

A MISSED OPPORTUNITY FOR EQUITY

MEDICAID UNWINDING SURVEY OF SPANISH-SPEAKERS



At the outset of the “unwinding” of Medicaid’s continuous coverage provision at the end of the COVID-19 public health emergency, it was projected that millions of people would lose their health coverage. The Protecting Immigrant Families Coalition (PIF) and its partners decided to take action, knowing that this disaster presented a unique opportunity to address not just the “unwinding,” but also to build understanding of the many obstacles to enrollment for immigrants. Because the scale of this massive health coverage loss led to a dilution of attention to the needs of particular groups, Medicaid officials did not adequately address immigrant families’ specific barriers. PIF’s Medicaid Unwinding Task Force gathered information on the impact of this unwinding on immigrant families through desk research and a survey of advocates. To ensure that the experiences and perspectives of immigrant families themselves were reflected in the research, PIF also conducted a survey of Spanish-speaking immigrants to more clearly understand where enrollment systems may be failing immigrant families. The Task Force used these findings for advocacy with the Centers for Medicare and Medicaid Services, and they provide a clear picture of the need to address obstacles to enrollment and re-determinations in an ongoing manner.

BACKGROUND

Medicaid coverage served as an essential lifeline for millions of Americans during the COVID-19 pandemic, growing by 32% to cover 94.5 million people - more than 30% of the population.¹ After nearly three years of continuous Medicaid coverage, the official declaration of the end of the public health emergency triggered an “unwinding” of Federally-mandated continuous coverage. This unwinding was predicted to cause significant loss of coverage among vulnerable, low-income people. The Department of Health and Human Services predicted that 15 million people would lose coverage during this re-enrollment period, and that 45% of those would lose coverage due to procedural reasons.² That includes 2.4 million Latinx people. And indeed, recent analysis³ of Medicaid unwinding data shows that Latinx families are losing Medicaid coverage at more than twice the rate of the next most impacted racial or ethnic category.

In March 2023, PIF brought together national, state, and local advocates and community-based organizations to focus on the experience of immigrants and their families as they tried to renew Medicaid coverage. The task force has worked to identify potential problems, successes, early observations and concerns for immigrant families during the unwinding and identify steps state Medicaid agencies and HHS can take to remove reenrollment barriers for immigrants and their families. The task force has also reported problems to the Department of Health and Human Services (HHS) and Centers for Medicare and Medicaid Services (CMS) and provided support for community education, earned media, and other communications.

¹ <https://www.kff.org/medicaid/issue-brief/medicaid-what-to-watch-in-2024/>

² [Commonwealth Fund Blog](#)

³ [State Health Access Data Assistance Center](#)

The Medicaid Unwinding Task Force conducted a survey of state advocates to assess their states' performance on conducting redeterminations for immigrants in their states. The survey assessed how 28 states were doing in:

- Addressing immigration concerns
- Providing language access
- Publicly reporting data
- Engaging stakeholders

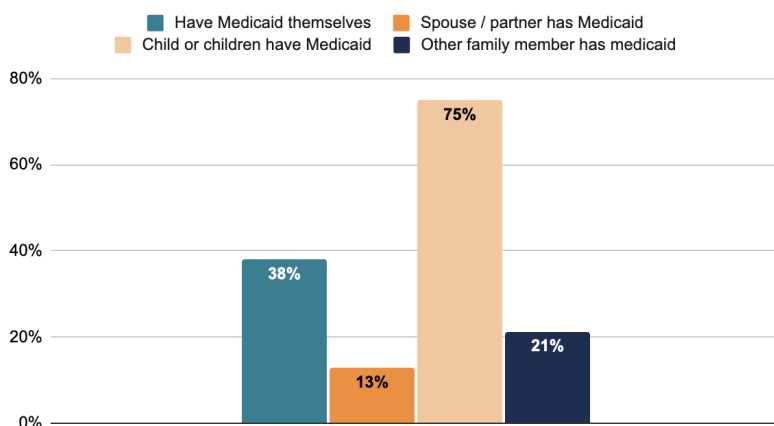
The survey showed significant deficiencies in language access, community engagement, and effective messages that dispel immigration fears, among other areas. This data helped advocates present a broader picture of the “unwinding” to Federal officials in hopes of preventing more immigrants from losing their Medicaid coverage unnecessarily.

In order to get a community view of the process, PIF partnered with UnidosUS, the nation’s largest Hispanic civil rights and advocacy organization and Noticias Para Inmigrantes (NPI), a media and communications organization with an audience of approximately 5 million US-based, Limited English-Proficient Latinos of all immigration statuses including naturalized citizens, to survey Medicaid recipients about their experiences with the re-enrollment process.

