



# Research Shows Access to Primary Care in Medicaid Managed Care Is Strong, But Improvements Needed for Specialty Care

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## Background

Medicaid and the Children's Health Insurance Program (CHIP) are vital to the health and well-being of children and families with low and moderate incomes, together insuring almost half of all children in the nation.<sup>1</sup> The larger of the two programs, Medicaid, covers about four in ten children nationwide.<sup>2</sup> Medicaid is a federal-state partnership, designed and administered by state agencies subject to federal requirements. Most state Medicaid agencies choose to contract with managed care organizations (MCOs) to oversee service delivery for people enrolled in Medicaid at a fixed amount per member or capitated rate. MCOs are tasked with delivering medical services for their enrollee population, which requires securing and maintaining an accessible provider network, managing enrollment, paying provider claims, and meeting quality metrics, among other responsibilities. Nearly 75 percent of people enrolled in Medicaid nationwide are in an MCO, and in the 42 states (including DC) with MCOs, 36 have 75 percent or more of their child Medicaid population enrolled in an MCO.<sup>3</sup>

MCOs play an essential role in delivering Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services, a mandatory comprehensive benefit package for all children enrolled in Medicaid. Under federal law, state Medicaid programs must cover all medically necessary treatments that a child needs to correct health conditions and maintain health, even if the service is not normally included in the Medicaid state plan. Screening and testing are required at

age-appropriate intervals typically determined by a periodicity schedule, and include a range of physical, behavioral and mental health, vision, hearing, and dental exams. States also have an obligation to notify all Medicaid enrollees under age 21 that these services are available to them.<sup>4</sup>

However, the extent to which children are able to access the range of services they are entitled to in Medicaid managed care states hinges largely on MCOs fulfilling the obligations set forth in their contracts. This signals the need for federal and state Medicaid agencies to establish and enforce performance and quality measures that hold MCOs accountable for providing accessible, affordable health care. In May 2024, the Centers for Medicare & Medicaid Services (CMS) took concrete steps towards refining MCO transparency and compliance, finalizing two regulations aimed at improving access to care in Medicaid for fee-for-service (FFS) and managed care delivery systems.<sup>5,6</sup> While these regulations check off many items on the MCO accountability wish list, state agencies alone cannot provide the amount of surveillance needed to successfully implement the changes the rules set forth. Therefore, outside stakeholders, including people with Medicaid lived experience, child health advocates, and providers, will be critical to ensuring that MCOs are complying with their required responsibilities to provide children with the essential health benefits to which they are entitled.



## About the Project

The Georgetown University Center for Children and Families (CCF), with support from the Robert Wood Johnson Foundation, sponsored focus groups of parents and guardians of children enrolled in Medicaid managed care, and providers who serve such children. The communications and research firm PerryUndem recruited participants and conducted the focus groups. Participants in the parent and guardian focus groups were chosen to provide a diverse array of perspectives, varying by demographic factors such as race, marital status, geographic area, and political affiliation. The provider focus groups included pediatricians, family physicians, and other providers that interact with children enrolled in Medicaid MCOs.

Eleven focus groups were conducted across four states: Michigan, Tennessee, Texas, and Washington. These states were selected in order to represent a range of demographic, geographic, and political perspectives. Some considerations that went into the state selection included the level of managed care penetration, geographical spread, population density, prevalence of Spanish speakers, the political landscape, and whether the state had adopted Medicaid expansion.

Two parent focus groups and one provider focus group were each held in Michigan, Tennessee, and Texas, while one parent group and one provider group were held in Washington. One focus group was held in Spanish for parents and guardians living in Texas. Four of the parent focus groups were conducted in-person (in Michigan and Tennessee) with the remainder of the parent and all of the provider groups conducted virtually via Zoom. The focus groups ran for approximately 1 hour and 45 minutes, and both the parent and provider focus groups had 7-8 participants each. All focus groups were held from March 19-April 4, 2024.

