



Don't Lose Your
Medicaid Coverage

The Stay Covered! Project

Engaging Family to Family Health Information Centers (F2Fs) to Support Families Navigating the End of the Public Health Emergency

Public Health Emergency Unwinding: Understanding the Impact on Families

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Project Overview

Family Voices was awarded funding from the Lucile Packard Foundation and Maternal Child Health Bureau (MCHB) to help families understand and address issues related to the unwinding of the Public Health Emergency.

Many families of medically complex children are impacted by the Medicaid unwinding. Family Voices will work with the F2F/AOs, Manatt and other partners to reach out to families from the national network to support understanding the process and changes.

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Where We Started: Medicaid and the Public Health Emergency Unwinding

The Public Health Emergency



March 2020

COVID-19 Public Health Emergency

- Families First Coronavirus Response Act (FFCRA)
- Medicaid Continuous Enrollment

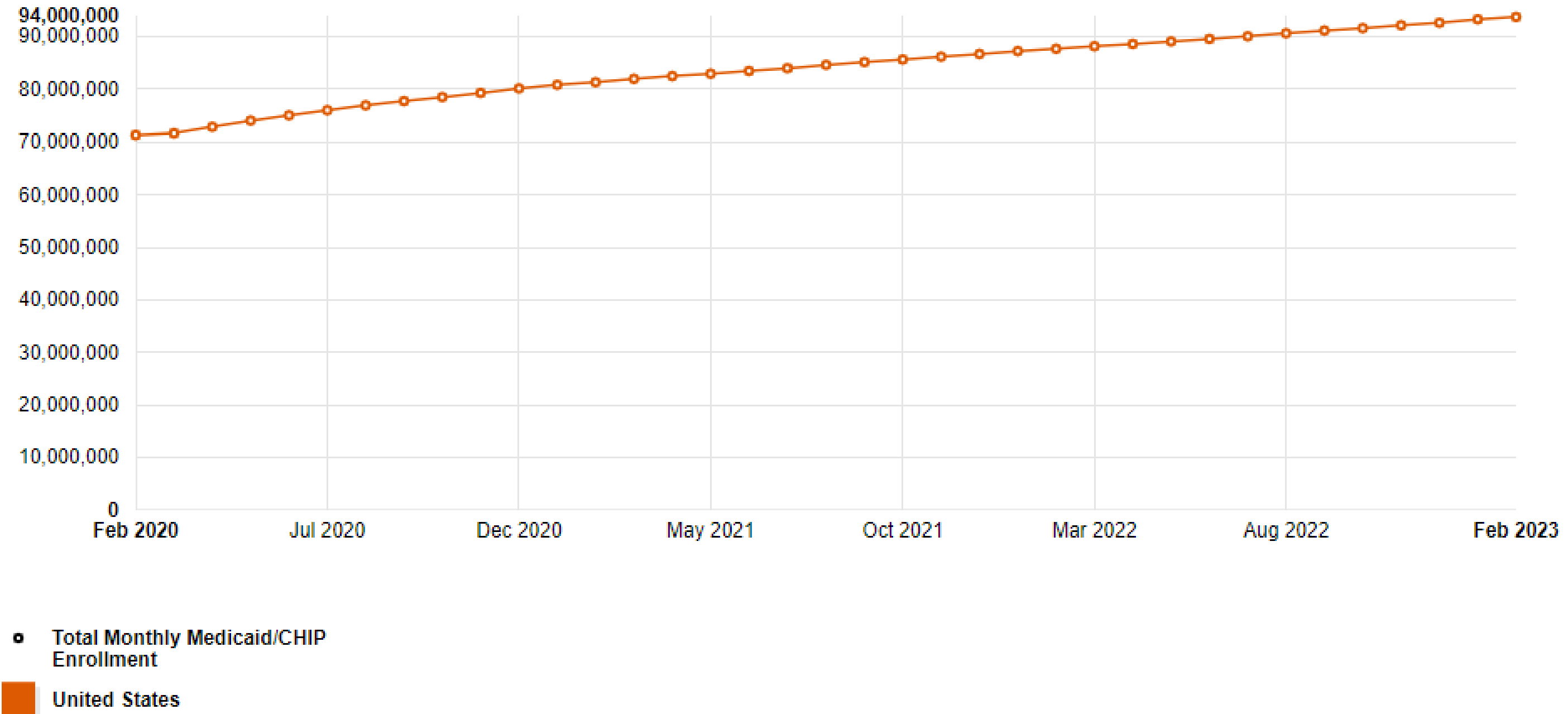
December 2022

Consolidated Appropriations Act, 2023

- End of Medicaid Continuous Enrollment effective March 31, 2023
- States given 12 months to return to normal eligibility and enrollment



Total Monthly Medicaid and CHIP Enrollment



Source: Kaiser Family Foundation <https://kff.org>

Disenrollments



Between April 1, 2023, and November 8, 2023

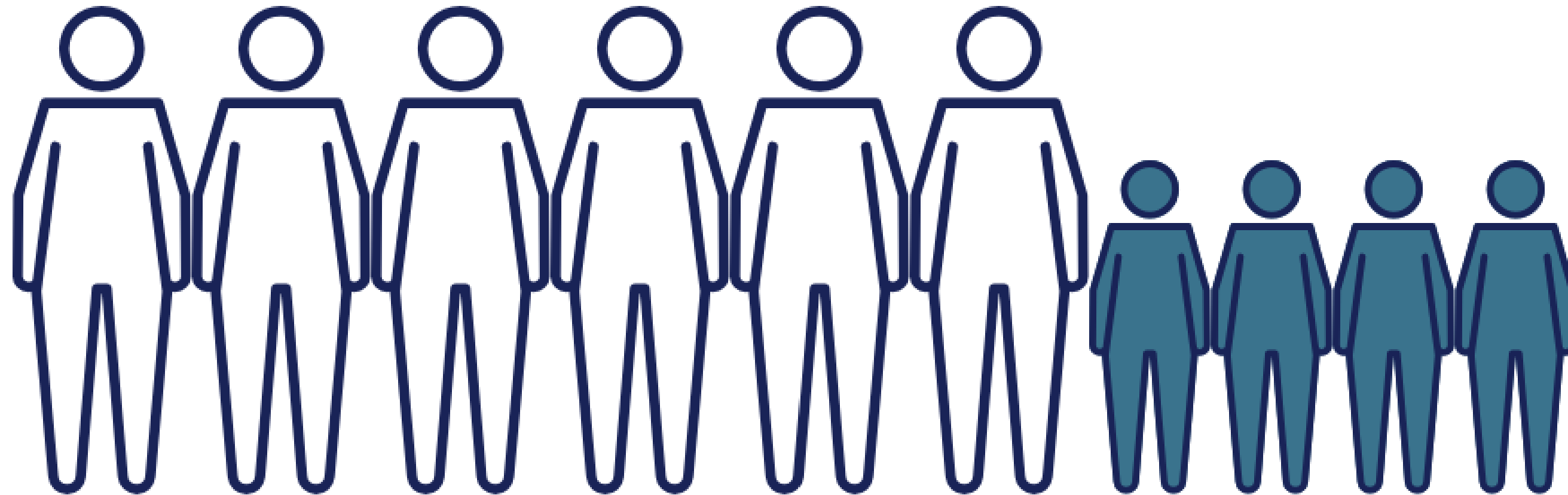
10,135,000

people had been disenrolled from Medicaid.