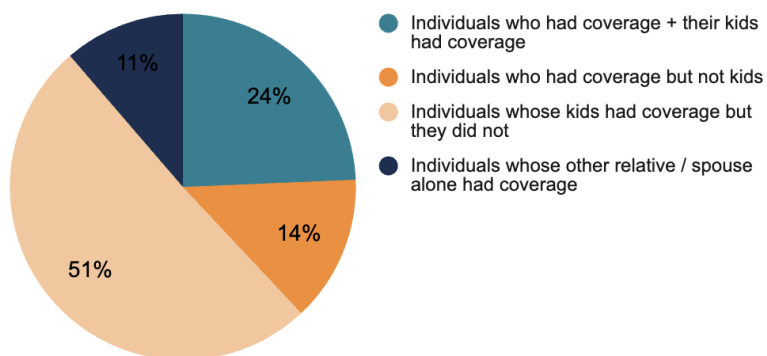
MEDICAID IS CRITICAL FOR IMMIGRANT FAMILIES

While all respondents had someone in their family who was covered by Medicaid, 75% of the respondents’ children had Medicaid and 38% had Medicaid themselves. Least commonly, 11% had only their spouse or other (non-child) family member with coverage. As expected in immigrant families with multiple statuses, 51% reported that only their child or children had Medicaid, and they did not.

Respondents' Relationship with Medicaid Recipients, All Respondents



Respondents' relationship to Medicaid Covered Person(s)



Variations in the respondents’ coverage show the broad differences in adult eligibility and barriers to accessing coverage for those who are eligible but not enrolled in each state. For example, almost 60% of California respondents had Medicaid themselves, but only 12% of TX respondents had Medicaid coverage for themselves.

The survey asked respondents if having Medicaid coverage had improved their or their family member’s health, as well as whether Medicaid coverage had helped in other aspects of their lives. In

these open-answer questions, many respondents praised the ability to get care in a timely manner and cover costs, bringing peace of mind. Many gave specific examples of serious health concerns that were treated and chronic conditions that were managed due to Medicaid coverage. Beyond health care, respondents shared that Medicaid gave them and their children access to critical education, greater capacity to care for their children, a reduction in worry over missed work, and security.



“Gracias a mi tarjeta que con eso tuve que pagar los gastos de mi parto cuando tuve mi bebé.”

Thanks to my card, with this I was able to pay for the costs of my delivery when I had my baby.



“Mi hija tiene medicaid y ha sido lo mejor que me ha pasado ella tiene acceso a atención médica completa y no me tengo que preocupar para saber cómo lograr pagar porque las facturas son muy grandes y no las puedo cubrir.”

My daughter has Medicaid and it has been the best thing that has happened to me. She has access to complete medical care and I don't have to worry about how to pay because the bills are very large and I can't cover them.



“Mi hijo necesitó una operación y el seguro cubrió todo y fue muy bueno para mí porque también necesita de un consejero y por 3 años lo ha tenido y no he tenido que pagar ninguna consulta.”

My son needed an operation and the insurance covered everything and it was very good for me because he also needs a counselor and for 3 years he has had one and I have not had to pay for any consultation.



“Por tener medicaid pude calificar en un programa de educación para mi niña de dos años”

By having Medicaid I was able to qualify for an education program for my two-year-old daughter.



“En lo personal me ayuda a que mis hijos se mantengan saludables por que se les hace sus chekeos anualmente y al estar saludables se trabaja más confiado”

Personally, it helps me keep my children healthy because they have their check-ups annually and being healthy makes one work more confidently.



“Ese dinero que no se gasta en doctores sirve para otras cosas de los niños por ejemplo comida.”

That money that is not spent on doctors is used for other things for children, for example food.

Texas mother of 4 US citizen children

Lurvin’s four daughters have all had Medicaid since they were born. This coverage has ensured they have ongoing medical care, especially important for one child who is diagnosed with epilepsy. Her experience of applying for, renewing, and receiving Medicaid coverage has been extremely positive.

