Impact of Gaps in Medi-Cal Coverage: Family Focus Group Findings

childrenspartnership.org

@kidspartnership
The Children’s Partnership is a California advocacy organization advancing child health equity through research, policy and community engagement.
The Children’s Partnership commissioned Lake Research Partners to conduct family focus groups:

**Objectives:**
- **Improve** health equity by ensuring stable coverage.
- **Elevate** voices of families of color; the stories behind the numbers.

**Phase 1:** May–Sept 2023
  - Understand the impact of gaps in children’s Medi-Cal coverage.

**Phase 2:** In Progress (Nov–Dec 2023)
  - Explore family experiences with Medi-Cal renewal process.
Families who shared their experiences:

10 focus groups totalling 83 parents/guardians

Race/ethnicity:
- 41 Latine
- 17 Asian
- 10 Black
- 8 Native American
- 7 Mixteco Indigenous

17 parents of CSHCN

Northern CA: 9
Central CA: 36
Southern CA: 37

Language:
- 33 English speaking
- 17 Chinese speaking
- 33 Spanish speaking
- 7 Mixteco in Spanish
Where are we so far on unwinding?

**Strides**
- Many new state flexibilities.
- Robust outreach campaign underway.
- Ex-parte (auto-renewal) rate improving — 43% for kids.

**Challenges**
- 700k have lost coverage in 4 months, including 150k children.
- 220k loss in children’s enrollment — 4.2% drop.
- 91% procedural disenrollment rate (4th worst in the nation).
- ~75% of disenrolled children remain eligible.
- Renewal barriers due to local call wait times, growing backlog of pending cases.
Summary: What we heard about impacts of gaps in coverage

Themes

1. Families often discovered coverage was dropped when seeking care, exacerbating families’ worry.

2. Gaps in coverage led to delays in needed care, missed medications and significant out-of-pocket costs.

3. Prominent procedural hurdles kept many families from staying covered.
In their words:
Family experiences with gaps in coverage
Theme 1

Families often discovered coverage loss when seeking care, exacerbating families’ worry.
Theme 1: Many families find out their child lost coverage while seeking health care

- Families greatly value coverage for their children — offering “security blanket” or “peace of mind.”
- Parents/guardians note coverage means:
  - **Routine care is affordable:** check-ups, screenings, dental care, immunizations.
  - **Needed treatment is accessible for:** injuries, mental health concerns, medications and treatment for chronic conditions like asthma and cystic fibrosis.
- Parents often confused why coverage was dropped. Some received termination notices, others did not.
- Finding out coverage is lost when seeking care adds to parents’ stress for their child’s health.

One parent recounts rushing in the ambulance with their child and his dislocated shoulder only to find out at the hospital their child no longer has coverage:

“It was a nightmare.”
“I was going to take her to a medical appointment and they said, I’m sorry, your daughter doesn’t have Medi-Cal. I was like, what do you mean? If I hadn’t gone there, I wouldn’t have realized it …”

SPANISH-SPEAKING PARENT/GUARDIAN, FRESNO

“When we went to Northeast [clinic] for a fever, they said that our Medi-Cal was no longer effective. I said why not? Our income is within limits, we are insured.”

CHINESE-SPEAKING FEMALE PARENT/GUARDIAN, SAN FRANCISCO

“… We took [our sick daughter] to the doctor’s office … they told us about her not being covered and we were in great shock. They never told us nor explained anything about their limits or anything.”

SPANISH-SPEAKING MIXTEC MALE PARENT/GUARDIAN, OXNARD
Theme 2

Gaps in coverage led to delays in needed care, missed medications and significant out-of-pocket costs
Theme 2: What even short gaps in coverage can mean for children

- **Stress and Panic:** A sick child in need of health care is stressful enough for families.

- Coverage gaps for even a few days can be **life-threatening**, particularly for children with special health needs and those requiring life-sustaining medications.