Supplementing the findings of the parent and provider focus groups, CCF also conducted a survey of providers and managers of pediatric practices who oversee administrative functions and may interact with MCOs in a different capacity. The survey was disseminated at an in-person pediatric conference and via email listservs geared towards pediatric practice office staff and pediatricians. While a paper copy of the survey was available to conference attendees, all responses were collected electronically through the survey platform Qualtrics. The survey consisted of questions in the following categories: demographics of pediatric practices, Medicaid managed care participation, and working with Medicaid MCOs. In total, the survey was open from February 2- April 5, 2024 and generated 94 responses, two of which were submitted blank and omitted in the results. Following the close of the survey, Qualtrics generated a report of the remaining 92 responses for analysis.

While the survey and focus groups only offer a snapshot of the experiences that families and providers have with MCOs, their findings provide insight on the challenges that children and families enrolled in Medicaid managed care face when trying to access care.





## Key Findings

The following provides a summary of insights collected from the focus group and survey findings:

▶ **Medicaid coverage is of high value to children, their families, and providers.**

Parents and providers alike agreed that Medicaid provides affordable, comprehensive coverage. Parent focus group participants remarked that primary care is accessible in Medicaid, and participants in both parent and provider focus groups shared anecdotes of Medicaid being more affordable and having more comprehensive coverage than private insurance.

▶ **The “unwinding” of the pandemic-era continuous coverage provision created access challenges for families and practices.**

In almost every parent focus group, at least one parent reported that their children had a lapse in coverage and some parents lost their own Medicaid coverage too. Many of these lapses and losses were due to procedural reasons—parents described a variety of administrative mishaps that resulted in missing paperwork needed to renew their child’s coverage.

▶ **Parents and providers work together to meet children’s needs.**

Throughout the focus groups, it was clear that most parents are highly engaged with their child’s care and valued having a strong relationship with their pediatrician. Pediatricians regularly “go to bat” for their patients, and when needed, they find creative ways to get children the services and medications they need. Parents and pediatricians commonly spoke about each other as partners in a child’s care, leaning on each other to find the best treatment plan.

▶ **Specialty care and mental and behavioral health services are among the hardest to access in Medicaid.**

Parents, providers, and practice managers expressed difficulty with the lack of access to specialty care. Workforce shortages, particularly for specialized pediatric mental and behavioral health providers, have led to excessively long wait times for appointments and parents traveling to other areas of the state for care, therefore

delaying diagnosis and treatment. Lack of financial incentives have further exacerbated these workforce shortages, dissuading providers from going into pediatric subspecialties and deterring mental and behavioral health providers from taking any insurance, including Medicaid.

▶ **MCOs play a role in restricting access to care.**

Providers and practice managers had strong feelings about managed care’s impact on access to care. Cumbersome prior authorization requirements, narrow networks, and poor care coordination have created many frustrations for providers and those who are on the administrative side of service delivery. Almost all survey respondents agreed that prior authorization requirements are often or sometimes very burdensome for their practice, and over 75 percent stated that these requirements are often or sometimes inconsistent with evidence-based practices.

▶ **Parent perspectives on MCO performance varied by personal experience and need.**

Parents had mixed feelings about their MCO and the frequency of communication. While some parents had few complaints about the services covered by the MCO and felt that their child could access everything they needed, quite a few parents were unsatisfied with their MCOs. This was especially the case when it came to difficulty accessing mental and behavioral health services.

▶ **Lack of education, outreach, and enforcement hinder the ability to utilize EPSDT services.**

For many parents and providers, the focus groups were the first time hearing the term “EPSDT.” Providers were more likely to be familiar with the concept, however, they knew it either as a general approach to screening or as “Bright Futures,” a nationally recognized periodicity schedule.<sup>7</sup> When provided with more details about the benefit, focus group participants felt empowered with this new information, but also skeptical of the extent of the benefit in practice. Even though EPSDT sounded good on paper, it did not match up with the experiences that parents and providers have had with getting medically necessary services approved.



## Detailed Findings

### ► Medicaid is of high value to children, their families, and providers.

Across all focus groups, parents and providers held Medicaid in high regard. Services provided through Medicaid are free or have minimal cost sharing, making it easier for children and families to get the care they need. Many parents stated that their children have been covered by Medicaid since birth, demonstrating its reliability and the role it plays in continuity of care throughout childhood. Most parents also felt that access to primary care was particularly good with Medicaid, allowing their children to remain with their pediatrician throughout childhood. Some parents and providers even remarked that compared to private insurance, Medicaid is more affordable and covers more services. A few providers in the focus groups also noted that Medicaid is more consistent with payment than private insurers, and they appreciated Medicaid's timeliness. A number of parents in each group had Medicaid coverage themselves and also expressed appreciation for it, even if their level of coverage differs from their child's.