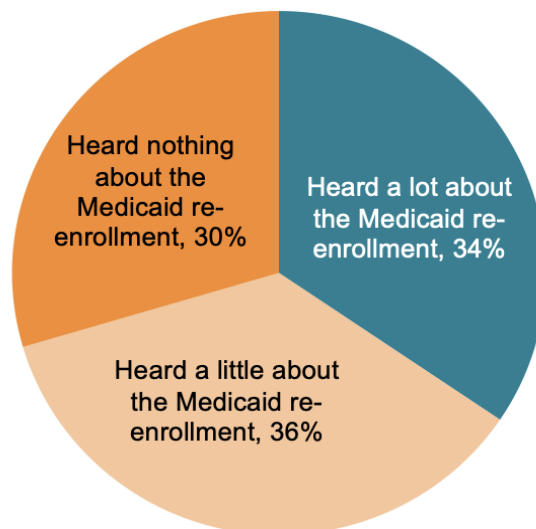
“Es una gran ayuda que garantiza que mis hijas estén bien cuidadas y también contribuye a que gocen de buena salud, permitiéndoles realizar sus actividades sin problemas. Gracias a que están saludables, pueden recibir educación sin inconvenientes, y están creciendo fuertes y sanas. A pesar de que una de mis hijas sufre de epilepsia, esta condición está totalmente controlada con su tratamiento específico.”

It is a great help that ensures that my daughters are well cared for and also contributes to their good health, allowing them to carry out their activities without problems. Because they are healthy, they can receive education without problems, and they are growing strong and healthy. Although one of my daughters suffers from epilepsy, this condition is fully controlled with her specific treatment.

2/3 KNEW LITTLE OR NOTHING ABOUT MEDICAID RE-ENROLLMENT AL FOR IMMIGRANT FAMILIES

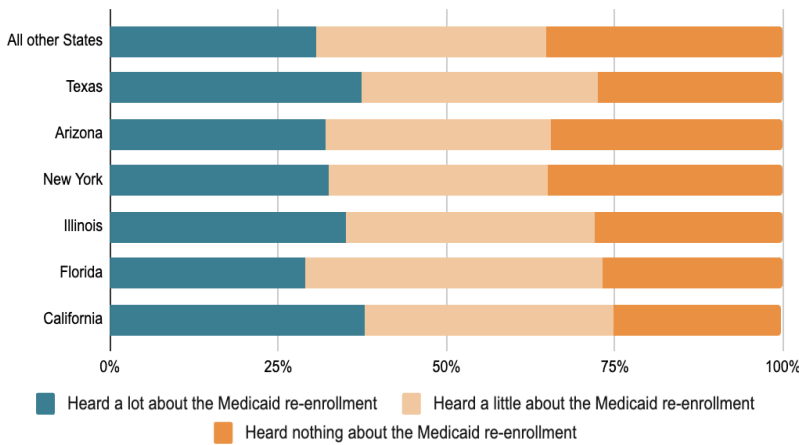
The survey probed respondents' awareness of the re-enrollment process underway across the country, where they got information about it, and what messages they had heard. The survey also asked respondents about the pervasiveness of common false messages that have been known to negatively impact Medicaid enrollment among immigrant families.

Overall Awareness of Medicaid Re-Enrollment



⁴ Paulhus DL. Two-component models of socially desirable responding. *J Pers Soc Psychol.* 1984;46:598. [[Google Scholar](#)]