- Gaps in coverage mean children faced:
  - Difficulty accessing medications.
  - Delayed immunizations, mental health therapy, physical exams and dental care.
  - Huge out-of-pocket costs for ER/hospital visits.
“In that lapse, there were two or three months that she didn’t have any coverage. She had appointments and she had to be in therapy, and everything had to stop. Why? Because I had no money to pay for all those therapists or take her to the doctor.”

SPANISH-SPEAKING PARENT/GUARDIAN, FRESNO

“When my daughter was a few months old, there was a gap of two or three months. We didn’t even go to get her vaccinated because I had to pay $700.”

CHINESE-SPEAKING FEMALE PARENT/GUARDIAN, SAN FRANCISCO

“My daughter needed a physical exam, I took her over to a doctor’s clinic, and they didn’t want to take us in. They … had us jumping from one clinic to another. She couldn’t receive attention. And it’s painful, she cries at night, sometimes.”

SPANISH-SPEAKING MIXTEC MALE PARENT/GUARDIAN, OXNARD
“...They haven’t fixed his tooth yet, so they gave me an appointment to take him to fix that, but I couldn’t take him … had to wait four to five months.”

SPANISH-SPEAKING MIXTEC FEMALE PARENT/GUARDIAN, OXNARD

“...We couldn’t get the medication. I was seriously crying, calling every doctor ... back and forth to the hospital, because he was about to run out any day. He needs it to live …”

FEMALE PARENT/GUARDIAN OF COLOR OF A CHILD WITH SPECIAL HEALTH CARE NEEDS, FRESNO

“...from medical bills that Medi-Cal said they were going to pay when my son was off [coverage], I owe thousands, thousands. Plus ambulance, just an ambulance ride alone was $3,200. I owe thousands.”

BLACK PARENT/GUARDIAN, FRESNO
Prominent procedural hurdles kept many families from staying covered.
Theme 3: For some, renewals were easy, others faced hurdles and stress

Commonly cited hurdles included:

1. **Inadequate** support.
2. **Difficulty compiling** and **submitting** required documentation.
3. Renewal packets getting buried at home, leading to **missed deadlines**.
4. **Insufficient language access** created barriers to renewal.
5. Experiences with **discrimination**.
6. **Challenges** transferring coverage when moving between counties.
7. **Lack of awareness** of Medi-Cal eligibility for children, particularly in mixed-status households.
“I get stressed out because I wonder what are they going to ask me for now? And if I fill it out wrong …”

“I get more complicated to enroll every day. They have more requirements every day. It has taken such a long time! I’ve had to pay for it with my time — missing work to be on the phone and such …”

“What is most confusing to me is that they ask you about your bank accounts, your checking account … cash … What if some days I do and then others I don’t? And that’s where you find yourself stuck with a problem, and not knowing what to write down.”

SPANISH-SPEAKING FEMALE PARENT/GUARDIAN, LOS ANGELES

SPANISH-SPEAKING MALE PARENT/GUARDIAN, SAN BERNARDINO

SPANISH-SPEAKING MIXTEC FEMALE PARENT/GUARDIAN, OXNARD
Hurdle 1: Inadequate support

- Parents expressed frustration about being unable to get their questions answered despite making multiple attempts to do so via phone, email and in person.
- Parents endured long call wait times — often 2 hours wait — to get help navigating complex and confusing requirements, materials and questions.
- Calls were often not returned even after leaving multiple voicemails; emails were not returned.
- While families frequently received reminders to return required documents in the mail, no one was available to answer their questions or provide clarification.
- Medi-Cal staff were seen as unhelpful and difficult to reach, did not know the answers to parents’ questions, were often in a bad mood, and lacked compassion or the desire to help.
“[…] You call them three times, and they answer you with three different answers for the same issue. It just feels like that they don’t know what they are talking about.”

“[…] it’s just complicated to me, and they don’t even communicate well, and when you call them, they don’t answer. When you email them, they don’t reply.”

