

April 2023 Illinois Medicaid Redetermination Survey

Health & Medicine Policy Research Group

Background

At the start of the COVID-19 pandemic, Congress passed the Families First Coronavirus Response Act (FFCRA), which included a provision for continuous coverage for those on Medicaid, meaning no one could be disenrolled and lose coverage. During the first three years of the pandemic, Medicaid and Children's Health Insurance Program (CHIP) enrollment rose by an estimated [23.3 million people nationally](#). The significant increase can be attributed to economic conditions caused by the pandemic as well as some states expanding Medicaid. This rise was also partly because continuous coverage eliminated Medicaid enrollment churn, in which Medicaid enrollees experience short lapses in coverage due to income fluctuations, changes in circumstances, or administrative issues with the renewal process.

On April 1, 2023, the continuous coverage provision for Medicaid was ended by the Biden Administration.

This policy will have dire consequences for many people.

Millions of people are poised to lose health care coverage due to the resumption of Medicaid disenrollments and redeterminations means that many people will lose health care coverage. Some, who will no longer be eligible for Medicaid, will need assistance finding other coverage. Others risk losing Medicaid coverage due to confusion surrounding the administrative process. So, "churn" is back, and [prior to 2020 affected nearly one in ten Americans on Medicaid](#). Additionally, [studies](#) have documented that lack of health insurance is directly linked to delaying seeking of critical healthcare and otherwise preventable deaths.

The Medicaid redetermination process is ongoing, with renewal letters being sent out monthly. People will begin losing coverage as early as July 1.

In Illinois, [upwards of 700,000 people could lose Medicaid coverage in the next year](#).

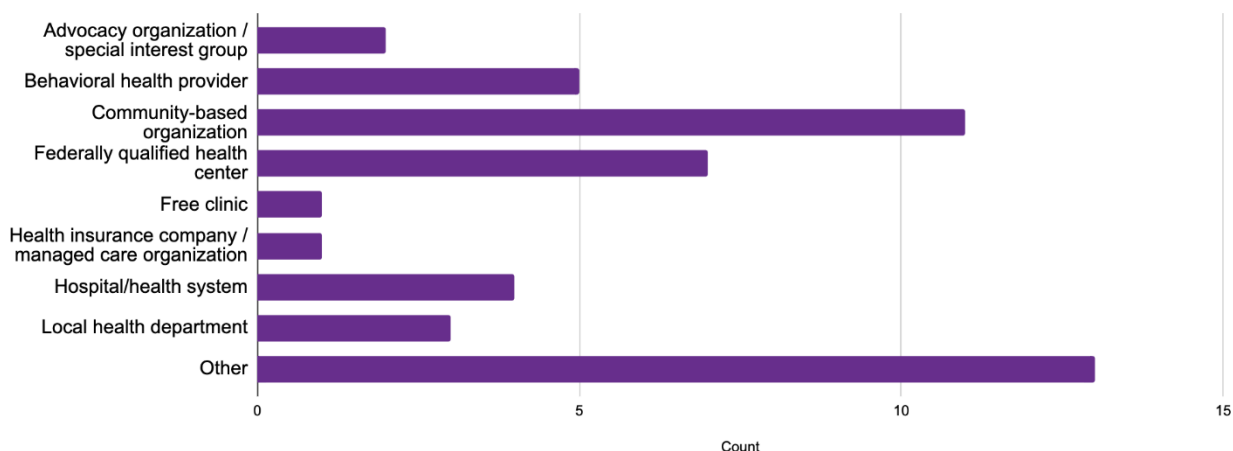
Survey Purpose

During April 2023, Health & Medicine Policy Research Group conducted a survey of Illinois-based organizations that interface with Medicaid populations to better understand the redetermination needs and experiences of these organizations and the people that they serve. We developed a brief questionnaire on a short timeline in response to a foundation's request for information on organizations' needs for support on Medicaid redetermination work. To view the survey instrument, which was deployed using the online forms tool, Formstack, see Appendix A.

The goal of the survey and this report is to support efforts to keep as many Illinoisans as possible covered by Medicaid. Our findings can facilitate knowledge-sharing and collaboration, inform advocacy and targeting efforts for financial and other supports from government and philanthropic foundations, and help organizations in their guidance of individuals facing the restart of the Medicaid eligibility redetermination process. Ensuring that organizations are well-informed and well-prepared to provide outreach, guidance, and administrative support to those potentially impacted by the end of continuous coverage is vital.