### NOTABLE QUOTES<sup>8</sup>

*"It's a stepping stone, my mom said it's not forever, but it's a stepping stone [...] to get yourself together, get your own insurance."*

– Michigan parent

*"... I think Medicaid is a great program for kids, I think it works really well in Washington."*

– Washington provider

*"I was reading an article the other day about parents of a NICU baby who, you know, Medicaid covered their million-dollar NICU stay, which, you know, if there was no Medicaid, that would be just unimaginable for many, many, many families."*

– Washington provider

*"Medicaid to me is really easy to accept and take because, you know they're, first of all, they're verified. Medicaid pays. The rate may be lower, but you're going to get paid. And you don't get a lot of push back if you do a test or don't do a test, you know, or if you order a test that you're just trying to be sure of something or parents want reassurance. It's not going to get rejected like [private] insurance is."*

– Texas provider

Because of the lack of financial barriers, providers acknowledged that families with Medicaid coverage are more likely to follow through with medication regimens, therapies, treatment plans, and get preventive screenings.

### ► However, Medicaid unwinding threatened this coverage.

In 2023, a pandemic-era rule that allowed Medicaid enrollees to keep their coverage, regardless of any changes in income or status, began to phase out.<sup>9</sup> During this "unwinding," states had to check the eligibility of all enrollees in order to determine if their coverage should be renewed. However, this process was plagued with a number of administrative mishaps, and the unwinding has had a measurable, negative impact on families' access to care. In each of the focus groups, there were parents who reported their children having a lapse in coverage. Most losses or lapses in coverage appeared to be due to procedural reasons. Parents shared stories of renewal packets being sent to the wrong mailing address, not being able to log into their online portal to update information, the wrong child losing coverage, agencies losing their application information, and other critical mistakes.

Lapses in coverage led to missed appointments, skipped medications, and providers reporting an uptick in emergency room visits. This has been noticed among practice managers as well, with one survey respondent noting, "Medicaid unwinding has contributed to children not being able to be seen for sick or well visits in a timely manner." Lapses also caused parents to worry more about their children getting sick or having an accident because they would not be able to afford emergency medical treatment, adding to an already stressful financial situation for parents.

Luckily, most of the parents that took part in the focus groups were able to get their children's coverage restored. Providers reported that their administrative staff played a significant role in helping families navigate the complicated renewal process. Several providers said that their staff called to make sure that a patient had coverage and alerted families of their child's insurance status prior to their appointments.





## ► Parents and providers work together to meet children's needs.

Throughout the focus groups, parents demonstrated that they are very engaged with their children's care. Many parents stated that they know their child best and will do whatever it takes to get them the care they need. Often, words like "fight" were used, showing the tenacity it takes to play an active role in decisions affecting their child's health care. For example, when parents said that they would have to travel far distances to see a provider, they would do whatever they could to make it work. Parents also reported that they would do research online beforehand so that they could come to appointments prepared with questions to ask. A large contingent of parents in the focus groups reported having a good grasp on their child's care; almost all parents in the focus groups immediately knew the name of the MCO that their child was enrolled in, and many stated that they felt 50-75 percent knowledgeable about their child's health care coverage.

There is also a sense of community among parents who have children enrolled in Medicaid that the structure of the in-person focus groups illuminated. During the groups, when hearing the struggles that their peers were going through, parents would have sidebar conversations to share advice, suggest people to contact, and offer words of encouragement — especially among the moms. A few parents also mentioned utilizing online groups to find community. This was particularly the case for parents who have children with special or complex healthcare needs such as autism spectrum disorder (ASD).

Parents are also very satisfied with their children's pediatricians. All but one parent stated that their child currently has a regular primary care doctor. Multiple parents said that their child has had the same pediatrician for years, following them to different practices. Some parents even said that they had the same pediatrician as children that their child has today. The focus groups made clear that there is a good patient-doctor relationship between parents and pediatricians. Pediatricians regularly "go to bat" for their patients. When needed, they get creative to get medications and services covered, make calls to other providers to schedule appointments, and help file appeals. Parents and pediatricians commonly spoke about each other as partners in a child's care, leaning on each other to find the best treatment plan. Overwhelmingly, pediatricians said their favorite part of their job is interacting with their patients.