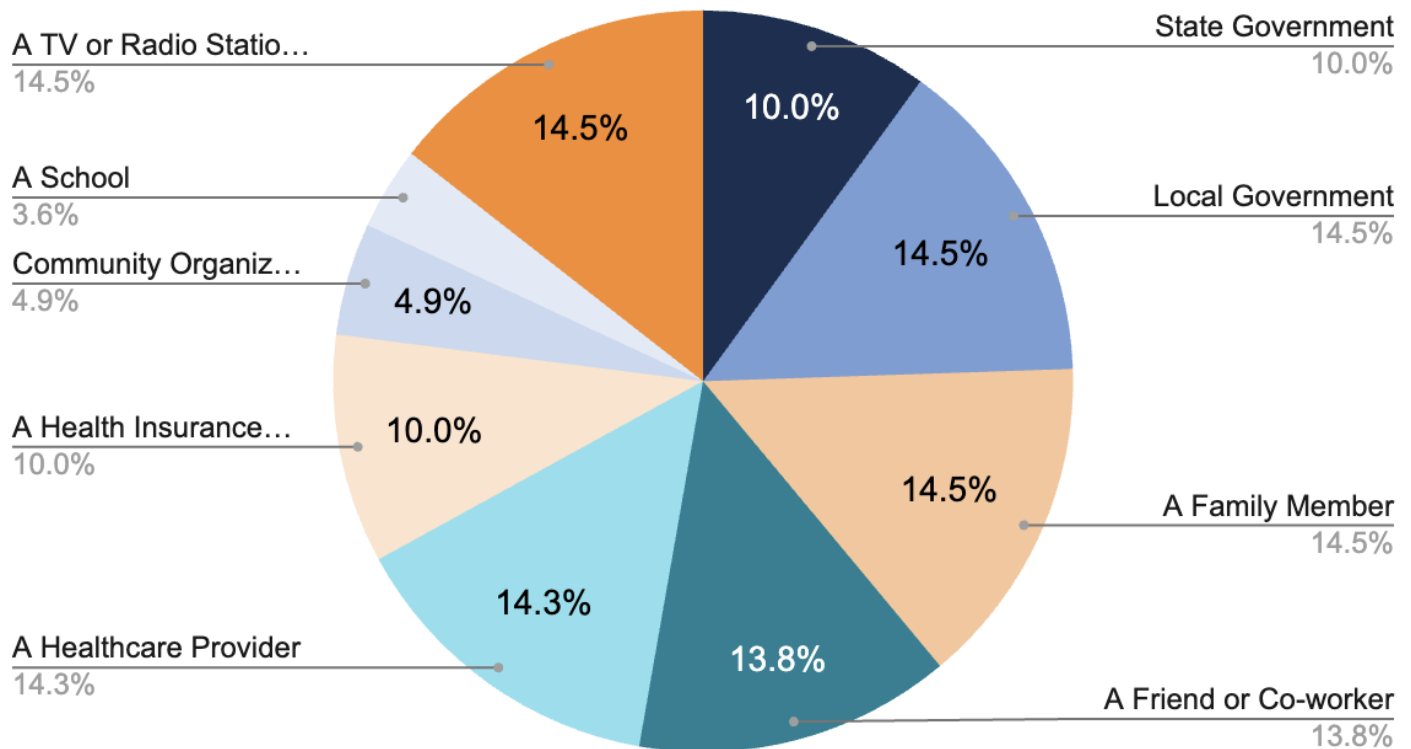
State-Level Awareness of Medicaid Re-Enrollment



Only 34% of respondents had heard “a lot” about the Medicaid re-enrollment process. 30% had heard “nothing” about it, and 36% reported hearing “a little” about the re-enrollment. These “a little” responses may be due to a “social desirability bias” -- the tendency to underreport socially undesirable attitudes and behaviors and to over report more desirable attributes⁴ -- toward indicating some familiarity with the subject of the survey. Among the state responses analyzed separately, awareness seemed to be highest in California, Texas, and Illinois. In Florida, 71% of respondents had heard nothing or “a little” about the re-enrollment.

Respondents reported multiple sources of information about the re-enrollment. Schools (4%) and community organizations (5%) were not common sources of information, providing a stark reminder to community-based organizations doing outreach that their efforts are challenged by scale.

Sources of Information About the Unwinding



⁴ Paulhus DL. Two-component models of socially desirable responding. J Pers Soc Psychol. 1984;46:598. [Google Scholar]

Among those interviewed, there was variation in how they heard about the Medicaid renewal process



“Sí, efectivamente, fui a la clínica para confirmar y parece que la renovación de Medicaid se realizó de manera automática. Al menos, al principio, no fue necesario completar ningún formulario.”

Yes, indeed, I went to the clinic to confirm and it appears that the Medicaid renewal was done automatically. At least, at first, no forms needed to be filled out.



“Recibí una carta y un mensaje de texto de ellos, junto con un enlace para completar el proceso en línea. Mi hija me ayudó a realizarlo a través de un sitio web, ya que no tengo mucha destreza tecnológica.”

I received a letter and a text message from them, along with a link to complete the process online. My daughter helped me complete it through the website, since I'm not very technologically skilled.



“Ellos me enviaron la carta, me llegó por el buzón y estaba en español. A mí también me llegó la carta, pero normalmente, recibo una notificación (por aplicación), voy a la página en línea y actualizar los datos”

They sent me the letter, it arrived through the mailbox and it was in Spanish. I also received the letter, but normally, I receive a notification (via app), I go to the online page and update the data



“No he recibido ninguna carta, pero he escuchado de la renovación de Medicaid, he visto anuncios, pero no sé muy bien.”

I have not received any letters, but I have heard about Medicaid renewal, I have seen advertisements, but I don't know very well.



“Recibí la carta, pero estaba en inglés y sinceramente no comprendo lo que están comunicando.”

I received the letter, but it was in English and I honestly don't understand what they are communicating.



“Recibí una notificación a través de la aplicación para renovar mi cobertura de Medicaid.”

I received a notification through the app to renew my Medicaid coverage.