Disenrollments



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38% of disenrollments were children*

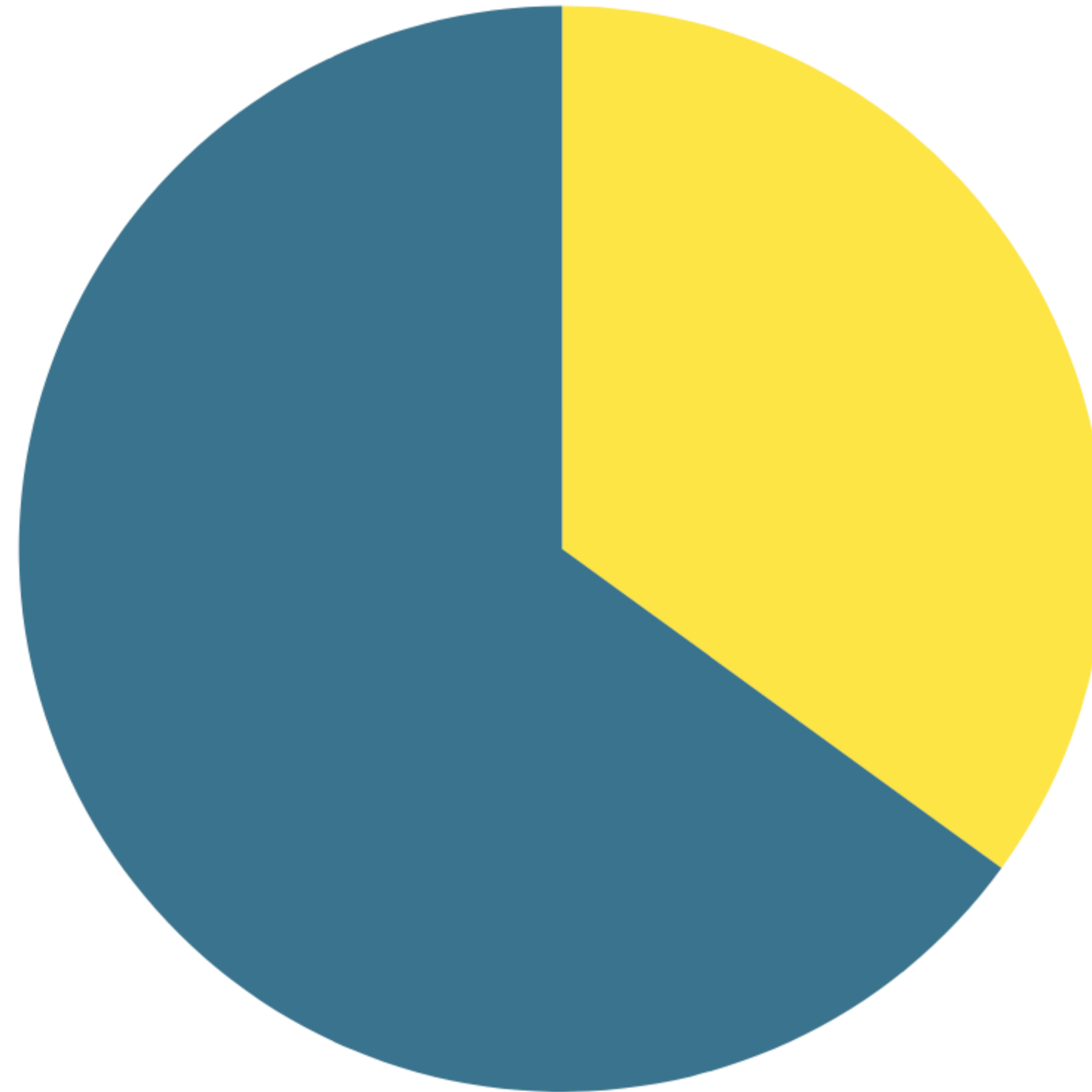
*Only 21 states are reporting on the age demographics of those being disenrolled.

Source: Kaiser Family Foundation <https://kff.org>



Disenrollments

■ Disenrolled ■ Renewed



At that point, **35%** of those who had completed the process were disenrolled.



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Source: Kaiser Family Foundation <https://kff.org>



Eligibility for Medicaid

- Income
- Disability
- Qualified Pregnant Women and Children
- Home and Community Based Services
- Foster Care
- TEFRA Medicaid Disability Option
 - Katie Beckett Program



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The Challenges

The Challenges

- Three years' worth of renewals in one year
- Outdated systems
- Families moved without notifying of the change in address
- Understaffed agencies
- Different rules and programs from state to state and in some cases county by county
- In many places, a lack of situational awareness delayed planning



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How it was going...



- 71% of terminations in July were for procedural reasons
- 25% of cases due for renewal by the end of July were still pending at the end of the month
- Average ex-parte renewal rate was 31%
- As of 9/20/23, CMS had approved 319 waivers for 49 states and the District of Columbia.

Impact on Families



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- Whole families lost coverage entirely.
- Some members of a family lost coverage while others in the same family did not.
- Variations between states caused confusion.
- Availability of programs for CYSHCN can be drastically different, even within the same state, adding to the confusion.
- Lost coverage meant impact to services.
- Lost coverage often came as a surprise.



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The All Hands on Deck Approach: Leveraging the Network

Family-to-Family Health Information Centers

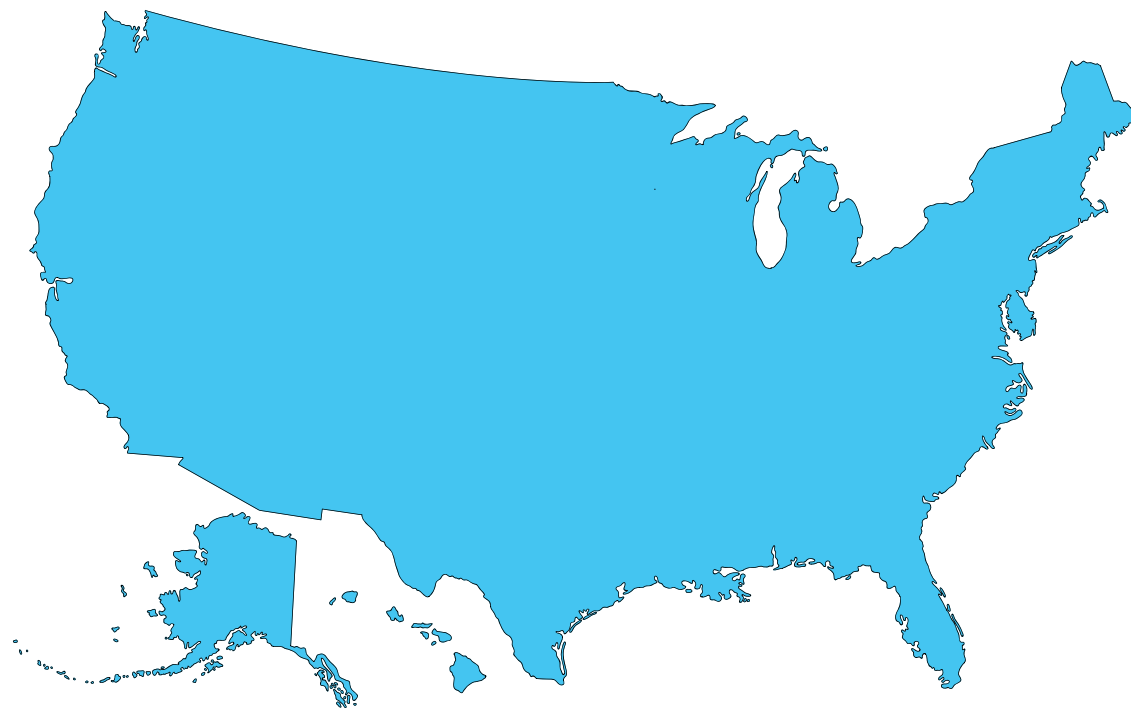


- Family-to-Family Health Information Centers (F2Fs) are family-led organizations that support families of children and youth with special health care needs (CYSHCN).
- Family Voices provides technical assistance to the F2Fs through the Family Engagement and Leadership in Systems of Care grant, funded through 2028 through the Health Resources and Services Administration (HRSA) Maternal Child Health Bureau.

