



FAMILY VOICES MATTER: Listening to the Real Experts in Medi-Cal Children's Health

JUNE 2022

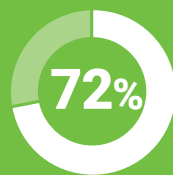


Executive Summary

Authentic family engagement is relational and moves at the speed of trust.



**MEDI-CAL →
CHILD HEALTH EQUITY**



of Medi-Cal children are children of color.



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. Families’ input is important within their own child’s multidisciplinary care team, as well as in designing and implementing programs and policies affecting children’s health care. Bringing equity to children’s health starts with listening and sharing decision-making with the experts, namely the parents and families of children.

Because three-fourths of Medi-Cal children are children of color¹, Medi-Cal plays a critical role in addressing child health inequities and preventing children from developing diseases later as adults. **However, Medi-Cal has not provided the well-child care² and follow-up services federally required to be provided to children.**

Fortunately, Medi-Cal is increasingly recognizing the important role that families play in decisions about their children’s health, and they are trying to better center families into their children’s care. **This report describes parents’ experiences with their children’s Medi-Cal coverage and their recommendations for improving children’s health care, as well as how health plans can collaborate with families on systems change.**

To learn from parents, The Children’s Partnership (TCP) partnered with **four community-based organizations**³ who serve families with children enrolled in Medi-Cal to conduct a total of nine parent discussion groups, including [Alpha Resource Center of Santa Barbara](#), [San Ysidro Health](#), [Eastern LA Family Resource Center](#) and [California Consortium for Urban Indian Health \(CCUIH\)](#). Each parent discussion group focused on parents of Medi-Cal children from specific racial and ethnic communities, specifically Latinx, Black, Chinese American and Native American parents.^{4*} The discussion groups were conducted in separate groups for English, Spanish and Chinese speakers. We also hosted a discussion group with parents who participate in a Medi-Cal managed care plan’s Community Advisory Committee (CAC) – a contractually required stakeholder engagement forum.

* Throughout this report we refer to the discussion group participants as “parents” because they all were parents of Medi-Cal children. Otherwise, we use the term “caregivers” to reflect all those who have responsibility for raising children, such as parents, guardians, foster parents, and grandparents.

ABOUT THE REPORT



This report is part of our Equity Through Engagement project. Through a Robert Wood Johnson Foundation grant, we are partnering with the California Children’s Trust and the Georgetown Center on Poverty and Inequality to examine the role of Medi-Cal managed care plans in addressing social determinants of health and in advancing child health equity. We explore opportunities for partnering with community collaboratives, community-based organizations and families.





Highlights

from Parents' Observations

Overall, parents were eager to share their experience with health care and managed care plans and wanted to contribute to improvements not only to their own children's care but for the benefit of other families and the system as a whole. Parents believed their perspective matters and wanted to know more about how they could more regularly share their feedback with their health plan. Below are highlights of the observations and suggestions for improvement parents shared.

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



MEDI-CAL PROGRAM



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 transitioning to an adult system of care.



Medi-Cal informational materials are difficult to understand.

Parents find that information is not written in plain language, 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).



Suggestions for Improvement:

Center the family experience:

- ▶ Incorporate in communication materials the information that families want to receive from Medi-Cal.
- ▶ Provide cultural sensitivity and family engagement training for staff.
- ▶ Train Medi-Cal eligibility workers on the eligibility changes needed for children of special needs as they transition to adulthood.
- ▶ Provide families a care coordinator to navigate the Medi-Cal program and their child's care.

Build a family engagement infrastructure:

- ▶ Provide families financial, transportation, translation, child care and other supports for their participation in engagement activities.
- ▶ Meaningfully incorporate family input into the California Department of Health Care Services (DHCS) decision-making.

Require family engagement in health plan contracts:

- ▶ Emphasize how family engagement strategies like CACs can be authentic (e.g., impacting decision-making).
- ▶ Demonstrate how family input has impacted decision-making.

MEDI-CAL MANAGED CARE PLANS



Health plans are not sufficiently helping families manage 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 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 strategies, such as Community Advisory Committees (CACs), but they need support in doing so.

