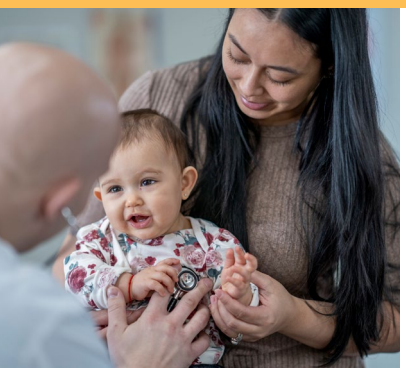
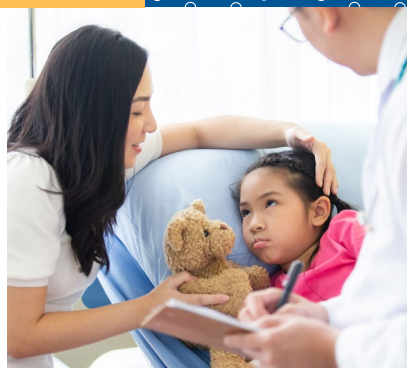
Family Voices Matter: Listening to the Experts in Medi-Cal Children's Health

FROM THE FAMILIES

This research snapshot captures the perspectives of families from a series of focus groups conducted by The Children's Partnership (TCP) and its local partners as part of a larger project focused on advancing child equity in Medi-Cal.*





Introduction

The Role of Medi-Cal in Children's Health Equity

Childhood is the time when health-promoting behaviors have the greatest influence on lifelong health and future well-being. When it comes to health, children of color face more challenges due to systemic issues like racism and poverty that manifest themselves in inequitable health outcomes such as low birth weight and high rates of hospitalization due to asthma. To help children grow up healthy and thrive at their full potential, health care must start upstream with a "whole-child" preventive care approach that acknowledges and responds to the various issues children and families face that impact their health and well-being, such as food or housing insecurity, caregiver depression or immigration concerns. **Because parents know their children and their lived experience best, their expertise is a critical component to integrate into any "whole-child" preventive care approach.**

Parent input is both relevant as part of their own child's multidisciplinary care team and also as part of designing and implementing programs and policies affecting children's health care.

Health coverage programs like Medi-Cal are designed to provide comprehensive and early preventive care and treatments that identify risks and address them early on in life.

5M+
children in California are enrolled in Medi-Cal

of whom are children of color from Latinx, Black, Native American or Asian American communities.

Because Medi-Cal is the primary source of coverage for children of color, Medi-Cal plays a critical role in addressing child health inequities and preventing them from manifesting in disease later on as adults. However, Medi-Cal has not provided the well-child care and follow up services federally required to be provided to children.

FAMILY VOICES MATTER

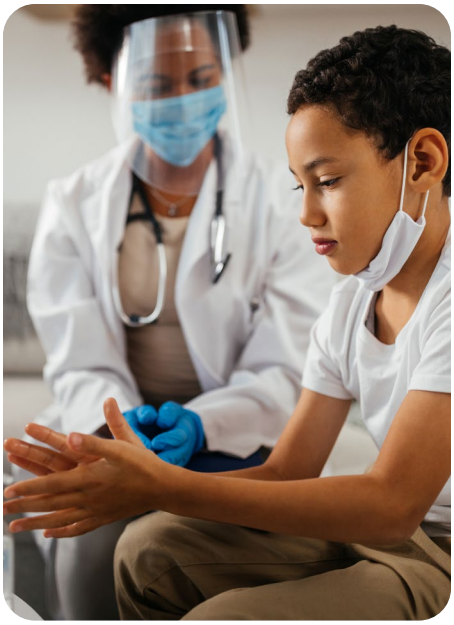
Improving children's care starts and ends with listening to the experts – their parents – to understand why the current system is failing them. Parents can identify what is not working and where there are gaps in the care their children need, and they can suggest solutions for improvement. The Medi-Cal program is increasingly recognizing the important contributions parents have to offer in improving quality and health equity in Medi-Cal: One of Medi-Cal's quality goals for 2022 is to "engage members as owners of their own care." The question is how to authentically bring parents' input into their child's care and into the Medi-Cal program.

Through a series of focus groups, primarily with parents of children of color enrolled in Medi-Cal, The Children's Partnership (TCP) gathered insights on families' experiences with Medi-Cal, health plans and health care providers. The parents also made suggestions for how health plans can better engage parents in the delivery and management of care for their children.