Family-to-Family Health Information Centers



The Maternal and Child Health Bureau (MCHB) funds F2Fs in every state, the District of Columbia, five US territories, and three F2Fs serving American Indians and Alaska Natives.



For a directory of all F2F and Family Voices Affiliate Organizations (FVAO) visit:
<https://familyvoices.org/felsc/whataref2fs/>



Family-to-Family Health Information Centers



Each F2F is staffed by highly skilled, knowledgeable families with first-hand experience of the challenges faced by CYSHCN and their families. These uniquely qualified staff provide critical support to families caring for CYSHCN, particularly families of children with complex needs and those from underserved communities.

F2Fs also help healthcare providers, state and federal agencies, and legislators understand and respond to the needs of CYSHCN and their families.

All Hands on Deck



With funding from MCHB, Family Voices launched the Stay Covered! project as an all hands on deck approach to focus resources in areas of need and support F2Fs as they worked through the challenges unique to their particular communities.

Strategies for Unwinding: Children and Families



- Reach children and families who are particularly vulnerable:
 - Parents of enrolled children ages 3 and under may have never had to complete a Medicaid renewal for their child
 - Immigrant families may need extra support; children in immigrant or mixed-status families and whose families may not speak or read English are at particular risk of losing coverage.
 - Although some children with disabilities may receive supplemental social security income (SSI) and be categorically eligible for Medicaid, many are not and may not be ex parte renewed, potentially leaving a large number of CYSHN and CMC vulnerable to losing coverage.

Strategies for Unwinding: Community Partners



- Every youth or family depends on trusted messengers to help answer their questions - we needed to make sure that the messengers had the answers about Medicaid and CHIP.
- Families need hands-on help getting through “the last mile” to complete and submit their renewals; states should make sure that there are “last mile” helpers in the community, in schools, and at providers’ offices.
- Youth depend on peers for answers—use trained peers whenever possible in settings where adolescents and young adults gather.

Strategies for Unwinding: Special Populations



- Families with children three and under have never had to complete a redetermination for their child; throughout their child's life, they have been told to ignore the paperwork and they can still maintain their coverage.
- Every pediatrician and family medicine MD needed to know that the unwinding has started; [AAP/GCCF state-specific toolkit](#) includes patient-facing flyers for primary care offices.
- WIC, Head Start, Home Visitors, Early Intervention providers, childcare providers, and others have access to support young families.

Strategies for Unwinding: Special Populations



- Families with children with special health needs (CYSHN) often depend on Medicaid and CHIP daily for life-sustaining treatment.
 - Parents benefit from peer support; Family to Family and other family support organizations should be involved to help with redeterminations.

Strategies for Unwinding: Special Populations



- Transition-age youth (ages 19+) were at particular risk of losing coverage if they aged out of children's Medicaid or CHIP or reached an age that could affect their Medicaid eligibility.
 - This should be considered a change in circumstances for which states need to reevaluate the child's Medicaid eligibility.
 - State Medicaid Agencies needed to partner with other transition age youth-serving agencies and community partners to reach transition-age youth and support them to maintain coverage.



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Assessing the Needs

The Needs Assessment



Conducted by Family Voices project staff in September-October 2023 to understand the needs of families of children and youth with special health care needs (CYSHCN) regarding Medicaid Unwinding and the needs of organizations that deliver services to these families

The needs assessment included a brief survey and one listening session with representatives of Family-to-Family Health Information Centers (F2Fs) and [Family Voices Affiliate Organizations \(FVAOs\)](#). Surveys were distributed to the network via direct email, Google groups and the Flash newsletter.

Needs Assessment Survey Participants



38 individuals submitted a Needs Assessment survey representing **35 organizations** across **33 states** and **territories**

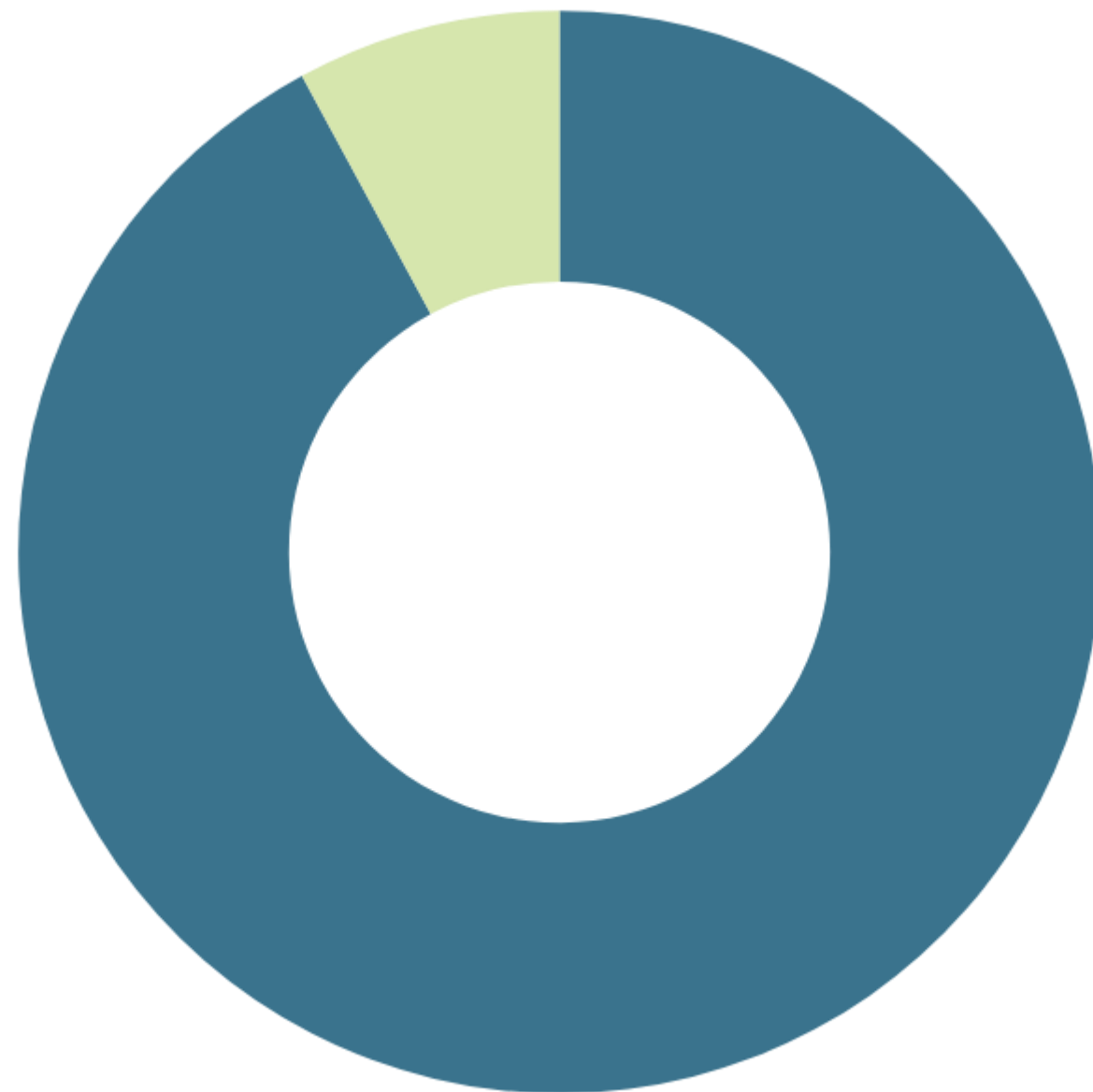


53% of participants represented organizations that are F2Fs only and **47%** represented organizations that serve as both F2Fs and FVAOs or FVAOs only.

