



Shriver Center on Poverty Law Focus Group Responses

to Selected Questions about Illinois' 2021 Healthcare
Affordability Feasibility Study

October 2021

Background



In 2020, the state of Illinois commissioned a study to explore policy options to make health insurance more affordable and easier to obtain for low-and middle-income Illinois residents. The study provided a menu of policy options with the goals of: improving health care affordability; reducing the number of Illinois residents who lack health insurance; and improving health equity – meaning that everyone has a fair opportunity to achieve their full health potential, regardless of their race, color, religion, national or ethnic origin, immigration status, sexual orientation, gender, gender identity, or gender expression.¹

For this project, Altarum (in partnership with Shriver Center on Poverty Law) conducted five 2-hour virtual focus groups to assess Illinois residents' views on policy options identified in the state's Healthcare Affordability Feasibility Study released in April 2021. The remainder of this slide deck describes the findings and important take-aways from these focus groups.

1. <https://www.communitycatalyst.org/initiatives-and-issues/issues/health-equity/full-description>

Methodology



▲ Responsibilities of Shriver Center

- ▲ Provide input and revisions to discussion guide and questions
- ▲ Obtain participants
- ▲ Manage technical aspects of Zoom links and recordings for transcripts
- ▲ Identify co-facilitators for Spanish-speaking focus group

▲ Responsibilities of Altarum

- ▲ Develop discussion guide and focus group questions
- ▲ Facilitate 5 focus groups (2 hours each)
- ▲ Synthesize discussions into categories and themes for analysis
- ▲ Present findings in a useful and actionable PowerPoint deck

Analysis



- ▲ Five focus groups were conducted during the last two weeks of September 2021.
- ▲ Approximately 30 total participants discussed their opinions on several questions about health care insurance and potential policy options the State of Illinois could implement.
- ▲ Two focus groups were unique – one Spanish speaking-only group and one Silver Access DuPage-only group. These groups are included in the overall analysis but have break-out findings as well.
- ▲ The findings of these discussions are divided into 7 categories:
 - ▲ General experience with health insurance & problems/barriers to accessing health insurance
 - ▲ Most important aspect of choosing health insurance
 - ▲ Potential policy options – Medicaid Buy-in and private insurance from Marketplace
 - ▲ Marketing new policy options for health care insurance
 - ▲ Education, outreach and enrollment assistance
 - ▲ Spanish-speaking focus group
 - ▲ DuPage County – Silver Access Program focus group



Demographics

- ▲ Focus group participants were racially and geographically diverse.
Out of 30 total participants:

Racial/Ethnic

- ▲ 23 were BIPOC
- ▲ 7 were white

Geographic

- ▲ 7 resided in Cook County
- ▲ 20 resided in Collar Counties
- ▲ 2 resided in Central Illinois
- ▲ 1 resided in Downstate Illinois

General Experience With Health Insurance & Problems/Barriers to Accessing Health Insurance



Question 1 – What is your general experience with your health care coverage. Do you currently have coverage or insurance, and how is it going for you?

Question 2 – Have you experienced any problems now or in the past getting health care coverage? (Cost, eligibility, access, not knowing how to enroll or what to choose?)

- ▲ Nearly all participants were currently or previously uninsured
- ▲ The two major problems/barriers to accessing health insurance were **cost** and **complexity**
 - ▲ Many participants discussed the lack of affordable health care coverage. They expressed that what you pay out-of-pocket can be enough to cause you to choose between health care and food, rent, or electricity.
 - ▲ Many participants also discussed the fact that health insurance is complicated. Submitting the documentation to get insurance isn't easy and is a repetitive cycle of providing documentation and being told that you either don't have the correct documentation or the documentation you submitted wasn't received.

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We are directly in the un-sweet spot.

– Focus Group Participant
9/22/2021



Race, Equity and Discrimination

- ▲ While the interviews were not specifically designed to illicit responses on race, equity and discrimination, as people talked about their health care experiences and what is most important to them, often the conversation included feelings of discrimination and a sense of knowing they were being treated differently.

“ You know when you’re being mistreated, when people are speaking to you some kind of way.