Health & Medicine distributed the questionnaire primarily via email and secondarily through social media to contacts and relevant coalitions across Illinois, and respondents include hospitals and health systems, community-based organizations, federally qualified health centers, and local health departments. Organizations that self-identified as “Other” were ones that identified as two or more of the categories (e.g. advocacy and community-based) or as a more specific category than the options listed (e.g. agency on aging).

Types of Organizations Responding to Survey



Questions addressed the type of organization, which populations the organization believes will require the most support, common knowledge gaps or misunderstandings, staffing and services dedicated to redetermination, and what additional funding might be needed.

We shared a [document](#) including relevant resources with organizations during survey distribution to help increase organizations’ knowledge and capacity on the redetermination process.

Summary of Findings and Recommendations

Concerns among organizations responding to our survey include issues regarding staffing, questions about the process, and the need for targeted guidance for specific populations. Enrollment assistance and information provision are expected to mostly be done by community health workers and social workers whose capacities are constrained by limited funding. The administrative burden of the process itself also weighs heavily, especially for organizations serving populations with limited time, low digital literacy, lack of access to digital tools, and unfamiliarity with renewal procedures.

Based on the concerns summarized below, Health & Medicine recommends the following, which will be elaborated on in the remainder of this report:

- Additional funding over the fourteen-month redetermination period to organizations working directly with Medicaid populations.
- Specific guidance should be developed and shared among organizations for supporting priority populations such as young adults aging out of their parents’ Medicaid, those on Health Benefits for Immigrant Adults/Health Benefits for Immigrant Seniors and anyone being disenrolled from Medicaid and needing to find alternative forms of coverage

- Coordination with health care providers and the Department of Human Services to monitor needs and rapidly respond to concerns elevated by direct service providers would reduce the number of people falling through the cracks

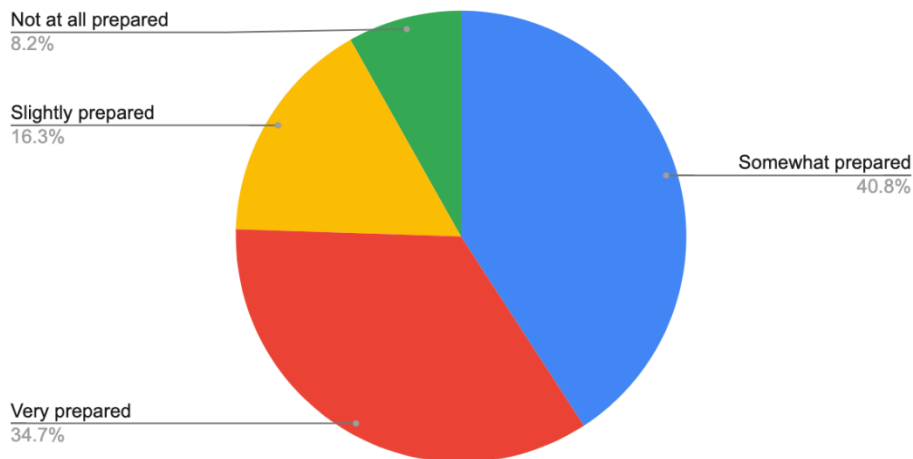
Detailed Findings

Health & Medicine received a total of 47 responses from organizations across 37 ZIP codes. Half were based in Cook County, five from the collar counties, seven from central Illinois, six from southern Illinois, and one from northern Illinois. The following sections summarize the approaches and concerns reported by these organizations.

Services and preparations underway

- Most organizations offer enrollment assistance (n = 36) and public-facing information (n = 29) as their primary activities
- Approximately half of all respondents—25 organizations—expressed a need for additional funding to be able to serve their populations dealing with Medicaid redetermination. More funding would help with hiring more staff and also to provide logistical assistance such as transportation to a DHS office or accompaniment through the process to get an ID.
- Six of the organizations that responded are hiring additional staff to assist with this effort, while 12 expressed that if funding were available, they would be hiring more staff

How prepared is your organization to manage and respond to the resumption of the Medicaid Redetermination process?



In response to this question, respondents offered the following insights:

At this time, we cannot afford to hire additional staff and are unsure how we will meet this capacity need.

No, unfortunately, due to Covid-19 funding going away, as well as other funding cuts made by our longstanding funders due to how the economy has impacted their investments, we will actually have to cut the hours in half of our current team of CHWs.

We do not have the capacity currently; we are being mandated to conduct the redeterminations without additional funding and there is no conversation as to the impact on older adults in Illinois.

Concern that Illinois organizations do not have enough internal staff/resources to competently handle incoming workload and how this will likely lead to burnout/exhaustion of frontline CHW staff having an unreasonable, additional workload amount without increase pay or job security.