Needs Assessment Survey Participants



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92% of participants reported that their organization is **working with families** on the Public Health Emergency (PHE) **unwinding for Medicaid**

Challenges Reported by Participants



Over 60% of Needs Assessment participants reported that families **don't understand the process** and **don't know what to do** about Medicaid redetermination and renewal with specific concerns that included:

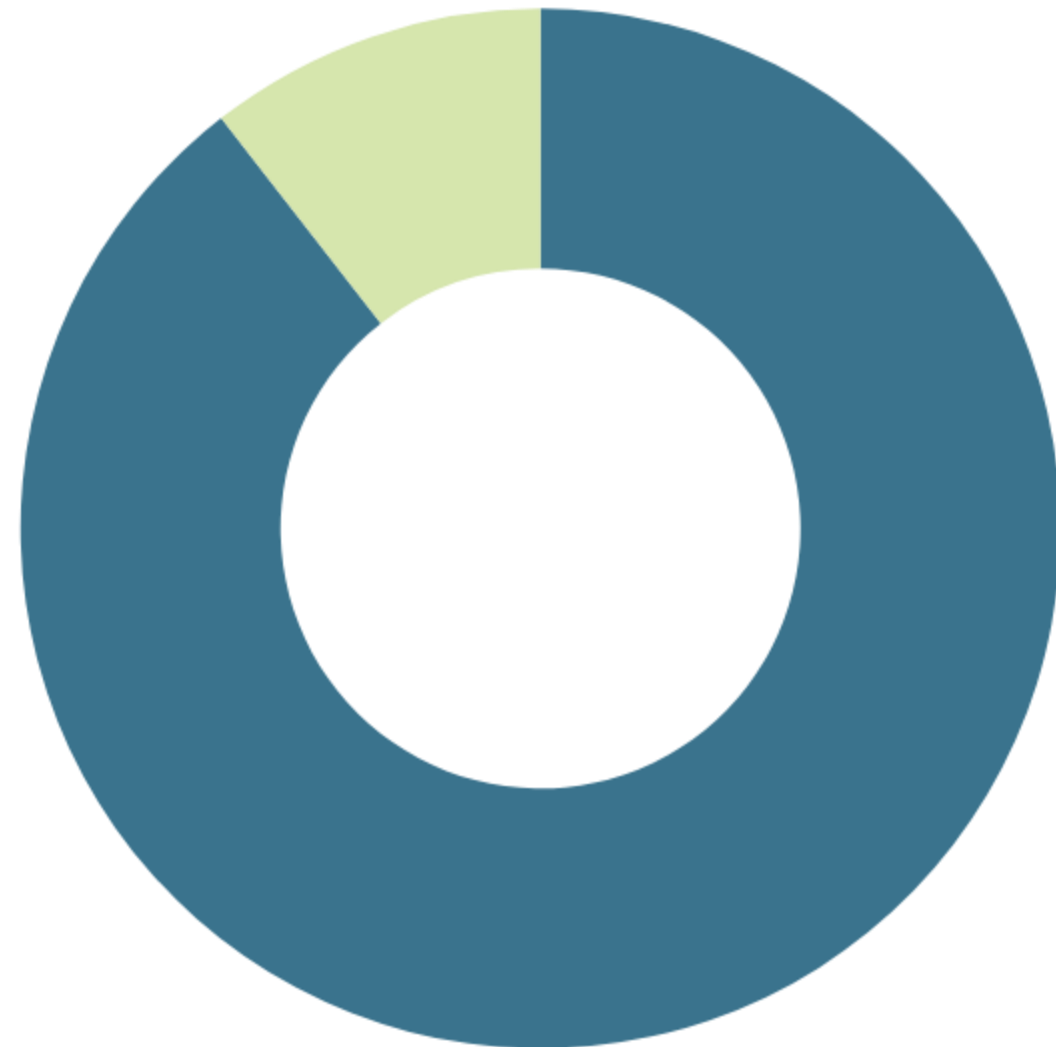
- Wrongful termination or denial
- Approval or renewal challenges
- Confusion about waivers
- Discontinued Medicaid for children with special needs
- Not having internet access
- Over income, needing coverage

Nearly 30% reported language accommodations are an issue

Survey Results



Participant Responses: “Would informational resources about the Medicaid renewal process help reach out to families in your community?”



Nearly **90% of** participants reported that **informational resources** about the Medicaid renewal process would **help outreach** to families in their communities

Survey Results

Participant-Requested Tools to Support Families



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Tip sheets
79%



Infographics
66%



Social media
posts
50%



Assistance
completing
application
26%



Webinars
24%



None of these
13%

Survey Results



Additional Comments – Select Responses Theme: Challenges Faced by Families

- Our biggest struggle is the systems not working as they are "supposed to" so even when families follow the correct steps, they are receiving denials.
- Our state is not processing applications correctly, people are losing Medicaid because of errors in processing the applications, families are struggling to find help to get the errors fixed and continue Medicaid coverage.
- For us the biggest problem has been our families on the waiver who have been discontinued and it takes forever to get them reinstated.
- We still have families throwing away the renewal letters.

Survey Results



Additional Comments – Select Responses Theme: Challenges Faced by Families

- Having materials in both Spanish and English would be helpful.
- Any additional languages beyond Spanish are helpful.
- Our state is moving away from paper/letters to paperless system. Many in our state would benefit from a phone app instead of a website because they don't have computers, printers, other forms of internet service.

Recommended Next Steps



1. Focus program efforts on disseminating information and resources on topics including CHIP, waivers, and the application process.
2. Ensure information and resources are available in the languages families need.
3. Consider strategies to engage more directly with families of CYSHCN when planning efforts to address Medicaid Unwinding.