Parents need support, such as child care and translations, to participate in a CAC. They would also like to be involved in developing the CAC objectives, meeting schedules and voting structure. Additionally, parents believe that CAC membership should be racially representative of the community in order to reflect the needs of the community. CACs offer an opportunity for parents to get their issues addressed but parents believe all plan enrollees should have that benefit.



Suggestions for Improvement:

- ▶ Co-design, with parents, information materials to be more relevant and provide the materials to parents with coordinators available to help them navigate and understand information they receive.
- ▶ Provide support services for children and their families, parenting classes, family counseling, care coordinators, and appointment assistance to mental health care.
- ▶ Co-design engagement activities with families and support them in their participation.
- ▶ Incorporate family input into health plan leadership decision-making.
- ▶ Assist families in accessing mental health care for their children in a timely manner.
- ▶ Implement training for interpreters to provide friendly and high-quality services to families.
- ▶ Provide self-advocacy training for parents to voice their concerns with providers.



HEALTH CARE PROVIDERS



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

In a "whole-child" approach, providers focus on prevention and integrate mental, social and physical health. 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 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 their conditions as a result.



Suggestions for Improvement:

- ▶ Focus on "whole-child" preventive care with parents as part of the care team.
- ▶ Assist families in identifying mental health care providers and resources so that children and their families can access such services in a timely manner.
- ▶ Implement cultural and consumer-friendly trainings for all provider staff.



Where We Go From Here

This body of work is particularly timely in supporting Medi-Cal's commitment to advancing health equity and its specific attention on children. The recent DHCS Medi-Cal Children's Comprehensive Quality Strategy and Medi-Cal managed care Request for Proposal outline a path forward to center families in their child's care and to seek their input on how Medi-Cal and managed care plans deliver care. In fact, many of the recommendations summarized are incorporated in the managed care contract requirements. The intent is there, and now the question is whether family engagement activities will be authentic. More specifically, will families be supported in attempts to provide input, and will their contributions be incorporated into decision-making?



In addition, the CalAIM implementation – particularly the Population Health Management program and Enhanced Case Management (ECM)/Community Support Services – offers an opportunity to ground their implementation within the family experience by co-designing the ECM benefit for children with family representatives and including families in the ECM provider team.

Notably, in addition to family engagement, Medi-Cal health plans need to collaborate with communities – including community leaders and community-serving organizations – to identify their population's risk and protective factors and determine how best to meet the needs of the community in which Medi-Cal children live and grow. This will be further covered in our forthcoming **Equity Through Engagement** report.



I like that they're asking for my opinion.



 **The Children's Partnership**



California Children's Trust

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

Introduction and Background



Childhood is the time when health-promoting behaviors and environments 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. Family’s input is important within their own child’s multidisciplinary care team as well as in designing and implementing programs and policies affecting children’s health care. Bringing equity to children’s health starts with listening and sharing decision-making with the experts, namely the parents and families of children — those who know their children and their lived experience best.



Medi-Cal covers more than half of California’s 9M children and is a critical avenue to advance child health equity.



5M+

children in California are enrolled in Medi-Cal



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

Medi-Cal is designed to provide comprehensive and early preventive care and treatments that identify risks and address them early in life. Because Medi-Cal is the primary source of coverage for California’s children of color,⁵ Medi-Cal plays a critical role in addressing child health inequities and preventing them from manifesting in disease later as adults. However, Medi-Cal has [not provided the well-child care](#)⁶ and follow-up services federally required to be provided to children.

The Medi-Cal program is increasingly recognizing the important role that families play in decisions about their children’s health. As Medi-Cal aims to better center families in its operations and services, this report explores how to make family engagement strategies authentic in pursuit of

advancing child health equity. To do so, The Children’s Partnership (TCP) went directly to the experts: the parents. We asked parents^{7*} of Medi-Cal children to share their perspectives and their experience with 1) the Medi-Cal program; 2) their child’s Medi-Cal managed care plan; and 3) their child’s health care providers. Parents also shared their suggestions for how these systems can better engage families in order to improve children’s health care.