– Focus Group Participant 9/23/2021

“ Let's be clear, I'm black, then I'm a woman. When I walk in there, I'm already pre-judged.

– Focus Group Participant 9/23/2021

“ Sometimes they [doctors] don't want to give you the best, they just give you enough.

– Focus Group Participant 9/22/2021

Most Important Aspect of Choosing Health Insurance



Question 3a – What is most important to you in choosing health insurance coverage?

Question 3b – What are the most important attributes of health insurance coverage?

- ▲ Overwhelmingly, participants cited cost (particularly affordable deductibles, affordable premiums, and affordable prescription costs) as important when choosing health insurance coverage.
- ▲ Services covered was also cited frequently by participants – ensuring that the health insurance covers services to address their medical needs is important to them.
- ▲ Choice of doctor was also cited as being important to the participants. Patients establish relationships with their providers and they want to be able to maintain that relationship.
- ▲ Finally, diversity of providers, in terms of race/ethnicity and language were also identified by some participants as important.

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We are seeing that this is not about people, it is about lucrative business in the United States.

— Focus Group
Participant 9/29/2021

Potential Policy Option – Medicaid Buy-in



Question 4 – Thoughts on “Medicaid Buy-In” Programs

- ▲ Most participants indicated that the cost of \$20 per month for a Medicaid Buy-In health insurance program would be great.
- ▲ OVERWHELMINGLY, the same participants voiced concern and skepticism that not all needed health care services would be covered, that there would be restrictions on which providers could be seen, and that they would have to travel distances to see lower quality providers.
- ▲ A number of participants voiced concern regarding the stigma associated with Medicaid, and that participating in a “Medicaid Buy-In” program would produce the same discrimination for them.
- ▲ The Spanish-speaking (i.e. immigrant) focus group expressed fear of any government program leading to deportation.

“ *It's important to think about us little people. You act like they are gonna get it, love it and accept it cuz it's free.*

– Focus Group Participant 9/23/2021

“ *I've been burnt already where I picked the lowest premium, and then found out when I need to have something done it wasn't covered. I don't have the lowest premium plan anymore.*

– Focus Group Participant 9/30/2021

Potential Policy Option – Medicaid Buy-in (*continued*)



In order to get people on board with a Medicaid Buy-In program, focus group participants recommended:

- ▲ Change the name of Medicaid and address provider stigma towards Medicaid
 - ▲ However, it's important to note that participants acknowledged that changing the name of the program does not change what it is. Doctors, hospitals, health care providers will still know that you are part of a \$20/month insurance plan (whether it's called Medicaid or not) and they are the ones who are treating people differently.
- ▲ Increasing transparency
 - ▲ Any Medicaid Buy-in type program would need to be completely transparent regarding what is covered, what restrictions there are on providers, and where people would have to go to get care. There is already great skepticism within these groups about what wouldn't be covered for \$20/month. Transparency would be key.

Potential Policy Option – Private Insurance Purchased on Marketplace

A Private Plan with a Wrap-around Subsidy

- ▲ Interestingly, focus group participants not participating in the DuPage Silver Access Program were skeptical about being able to go on to the Marketplace and select an insurance plan that would be subsidized by the state government.
 - ▲ Again, issues with coverage and cost arose:
 - Will we get coverage for the services we need?
 - What will this cost us?
- ▲ But, by far, participants were concerned about the complexity of using the Marketplace, getting reliable help understanding their options, and navigating the system.

Marketing New Policy Options for Health Care Insurance



- ▲ Regardless of whether there is a new Medicaid Buy-In program or a Private Market option that mirrors DuPage Silver Access, a number of “Do’s and Don’ts” were communicated by the participants.
- ▲ DO
 - ▲ Partner with trusted agents – Finding community organizations and other trusted agents (like public assistance programs such as SNAP) to partner with may yield a number of benefits for promoting a health insurance program in Illinois:
 - This could be the beginnings of a “one-stop shop” concept where community workers could be cross-trained to help identify when someone needs SNAP assistance, health care assistance, or other public benefits.
 - Community resource organizations, churches, trusted health care clinics, and hospitals may be good options for trusted agents.