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The Stay Covered! Project

The Approach

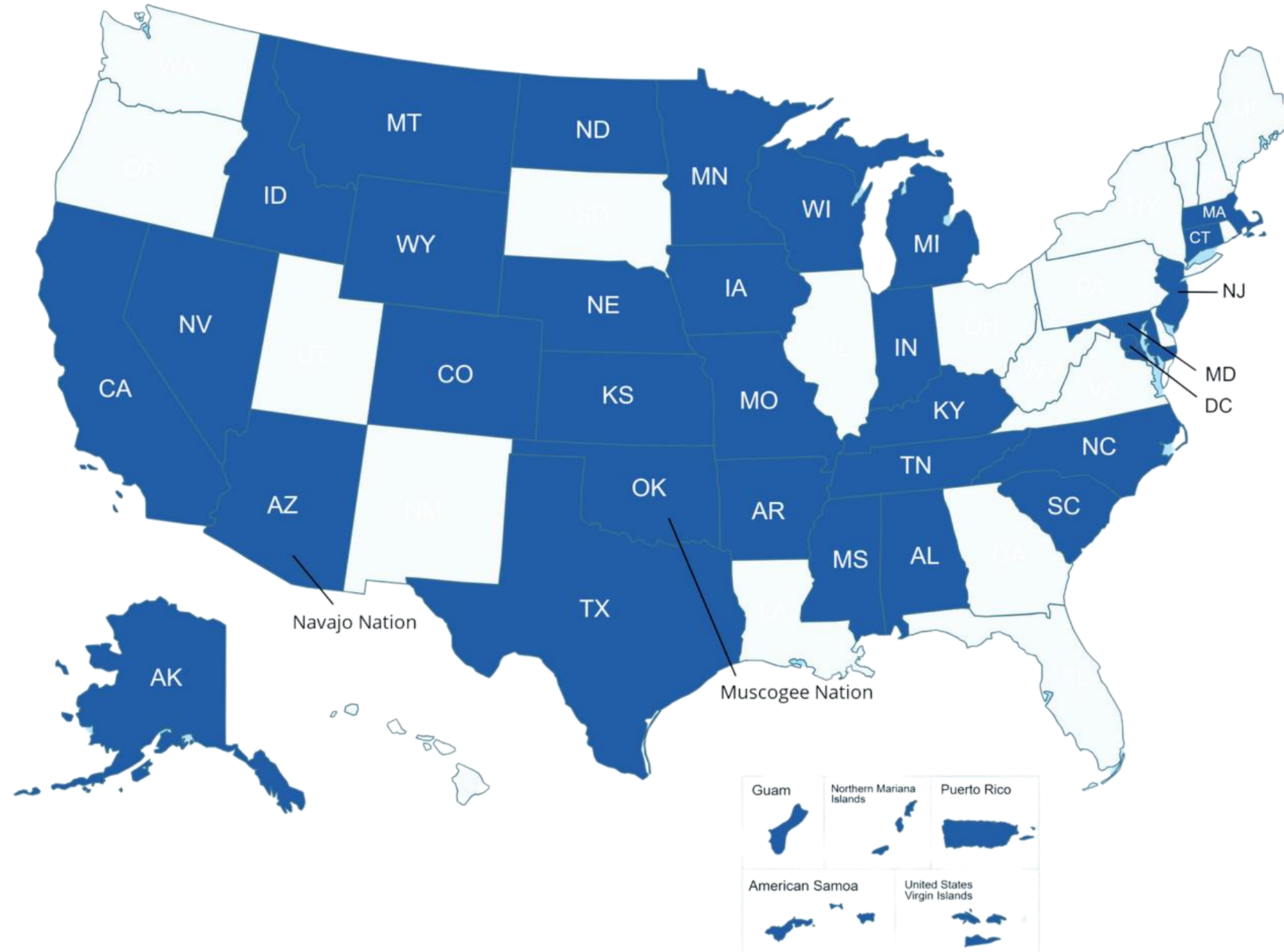


- Mini-grant funding to support staff in the F2Fs
- Stay Covered Academy
 - Webinars
 - Training Curriculum with Facilitation Guides
- Social Media Toolkits including State Specific Pieces
- Tip Sheets
- Materials in English, Spanish, Arabic, Mandarin, Vietnamese

Mini-Grants



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Stay Covered Academy

Stay Covered! Academy



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Module 1

Public Health Emergency
Unwinding: Understanding
the Impact on Families.



Module 2

I've Lost Coverage, Now
What?



Module 3

Navigating Redetermination
with Special Populations



Social Media Toolkits

Keep your Medicaid coverage



Don't Lose Your Medicaid Coverage

A graphic for a social media toolkit. It features two circular images: one of a woman hugging a child, and another of two children on a swing set. In the center is the 'stay covered!' logo with the tagline 'Don't Lose Your Medicaid Coverage'. Below the images is the text 'Keep your Medicaid coverage' and 'Complete your Medicaid Renewal forms and send them back right away so you don't lose coverage.' At the bottom left is the 'FAMILY VOICES' logo with a red heart, and at the bottom right is the URL 'familyvoices.org/unwinding'.

Keep your Medicaid coverage

Complete your Medicaid Renewal forms and send them back right away so you don't lose coverage.

FAMILY VOICES[®] familyvoices.org/unwinding

Download

Click the link below to download this resource in English, Spanish, Arabic, Mandarin Chinese, and Vietnamese.

[Keep your Medicaid coverage](#) 



Tip Sheets



Don't Lose Your Medicaid Coverage

We lost Medicaid coverage. Now what?

2-page fact sheet



We lost Medicaid coverage. Now what?

During the COVID-19 pandemic, children and families with Medicaid could keep their coverage without having a review to see if they were still eligible. Now that the public health emergency is over, most people who have Medicaid need to go through redetermination, the process to see if you are still eligible for Medicaid.

Millions of families have lost their Medicaid coverage in the Medicaid redetermination process, which puts children at risk of having gaps in their medical care. It's important to understand the redetermination process and what to do if you no longer qualify for Medicaid.

Why did we lose our Medicaid coverage?

You can lose Medicaid for a few different reasons:

- Filing paperwork incorrectly or missing renewal notices in the mail is the main reason families lose Medicaid coverage.
- Your family's income may be too high now to qualify for Medicaid. However, there are different income eligibility levels for adults and kids, so your child may still be eligible even if you aren't.
- Your child may have aged out of the Medicaid program. In most states, children are no longer eligible for Medicaid once they turn 19.

Where should I go for more information and help with the redetermination process?

The following resources can provide assistance to you and your family:

- Family-to-Family Health Information Centers (FFHCs) (national)
- Insurance Skills Matter (national)
- The Health Insurance Marketplace: Find Local Help (national)
- CMS Health Insurance Navigator program (in 29 states)

Medicaid redetermination is the process your state uses to see if you still qualify for Medicaid coverage. Everyone with Medicaid is now required to go through redetermination. Medicaid redetermination is also called Medicaid re-enrollment and Medicaid renewal.





What options do we have?

- 1 Request that your coverage be reinstated.** If you lose Medicaid coverage or if you think it was a mistake, you can ask for your coverage to be reinstated. You usually have 90 days from the date posted on the notice from your state Medicaid agency to send all the information they need to decide if your coverage should be reinstated.
- 2 File an appeal.** Everyone has a right to appeal a Medicaid decision. Each state decides how much time a person has to ask for an appeal. If your family missed the deadline to appeal, you might be able to ask for more time with an extension.

Check your state's Medicaid website for information. You can ask for an appeal online, in person, or by mail. Be sure to keep track of the date you ask for the appeal.

If your child has complex medical needs - including children on Medicaid waivers - their health may be in danger with a long appeal process. You can ask for an appeal hearing that happens sooner. This is called an expedited hearing.

The appeals process can be complicated, but you can get help. See information about finding help on the other side of this sheet.
- 3 Enroll for Medicaid.** If you have lost coverage, you can reapply for Medicaid at any time. Help is available if you need it. (See information about finding help on the other side of this sheet.)
- 4 Enroll in a low-cost health insurance plan.** You may qualify for a high-quality, low-cost plan through the Health Insurance Marketplace (HHS) www.healthcare.gov to get coverage that begins the first of next month. Your child can stay on your Marketplace coverage until age 26.

