



Statewide Listening Tour Report

Summer 2022



Who We Are

The Colorado Consumer Health Initiative (CCHI) is a non-profit, consumer oriented, membership-based health advocacy organization that serves Coloradans whose access to health care and financial security are compromised by structural barriers, poor benefits, or unfair business practices of the health care industry. We work statewide for progress towards achieving equitable, affordable, accessible, and quality health care for all Coloradans.

How We Work



Strategic Engagement

Through organizing, CCHI unites consumers across the state through story collection and calls-to-action to ensure that Coloradans are front and center in our advocacy efforts.



Direct Service

The Consumer Assistance Program (CAP) helps individual consumers navigate billing issues with insurers and health care providers.



Public Policy

Each year, at the legislature and within state agencies, we advocate for bills and policies that improve the dependability, accessibility, and affordability of health care for Coloradans.

Listening Tour Series

August 2022

In 2021, staff members refined CCHI's organizational priorities to ensure that health equity and consumer voices remain centered in our public policy, strategic engagement, and direct service work. As one step in this ongoing commitment, CCHI spent the past year hosting listening sessions across the state. During these sessions we heard directly from Coloradans, many of whom face structural barriers to accessing and affording care, about their experiences navigating the health care system in their region.

As of the writing of this report, CCHI had facilitated four listening events — stretching from Durango in the southwest corner of the state, to the mountain towns of the Roaring Fork Valley, to Westminster and Aurora in the greater metropolitan area of Denver. Due to the unpredictability of COVID-19 surges over the past year, some of these events were held in person while others were conducted over Zoom. Each of these events ran as small focus groups, with about 15-20 people participating per region. We partnered with community organizations for help with recruitment, and all participants received gift cards as compensation for their time.



These locations were selected based on data from the 2019 Colorado Health Access Survey (CHAS) which identified areas where Coloradans have the highest percentage of prescription drug affordability issues.



The questions we set out to understand were:

- What have your experiences been seeking healthcare or finding coverage?
- What are your biggest barriers to care?
- Has there been an instance where seeking healthcare has been positive for you?
- Have prescription drug costs affected your ability to pay for healthcare or essential needs, like housing or food?

While all of the sessions were facilitated similarly, these conversations were participant led. As a result, no two sessions looked the same. Folks discussed a range of matters that affect their health— many of which included social factors that extend past seeking access to high quality and affordable healthcare. While some of these issues lay beyond the realm of CCHI's work, we remain committed to advocacy that encompasses the full scope of health.

The reflections summarized in this report are not meant to generalize the experience of any one community, nor do they tell the whole story of any one individual. Instead, we hope this sampling of anecdotes will continue to ground our work in the lived experiences of Coloradans who face the biggest barriers to care.

A note: The Westminster and Roaring Fork Valley events were conducted in Spanish. The East Colfax event included many participants whose primary language was Burmese—this focus group was facilitated through a translator.

A huge thank you to our partners at The Rainbow Youth Center, Growing Home, The Colorado Immigrant Rights Coalition, and The Spring Institute. A special shoutout to Gaye Weiss, Whitney Leeds, Laura Segura, and Brandy Kramer — your efforts were crucial to the realization of these events.

9 Durango

Access

- Long waits for routine visits because of limited providers
- Interpretation services for care are insufficient.
- Services aren't culturally appropriate. Many don't seek care for fear of how they will be treated or how much it will cost.
- No infrastructure in place for behavioral health care and navigators are rare in rural areas.

Affordability

- Premiums are completely unaffordable. A lot are more than 10% of income.
- The cost of care has gone up and the amount of coverage has gone down.
- There is little transparency about sliding scale costs at clinics.
- There are more affordable clinics in towns an hour away from Durango.

Local Issue:

Hospital Consolidation

Long-time residents of the region described a deterioration of the health care system over the past twenty years, largely due to hospital consolidation,

Participants explained that the hospital system had at once absorbed the majority of local physicians and cut much of the frontline staff. This has been exacerbated by a mass exodus of providers from the region, with participants citing that there is essentially only one of each specialist left. Significant staffing shortages and huge provider turnover rates have made patient-doctor relationships less

accountable, particularly as providers

feel overworked and are experiencing

compassion fatigue,

Participants also expressed explicit frustration that as a non-profit, the hospital system doesn't pay taxes.

Although legally required to give back through a "community benefit dollars" funding reserve, this had not been

done to serve actual need.

Prescription Drug Affordability



A program in Pennsylvania (PACE) lowers the cost of prescription drugs for Medicare clients, so the highest drug cost would be \$8.50, which was affordable. Recently relocated here and worried about affording medications

I pay almost \$100 a month for medication for mental health, asthma, and acid reflux without insurance. Most months this is a struggle.

Even generic prescription drugs options aren't cheaper on some insurance plans.

As a provider, I see someone in the hospital every month because he runs out of his prescription drugs.



\$150 for an inhaler is too expensive. \$10 would be manageable. My friend had a stroke and now has to spend over a \$1000 a month on prescription drugs. A couple hundred bucks would even be more reasonable.

NW Metro Denver Westminster

Access

- More information that is bilingual is important. Often community members don't have information about what is available.
- Hard to cover costs in hospital without coverage, but information about charity care is often not provided.
- People fear going to the hospital and prefer going to clinics, where there is often no capacity.