From these findings and research, we offer [policy recommendations for the Medi-Cal program](#) on contractual directives for Medi-Cal managed care plans on requisite family engagement activities and how to assess effective family engagement. Additionally, we offer [practice recommendations for health plans](#) in developing their family engagement strategies, including how to implement effective community advisory committees. In engaging parents more authentically, the Medi-Cal program can more meaningfully gather family input and partner with parents in order to transform our health care delivery system toward advancing child health equity.

* Throughout this report we refer to the discussion group participants as “parents” because they all were parents of Medi-Cal children. Otherwise, we use the term “caregivers” to reflect all those who have responsibility for raising children, such as parents, guardians, foster parents, and grandparents.



What Is Family Engagement?

Across a variety of disciplines, including child welfare, juvenile justice, education, early childhood, and health, family engagement is a critical tool for system transformation. Family engagement is more than a data point collected through consumer surveys and focus groups to be analyzed and acted upon by health systems' decision-makers. Family engagement is an iterative, relational, and collaborative process. Because families are experts in their own experience, a system devoted to serving them must center the parent perspective and respond to their child's needs as parents define them.

Authentic family engagement is relational and moves at the speed of trust.

As shared in the Family Engagement Inventory through the federal Children's Bureau, "family engagement refers to the systematic inclusion of families in activities and programs that promote children's development, learning, and wellness, including in planning, development, and evaluation."¹⁵

Family engagement occurs at multiple dimensions in health care delivery: At the individual patient level, the parent and youth themselves should be part of the child's health care team and collaborate on treatment plans. At a system level, such as within a managed care plan, families' input should be incorporated into how a health plan makes operational and investment decisions.

Family engagement is a microcosm of another dimension of engagement in population health – namely community engagement, whereby local leaders, community-based organizations, and local agencies partner with health plans to identify social and environmental issues, both risks and assets, of their population and to develop and provide appropriate interventions.

For the purposes of this report, we will focus on family engagement at the individual provider level and at the managed care plan level.

In our upcoming Equity Through Engagement report, we will also address community engagement and its role in advancing child health equity.

In order to assess what family engagement strategies are most effective in systems, like managed care plans, research studies¹⁶ have identified four core domains: 1) representative input from those who reflect the diversity in demographics (e.g., race/ethnicity), in needs, and in experiences of those being served; 2) transparency on how input is incorporated into the decision-making process; 3) involvement of parents/caregivers in the decision-making process and outcomes evaluation; and 4) commitment from leadership. Families need to trust that their time and input is valued and will be heard by plans' decision-makers.

AUTHENTIC FAMILY ENGAGEMENT



1. Diverse representation:

Does the health plan fund and partner with community-based organizations and family-led organizations to help identify, support and mentor family participation? Do family participants reflect the community (e.g., race, ethnicity, income, language, geography)?

2. Transparency and inclusivity in the decision-making process:

Does the health plan provide supports and information families need to be informed participants in providing input? Are they partnering at each stage of the process?

3. Involvement in the decision-making process:

What is the health plan doing differently because families were involved?

4. Commitment from leadership:

Is leadership involved and incorporating family input into decision-making? Does the health plan educate and inform all staff about the importance of engaging families at all levels of the system, valuing families' time, and respecting their contributions?



In addition, there are varying degrees of engagement (whether family or community engagement) along a spectrum ranging from informing, whereby community members are provided information but with little opportunity for feedback on that information or policy, up to shared decision-making and empowerment, whereby community members are making decisions that are supported by systems. One description of the degrees of engagement envisions a spectrum of public participation,