Can my child get coverage through the Children's Health Insurance Program (CHIP)?

CHIP provides low-cost health coverage to children in families with incomes too high to qualify for Medicaid and who are otherwise uninsured. Some states combine Medicaid and CHIP into a single program. In other states, CHIP is a separate program. If your child no longer qualifies for Medicaid, make sure to ask your Medicaid agency if CHIP is an alternative. More information on CHIP can be found at www.hhs.gov.

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Language Access



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¿Ha perdido su hijo los beneficios de Medicaid o CHIP?

Comencemos aquí:

- 1 Comuníquese con la agencia estatal de Medicaid o con su plan de salud para **actualizar su dirección, número de teléfono y dirección de correo electrónico**. Puede hacerlo por teléfono o en el sitio web de Medicaid de su estado.
- 2 Comuníquese con la agencia estatal de Medicaid o con su plan de salud para **conocer la cobertura de su hijo**.
Si no recibió una carta sobre la finalización de la cobertura de su hijo, **pidales que le envíen una carta**.
Si recibió una carta que dice que los beneficios de Medicaid o CHIP de su hijo están por terminar, verifique si hay un **formulario de renovación** que pueda enviar para conservar los beneficios de su hijo y asegúrese de enviarlo **antes de la fecha límite**.
- 3 Encuentre **otras opciones de seguro médico** si su hijo ya no califica para Medicaid o CHIP.
La mayoría de las personas califican para ahorrar dinero en un plan de salud a través del Health Insurance Marketplace®.
La cantidad que puede ahorrar es determinada por los ingresos de su hogar y la cantidad de personas que viven en su hogar.
Todos los planes disponibles en el Mercado de Seguro de Salud, cubren beneficios, tales como medicamentos recetados, visitas al médico, servicios de urgencia, visitas al hospital y más.
Obtenga más información en familyvoices.org/spanish

Mantente Cubierto!
No pierdas la cobertura de Medicaid

هل فقد طفلك مزايا إشتراكه في برنامج ميديكيد أو برنامج التأمين الصحي للأطفال (CHIP) ابداً من هنا:

- 1 اتصل بوكالة ميديكيد في ولايتك أو بخطتك الصحية لتحديث **عنوانك ورقم هاتفك وعنوان بريدك الإلكتروني**. يمكنك القيام بذلك عبر الهاتف أو على موقع ميديكيد الخاص بولايتك.
- 2 اتصل بوكالة ميديكيد في ولايتك أو بخطتك الصحية لمعرفة المزيد عن **التغطية التأمينية الخاصة بطفلك**.
إذا لم تثنق خطابًا بخصوص انتهاء التغطية التأمينية الخاصة بطفلك، **اطلب منهم إرسال خطاب**.
إذا تلقيت خطابًا يفيد بانتهاء مزايا ميديكيد أو برنامج التأمين الصحي للأطفال (CHIP) الخاصة بطفلك، تحقق ما إذا كان هناك **نموذج تجديد** يمكنك إرساله مرة أخرى للاحتفاظ بمزايا التأمين الخاص بطفلك - وتأكد من إرساله **قبل حلول الموعد النهائي** لاستلام المزايا.
- 3 ابحث عن **خيارات التأمين الصحي الأخرى** إذا لم يعد طفلك مؤهلاً للاستفادة من تغطية ميديكيد أو برنامج التأمين الصحي للأطفال (CHIP).
معظم الناس مؤهلون لتوفير المال عن طريق الاشتراك بخطة تغطية صحية عن طريق Health Insurance Marketplace®.
يعتمد المبلغ الذي يمكنك توفيره على دخل أسرته وعدد الأشخاص فيها.
تغطي جميع خطط Marketplace العديد من الجوانب، مثل الأدوية الموصوفة، زيارات الطبيب، والرعاية العاجلة وزيارات المستشفى وغيرها.
تريد المزيد من المعلومات، يرجى زيارة familyvoices.org/spanish

حافظ على تأمينك الصحي!
لا تخسر أبداً تغطيتك التأمينية من ميديكيد

您的孩子是否失去了 Medicaid 或 CHIP 福利？

从这里开始：

- 1 请联系您所在州的医疗补助机构或您的健康保险公司已更新您的地址，电话号码和电子邮件。您可以通过电话联系所在州的补助机构或是上网进行修改。
- 2 请联系您所在州的医疗补助机构或您的健康保险公司去了解您孩子的承保范围。
如果您没有收到有关您孩子承保终止的信息，**请要求医疗补助机构寄一封信告知该消息**。
如果您收到一封信，告知您孩子的 Medicaid 或 CHIP 福利即将结束，**请检查是否有续保表格**可以寄回以保留孩子的福利，**请确保表格在截止日期之前寄回**。
如果您的孩子不再符合 Medicaid 或 CHIP 的条件，**请寻找其他健康保险**。
大多数的人符合通过健康保险市场来节省健康保险费用。
- 3 您节省多少钱取决于您的家庭收入和家庭成员数。
所有市场健康保险都涵盖处方药，医生看诊，紧急护理中心，医院就医等。
了解更多信息，请访问 familyvoices.org/spanish

保持受保!
不要失去您的医疗补助计划保险 (Medicaid)

Con của quý vi có bị mất phúc lợi Medicaid hoặc CHIP không?

Quý vị có thể bắt đầu tìm hiểu tại đây:

- 1 Liên hệ với cơ quan Medicaid của tiểu bang hoặc chương trình chăm sóc sức khỏe của quý vị để **cập nhật địa chỉ, số điện thoại, và địa chỉ email của quý vị**. Quý vị có thể thực hiện việc cập nhật này qua điện thoại hoặc trên trang web chương trình Medicaid của tiểu bang của quý vị đang sinh sống.
- 2 Liên hệ với cơ quan Medicaid của tiểu bang hoặc chương trình chăm sóc sức khỏe của quý vị để **tìm hiểu về phạm vi bảo hiểm của con quý vị**.
Nếu quý vị không nhận được thư thông báo về việc kết thúc bảo hiểm của con quý vị, **vui lòng yêu cầu họ gửi thư**.
Nếu quý vị có thể nộp lại để duy trì quyền lợi của con quý vị hay không, và quý vị cần lưu ý nộp đơn **trước ngày hết hạn**.
- 3 Tìm kiếm các **lựa chọn bảo hiểm y tế khác** nếu con quý vị không còn đủ điều kiện nhận Medicaid hoặc CHIP nữa.
Hầu hết mọi người đều đủ tiêu chuẩn tham gia tiết kiệm các chi phí liên quan đến bảo hiểm y tế thông qua dịch vụ Thị Trường Bảo Hiểm Sức Khỏe® (Health Insurance Marketplace®).
Số tiền quý vị có thể tiết kiệm được phụ thuộc vào tổng thu nhập và tổng số thành viên trong gia đình của quý vị.
Tất cả các chương trình bảo hiểm cung cấp qua Health Insurance Marketplace đều chi trả các chi phí chăm sóc sức khỏe, như thuốc kê toa, thăm khám bác sĩ, dịch vụ chăm sóc khẩn cấp, thăm khám trong bệnh viện, và nhiều dịch vụ khác.
Để biết thêm thông tin, vui lòng truy cập familyvoices.org/spanish