Affordability

- Health insurance is too
 unaffordable for many people to
 use in the community.
- People struggle to afford rent, food, and other necessities with the costs of health care and medications.
- Hard to save money to cover medical costs, and even if you do, it can get eaten up if something unexpected happens.
- Extremely hard to get out of medical debt once it accrues.
- When people find significant discounts it can really alleviate financial stress and make a big difference.

Local Issue: Cost Transparency + Navigation

Participants from Westminster identified cost transparency as a considerable barrier to receiving—and paying for— care. Across the board, those we met with pointed to the challenges of navigating the healthcare system. Many who were uninsured spoke of the difficulties of using discount care programs, citing inconsistencies in how discounts were applied from clinic to clinic and across various services. Another major challenge in accessing these programs is the application process, where clinics often use income to determine what someone pays for services or medication, but if income changes (even slightly) it can change costs significantly and make services unaffordable. A slight raise in income may also rule out the availability of coverage programs, where folks may be making more money, but can no longer afford health services. These uncertainties can discourage people from seeking care, which often worsens medical conditions.

Prescription Drug Affordability



Many pharmacies outside of community clinics don't provide discounts, and if the clinic doesn't have a drug, it's hard to afford and follow the treatment a doctor gives you.

Lots of variation in the costs faced depending on where someone tries to access medications. Even if someone has discounts, it could cost less at a different pharmacy.

Medications seem to be automatically prescribed as a way that's easier for doctors to treat quickly. Many people have many medications, but not clear those are all needed and it's very costly and adds up quickly.

Medicaid changed what medications were covered and that made the cost prohibitive. When it used to be a couple dollars, it jumped to \$200.



Very difficult to afford medications without insurance.

How much insulin is provided is limited by some pharmacies (potentially limited by Medicaid/Medicare). Makes it hard to ensure enough insulin in a given month. Hard to take care of health/control sugar levels consistently which raises risks of other costs.

SE Metro Denver Colfax

Local Issue: Intersecting Oppression

Participants at the East Colfax event spoke to a wide range of social issues, summarized below, that negatively impact their health.

Employment

Some participants explained the challenges of working a job that did not provide sick leave, making it difficult to care for themselves or a family member if they had fallen sick, citing that this was especially challenging in single income houses.

Family Support

Many participants were Burmese immigrants, who spoke of the toll that not being able to see family members had on their physical and mental health, despite visits to mental health professionals.

Transportation

Participants spoke of missing doctors appointments because they applied for transportation support and were denied. Others spoke of the inconsistencies of Intelliride, where it may take up to an hour for a car to show up and support people are not allowed to join.

Access

- Sometimes low-cost resources are unreliable, people show up for clinics and wait but they don't open.
- Anti-Black racism and language barriers prevent access to care, and make experiences harmful if people do see medical providers.
- Living in between two major hospitals, you get bounced around and discriminated against based on your insurance.

Affordability

- Copays are a challenge. They are expensive with a husband and kids.
- Some hospitals send bills or engage in debt collection practices to people enrolled in Medicaid.
- Orthodontics are incredibly expensive for kids.



"I have health issues because I had to struggle raising kids, being single, and living in crappy neighborhoods."

Prescription Drug Affordability



Even over-the-counter drugs are hard to afford. Arthritis cream used to be prescription but now it is over-the counter and still unaffordable.

People have to navigate many different resources to get the best prices for the drugs they need.

Copays can be unaffordable, even on Medicaid.

Medications needed for chronic conditions are very expensive and refills can be hard to pay for.



Many people in the community don't know about resources or their rights related to insurance coverage for prescription drugs.

Carbondale + Glenwood Springs Roaring Fork Valley

Access

- Dialysis is covered by Medicaid and Emergency Medicaid, which is good, but these services are very hard to access in rural areas.
- A lot of information gaps in how to access care. For dental care in particular, there is not much accessibility for immigrants.

Participant Snapshot

One participant described how challenging accessing care can be at each stage of delivery. When her husband went to a provider to treat back pain, he was treated unfairly because he didn't have insurance. After being billed inappropriately for meds he didn't receive, the couple then had to jump through numerous administrative hoops in order to access charity care services.

Affordability

- It's difficult to pay for insulin which makes it hard to manage diabetes.
- Cost of living is quite high, especially rent. Payment plans for healthcare services eat up all the money.
- Preventative services are hard to afford.

Local Issue: Discrimination Against the Uninsured

Participants from the Roaring Fork Valley called out one of several salient themes in their experiences navigating the health care system in the region: facing poor treatment from hospitals and clinics due to a lack of health insurance. Participants specifically cited feeling disrespected and dismissed in hospitals when disclosing that they lacked health coverage. Describing the process as one lacking dignity, folks outlined the long process to receive authorization for services, and the trouble in receiving clear answers about patient financial assistance. Accessing charity care also proved to be difficult for participants, with providers asking for lots of information about assets which can be tricky to navigate and burdensome to comply with. As one participant put it succinctly: "It seems like they are there to deny you help."



Looking Forward

While there are many more communities across the state with differing health care needs and experiences we have not yet had the chance to talk to, we can still learn several lessons from this initial listening tour.

We have a long way to go. If there can be one takeaway from these sessions, it is that so many in Colorado continue to lack access to quality, affordable, and equitable health care. From fear of seeking care because of cost to being unable to attend a doctor's appointment because of lack of transportation, the barriers to health care in this state remain high.

We must center lived experience in our work. The healthcare industry must be held accountable by the people they purport to serve. As advocates, we are committed to working— in community— toward health equity by combatting systems of oppression to ensure all Coloradans are getting the health care they need and deserve.





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