## NOTABLE QUOTES

*"When they have a checkup, not when they are sick, but when they have a checkup, I make a list of my questions, and like other people commented, the checkups are too short, or too fast, so I like writing it down, so they tell me more or less what we can do, or they give me an answer at that moment, and I go online and search. I inform myself online so I can also be active with what the doctor is going to do and follow the tests that they are doing."*

– Spanish-speaking parent in Texas

*"...you've just got to fight. I mean you say you fight; you have to fight and that means hours on the phone, call them every day, get on their nerves, talk to the supervisors..."*

– Tennessee parent

*"With me because I don't fight for myself, but I will fight for my children. My children give me my superpowers really, and if I'm taking care of them, I'm taking care of myself really."*

– Michigan parent

*"Yeah, I mean, my kids have had the same doctor for a really long time and we actually followed her to an office, and she always goes above and beyond and she's more holistic. And if I ever do have an issue with the medication, like I said, she'll go back in and you know make sure it's how it needs to be so it is covered, because they change criteria every year it seems like."*

– Tennessee parent

*"...the one benefit I love about family medicine is not only getting to know the pediatric patient, but also the parents, the aunts, the uncles, the grandma. You get a really good dynamic of what's going on in the family to have those long-term relationships and build into the community."*

– Michigan provider



► **Access to specialty care, especially mental and behavioral health services, is limited.**

Almost all parents and pediatricians in the focus groups expressed that specialty care providers, such as providers who offer ASD and attention-deficit/hyperactivity disorder (ADHD) assessment and diagnosis, allergists, dermatologists, and orthodontists, are difficult to access. As did practice managers—finding a pediatric subspecialist to whom providers could refer Medicaid patients was an issue for just under 75 percent of survey respondents, with child psychiatrists being the most difficult subspecialty to access.

For some children, early intervention is especially critical. Problems with accessing timely assessments to diagnose mental and behavioral health conditions were prevalent—for example, children waiting for a year or more for an assessment may miss out on early intervention services that are only available to children under three years old.<sup>10</sup> These delays in care can also negatively impact the emotional and mental health of the whole family; parents expressed feeling unsupported when trying to find mental and behavioral health services and some became visibly sad describing the process.

The provider focus groups identified systemic issues that contribute to access limitations. Providers commented that specialists, mental and behavioral health professionals, and other practitioners are deterred from taking Medicaid patients—or sometimes taking insurance at all—because of low reimbursement rates and complicated paperwork requirements. Often, those that do take patients covered by Medicaid cap the number of Medicaid patients in order to have a sustainable payor mix. Results from the practice manager survey validated this—nearly two-thirds (65 percent) of respondents served populations in which less than half of patients were covered by Medicaid and only ten percent of practices had patient populations in which 75 percent or more were covered by Medicaid. Providers also mentioned that low reimbursement rates can deter providers from going into subspecialties, leading to wait times of six to 12 months for appointments and/or long drives for families.

Even if parents were able to get appointments for their child, the suggestions given by mental and behavioral health providers, particularly relating to therapy options, were sometimes unrealistic and burdensome (e.g., too far away). Parents also noted that there were instances where the MCO put a limit on the number of sessions that they would cover, preventing their child from getting the full amount of treatment required to meet their needs.

## NOTABLE QUOTES

*“In general, they [Medicaid managed care organizations] are failing our children. They make access to care extremely challenging and do not take the needs of the population into consideration. The absolute greatest atrocity is the lack of mental health services available to children with MCOs. The need is astronomical and the availability is nearly non-existent.”*

– Survey respondent

*“... I’ve had just an issue with trying to get my daughter in for mental health care. I’ve probably fought with this since she was in seventh grade. [...] But her PCP, her doctor, is the one who sets everything up. Whenever I try to do my own, making the appointment, it never goes well. They don’t take the insurance or they’re not accepting patients at that moment. They need a referral, like, there’s just always something that comes up, but that’s again with the behavioral, the mental health.”*

– Tennessee parent

*“Yeah, from a business model in our case, we’re just trying to maintain the percentage of Medicaid that we take and we’re not, you know, we’re trying to be sensitive from a business model not to become flooded with Medicaid in terms of the percentage of our practice.”*