Findings

Parents' Experiences

Overall, parents were eager to share their experiences with health care and health plans and appreciated being asked for their feedback. **They believed their perspective matters** and were interested in learning how they can more regularly share their feedback with their health plan. The parents we spoke with wanted to contribute not only to improve their own children's care but to also help benefit other families, as well as the system as a whole. Moreover, they appreciated discussing their experience with other parents and wanted to get together in similar peer discussion groups again. **Parents liked hearing about others' experiences and learning from each other.**



Parents spoke about their experiences – both negative and positive – that highlight systemic issues they face in accessing and navigating health care for their children as shown by their interactions with the Medi-Cal health system, health plans and health care providers.

METHODOLOGY

TCP partnered with the Georgetown Center on Poverty and Inequality and California Children's Trust to identify opportunities for Medi-Cal health plans to improve child health equity through family and community engagement. As part of this Equity Through Engagement project, we hosted focus groups in partnership with four community-based organizations, including Alpha Resource Center's Family Resource Center, San Ysidro Health, Helluna Health/Eastern LA Family Resource Center and California Consortium for Urban Indian Health (CCUIH), who directly engage with Native American, Asian American, Latinx and Black families who have children enrolled in Medi-Cal. As part of the focus groups, parents[1] were asked about their experiences with their children's health plan. Parents shared their suggestions for how Medi-Cal can improve health coverage and health care for their children. Parents who participate in their health plan's Community Advisory Committees (CACs) also shared their experiences and suggestions — CACs are intended to provide health plans with feedback and input from those enrolled in their plan including informing health plans on community resources and information and providing input on the design of culturally appropriate education, outreach and services.

1. We refer to "parents" as all individuals who participated in the focus group discussions. Parents include guardians, adoptive parents, foster parents, grandparents and others who have or share responsibility for raising children.

MEDI-CAL HEALTH SYSTEM

Maintaining their children's Medi-Cal coverage is cumbersome and time-consuming.

Parents fear losing coverage for their children and work hard to keep it. Parents seeking Medi-Cal consumer assistance can experience long wait times and unprofessional, apathetic and/or impatient representatives.

Families have great difficulty transitioning their children with special needs' coverage to adult coverage.

Parents note that Medi-Cal workers do not sufficiently understand children with special needs and how their coverage eligibility transitions into adulthood. As a result, children transitioning to adulthood experience disruptions in Medi-Cal coverage at a time when their complex care is also transiting to an adult system of care.

Medi-Cal informational materials are difficult to understand.

The information parents are given is not written in plain language. It is too broad to know which information applies to their child, and the volume of information is overwhelming. Non-English speaking parents noted that translated materials are not always accurate or understandable.

Parents want more support in choosing a health plan.

Parents would like materials that compare plans with concise options to distinguish between the plans, as well as provider directories that reflect relational aspects of providers (e.g. wait times or demeanor with patients).

MEDI-CAL HEALTH PLANS

Health plans are not sufficiently helping families coordinate their children's care.

Health plans are not always communicating clear, accurate or timely information to parents about their children's coverage and specific needs. Parents find that care coordination and support with accessing services are lacking, particularly in accessing community support services. In addition, parents note that it is unclear and difficult to raise issues they have through a plan's grievance process.

Families do not always receive accurate interpretation services.

Interpreters provided to assist families do not take the time to translate everything between health care providers and parents or do not have the necessary skills and knowledge to relay accurate information to the parents or providers. Interpretation services are also not always aligned with families' language needs including, for example, providing Mixteco language interpretation in the varying Mixteco dialects. Many times parents do not feel comfortable informing their providers they're receiving inadequate interpretation services.

Parents want to participate in plans' community engagement, such as Community Advisory Committees (CACs), but they need support in doing so.

Parents need support, such as child care and translations, to be able to participate in a CAC. They would also like to get involved in the structuring of their CAC's objectives, meeting schedules and voting structure. Otherwise, CAC meetings are rescheduled when parents cannot attend and their input is not represented. Membership of the CACs should also be racially representative of the communities they serve to be able to incorporate and reflect parents' and children's needs and recommendations. CACs offer an opportunity for parents to get their issues addressed but parents believe all plan enrollees should have that benefit, not just select members of a committee.

HEALTH CARE PROVIDERS

Parents want a more holistic, "whole-child" approach to their children's care.