Marketing New Policy Options for Health Care Insurance (*continued*)



▲ DO

- ▲ Make sure the information provided on the option comes from a source that is easily recognized as legitimate, such as government letterhead “snail mail” or a .gov website. (Participants noted there are a lot of scams out there and people have to trust the authenticity of the information.)
- ▲ While potentially still difficult to do with COVID-19, participants discussed town-hall meetings and community events as a way to connect with people, build awareness, and establish a trusting relationship.
- ▲ To a lesser extent, participants suggested things such as:
 - Billboards and TV advertisements
 - Linking any financial assistance for the state of Illinois to the Marketplace website
 - Linking the opportunity to sign up to other public requirements like DMV forms, tax forms, or applications for unemployment benefits

Marketing New Policy Options for Health Care Insurance (*continued*)



▲ DON'T

- ▲ Phone, text, or email information that was unsolicited. There are too many scams out there.
- ▲ Send informational materials that look unofficial. Giving people any reason to believe this program is a scam would not work well.
- ▲ Overall, marketing a new policy option for health care insurance would need to be done at the community level from trusted community agents and the information would need to look official (for example, using state government letterhead, the seal of the state of Illinois, etc.)



Education, Outreach and Enrollment Assistance

- ▲ With respect to education, outreach and enrollment assistance, the most discussed problem regarding access to health insurance (either Medicaid/Marketplace), by far, was that the current process is incredibly complex and frustrating:
 - ▲ Most participants were not comfortable navigating the Marketplace on their own.
 - ▲ Those that *did* talk with frontline staff (either in-person or on the phone) found that, often, the information received is inconsistent – one person tells you something and the next time you call another person tells you something different.
 - ▲ Some participants turned to Google or YouTube for help in filling out the forms because frontline staff were so unhelpful.
 - ▲ If English is not your first language, it is even more complicated.

“

I was told to go to the Marketplace to look for insurance. Great, where's the marketplace?

– Focus Group
Participant 9/22/2021

Education, Outreach and Enrollment Assistance (*continued*)



- ▲ While cost was one of the main reasons why people did not have health insurance, participants discussed their frustration with understanding both the eligibility requirements of Medicaid and the Marketplace.
 - ▲ Participants noted that frontline staff for these programs need to be trained better:
 - Information about required documentation should not change with each person who answers the phone;
 - You should be able to create a relationship with your navigator, know their name, and get their email address and phone number so you can establish continuity. Right now, you may never talk to the same person twice (even if you try);
 - There never seems to be a simple, clear answer to any questions when you're trying to find something in the Marketplace.



There have been times that I will hang up to see if I get lucky and get someone else.

– Focus Group Participant
9/30/2021

(Interestingly, one participant on Medicare could pull up her enrollment navigator on her cell phone and had his name and phone number to reach him directly.)



Findings from Spanish-Speaking Focus Group

- ▲ There were many issues plaguing members of the Spanish-speaking focus group that comprised Spanish-speakers with mixed citizenship, including some with legal status and some undocumented. Issues included:
 - ▲ Affordability – Many discussed how they cannot afford health care
 - ▲ Eligibility – Many discussed how they are not eligible for public assistance because of their immigration status
 - ▲ Fear – Many expressed fear of signing up for any government program as it could result in deportation
- ▲ This group is skeptical, untrusting of those not belonging to their community and culture, and in need of good, quality, affordable health care.
- ▲ Additionally, this group appeared to work really hard at trying to figure out how to get the health care they needed affordably, for example, by utilizing FQHCs and/or county clinics and applying for charity care. They understand how important their health is.

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As an immigrant, one of the most significant things I have suffered from in this country is lack of medical care, until I found Access DuPage.