– Michigan provider

*“[...] there just aren’t enough trained developmental behavioral pediatricians who are available to do these structured autism diagnoses... If there was more money in it, if you know, if you could get rich being a developmental behavioral pediatrician the way you could doing a procedural specialty, there would be all kinds of developmental behavioral pediatricians around for us to refer to.”*

– Washington provider

*“I’m still paying on the credit cards that I had. TennCare has never paid for any of my kid’s braces. [...] I tried to get them, I appealed it, they said no, because they’re on a point system to approve them, and she barely missed it, but they didn’t give it to her. So, I put it on a credit card. And during that time, COVID or something hit, I wasn’t working, got behind on the credit cards, so the credit card is now in collection. So, my daughter’s braces been out, and I’m still paying on it.”*

– Tennessee parent

Outside of mental and behavioral health care, another Medicaid service that parents frequently expressed dissatisfaction with is dental care. A number of parents said that the dental coverage that Medicaid provides is insufficient. There were several complaints that their child’s MCO wouldn’t cover braces, even when they were



deemed to be medically necessary. As a result, parents had to pay out-of-pocket for dental care, with one parent explaining that they went into credit card debt to cover their child’s braces.<sup>11</sup>

► **Many MCOs erect barriers that inhibit access to care such as narrow provider networks, cumbersome prior authorization requirements, and poor care coordination.**

- **Narrow networks:** During the focus groups, providers felt that limited networks made their jobs harder because it makes finding subspecialties, especially mental and behavioral health providers, for families with Medicaid coverage extra difficult. Several primary care providers lamented that there was nowhere that they could refer their patients for mental or behavioral health services, and this was especially the case for providers in rural areas where the workforce shortages are even more pressing. Survey results also revealed that provider credentialing is a major barrier to joining an MCO network. Long wait times for approval and excessive requirements for provider credentialing were identified as an unexpected barrier to working with MCOs. According to some survey respondents, mental health providers are subjected to additional requirements to enroll with an MCO, exacerbating the widespread issues with accessing mental and behavioral health services.

**NOTABLE QUOTES**

*“When adding pediatricians and nurse practitioners, credentialing process can take ridiculously long. Additionally, struggles credentialing [mental health] providers due to AHCA’s MH provider requirements (must be linked to community behavioral health services provider, cannot credential into MD practice or group).”*

– Survey respondent

*“So, there’s lots of...it looks like you have lots of options but yet; I have to end up going to the health department for, or my primary care physician. I have all these other doctors and I will look up the reviews and be all excited and then I call and they’re [like] no, we don’t take it, we don’t take Well Care or we don’t take Amerigroup, you know. And so, I really don’t have a big choice. I’m grateful for it, but I don’t have a lot of choices.”*

– Tennessee parent

- **Prior authorization requirements:** “Game” was the most common term used among pediatricians when asked about their experiences working with MCOs. Providers and parents felt as though working with insurance is a game that they have to play, and in order to get the treatment their patient or child needs, they have to know how to game the system. The term “magic words” was also used by a couple of providers, explaining that in order to get something covered by an MCO, there are specific words that have to be used when seeking prior authorization approval. Practice managers concurred—98 percent of survey respondents reported that prior authorization requirements are often or sometimes very burdensome for their practice. Pediatricians and parents expressed that the MCOs have essentially assumed the role of the doctor, even though 84 percent of survey respondents said that prior authorization requirements are often or sometimes inconsistent with evidence-based care.

**NOTABLE QUOTES**

*“Right, they kept denying, and I was like he has insurance and they’re like insurance won’t cover it and they were like you have to pay a hundred and something dollars. And I was like, for like two weeks of — and I’m like that’s when I was desperate. And I was like he needs his medicine.”*

– Michigan parent

*“They all have their same kind of format, right. Like you need to put this information into their boxes for them to get approved or denied, to move forward... So, it’s just, again, the medical assistant is the smartest person available who knows that and knows how to game the system or go to a couple of My Meds and upload whatever... she or he needs for the family.”*