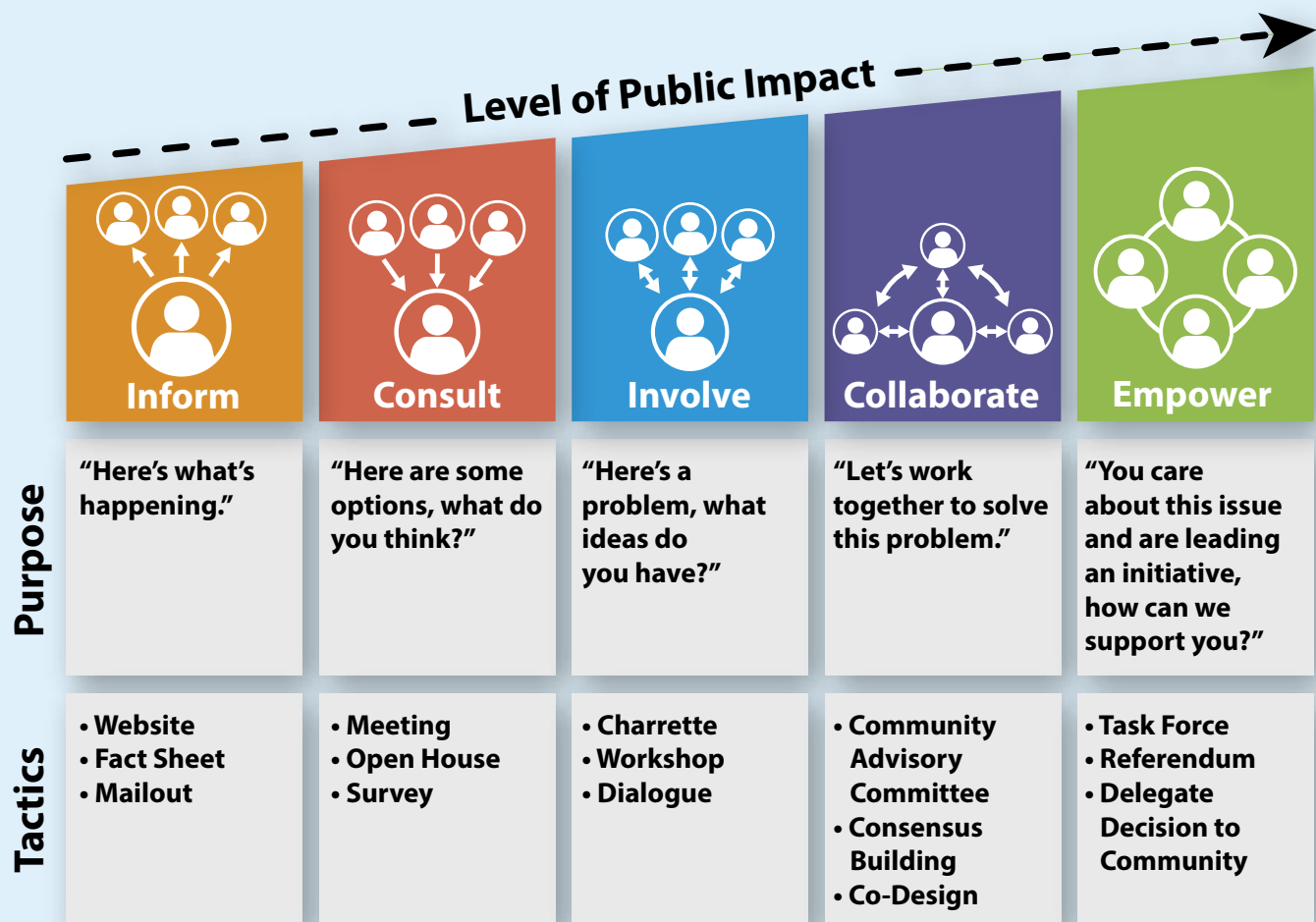
in which a more equitable system is achieved when decision-making authority is more evenly distributed between the public and the government.¹⁷

The higher up the spectrum of engagement, the greater agency given to families and the community. In the context of health systems and health plans, we would argue that collaboration should be the aim.

In the recently released Medi-Cal managed care plan RFP and model

contract, DHCS does envision plans developing a consumer engagement strategy that involves those enrolled and their families as partners in the delivery of health care services. As part of this strategy, managed care plans must develop processes to measure and monitor the impact of consumers' input into policies and decision-making, and develop processes to share the results of that input. This lays the framework for greater involvement and collaboration.

COMMUNITY ENGAGEMENT CONTINUUM



Adapted from the IAP2 spectrum of public participation¹⁷



Why Is Family Engagement Needed to Advance Child Health Equity?

