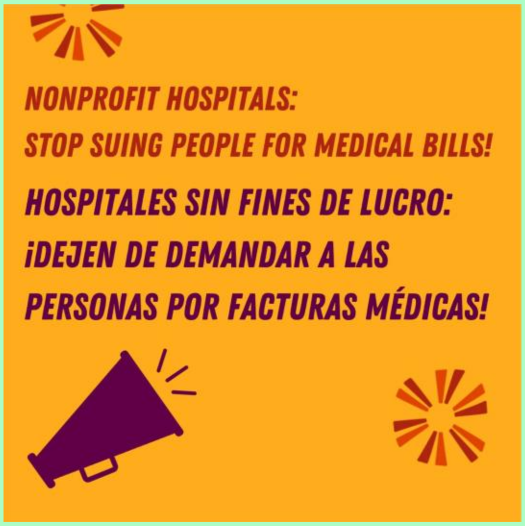


Photo courtesy of Center for Health Progress

Additional Resources

Resources from our Medical Debt Partners

- Illinois Coalition for Immigrant and Refugee Rights - Crisis in the Shadows: Medical Debt in Illinois
- Pennsylvania Health Access Network - Promises Made; Promises Broken: What Really Happens when Local Hospitals are Acquired
- New Mexico Center on Law and Poverty - New report shows hospital pricing discrimination in New Mexico
- Center for Health Progress - Nine Months of Impact: Celebrating Victories in CHP's Campaigns
- Colorado Center on Law and Policy - Medical Debt & Your Credit Report: Know Your Rights Resources / La deuda médica y su informe de crédito: Recursos para conocer sus derechos - CCLP
- Consumers for Affordable Health Care - From Medical Debt to Health Coverage Access, CAHC Helps Mainers

Resources/Toolkits Related to Health Equity and Race Equity

- Annie E. Casey Foundation - Racial Equity Impact Assessment
- National Partnership for Women and Families
  - Health Equity Decision Point Interactive Tool
  - Guide for Decision Makers and Advocates
- Community Catalyst – Oral Health Policy Equity Tool
- State Health & Value Strategies – Health Equity Impact Tool