– Washington provider

*“It seems like SoonerCare prior authorizations are sent to the provider without human input - an example is when Vyvanse is prescribed. SoonerCare only pays for the brand name product but the pharmacy automatically changes it to a generic which is denied and a PA is sent to the clinician which is a huge waste of time. SoonerCare prior authorizations also do not delineate \*why\* a PA is required - it’s a guessing game.”*

– Survey respondent



On the whole, prior authorization requirements were depicted as an ever-moving target. For example, a provider would receive a denial for a treatment one day, and then submit the same claim to the same MCO two days later and get an approval. Because prior authorization requirements vary by plan, these issues were amplified when pediatricians contracted with multiple MCOs. Several providers mentioned that they have people on staff at their practice who are well versed in the intricacies and keep up with the different documentation requirements. However, when these staff members leave the practice, all of the institutional knowledge goes with them, making it difficult to maintain continuity.

Over 80 percent of survey respondents stated that prior authorization prevents the provision of medically necessary services and medications, particularly ADHD medications. This puts a financial burden on families as many parents in the focus groups reported paying out-of-pocket for medications that their plan denied. Throughout the focus groups, many parents and pediatricians shared stories where the appropriate medication was prescribed, only for the pharmacist to call and say that it could not be filled because the MCO would not cover it. As a result, the provider and parent typically have to work together to find a close equivalent that the plan covers, but in some cases, providers are forced to prescribe less-effective alternatives.

- **Care coordination:** All of the parents felt that their MCOs could help more with care coordination. When parents reached out to their MCO for help, many times they could not get a hold of a representative, and if they did, the representative often did not have the answers they were seeking. There were rarely stories of an MCO helping to solve problems, and many times, the MCO exacerbated them. For example, if a parent called their MCO to find an in-network provider, many times they were given out-of-date provider directories. Parents reported having a hard time with navigating insurance jargon, making it difficult for them to express their needs to representatives. Navigation was difficult for providers as well, especially when working across MCOs. Figuring out which services and medications each plan covers is cumbersome and daunting for providers and their staff.

Among practice managers and providers in the survey, 71 percent reported that MCO care coordinators rarely supported or coordinated care for their practice and patients. As a result, practices are taking on the burden of care management, but reimbursement rates do not reflect the additional work.

## NOTABLE QUOTES

*“MCO care coordinators are duplicative of the nurse care manager I have in the office, and the MCO team does not communicate with my team. MCOs should drop their care coordinators as they often get in the way of our effective work.”*

– Survey respondent

*“They [Medicaid managed care organizations] are not working, they take the money the state gives them, gives us even less and keep the rest for themselves. The insurance companies have millions or billions in profits each year and I only have enough money saved for my next payroll.”*

– Survey respondent

*“So, I called the insurance company and they acted like they didn’t know what I was talking about. So, my sister had to get on the phone and she had to speak on my behalf.”*

– Michigan parent

*“So, knowing what Molina will cover versus what Coordinated Care will cover or United will cover for individual disease categories or treatments, is, it’s opaque at least at this point. And if you go to their websites, their provider portals, those have a ton of barriers. Like, you have to log [in], register through your institution and then when you get in there, it’s a pdf that you have to read through to find out what the prior authorization [is] ...it’s really not helpful. You know, they say they make their information available to providers, but it’s, it’s not, it’s just a barrier, I think.”*

– Washington provider

*“[...] For example, Molina on theirs, they have a long list of these are the providers in your area that are supposed to take Medicaid or supposed to take Molina. And then I’ll call them one-by-one. And they have said no, we don’t, we don’t take it. So, it’s frustrating because it’s not accurate.”*

– Washington parent





► **Parent perspectives on MCO performance varied by personal experience and need.**

Despite these access challenges in managed care, parents had mixed feelings about their MCOs overall. Some parents were happy with their choice of MCO. These parents had few complaints about the services covered by the MCO, and felt that their child could access everything they needed. Some also liked the incentives than their plan provided for seeking preventive care, such as gift cards. On the other hand, quite a few parents expressed dissatisfaction with their MCO, particularly as it pertained to difficulty accessing mental and behavioral health services. They also differed in terms of communication preference. While they were in the minority, some parents liked getting regular communications from their MCO, but the majority only wanted to be contacted when there were action items such as their annual renewal or annual check-ups. Parents expressed the most satisfaction with MCO interaction when they are contacted through paperless methods such as an online portal or app.

