

Why establishing a primary care provider is not so simple for some.

We talked with 35 people from the City of South Salt Lake as well as Salt Lake City's westside neighbor of Glendale whom we had tried to link to primary care providers over the past five years. During six focus groups, we sought to learn firsthand why establishing a primary care provider was difficult and what factors and circumstances played a role in establishing or not establishing a primary care provider.

Definition of Primary Care Provider

A primary care provider (PCP) is a medical professional or a place where people usually go when they are sick, have health problems, or need preventive health care, such as general check-ups or examinations. It can be a doctor's office, clinic, or health center. Emergency rooms and urgent care clinics ARE NOT primary care providers.

In our conversations, people brought up reasons we are all familiar with: cost, insurance, complex systems, etc. Not satisfied with these general answers, we sought to truly understand what people meant by their comments. Out of that approach come these findings and considerations.

The healthcare system isn't for me.

People shared complex and complicated life circumstances.

- "I raised my six kids, plus my 16 grandkids as a single parent, and now my six great-grandkids. I am constantly going. I run kids everywhere. It's about time."
- "It depends on the seasonality of my job."
- "Sometimes we have work accidents and the employers don't take care of the accident; they prefer to let you go rather than to help you cover your accident."
- "It's hard when you are homeless to keep everything straight when you don't know where you're going from one minute to the next."
- "There are three members in our family who tried to commit suicide."
- "I took care of my mom and my dad, I had a job that I used to work 60 hours plus. Nine months after she passed I had my heart attack."
- "My older son has been helping to support the family since he was 16 years old. I hate knowing that I did that to my son."
- "I was working and got electrocuted. It blew off my toes and messed up my hand."

Although skilled at decision-making, people faced serious opportunity costs and trade offs.

- "What would you rather do? Have food to live or go without health insurance?"
- "I needed glasses. Do I buy glasses or get a check up? I need to be able to see to get to work."
- "You either pay rent or health insurance."

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- “They say if you have food stamps or Medicaid, you’re not going to get papers. The most important thing right now is my kids. If I’m someday back in [my home country], they should be thankful that I got them Medicaid (jokingly).”
- “We don’t have enough income and we are working to have more income, if not we wouldn’t be here.”
- “I’d rather die than go to the hospital. It would not be good to drag the whole family down with a large bill. I don’t want to do that. It might sound stupid.”
- “If you do not pay then you go to jail, it scares you and it is better not to go to the hospital or the doctor.”
- “You get disability and it’s not that much so you have to spread it.”
- “I own a house, a car, and it is super expensive to get sick. It is very frustrating. Even if they saved your life, sometimes you wonder if it would have been better to die. I know a lot of people who have suffered through this.”

They explained the unpredictability of health care costs made getting sick a privilege they simply could not afford.

- “At my house, I changed my food and what I buy for my family and we exercise now too. I focus on more good health. But a clinic is just too expensive only for a check up for something.”
- “If it were a little more accessible to all pockets, we could go easily.”
- “If you don’t die from the illness, you die from the amount of the bill you receive after going to the doctor or hospital.”
- “My dad tormented us telling us not to get sick because it’s very expensive.”
- “I’m short of breath, my chest is tight, I have all the warning signs and I need to go in, but it’s all something that I can’t afford.”
- “You can spend a lot of money on insurance and not really know if it’s going to cover everything.”
- “I stay as healthy as I can so that I don’t have the bill behind me.”

When weighing the benefits, people felt like health insurance was not the best investment for their family.

- “Health insurance is taking money from the family. It is better to forgo the insurance to provide more money for the family.”
- “I would rather go without health insurance and then take care of everything else.”
- “It would be nice if there was access to health insurance that is affordable so we could pay little by little.”
- “I already made a budget and \$10,000 is not enough.”
- “It has been about three years [since I had health insurance] and I say that was money I would be throwing away for that long.”
- “I think it’s a good thing, but the insurance costs hundreds of dollars a month. As he says, if you did not need it, it weighs you down.”

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- “I had medical insurance, but I did not get sick for five years, so I decided to cancel the insurance and I prefer to go to the doctor and pay when I need it.”
- “I have five kids, bills, food, rent, and it’s too expensive. And you don’t even use it.”

Moreover, those who had health insurance explained it did not mitigate the cost of healthcare enough for them.

- “If you don’t hit the deductible then what? What are you supposed to do?”
- “If there is something serious, it’s your problem, never the insurance company or hospitals, and all you can do is cry.”
- “I went to a clinic that the insurance covers, but I had to pay \$300 anyway.”
- “It’s all too expensive. Even with insurance.”
- “It was a \$50 copay and I didn’t have the money so I asked my daughter to help me out and she did.”
- “If you do the math, \$4,098 would only cover a family with two kids with a minimal plan. And that’s just for health insurance alone. You have copays and visits, and prescriptions. \$5,000 wouldn’t take care of most anyone in this room and their family.”
- “But that’s why we didn’t have insurance for so long. That still had \$100 copay and no prescriptions. No one can afford that. I would at least like to buy some groceries this month or not sleep in my car.”
- “He has health insurance, but it doesn’t cover all of his insulin and everything he needs.”