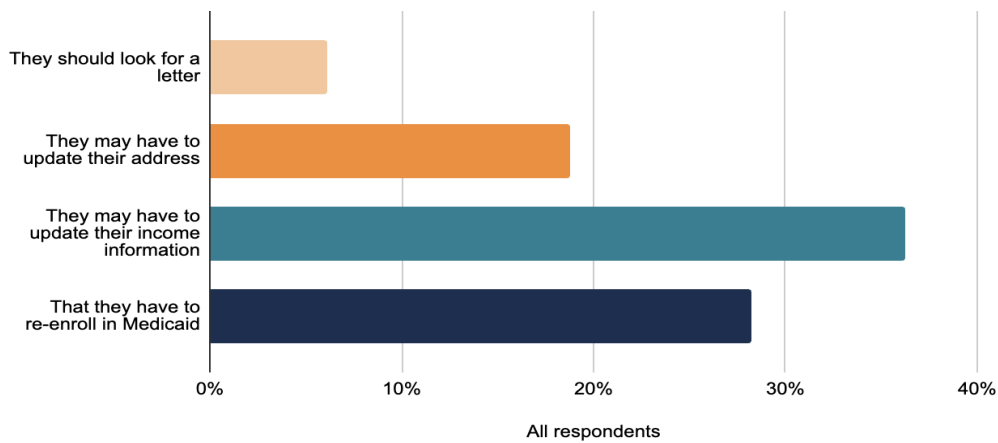
The messages promoted by CMS in their communications toolkit⁵ included:

- Update your contact information
- Check your mail
- Complete your renewal form (if you get one)

The marketing and communications materials were sophisticated, colorful, and translated into multiple languages. They did not specifically address immigration-related concerns, leaving a critical gap in messaging to mixed-status immigrant families, which has been known to be a barrier to enrollment.

Among NPI survey respondents, only 6% had heard that they should look for a letter with information about updating their information. 36% reported that they had heard that they may have to update their income information, 19% heard that they may have to update their address, and 28% heard that they have to re-enroll in Medicaid.

Messages About Re-Enrollment Heard By Respondents

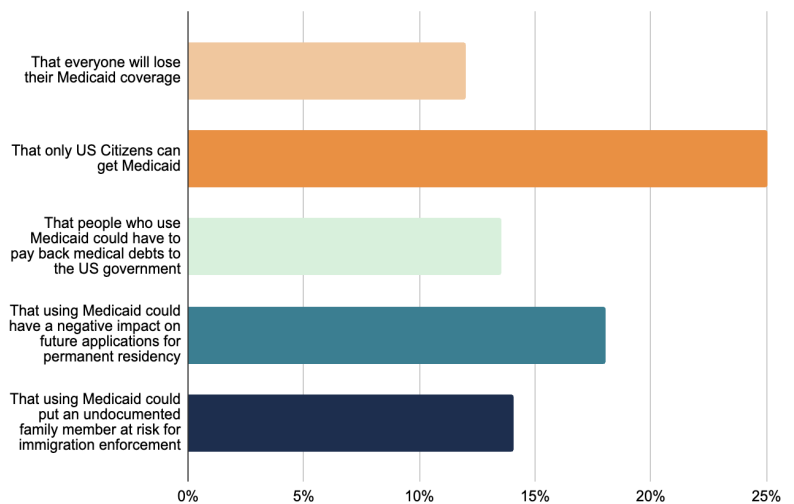


MORE THAN HALF HEARD MISINFORMATION

With so little general awareness of the Medicaid re-enrollment process, information gaps are easily filled by misinformation, rumor, and harmful fears. This survey asked respondents whether they had heard several common false messages and invited them to share any additional misinformation they had heard related to Medicaid enrollment.

Overall, 57% of respondents reported hearing common misinformation about Medicaid. Most common among the false messages, 25% had heard that only US Citizens could get Medicaid. In some states, these rates were higher: 31.5% in Texas reported hearing this false message. 12% of respondents had heard that everyone will lose their Medicaid coverage.

Misinformation Messages Heard by Respondents



PUBLIC CHARGE AND IMMIGRATION WORRIES WERE PREVALENT

Immigration-related concerns were prevalent in common misinformation heard about Medicaid coverage. 18% reported hearing that using Medicaid could have a negative impact on future applications for permanent residency. This rate is higher in some states: for example, 20% in Arizona and 19% in California. The pervasive chilling effect of the Trump public charge rule has continued to fuel misinformation about Medicaid, including among those who already have family members with Medicaid and who have personal familiarity with the program.

