

Community Voices

CVHMC heard from a variety of community members about what matters to them about health and what they wanted decision makers to know. Details from previous participants, in their own words (*italicized*) or paraphrased appear below.

Health Insurance Concerns

Perhaps because of immigration status, it is not possible to buy health insurance. It's sad for many people because, with me, everything turned out okay. But with other people, it might not be okay and then they can die. In my situation, it was people with good intentions that helped me put the money together. I am aware that not many people have the chance to get that amount of money to get surgery.

One of my clients this past January was a Type 1 diabetic with a hearing impairment. She ran out of insulin, was no longer in HIP, had no insurance. She was working 18 hours a week at \$10/11 hour and could not afford to purchase insulin. I made 30 calls over 2-3 weeks to try to straighten out the situation. She should not have been thrown out of HIP. She was alone with no family. The system makes it very difficult at times. There is no safety net.

I am also an activist trying to get universal health care. I think locally, people with "good" insurance are happy until they get sick and see the holes in the plan. People without insurance just pray that they will not get sick.

With Part D insurance [for prescriptions], everything is a nightmare. First, you have one time in the year to choose, but you don't know what your medications will be for the next year, so it's a gamble. And if you do have medications, you can't do the calculations without a computer. When you can compare the costs, it is often the case that it changes. Which you couldn't know when you picked it, because it just changed. So I can't figure out what is the best plan, I just suffer financially. It's not easy for young people either! If you throw our hands up to choose the cheapest or the one with the most coverage, there might be changes.

To qualify for Medicaid, you have to promise to be poor for the rest of your life.

HealthNet [isn't open] on Saturday or Sunday. My husband was sick, he had a fever and chills. We are responsible and we were very scared to have a lot of debt because we don't know how much or when we will be able to. We want health insurance that is accessible so that we can pay.

What it seems we are missing is "empowerment." People always feel as if they are always behind. Part of that is trying to find a physician. How do we empower people to take control of their own healthcare, so that is on hand, and affordable? We are not making our own choices now, because of the complexity of the system. Insurance makes the choices for us.

We just want something more accessible. Every single human has a right to live. Every person in the US should have access to health insurance. I don't need anything for free. I want to buy accessible and valid insurance for all of my family.

I've lived in Bloomington over 50 years, so think I know the community fairly well. As a senior citizen whose insurance is Medicare, there are a number of problems. The cost of medication Medicare doesn't cover, so people need separate insurance for medication. The cost of medication, with insurance, can be difficult to navigate since plans differ in coverage. This is a difficult problem for people who are not well versed in navigating systems. I would like to have medication coverage to have manufacturers to get the cost down. We should have Medicare for all.

What I'm hearing is forming relationships with policy makers is key. Understanding how to get those folks on board. Medicaid and state programs need to be easier for people who need to get access to them quickly but also for policy makers to be on board and supportive.

The other thing that's a big issue for my family is the cost of health insurance. My husband has his own business and I've had a variety of jobs. Right now I only have insurance for myself through my job. My husband needs to use state health insurance. If we both had to use Bronze-level state care, we'd be spending almost as much as our mortgage payment. It's extremely expensive for a self-employed individual, especially when you don't even use it that much, you're healthy. This high healthcare cost is a deterrent to entrepreneurs.

I'm on Medicare also, but it's not comprehensive. It doesn't cover dental, vision, hearing. We also had a good supplemental plan and I was paying almost \$3,000 a year for that. I agree with people. I had an unexpected cardiac stint and maybe paid \$80. It's incredible how much it cost. There is a real need for transportation out in the rural areas. People need medical care. There's not as many resources there as there need to be.

Quality & Availability of Health Services

Completely not having access to healthcare is not just low income. The elderly, unhoused, self-employed, small business owners, college students also have access issues. It is important not to underestimate the number of people who don't have access.

What matters to my family is to find a medical caregiver. It is difficult to find a new doctor when your doctor retires. It is important to find and access a specialist, or any doctor, someone who really cares. My family physician retired a year ago, and I spent a year trying to find a new doctor. It also happened to my husband, so we were without

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physicians for a year. I would like to see more choices and an easier way to find a doctor.

I was once referred to Indy. It is frustrating to be referred to a doctor an hour away because no one in Monroe County can address my issue. It shouldn't take 7-8 months to see a doctor. You are more or less on the Internet trying to find your own information, because it is so frustrating to always try to find a new doctor when you have been in a community for 40 years and you feel as if you are starting out brand new. The situation may be better for children, but the primary care situation for adults is frustrating.