► **Lack of EPSDT education, outreach, and enforcement undermine its objectives.**

In each focus group, participants were shown or given a flier that described EPSDT and all of the services it covers for children in Medicaid. For many, this was their first time hearing the term. Parents did not seem to realize that their child is entitled by law to receive any service that their child's provider deems medically necessary. On the provider side, some knew EPSDT as Bright Futures (a nationally-recognized periodicity schedule for pediatric preventive care), but thought that it was only a screening and diagnosis tool, not a comprehensive benefit package for children. Knowing that there is a legal basis for receiving services made some parents and providers feel more empowered to be better advocates for their children and patients. Though a few providers thought that the EPSDT flier would be too difficult for the families they serve to understand, parents in both the English and Spanish groups commented that they liked having as much information as possible about the services their children can receive.

That being said, a common reaction that parents and pediatricians had to the flier was skepticism. While many felt that EPSDT is a helpful tool in theory, what they read on the paper was not reflective of their experience seeking and providing care. MCOs impose narrow networks, rigid formularies, cumbersome prior authorization requirements, and lack care coordination, making it difficult for families to access the services that Medicaid covers. And while most parents know that they could appeal MCO service denials, many felt discouraged or intimidated by the process and chose instead to take on the financial burden of paying for services themselves.

Even though providers and parents are doing their part to ensure that children have the widest possible range of services to promote and maintain health, in the end, MCOs can hinder the effectiveness of Medicaid for the people it is meant to serve.

### NOTABLE QUOTES

*"I think we've all taken an oath to try to get our patients the services that they need and the care that they deserve, but ...am I going to get the fax from the insurance company two days later saying that they must first fail these two medications before they can get access to the medicine that I have prescribed?"*

– Washington provider

*"It's very helpful. I feel like I can quote this [flier] ... if I need to go to bat."*

– Tennessee parent

*"You do feel empowered. I do, because I know my rights."*

– Michigan parent



## Reflections

The focus group and survey findings bring to the forefront a few key issues stakeholders should keep in mind when considering making changes to Medicaid.

► **First, Medicaid is valued by families and providers with lived experience.**

Across all four states in the focus groups, parents commented that their children with Medicaid coverage have reliable access to primary care. Pediatricians and parents described having a close working relationship, partnering together to make sure children have the health care services they need. Families and providers also value the critical financial protection that Medicaid offers. Free and low-cost doctor visits and prescriptions allow low-income families to access preventive services and treatment for routine conditions without worrying about the cost. For children with greater health care needs, such as infants in the neonatal intensive care unit, Medicaid's comprehensive coverage protects families from incurring insurmountable medical debt. Providers say Medicaid makes their job easier because they know necessary services will be covered. Parents understand and appreciate this protection too, leading them to fight to keep their children covered. Losing Medicaid coverage, as happened to many during the unwinding, is stressful for families and re-enrolling is overly complicated. As 12-month continuous eligibility rolls out across the country, continuing to adopt longer periods of coverage (e.g., multiyear continuous eligibility<sup>12</sup> for children under age six followed by 36-month continuous eligibility) would make it much easier for children to stay covered.

► **Second, while families and providers felt that access to primary care in Medicaid managed care is strong, they noted that it can be much harder to access specialty care.**

Focus group participants shared that narrow networks and out-of-date provider directories make it hard to know how they can access timely specialty care. This was especially true for mental and behavioral health services, including developmental screenings that are often a prerequisite to accessing critical early intervention services. Parents felt supported by their primary care pediatricians as they tried

to navigate the process, but generally did not find MCOs helpful in coordinating their care. Providers and practice managers felt that MCOs got in the way —citing slow and complicated credentialing processes that make it hard for willing providers to join the MCO networks and, once in, cumbersome prior authorization requirements that make it hard to deliver needed care. The lived experiences of the families and providers in the focus groups indicate that MCOs are managing care only in the negative—that is, only in limiting and restricting access to services—and it is the primary care pediatricians who are doing the true care coordination. Stronger enforcement of existing network adequacy requirements is needed, and policymakers may want to consider going further by limiting and streamlining prior authorization, credentialing, and other managed care practices that impede access to medically necessary services.