Among interviewees, public charge and immigration concerns were highly prevalent. **One interviewee from Delaware shared that when she initially received Medicaid for her children, she had no concerns about public charge and medicaid, but then reported increasing concern as she**

⁵ [Medicaid.gov](https://www.Medicaid.gov) Communications Toolkit

listened to the news. Another, from California, explained, *“El temor a la carga pública es persistente, y tratamos de evitar solicitar cualquier tipo de ayuda debido a esa preocupación.”* (The fear of public charge is persistent, and we try to avoid applying for any type of help because of that concern.) The ongoing confusion around Medicaid’s impact on public charge reflects the depth of the chilling effect and its real impact on families’ health coverage.

In addition to permanent residency worries, 14% of respondents reported hearing that using Medicaid could put an undocumented family member at risk for immigration enforcement. Additionally, 14% of participants had heard that people who use Medicaid could have to pay back medical debts to the US government, which echoes widespread rumors among immigrant communities about public benefits encumbering the children of immigrants with future obligations.

Illinois mother of 3

Evelyn is a US citizen and has had Medicaid since her kids were born. Her husband didn't have Medicaid because he is undocumented. While going to the clinic for her husband’s medical care, they told her that her husband qualified for Medicaid, and she was surprised because she thought Medicaid was only for those with documents. They told her Medicaid in Illinois* is now for everyone regardless of documents and it is not a public charge. Her entire family now has Medicaid, and it has been life-changing. They use it all the time, such as her husband using it to pay for his medication. She has never had problems getting appointments, and she reported that the application process is so easy and fast. In one week all of the documents were approved for her husband.

She was alarmed when she got a message notifying her of her renewal requirement. She thought first of her undocumented husband, and then she worried that her Medicaid coverage would end because she had used too much healthcare and Medicaid didn’t want to cover those costs. Next, she was concerned it was a scam, because she had gotten a text about her coverage possibly ending, and she thought it was an attempt at identity theft. Evelyn immediately called her office because she thought it was suspicious. Her office told her to ignore the letter and she didn't have to renew anything at the time.

*Likely HBIS or HBIA, which are Illinois-specific, Medicaid-like coverage programs.

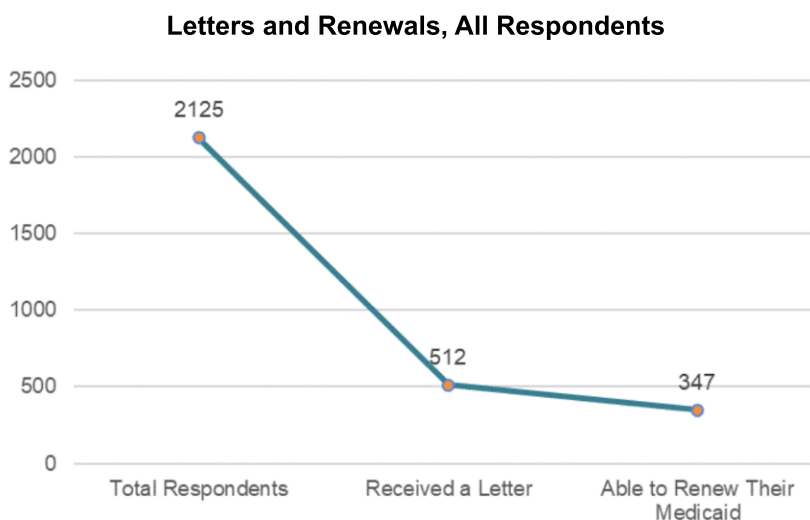
Survey respondents were invited to complete an open-answer question and share “other” misinformation that they had heard related to Medicaid and the re-enrollment process. A very small number of respondents (41) completed this question, and their responses demonstrated significant confusion about eligibility, enrollment, and coverage. Over half of the “other” misinformation reported (21 responses) was related to eligibility criteria. Notably, more than half of those eligibility-related misinformation examples (11 responses) were actually true, and not misinformation. All of those reports were from California-based respondents, who did not believe that Medicaid eligibility had been expanded to include undocumented individuals.

Five reports of “other” misinformation were related to the re-enrollment process, and four of those examples were factual. Again, this reflects that the respondents did not have clear, reliable information about the re-enrollment underway. The confusion around program eligibility and enrollment leads to distrust of programs in general.