“[When calling the county] it was solved. They said we were indeed eligible. They might have made a mistake. That’s it.”

“They [Medi-Cal] just tell you to fill out a form, finish the process … they don’t really give you any extra information on any additional services.”

CHINESE-SPEAKING MALE PARENT/GUARDIAN, LOS ANGELES

CHINESE-SPEAKING FEMALE PARENT/GUARDIAN, LOS ANGELES

CHINESE-SPEAKING FEMALE PARENT/GUARDIAN, SAN FRANCISCO

SPANISH-SPEAKING MALE PARENT/GUARDIAN, SAN BERNARDINO
Hurdle 2: Finding required documentation

- A big hurdle or pain for families while renewing was finding the documentation required and submitting it successfully.
- It was not always clear what documentation is needed until after they were disenrolled.
- Several found the process for submitting documents online fast and easy but some did not know about the online option and thought documents needed to be faxed or mailed.

“When we enroll, they didn’t tell us what we need ... And we disenrolled and they asked us to sign some affidavit form, and then there was a one-to-two-month gap.”

CHINESE SPEAKING FEMALE PARENT/GUARDIAN, LA

“.... Providing them with the supporting documents. I think the real work comes in when you have to gather your documents as opposed to on their [county] end ...”

NATIVE AMERICAN/INDIGENOUS FEMALE PARENT/GUARDIAN
Families often get so much paperwork that it is hard to tell what needs a response.

When they do know they need to respond, they put it aside to do but forget.

Parents say the best way to reach them with information about potential changes to Medi-Cal would be through digital means rather than by physical mail. They say text, email or through an official app would be best.

Families ask for Medi-Cal to use multiple communication avenues to inform families before coverage is taken away rather than relying on written notices that get lost or go unread.
“I’ve missed the deadline. Because you get the packet and say, ‘I’ll do it in just a little bit.’ And then it gets hidden and you can’t remember.”

SPANISH-SPEAKING PARENT/GUARDIAN, FRESNO

“Sometimes things get misplaced, or you’re so busy and you forget to send something off, or you think you send it … then I have 30 days before your Medi-Cal expires, and I’m like, wait a minute, what did I not do?”

FEMALE PARENT/GUARDIAN OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS, FRESNO
Hurdle 4: Insufficient language access

- The quality of interpretative equipment and interpreters is not sufficient.
- Translators did not always speak a language fluently and often relayed incorrect translations.
- Parents faced long wait times to get interpretation services over the phone and many times interpreted instructions on phone/in-person varied from written guidance.
  - Particularly difficult for Mixtec parents who do not speak English or Spanish.
“When you apply [in the Medi-Cal office] the worker speaks Mandarin. Later, when I have some problem, when I make phone calls there’s nobody to answer me in my language.”

“[Identifying challenges at renewal]: For my family members that don’t speak English well, [language is] always a problem … Always.”

“Always.”

“It’s a little difficult to fill out the application by yourself, especially if you don’t understand English very well.”

CHINESE-SPEAKING FEMALE PARENT/GUARDIAN, LOS ANGELES

SPANISH-SPEAKING PARENT/GUARDIAN, FRESNO

ENGLISH-SPEAKING LATINE PARENT/GUARDIAN, FRESNO
Hurdle 5: Parents experienced discrimination when applying for or renewing coverage

- **Discrimination** was predominately mentioned by Spanish-speaking Latino parents, Mixteco parents and Chinese parents.

- Parents felt they were denied coverage when *judged based on their appearance and possessions*.

  "They never find anybody who speaks Spanish. Yes, you feel discriminated, that’s the truth. They make you feel like you’re less than, and they make you feel like you have to wait for them to have time for you."

  - SPANISH-SPEAKING LATINA PARENT/GUARDIAN, LOS ANGELES

  "... He told me that I was a burden to society. I told him no, I’m not, because we pay taxes, and I said in the long run my husband is working on getting my paperwork. I’m going to be legal here."