These answers make clear that staffing and funding to support hiring such staff are important factors shaping the capacity of surveyed organizations to help clients with the redetermination process.

Concerns about the redetermination process

Respondents expressed the following concerns about the redetermination process:

- Documentation challenges:
 - o whether people receive their notifications and forms, especially given address changes
 - o how they will obtain another copy of the forms if they get lost
 - o errors made while filling out form information (e.g. misspelled name, incorrect date of birth), thus impeding renewal
- Illinois Department of Healthcare and Family Services processing time causing confusion regarding coverage start and end dates and retroactive eligibility
- Identity verification process can be difficult to complete
 - o Many Medicaid members may not have the time or access to transportation necessary
- The Application for Benefits Eligibility (ABE) website can be difficult to use or users may face technical issues

Dealing with our local Medicaid office is not easy. You can never get ahold of anyone or speak to an actual person. Our seniors are also not very tech savvy, so utilizing the ABE website can be complicated for them.

Concerns about public awareness

Respondents expressed the following concerns related to public awareness and communications:

- Many members of the public lack knowledge of alternative options if they become disenrolled from Medicaid and of the differences among health plans and types of coverage
- Some people lack awareness of the different ways renewal can be done (over the phone, online, in person at a DHS office, via mail)
- Still others may lack awareness of the different due dates, especially for those with due dates later in the year

Timing and when forms are due and how comprehensive the form is. Terms are intimidating.

Concerns about specific populations

Respondents raised the following populations as ones of highest concern:

- Young adults aging out of coverage from their parents' Medicaid, especially those without citizenship or residency who lack coverage options
- Older people who now qualify for Medicare or are dual-eligible
- Health Benefits for Immigrant Adults (HBIA) and Health Benefits for Immigrant Seniors (HBIS) patients who have never dealt with the redetermination process
- Medicaid members who are not in managed care organizations
- Housing-insecure and houseless people

This is a challenge with a transient homeless population where [they] can come and go from caseloads making on-going monitoring and assistance an increased challenge.

Plans for escalating complex cases

The following plans were shared by respondents related to helping Medicaid members facing complex cases related to redetermination:

- Seeking guidance from the Illinois Department of Healthcare and Family Services and the Illinois Department of Human Services; there are concerns about being able to reach anyone
- Refer to other organizations and resources:
 - o Shriver Center on Poverty Law HelpHub
 - o Health Justice team at Legal Aid Chicago
 - o Refer to partner agencies

Recommendations

Based on the survey data, Health & Medicine makes the following recommendations related to redetermination.

For Illinois state government:

Illinois state government should provide public funding in the form of grants to relevant nonprofit health and community-based organizations to support Medicaid members going through the restart of the eligibility redetermination process. Sites like hospitals, federally qualified health centers, and community-based organizations, as well as local health departments, should receive additional funds to support community health workers, social workers, and health navigators to support people facing the redetermination process.

Given that these funds are unlikely to be in the soon-to-be passed FY 2024 state budget, the state might explore using already established grant monies, such as the Healthcare Transformation Collaboratives grants for this purpose. In that case, perhaps a portion of these dollars could be committed to supporting redetermination or including such support could be a criterion for such funding. While it is difficult to put a dollar figure on the total amount of funding needed, we suggest distributing grants over the next year and a half to make a tangible difference in supporting redetermination as well as the critical community health worker and navigator workforce. A large existing pool of funding such as the aforementioned Healthcare Transformation Collaboratives grants may be leveraged to support this effort.

The state government and its partners should pursue strong and urgent messaging throughout the restart of redetermination, including later redetermination dates, as public attention may wane as the process unfolds. Also, tailored outreach, communications, and supports should be developed and implemented for the populations mentioned above, such as young adults and people in the Health Benefit for Immigrant Adults and the Health Benefit for Immigrant Seniors programs.

Critically, Illinois government must provide sufficient funding and staffing for the Illinois Department of Human Services to manage the volume of calls the call center will receive for support. Additionally, information on the ABE website, especially the identity verification process, should be clarified and simplified.

Lastly, Illinois government should support coordination with health care providers and the [Medical Electronic Data Interchange \(MEDI\)](#) to track redetermination dates for individuals.

For Illinois' Philanthropy Sector:

Foundations, especially those with health care access, health equity, social justice, or economic justice missions, should provide grants to support paid positions at various sites to support Medicaid members through redetermination. Funding should be dedicated to the workforce on the frontlines of redetermination and enrollment—such as social workers, community health workers, and health navigators—at federally qualified health centers, hospitals, community clinics, community-based organizations, and other nonprofits.

Foundations can also support organizations and individuals by connecting them to existing trainings.