Giữ vững quyền lợi của bạn!
Đừng Mất Quyền Lợi Medicaid của Bạn





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From the F2F Perspective

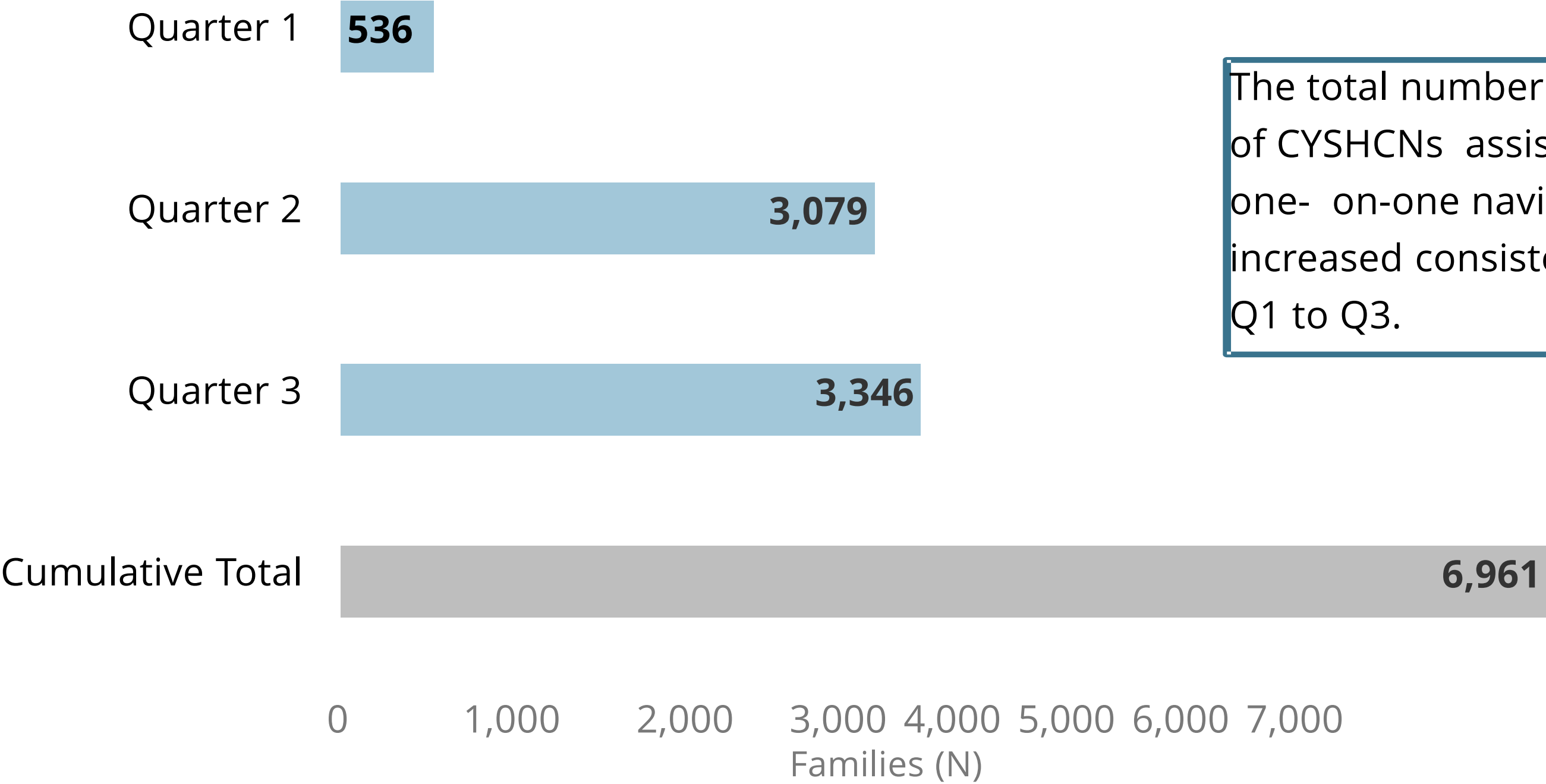
Octavia Guthrie
Parents' Place of Maryland



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The Impact

Total Number of Families of Children and Youth with Special Health Care Needs (CYSHCNs) Assisted Through One-on-One Navigation Services to Navigate the Public Health Emergency Unwinding and Related Medicaid Redetermination Process by Quarter



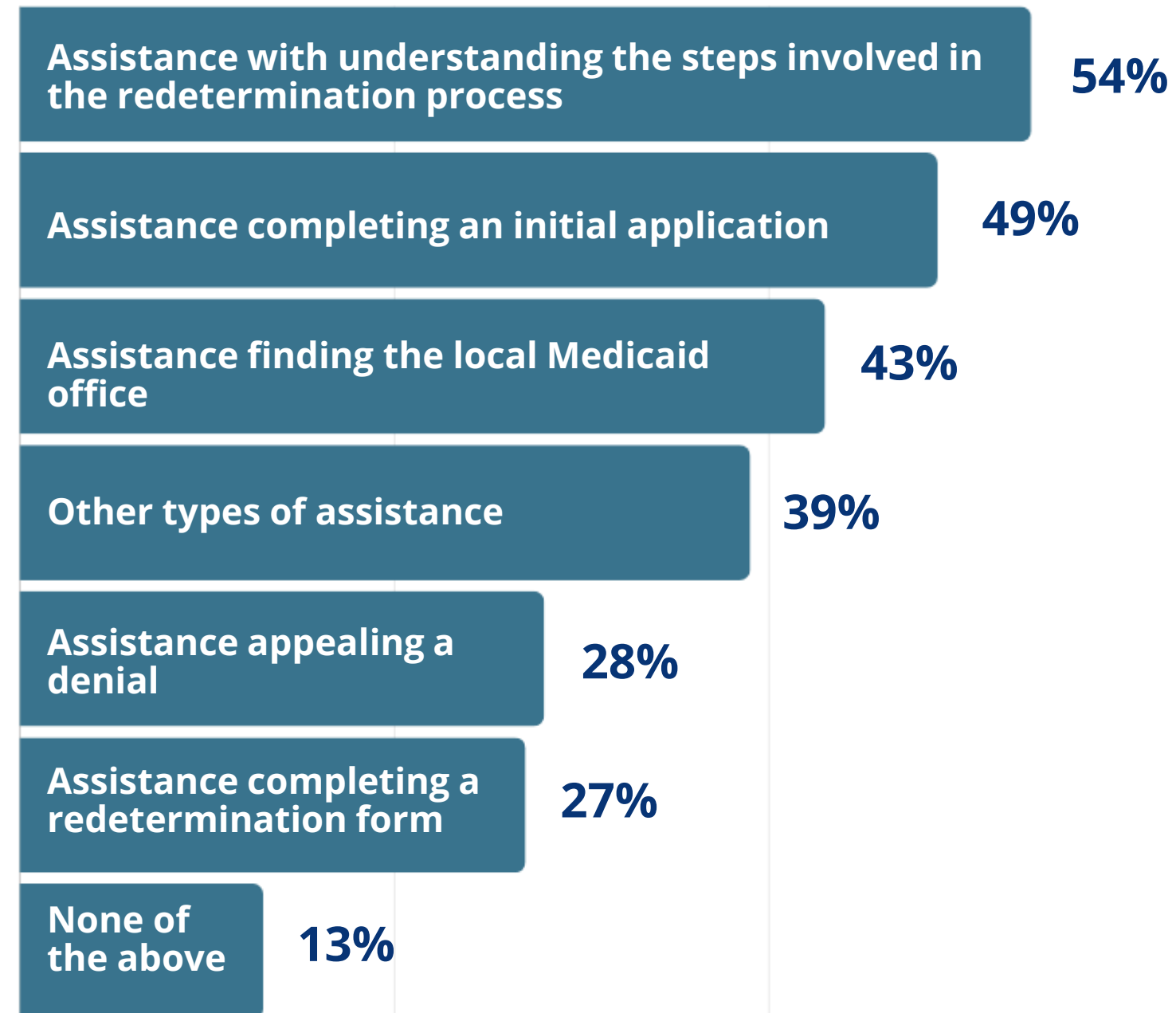
The total number of families of CYSHCNs assisted through one-on-one navigation increased consistently from Q1 to Q3.