  - SPANISH-SPEAKING LATINA PARENT/GUARDIAN, LOS ANGELES
Hurdle 6: Challenges transferring coverage between counties

Moving from one county to another:

• Does **not require re-applying** for Medi-Cal.
• Transferring coverage to a new county **should not result in coverage gaps**, and yet ....

Several parents experienced gaps in Medi-Cal coverage when trying to transfer their coverage to a new county — some up to six months.

Some had to go to the county office to re-apply after they moved.
“They told me it would just go straight over from San Joaquin to Fresno, but it didn’t. I still had to come here and talk to a worker and get it back — so I had to fill out the papers again.”

FEMALE PARENT/GUARDIAN OF COLOR OF CHILD WITH SPECIAL HEALTH CARE NEEDS, FRESNO

“They told me it [Medi-Cal county transfer] would take a month. That’s when my son got sick and I was ... really concerned, because he’s had pneumonia twice.”

SPANISH-SPEAKING PARENT/GUARDIAN, FRESNO
Some families assumed their undocumented immigrant children and other family members do not qualify for Medi-Cal.

Many thought their entire family no longer qualified with modest income increases when in fact their children would still qualify due to children’s higher income eligibility levels compared to adults.

Few knew they could get their coverage reinstated even if the renewal deadline is missed by 90 days.

“Medi-Cal doesn’t cover my children if they have no documents.”

SPANISH-SPEAKING MIXTEC PARENT/GUARDIAN, OXNARD
“There’s four of us; the limit is $48,000. **If we make more than $48,000 then we don’t qualify.**”

*children actually qualify up to $79,800*

“*children actually qualify up to $79,800*

“**We thought that once they cut it off, you have to start from zero. You have to start over, all over, starting all the renewal process, everything, a new case.**”

“I didn’t know about the 90 days [for reinstatement]. A social worker told me that if you don’t renew it before the deadline, then it’s over. And another one told me you have 30 days until next month.”

**SPANISH-SPEAKING LATINE PARENT/GUARDIAN, LA**

**SPANISH-SPEAKING LATINE PARENT/GUARDIAN, LA**

**SPANISH-SPEAKING FEMALE PARENT/GUARDIAN, SAN BERNARDINO**
Recommendations: Make process work for families, not just the system

Recommendation 1:
Implement CA’s continuous Medi-Cal coverage for children

- Access to stable coverage is a fundamental health equity strategy.
- Continuity of coverage protects healthy childhood development. Even small gaps in coverage impact early detection and intervention.

Action Needed: Governor’s January budget to greenlight and fund implementation of multi-year continuous coverage for young children.

“... I feel that they shouldn’t do it [renewals] every year, maybe every two years ... time goes by very fast and sometimes we don’t have time.”

SPANISH-SPEAKING LATINO PARENT/GUARDIAN, LOS ANGELES
The Public Health Emergency (PHE) continuous coverage provision is an example of a successful equity strategy. The provision protected coverage and reduced the uninsured rate.

Recommendation #1 (continued)

Continuous coverage protections work!

The federal Continuous Medicaid Coverage Protection during PHE successfully increased stable coverage and reduced the uninsured rate for children.

From 2019 to 2022 the uninsured rate dropped from 3.6% to 3.2%

From 2019 to 2022 the churn rate dropped over 6.5% points.
Recommendations: Make process work for families, not just the system

2. Prioritize coverage over process
CA must pause procedural disenrollments to meaningfully address acute barriers to coverage facing families such as staffing shortages and long call wait times.

3. Keep kids covered
Deploy child-specific outreach and education strategies including distinct eligibility messages for children compared to adults.

4. Streamline renewals beyond this unwinding period
Make unwinding flexibilities permanent such as self attestation on renewal forms and ex parte reviews for those with $0 or stable income or below poverty.