I am a Latina woman who grew up within the Latinx/Hispanic community and didn't realize it until my mid-20s that mental health trauma was not known as a health concern. I remember being depressed but I had to keep quiet because otherwise I would have been labeled as being loca (crazy). Mental health trauma was not discussed in our household and the expectation for me was that I would grow out of that. Depression or suicide is something that is not openly discussed amongst others outside our immediate family members. The Latinx/Hispanic community is less likely to seek mental health professionals.

Having access to health care, specifically mental health services, is of great importance to me. As a mother of a child who has struggled with mental health for several years, I have been witness to lack of pediatric mental health care professionals and services here in Bloomington. Additionally, services that are available are not easily accessed, and can be extraordinarily expensive for families who have private or employee sponsored health insurance policies. No family should be placed in a situation on whether or not mental health care services should be rendered to their child based on their financial situation. Access to mental health services should not bankrupt parents or guardians who are already dealing with the emotional ramifications of raising a child who is struggling.

We need providers to be more open to working with us, especially when people [with disabilities] have challenging behaviors that prevent them from sitting in a chair or hopping up on a table, or what have you. We are a bit more lucky in that sense. Our son's doctors are our doctors. Our doctors have been willing to see our son. If parents [of children with disabilities] don't have the connections we do with doctors, it can be a lot more difficult. Some doctors won't work with you.

We have some providers who are incredible. There have been some issues our clients have had with implicit bias. There are clients who haven't gotten the same suggestions for medical care or medical tests or certain things. I can't prove this, but my perception is the provider didn't value the life of that individual [with disabilities] as much as someone who could speak to them and tell them about their health issues.

I want healthcare providers to not make assumptions. It is not fair to assume that a patient doesn't know their symptoms, or the diagnosis, or may not have researched the issues on their own. Doctors should not make assumptions about the patient or

stereotype, so the doctor doesn't have to listen to the patient. I have been to a lot of doctors. It can be off-putting, so that you tend to Google, and do your own thing, trying to find your own alternative care because you don't want to feel as if what you paid a lot of money for was not really worth it. You are not getting what you are paying for when the doctor brushes you off.

Health care is the goal, not insurance. I've had triple bypass. My world revolves around good food. The system and bureaucracy is illogical. I'd like to see collaborative case management. I'd like to know my doctors better so they can provide better care. My doctor gave me the wrong medicine even though it was in my file. Technology and information are not really working.

Being heard is the first thing that comes to my mind. Sometimes, I feel like my doctor dismisses my concerns. I've had a lot of health issues and my mom has had even more. I have had to try to get clarifications between the two of us. I also try to help my neighbors even more. A lot of them don't read very well and I am often interpreting what I don't understand. Well yeah, I am an authority of sorts where I live and I am trying to be helpful and lead people to information and others and agencies that can help.

Through my clients, I know most don't have insurance. We take everyone through the charity I work at. We have a sliding scale for payment. We always have a waiting list, which sometimes gets closed and I feel bad for them. It's an issue in the mental health community. There are not enough providers. People want medications and may not feel comfortable with a primary provider.

As a trans person, we don't have that complicated of problems. Our hormone treatments are very simple. Doctors are scared to death to see us. I've been declined twice for non-gender-related procedures for "Procedure and Sex Don't Match." It took me 12 hours on the phone talking to them until I couldn't handle it anymore, until I had to walk away and handle it 2 days later. I'm writing 6 appeals to Indiana's Human Health Services Division, and eventually I had to write a lawyer, who wrote a letter for \$300. I think it was \$1300 that it was going to cost me for a procedure. I paid \$300 for something I shouldn't have had to go through. You know we have to go to a counselor before we can get medical care for something that's pretty darn routine for men or women who want hormone treatment.

I have been using the term historic, systemic transphobia. We have been denied healthcare for the last 10 years. We have never experienced equality and don't expect it. People in the medical industry understand us because we have to get counseling for gender dysphoria before we're allowed to be considered transgender. Some doctors won't work with us because they aren't trained in gender dysphoria. We're not recognized. People don't understand us. We get misgendered by insurance, providers, everyone. That is malpractice. The medical industry recognizes dysphoria; they know being misgendered is the worst trauma that can occur. When I went in for COVID test I had to correct the provider repeatedly on my preferred gender.

Housing is another important part of health, especially in rural areas. There is housing that is almost unbelievable people are living in.

There is a great issue with the older people I work with, not having access to some of the things at the grocery store. They have to take a bus - imagine relying on a cane and you have to take a bus to get to the store. Trying to carry bags of groceries when using a cane, having to get on and off the bus, getting into your apartment. Big issues for a lot of the folks that I help. One lady was given 30 minutes, imagine being 80 and you have 30 minutes to go through Kroger. You don't have time to find what you need. When you do find what you need, carrying it home is another issue. I see a lot of seniors with poor nutrition. They don't have the money to get it delivered. I see a lot of older folks who can't drive to food pantries. Food delivery can be inconsistent. There's a huge need. I don't know what the answer is. I'd like to see a bus like the ones they have that go to food deserts. It'd be great to see a big Kroger bus come to these communities. They'd have more access to things from the grocery store. It's a huge deal for them to have food. They don't want to get out every week and don't have the strength to go, this time of year they're afraid of falling and it's cold. COVID has really brought out people calling me at home asking for help.