Number of Children Across Households Assisted Through One-on-One Navigational Services by Age and Quarter

	Number of Children			
Child age	Q1	Q2	Q3	Cumulative
Birth-3 years	287	395	544	1,226
4-13 years	582	761	948	2,291
14-17 years	127	267	244	638
18+ years	137	219	234	590
Unknown/Missing	117	734	942	1,793
Total	1,250	2,376	2,912	6,538

The total number of children potentially reached through one-on-one services increased consistently from Q1-Q3 with the greatest increases seen for children in the 2 youngest age groups (Birth - 3 and 4-13 years)

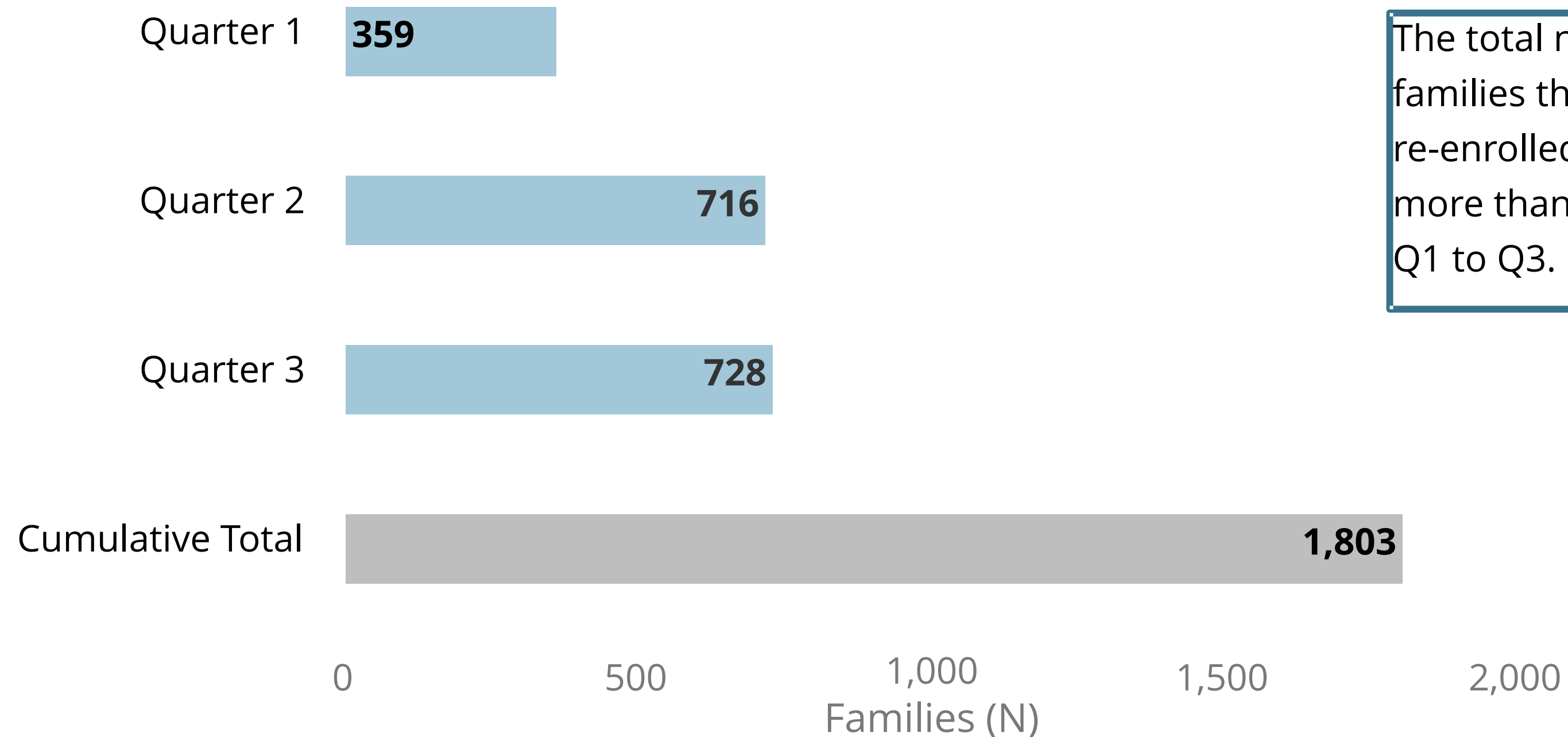
Types of One-on-One Navigation Services^a Provided to Families of CYSHCN by Grantees in Q3 (N=107^b)



^aParticipants could select all that applied.

^bNote: Grantee service data was combined across April, May, June, and July to create a cumulative analysis sample size of N=107.

Total Number of Families of CYSHCN Engaged by Grantees that Enrolled in Medicaid for the First Time or Re-enrolled in Medicaid After a Previous Disenrollment by Quarter



The total number of families that enrolled or re-enrolled in Medicaid more than doubled from Q1 to Q3.

Number of Children Across Households Engaged by Grantees that Enrolled in Medicaid or Re-enrolled After Previous Disenrollment by Age and Quarter

	Number of Children			
Child age	Q1	Q2	Q3	Cumulative
Birth-3 years	114	71	294	479
4-13 years	98	173	446	717
14-17 years	28	50	104	182
18+ years	36	96	84	216
Age Unknown/Missing	160	332	698	1,190
Total	436	722	1,626	2,784

Notes from the field...

We are grateful for the families we've connected with through various resources to help them re-enroll in Medicaid after being dropped due to PHE. Some families aren't aware they've lost coverage until they try to use it, often finding out during a crisis after it has been canceled for 3-6 months. Fortunately, we've been able to assist these families in getting back on Medicaid through the Stay Covered! mini grant.

Many families have derived significant benefits from accessing valuable information, resources, and tools, as well as receiving dedicated support from our staff to navigate through the Public Health Emergency (PHE). The assistance provided by our team has not only empowered these families to access the necessary resources but also ensured their continued coverage. It is crucial to acknowledge that the successful outcomes realized would not have been achievable without this project.

Notes from the field...

"In April, I began assisting a family in re-enrolling in Medicaid after they had been disenrolled due to the end of the Public Health Emergency (PHE). I dedicated significant time to emailing and calling member services to address the issue. . . I wanted to share a little message she sent me:

'I just want to say a huge thank you for all the time you spent making sure my daughter and I were covered. This has been one of the hardest times in my life and thinking I didn't have insurance was incredibly stressful. You took the time to walk me through everything, follow up, and make sure my coverage was not only active but backdated to cover all my treatments, hospital stays, and surgery. Now I can focus on my health without worrying about insurance. Thanks for having my back!'"



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Questions?