RE-ENROLLMENT NOTIFICATIONS AND PROCESS

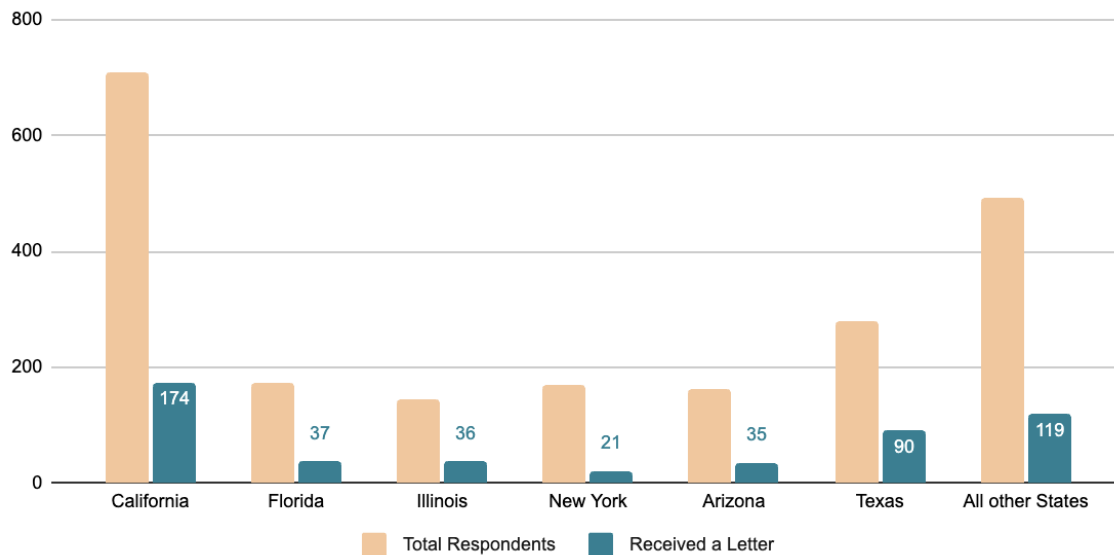
While the “unwinding” of continuous coverage officially began in April, 2023, states had significant leeway to roll out their re-determination over the following months, with re-determinations to be completed by March 31, 2024. By December of 2023, when this survey was conducted, only 24% of respondents had received a letter about re-enrolling. Of those who received a letter, only 67% were successfully able to renew their Medicaid.

This low rate of letters received could have multiple explanations, including respondents who may have received an electronic notification and not viewed that as a “letter.” Further analysis of the experiences of those who received letters is limited by the very small data set (512). Understanding that limitation, it is notable that there were differing experiences by state in terms of language access, the clarity of their communications, and the difficulty of completing all of the steps necessary to renew their Medicaid coverage.



In interviews, respondents mentioned state offices, clinics, and community based organizations as places for information about the renewal process and completing the renewal process. Those who reported calling their Medicaid offices to get more information and renew had mixed experiences. One interviewee in Washington shared, *“El personal que habla español hace todo lo posible por atendernos de manera efectiva. Incluso cuentan con un intérprete para garantizar que la comunicación sea clara y precisa cuando nos hablan en español.”* (The Spanish-speaking staff does everything possible to serve us effectively. They even have an interpreter to ensure that communication is clear and accurate when they speak to us in Spanish.) An interviewee in Louisiana recounted, *“Me sentí discriminado porque durante la llamada la persona me juzgó porque me vine con mi familia para acá.”* (I felt discriminated against because during the call the person judged me because I came here with my family.)

Respondents Who Received Letters



Other interviewees preferred to go to their clinics and or CBO's to get more information and complete the renewal process. One interviewee from Indiana went to a community office where she also received food assistance. Another from Washington was able to renew through her clinic. In Texas, one respondent explained, *“En mi caso, la renovación se llevó a cabo inicialmente en la clínica y luego se completó en línea a través de My Texas Benefits...aunque también recibimos cartas en nuestro correo, encontramos que realizar el proceso en línea es más conveniente.”* (In my case, the renewal was initially completed in the clinic and then completed online through My Texas Benefits...although we also received letters in the mail, we found completing the process online to be more convenient.)

Texas Mother of 1

Before losing Medicaid during the renewal process, Petra (a US citizen) used Medicaid for preventive health services such as injections and medication for migraines, anxiety and asthma. She currently has no income and lives in subsidized housing, and she has complications with receiving child support. Recently, while still covered by Medicaid, she underwent a surgery; however, she lost coverage shortly after the surgery. As a result, Petra fears that without Medicaid she will not recover fully. During her renovation process, she mentions calling 211 multiple times for information on why her application was rejected and going in-person to the office with documents. Every time she has been denied. This had led to feelings of frustration and being discriminated against. Petra's daughter has Medicaid.

“Comencé a recibir Medicaid en 2012, pero este año perdí la cobertura durante el proceso de renovación. En abril, me sometí a una cirugía de espalda, y actualmente me encuentro sin acceso a seguimiento médico debido a la pérdida de mi cobertura.”