For nonprofit organizations, such as hospitals, federally qualified health centers, community clinics, community-based organizations, and health advocacy organizations:

The stories and data related to the amount of work needed to successfully support people with Medicaid redetermination need to be gathered and shared. Phone calls to relevant state elected and appointed officials communicating the difficulty for both agencies and individuals are essential. Calls will provide officials with an understanding of the on-the-ground impact of the restart of Medicaid redetermination, including both the burden of paperwork as well as the loss of health insurance coverage for their constituents. Communicating clearly and consistently about these hardships may help with both resource allocation and larger health reforms needed for both an improved health insurance system and improved health policies. Right now, people need help jumping through bureaucratic hoops. In the future, policymakers should consider removing some of the burden altogether.

Limitations

This survey was developed rapidly in response to a local philanthropic foundation's interest in assessing the potential need for funding to support organizations seeking to help Medicaid members with eligibility redetermination. Given the short timeline, there was not extensive time to pilot test and refine the survey. In addition to internal review, the survey team solicited reviews from a handful of relevant external partners and incorporated their feedback and input for improving the survey instrument and information related to it. Still, the short timeline limited opportunities for further refinement and improvements that would have made questions and answers clearer.

From the responses, it appears that some questions were interpreted differently by different respondents based on varied understandings of the questions. Each organization had its own constraints in mind when answering (e.g. assumptions about funding access), which made questions such as specific funding and staffing needs challenging to generalize from.

Also, respondents were being surveyed about capacity and level of preparedness at the same time that a resource list related to Medicaid redetermination was included in the invitation. This may have helped increase respondents' levels of capacity and preparedness just as they were about to take this survey. The survey team recognized this might slightly skew results yet decided to prioritize resource distribution given the stakes of the matter.

Finally, this survey used a convenience sample of Health & Medicine's existing contact list and connections with relevant coalitions. Due to this distribution method, the survey respondents do not perfectly represent the wide body of affected organizations across the state. The relatively short timeframe also coincided with the start of redetermination letters being sent out, so particularly overwhelmed organizations may have been unable to respond. Additionally, many local organizations that provide benefits application assistance that are not specifically health-focused were not reached but will likely serve Medicaid populations.

Appendix A: Survey Materials

The survey was distributed online using Formstack. The text of the survey is reproduced verbatim here.

Name

Name of organization

Your title at the organization

Email

Phone

Your organization's ZIP code

What type of organization are you representing?

Federally qualified health center

Free clinic

Hospital/health system

Behavioral health provider

Dental provider

Local health department

Community-based organization

Advocacy organization / special interest group

Health insurance company / managed care organization

Other:

How many full-time equivalent workers does your organization employ?

1-10

11-50

51-500

501-1000

1000+

What are the populations served by your organization that require the most support and assistance in navigating the redetermination process?

Historically excluded racial and ethnic groups

Immigrants/non-native English speakers

Undocumented Immigrants/Migrant workers

Returning citizens

Older persons

Young adults

LGBTQIA+ individuals

Disabled individuals

Individuals/families near or below the federal poverty line

Persons experiencing homelessness or housing insecurity

Individuals with severe mental illness

Individuals with literacy challenges

Single parents

Individuals with substance use disorders

Other:

Approximately how many clients does your organization expect to support with the Medicaid redetermination process in the year ahead?

What common knowledge gaps or concerns are you hearing from your partners and community members about Medicaid Redetermination?

How prepared is your organization to manage and respond to the resumption of the Medicaid Redetermination process?

Very prepared

Somewhat prepared

Slightly prepared

Not at all prepared

What services will you provide to Medicaid recipients to facilitate their continued enrollment in the Medicaid program?

Enrollment assistance

Referral to another organization for enrollment assistance

Information sessions

Public-facing information (handouts, flyers, etc.)

Financial counseling

Other:

What type of staff do you plan to use to support community members regarding Medicaid redetermination?

Healthcare/insurance navigators

Community health workers

Finance/billing staff

Medical assistants

Clinicians

Mental health professionals

Social workers

Other:

Will you be hiring additional staff members to support your Medicaid Redetermination work? If yes, how many?

Is your hiring plan sufficient for your Medicaid redetermination workplan?

Yes

No

Not Applicable

(If they answered "No" to the previous question) How many additional staff members does your organization require above and beyond your planned hiring for redetermination work?

How much ADDITIONAL funding does your organization need for the next 12 months to fully execute your Medicaid redetermination work?

How will you handle Medicaid redetermination issues that your staff members are unable/unsure of how to address?

Do you have any outstanding questions or concerns relating to Medicaid redetermination?