- ▶ **Third, Medicaid’s prescription drug benefit is robust but navigating the utilization management rules imposed by different plans is difficult for families and providers.**

Pediatricians noted that the information in the electronic medical record system is often out-of-date so they are not able to discern which MCOs cover which drugs, or under what circumstances, when they are writing the prescription. Instead, families often find out when they go to the pharmacy that prior authorization is required or that a different drug must be tried first. Even with these hurdles, some providers said that Medicaid’s prescription drug coverage is better than private insurance, particularly when drug shortages make it harder to prescribe a certain medication or to only prescribe generic drugs. The structure of Medicaid’s prescription drug benefit and the lived experiences of families and providers navigating it will be explored further in a future brief.

- ▶ **Finally, more needs to be done to ensure families and providers understand and utilize Medicaid’s pediatric benefit, EPSDT, to support children’s healthy development.**

Federal law requires states to inform families about EPSDT services, and yet, families and providers were generally unfamiliar with it. A few providers knew about EPSDT’s breadth and scope, but more described it as simply a checklist to use during well-child visits. Similarly, a few families understood their children had a right to medically necessary services, but more questioned EPSDT’s scope given the difficulty they experienced with getting some services approved. Relatedly, provider payment needs to be reexamined. Providers noted that there is a disincentive to subspecialize because primary care pediatricians earn more, with less schooling, than pediatric subspecialists. Increasing provider payments to better align incentives to fill known workforce gaps could help EPSDT live up to its promises.

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[The Georgetown University Center for Children and Families \(CCF\)](#) is an independent, nonpartisan policy and research center based at Georgetown University’s McCourt School of Public Policy. CCF conducts research, analyzes data, develops strategies, and offers solutions to improve the health of America’s children and families, particularly those with low and moderate incomes.

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The views expressed here do not necessarily reflect the view of the Foundation.*

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## Endnotes

<sup>1</sup> Centers for Medicare & Medicaid Services, “April 2024 Medicaid & CHIP Enrollment Data Highlights,” available at <https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>.

<sup>2</sup> Rudowitz, R., Burns, A., Hinton, E., and Mohamed, M., “10 Things to Know about Medicaid” (Kaiser Family Foundation, June 30, 2023), available at <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid/>.

<sup>3</sup> Hinton, E., and Stolyar, L., “10 Things to Know about Medicaid Managed Care” (Kaiser Family Foundation, May 1, 2024), available at <https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-managed-care/>.

<sup>4</sup> Centers for Medicare & Medicaid Services, “Early and periodic screening, diagnostic, and treatment” (2017), available at <https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>.

<sup>5</sup> Centers for Medicare & Medicaid Services, “Ensuring Access to Medicaid Services” (May 10, 2024), available at <https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services>.

<sup>6</sup> Centers for Medicare & Medicaid Services, “Medicaid and Children’s Health Insurance Program (CHIP) Managed Care Access, Finance, and Quality” (May 10, 2024), available at <https://www.federalregister.gov/documents/2024/05/10/2024-08085/medicaid-program-medicaid-and-childrens-health-insurance-program-chip-managed-care-access-finance>.

<sup>7</sup> American Academy of Pediatrics, “Bright futures” (2023), available at <https://www.aap.org/en/practice-management/bright-futures>.

<sup>8</sup> Throughout this report, quotes have been lightly edited for length and clarity.

<sup>9</sup> H.R.2617 - Consolidated Appropriations Act, 2023, Sec. 5131 (2022), <https://www.congress.gov/bill/117th-congress/house-bill/2617/text>.

<sup>10</sup> Centers for Disease Control and Prevention, “What is ‘Early Intervention’?” (April 11, 2018), available at <https://www.cdc.gov/ncbddd/actearly/parents/states.html>.

<sup>11</sup> States must provide orthodontic services to EPSDT-eligible children to the extent necessary to prevent disease and promote oral health, and restore oral structures to health and function. Centers for Medicare & Medicaid Services, “EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents” (June 1, 2024), available at <https://www.hhs.gov/guidance/document/epsdt-guide-states-coverage-medicaid-benefit-children-and-adolescents>.

<sup>12</sup> Georgetown University Center for Children and Families, “Multiyear Continuous Eligibility for Children” (2024), available at <https://ccf.georgetown.edu/2024/02/01/multi-year-continuous-eligibility-for-children/>.