When they did engage with the healthcare system, people felt disoriented and disrespected.

- “I don’t feel comfortable there. They look at you funny.”
- “If you don’t have insurance or you’re on Medicaid, you feel like a nobody, like they are wasting their time and like you’re not important.”
- “Sometimes it can make you feel that big (motioning to the floor).”
- “I thought that they would treat me well because I had medical insurance.”
- “The doctor treated me very badly. I wanted to go back to file a complaint, but never went back.”
- “When you ask for help, they look at you like, here’s another ‘help’ case.”
- “I told them that I feel like I was so unimportant to you guys.”

People said they felt like commodities bought and sold in the healthcare system: undervalued and taken advantage of.

- “I call it ‘milking’ because institutions milk us so much.”
- “Doctors only care about money.”
- “They will never let profits go so they want more people sick so we keep coming to them.”
- “This is a monetary system, they just care about the money.”
- “It’s all a business.”
- “And then, we’re just another number.”

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- “The sooner they can wipe us off the planet, the more money they’ll save.”
- “It seems like we’re in it for their paycheck, not for our health.”
- “It’s more important to protect the business than it is to cure you. As long as you keep coming back, we’ll make sure you’re comfortable.”

They no longer trust in the healthcare system and systems in general.

- “I do need the assistance, but I don’t trust the doctors. I do believe they know a lot, but I just don’t trust them.”
- “I have heard they do wrong diagnoses and we end up getting worse than how we were.”
- “They treat you en masse. They don’t put the time and effort to know you as a person and that makes me doubt [the system].”
- “Hospitals do what they want. They might take some liquid from your spine just because you have a fever and then the mom doesn’t ask questions and then the child can’t walk. (Participant is giving an example of what could happen - in her opinion.)”
- “Here is all a fraud, they do tests and you never have anything.”
- “When providers were young, they wanted to help people. But later, they forget about that and it’s all about the money.”
- “But when it comes to making sure that its people are taken care of, especially in healthcare, they don’t care for us.”
- “Maybe they make us wait because they’re higher than us.”

Those who needed care found “another alternative,” indicating a subset of our community is disenfranchised from our healthcare system.

- “I do check myself, but I take advantage of the health fairs.”
- “We go from place to place, which makes it hard since we don’t have a record with just one specific provider.”
- “I try to inform myself and buy the medicines without going to the doctor.”
- “I can usually stand the pain and I go with the natural cure. We go online to find what we have to take.”
- “God is my doctor. I don’t get sick, but if I do, I take ibuprofen.”
- “I go to free clinics, too.”
- “So I went to my house and pulled the tooth out myself. It was really painful. I was bleeding really bad. But, I didn’t pay any money and now I feel good.”
- “Then you have to find another alternative to go and be seen, or you just have to deal with your illness or sickness.”
- “I’ve had abscesses and I’ll take a needle and pop it myself. I have pulled a couple of teeth before.”

Ultimately, some preferred not to know their health concerns and others felt the only option was to go untreated.

- “I just let it go. I would rather not think about it.”

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- “It’s less stressful to think about the pain than the bill.”
- “Well I know that I need to [go in for care], but I just don’t go.”
- “We just let the symptoms be.”
- “That’s why we simply endure our pain.”
- “Like for two weeks now, I’ve been feeling a little sick. I feel like something is wrong in my body.”
- “I can stand the pain.”

Primary care for people.

- People wanted a lasting personal relationship with one primary care provider.
- People wanted to feel accepted and respected by the health care system.
- People wanted to connect with others who have similar life experiences.
- People wanted to feel taken care of by a health care system that is responsive to their health needs beyond health care and in the context of their lives, particularly their financial situations.
- People wanted to pay for health care services, but at a reasonable cost to avoid unbearable financial stress.

Practices valuing people.

- Treating people with respect is critical to sustained engagement in the healthcare system.
- Transparency of price is even more valuable to individuals with no disposable income.
- Staff conscience of people and their circumstances, like community health workers (CHWs), build trust through empathy, not sympathy.
- Asking for people’s perspective can be a gesture of humility, recognizing that communities are experts in their own lived experiences.

These findings beckon us to reconsider what is healthiest for our most vulnerable communities. They ask us how we will respond to their most pressing needs. They draw attention to the very small margin of error that exists in engaging these populations. Most of all, they require accountability for how we serve our most vulnerable populations experiencing health disparities.

More detailed information on the focus groups including background and methodology can be found at health.utah.gov/disparities.

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