La situación es especialmente preocupante, ya que después de la cirugía es crucial contar con un seguimiento médico para garantizar una recuperación adecuada. La falta de acceso a la atención médica postoperatoria compromete mi capacidad para recibir la atención necesaria para gestionar mi salud y recuperarse completamente.

Recibí una notificación a través de la aplicación para renovar mi cobertura de Medicaid. Tan pronto como recibí la notificación, procedí a renovarla en inglés. Sin embargo, después de renovarla por primera vez y recibir la aprobación, recibí una segunda notificación que indicaba que la renovación había sido negada. Inmediatamente, tomé medidas y me comuniqué al 211 y visité la oficina correspondiente.

Durante mis visitas, se me solicitó que presentara estados de cuenta y detalles sobre mi empleo. A pesar de haber cumplido con todas las solicitudes y haber ido varias veces, aún enfrentó problemas, especialmente con la negación relacionada con el estado de child support. Aunque he proporcionado todos los documentos y cumplido con los requisitos adicionales, mi renovación ha sido negada en múltiples ocasiones, incluso después de haber intentado entre 6 y 7 veces.”

“I started receiving Medicaid in 2012, but this year I lost coverage during the renewal process. In April, I underwent back surgery, and am currently without access to medical follow-up due to the loss of my coverage.

The situation is especially worrying, since after surgery it is crucial to have medical follow-up to ensure adequate recovery. Lack of access to post-operative medical care compromises my ability to receive the care necessary to manage my health and fully recover.

I received a notification through the app to renew my Medicaid coverage. As soon as I received the notification, I proceeded to renew it in English. However, after I renewed it for the first time and received approval, I received a second notification stating that the renewal had been denied. Immediately, I took action and contacted 211 and visited the corresponding office.

During my visits, I was required to submit account statements and details about my employment. Despite having complied with all requests and going several times, I still faced problems, especially with the denial related to child support status. Although I have provided all documents and met additional requirements, my renewal has been denied multiple times, even after trying 6-7 times.”

CONCLUSION

The Medicaid Unwinding Task Force made a series of recommendations for state Medicaid administrations as well as the Centers for Medicare and Medicaid Services. The findings of this survey support those recommendations; in particular, they reinforce the following recommendations of the Task Force:

- **CMS should engage in a targeted outreach campaign to immigrants and their families.**
Revise the unwinding outreach toolkit to include messages that it is safe to apply for Medicaid and re-enroll.
 - PIF's [research about effective public charge messaging](#) offers guidance and insight into ways to communicate about public benefits access and immigration.
- **CMS should ensure that states follow federal guidelines** to provide meaningful language access in outreach, in-person assistance, call centers, notices, and online renewal portals.
- **CMS should conduct regular assessments to ensure compliance**, such as secret shopper efforts and other testing to ensure that meaningful language access is provided, such as call center wait times.
 - UnidosUS' [study of Florida's call centers](#) offers an excellent example for further efforts.

With the added information provided by this survey, we also recommend:

- **States should invest in educational campaigns about Medicaid eligibility**, enrollment requirements, and the general parameters of Medicaid coverage. The widespread confusion and misinformation, along with the complexity of the program in each state cause significant challenges for community members to stay enrolled.
 - State-sponsored educational campaigns would be most effectively executed by Community-Based Organizations who have direct connections with those most likely to struggle to maintain enrollment.
 - Educational campaigns should directly address public charge and immigration-related concerns about enrollment in order to better speak to concerns from immigrant families.
- **States should invest in Community-Based Organizations** as locations for re-enrollment, with funding, training, and access to enrollment processing.
 - Many respondents who reported successful re-enrollment did so through trusted community organizations, which are more likely to provide language access and cultural responsiveness while helping immigrant community members navigate the re-enrollment process.

ADDENDUM - SURVEY ADMINISTRATION

The 19 question survey was advertised to NPI's Facebook Messenger subscribers from December 4 - 8, 2023. Subscribers were screened to attest that they all had someone in their family who had Medicaid. Upon completion, survey respondents were entered into a raffle for a \$50 gift card. Survey respondents could opt into a follow-up interview, and over half of the participants opted in.

2,125 respondents from 43 states and the District of Columbia successfully completed the survey.

The largest number of survey responses came from Arizona, California, Florida, Illinois, New York, and Texas; PIF and

UnidosUS analyzed those states' data individually, in addition to the full data set. NPI collected 15 stories from interviewees between December 15, 2023 and January 30, 2024, who received \$75 in compensation.