Sometimes it is discrimination. Maybe the mother of this child who needed the same surgery that my son needed has more opportunities and a good job. But as someone who wasn't born here or does not have documents has more difficulties to get medical care. Yet I still think it's a good idea to try to find medical care when one is sick.

The education and lack of awareness - when people do not look like the doctors, they often don't seem to "see" the patient. My doctor mistook me for someone else, because it would seem everyone from my racial group looks the same to the doctor.

If I had the ear of people who make choices, I would tell them racial and class disparities are rooted in policy. Comb through these policies and see where the implicit bias is that is really preventing people from getting the care they need.

Poor people are often penalized for being poor. There are massive fees for things. Example is applying for food stamps with fax costs \$1 a page. Another example is going to jail. Fines are punitive.

Listen to actual disabled people and not so-called specialists; I remember a newspaper did an article about autism and they didn't talk to anyone with autism at all; and also involve disabled people in their decision-making and walk them through the bills.

I would like for the politicians from the legislatures to have a lesson in poverty. . . Those are people who need poverty training or need empathetic training.

I run a weekly pantry in public housing. I always push vegetable and fruits to my neighbors. I try to share the joy of cooking with everyone. Kids from the Boys and Girls Club helped me and got information on fruits they haven't seen before. You can be fed in Bloomington but you may have to take a bus. But the pantry is open to everyone.

Since we are all having problems with access, it would be nice to have a central navigation point. It would be cool to have a general case management agency or city position where someone can go in state a problem and get someone to help them.

I am an immigrant from Peru and at some point, I got a box of greens and squash but had no idea how to cook it. Half of the box spoiled because not sure how to cook it. My family didn't like it the way I cooked it – so there is an issue on how to cook foods and get adequate nutrition.

In my experience, if someone has a problem with addiction, and not willing to commit to get services to get help, then they are disqualified to get help. They are on the streets and lose children. But they are not in a mental state to make those decisions, even though they are adults. I was in the experience where I was not able to make decisions, not because of addictions, but had to step out of the situation for my children. I had many resources but it was so hard to do. When you are not in the position to make that decision, to understand that person and create a safety net to at least have a home to eventually making that decision. I was brave enough to do it, but others that I've seen lost their home because of being mentally unstable or addiction issues. I want to express that helping people connect, those who are not themselves at that moment, to get stability and believe that it is possible to them to rebuild their homes.

Bloomington doesn't have the housing to put people in. It's a limitation for a housing-first policy since there are not affordable units to place people. For me, a good starting spot is to commit to create affordable housing for people to go – whether that's rooms or studios—we don't have it but we have empty building. Decision makers need to make a commitment to put money to truly affordable housing. What's being discussed now is not affordable.

Climate change should be added to list. Increase in temperatures have a very real affect. Our community need to be doing more about this.

The costs of buses can be too expensive for individuals with low-income. Some clients may not have Smart phones and apps to use RideShare vouchers to get around.

We hear about connecting the dots and yet we operate in silos. As a member of a governmental unit, we need to know how to do coordination, help with navigation, and make the system as easy as it can be. Also, where does universal healthcare come in? Because it seems like insurance companies. . . How do we do that coordination? That is so critical to helping people with the navigation - helping them with, you know, making the system as easy as it can possibly be.

Health is about more than just health insurance. We need to build good neighbors. There are so many layers, and we need to plug everyone into the thing they want to do. There is not a shortage of people who want to help.

I couldn't help to think of neighborhoods with caring neighbors who bring the sick a meal, etc. We need to feel connected again. We believe in the power of neighborhoods. I have had an opportunity to visit the Crestmont neighborhood, and there is no lack of generosity. Maybe we can do pitch-in BBQ and educate folks on things they need help with such as taxes. Neighborhoods are better rather than a top-down approach.

Right now, Area 10 has a freezer and an oven and does a weekly dinner outside. The community dinner is with Area 10 and WIC is twice a month and also vaccines were given. I would love to have other groups come and utilize that space. We have computer hours and energy assistance and things like that. I would love to have more health screenings. We need the organizations and groups to come to us. That would be helpful. Because we are expanding the community center, we are trying to expand the ideas of the neighborhood so we can use that space. It would be a good foundation and physical space to do things.