– Focus Group Participant
9/29/2021

Findings from DuPage County – Silver Access Program



- ▲ Participants expressed overwhelming appreciation for the Silver Access Program
 - ▲ *“This has been a God-send.”* – Participant 1
 - ▲ *“I could not afford health insurance without it.”* – Participant 3
- ▲ However, there is greater variability when it comes to confusion about the process and logistics of filling out the forms/applications for both Silver Access and the Marketplace.
 - ▲ The expectation was that this group would have a better understanding of selecting insurance options and navigating the Marketplace because they have undergone required training and have access to enrollment assistance.
 - ▲ However, the findings were scattered – some had no issues, while others had to “Google” and “YouTube” how to make selections and fill out forms. The reduction in in-person training sessions due to the COVID-19 pandemic could have exacerbated these issues.

Findings from DuPage County – Silver Access Program (*continued*)



- ▲ Issues with the Silver Access Program:
 - ▲ Every participant had wonderful things to say about the staff at the Silver Access Program, HOWEVER:
 - Participants said the program needs more help
 - Participants would like more in-person informational sessions (or even live Zoom sessions)
 - Participants seemed to stumble upon this opportunity – more marketing and outreach is needed
 - The payment process is complicated (requiring refunds at times)
 - Improvements in multi-lingual capacity and interpretation services are needed
- ▲ Issues with the Marketplace:
 - ▲ More frequent and more consistent training for the call center staff is needed
 - Answers are often different from one representative to another
 - It is often challenging to get the answers you're looking for without escalating the request through the chain of command

Overall Findings



These findings provide understanding of a small group of mostly uninsured individuals from across the state of Illinois. While not generalizable, they have provided insight as to what is important when discussing health insurance. Key take-aways include:

- ▲ Affordability is vital, but participants were skeptical of costs perceived as too low, wondering whether they would receive coverage for the services they need.
- ▲ While cost (premiums, deductibles, co-pays, and prescription drugs) is *most* important for participation, being able to choose/keep your doctor and making sure you are covered for the services you need are also very important.
- ▲ Addressing the stigma and discrimination that occurs will be key to developing trust in any health care program.



Overall Findings (*continued*)

- ▲ Medicaid Buy-In for \$20 per month
 - ▲ Some participants would be happy to spend only \$20 per month and get some health care coverage, expressing a “something is better than nothing” mentality. However, many more participants’ first reaction to this idea was more negative. They pointed out that:
 - There is a stigma that comes with being on Medicaid and a feeling of getting less care
 - Even if you change the name of the program, doctors and hospitals are still going to know it’s not private insurance and will treat you differently
 - They asked “What aren’t we getting for \$20/month?” and expressed suspicion this would cover everything they needed.

Overall Findings (*continued*)



▲ Private Insurance Policy Option

- ▲ Participants also met this idea with a bit of skepticism, this time not only about the sufficiency of coverage but on cost and their ability to navigate the Marketplace:
 - Participants were not confident in their ability to navigate the Marketplace on their own. For those that were confused and frustrated with the lack of understanding that they had (but also that their frontline staff have had), the Marketplace is not a friendly place to be.
 - Participants were leery of Marketplace insurance being unaffordable to them.
 - While they had a bit more confidence that their health care needs would be covered, they also distrusted that everything would be covered, even by a private insurance option.

Overall Findings (*continued*)



- ▲ Trusted Agents:
 - ▲ Finding community partners that people trust to engage as enrollment assistants may yield the best results for increasing enrollment as well as improving understanding of the need for and benefits of health insurance (Silver Access in DuPage County is a good example).
 - ▲ This may be especially true for Hispanic/Latinx and African American/Black populations who have a distrust and fear of the government.
 - ▲ Community resource organizations, churches, trusted health care clinics, and hospitals may provide good options as trusted agents.

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Chestnut Health Systems
COFI
DuPage Silver Access
EverThrive Illinois
Family Focus
Family Health Partnership Clinic
Heartland Alliance, READI Program
Howard Brown Health Center

Illinois Association of Free and Charitable Clinics
Illinois Coalition for Immigrant and Refugee Rights (ICIRR)
Illinois Primary Healthcare Association
Lake County Health Department
Legal Council for Health Justice
Phoenix Center
Rush University Medical Center
Small Business Majority
Southwest Suburban Immigrant Project (SSIP)
Workers Center for Racial Justice
Young Invincibles