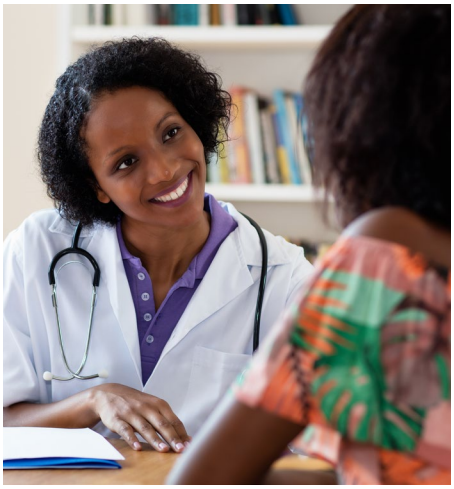
This approach focuses on prevention and the integration of mental, social and physical health needs like food and housing insecurity. Parents want more access to mental health care as well as more support in transitioning their children from pediatric to adult care, particularly when their children have complex health care needs.

Parents are often dismissed and not recognized as experts in their children's condition and care.

Providers are often seen as lacking cultural awareness and sensitivity, making assumptions about children and their family's experience, and misdiagnosing children's conditions as a result. Parents shared that they would like to have access to more providers that reflect the linguistic and cultural background of the children and families they serve.

Recommendations
From Parents

Parents had a number of important recommendations that seek to address the systemic issues they face in accessing and navigating health care for their children laid out in the previous section. They include recommendations that would improve the health care delivery system, communication with children and families, resources they receive, and how families are engaged in the care of their children.



To improve health care delivery, Medi-Cal/health plans can:

- Implement a whole-person approach for children emphasizing preventive care.
- Train Medi-Cal eligibility workers on the eligibility changes needed for children with special needs as they transition to adulthood.
- Provide a designated person to help parents navigate the Medi-Cal system itself.
- Provide families with a care coordinator to assist them in connecting their child's services, surgeries and treatments across multiple systems of care.
- Require inclusion of families in treatment plans.
- Send reminders via text message for appointments and vaccinations.
- Implement a transition team for children moving into adult care.
- Provide cultural and customer-friendly training to staff and providers.
- Implement training for interpreters to provide friendly and high quality services to families.
- Allow families to consolidate their child's multiple needs in a single doctor visit.

To improve communication with parents, Medi-Cal/health plans can:

- Highlight informational materials that are relevant for children.
- Offer parents social/care coordinators to verbally share information, including assistance with adult care transitions.
- Provide parents discussion opportunities on specific child health topics (e.g., parent group webinars for children with special needs).
- Provide all materials in plain language and translations by native speakers.
- Use trained and certified health care interpreters and monitor them for access and quality.
- Promote availability and parents' right to interpretation services.
- Make benefit and provider directories available online and providers searchable by language and specialty, and include provider reviews and cultural familiarity.
- Provide concise information about COVID-19 updates.
- Provide and promote easier processes for parents to share concerns about plans, Medi-Cal staff and health providers.
- Improve and increase tailored information to help teenagers navigate their health plan.

To improve resources for children and families, Medi-Cal/health plans can:

- Provide classes on stress reduction, parenting and nutrition.
- Assist families in accessing mental health care for their children in a timely manner and provide greater access to mental health resources.
- Provide self-advocacy training for parents to voice their concerns with providers.
- Provide and promote more resources about family counseling options for children and families.
- Provide classes about Medi-Cal for parents.

To improve CAC engagement, health plans can:

- Co-design the CAC's agendas and schedule with community members.
- Offer more regular meeting times when most parents are available.
- Make parents feel welcome by providing basic support and background information.
- Proactively follow up with parents to address their concerns.
- Increase recruiting efforts through outreach to child-serving centers in the community.

CONCLUSION

Medi-Cal and its health plans have a responsibility to meaningfully engage parents in the delivery and management of care for their children. In fact, the recent Medi-Cal contracts with health plans lay out explicit family engagement requirements for health plans. In order for this engagement to be meaningful, health plans and Medi-Cal need to invest in supporting parent participation and build it into their own business flow as a way to truly integrate parents' input into health plans and Medi-Cal's decision-making. Family engagement is relational rather than transactional, and thus, requires additional time and resources. Incorporating these parent-driven recommendations can strengthen health plans' commitment to family engagement and serve to strengthen the health care system's ability to advance children's health.

The Children's Partnership

The Children's Partnership (TCP) is a California advocacy organization advancing child health equity through research, policy and community engagement.

* This issue brief is part of a larger body of work known as the Equity Through Engagement project, a partnership between The Children's Partnership, the California Children's Trust and the Georgetown Center on Poverty and Inequality. Funded by the Robert Wood Johnson Foundation, the partners are conducting policy-relevant quantitative and qualitative research and analysis to highlight opportunities for California to integrate community partnerships and interventions into its Medi-Cal health care financing and delivery systems in order to advance child health equity. The views expressed here do not necessarily reflect the views of the Foundation.

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