Dismantling systemic racism starts with acknowledging racism not just as a relic from our health system's history but its embodiment in the current structures. Medi-Cal and the health care system today yield persistent health and health care disparities by race and ethnicity, ranging from well child visits,⁸ screenings⁹ and COVID vaccines,¹⁰ to patient experience,¹¹ low birth weight, and infant mortality.¹² The path toward health equity requires restoring and providing agency and power to children, youth and families in their health care: "[Nothing about us, without us.](#)"¹³ Families are not only the experts on their children and their lived experience, but they also know best how the barriers inherent in the health care system are

failing them and know the existing community and family protective factors as well as the culturally relevant care needed to best remedy those barriers.

Effective delivery and management of care for children starts and ends with the input of and collaboration with parents/caregivers. Family Voices — a family-run, nonprofit organization — advocates for placing families at the center of children's health care because of their direct expertise and representation of their community experience.¹⁴ In other words, system transformation involves fundamental shifts toward shared decision-making and centering families and communities as essential partners in the delivery of care.

CHILD HEALTH EQUITY



Child health is equitable and just when every child has a fair and intergenerational opportunity to attain their full health and developmental potential, free from discrimination. Advancing child well-being also requires effort to *restore or provide agency and power to children, youth, and families.*

— from California Children's Trust,
a partner on our Equity Through
Engagement Project



An Example of a Family Engagement Activity: Consumer Advisory Committees

One way for managed care plans to involve families and gain their input is through a consumer advisory board or committee, which is a formal group of patients (or caregivers of patients) regularly brought together to provide input on how health care systems can better understand priority health issues and improve care delivery. As outlined by the Center for Health Care Strategies research,¹⁸ establishing and maintaining consumer advisory committees require substantial time and effort to be successful. From the outset, managed care plans need to explicitly commit to a collaborative and sustained relationship with the advisory members in which their input will be heard, valued and incorporated into the plans' decision-making. Participation in consumer advisory committees has been particularly vital for parents of children with special health care needs. Given the sophisticated and customized services and case management these families require, these advisory committees are often the only opportunity to provide input that can shape the delivery of services available to their children.



COMMUNITY ADVISORY COMMITTEES (CACs)



Medi-Cal's managed care plans have had a diluted version of consumer advisory committees, called Community Advisory Committees (CACs). Starting in the 1990s, Medi-Cal plans were contractually required to establish CACs, which are made up of consumers, community advocates, and safety-net providers. Their role is to advise plans on their ability to provide services in a culturally and linguistically appropriate manner. The advisory functions include informing plans on community resources and information; providing input on the design of culturally appropriate education, outreach and services; receiving results of member satisfaction surveys; and sharing findings of health education and cultural and linguistic group needs assessments.¹⁹

Currently, the scope and role of CACs have varied across plans, with some providing feedback on managed care plans' population needs assessments and quality improvement projects, while others do not report feedback on these. There is also little tracking and accountability to determine whether these consumer engagement forums are effective.

Most recently, Medi-Cal has issued a new contract template as part of its managed care plan re-procurement, which outlined far

greater specifics on the required scope and operation of the plans' CACs, as well as accountability to Medi-Cal on compliance with these new standards. Most notably, there is far greater attention to managed care plans demonstrating how CAC participants' input has impacted plans' policies and practices. In other words, Medi-Cal wants to ensure that CACs are a meaningful forum where input is heard and incorporated into structural changes — collaboration, not just information sharing.

Equity Through Engagement Project

As part of a Robert Wood Johnson Foundation grant, The Children’s Partnership (TCP), in collaboration with the California Children’s Trust and the Georgetown Center on Poverty and Inequality, launched the Equity Through Engagement project to explore the role of Medi-Cal managed care plans in addressing social determinants of health and the opportunities for plans to advance child health equity. The project started from the premise that community engagement at multiple levels can strengthen Medi-Cal’s commitment to child health equity. Engagement would occur by 1) centering the family in determining an individual child’s health care regimen; 2) engaging parents’ input into the system of care provided by managed care plans and Medi-Cal; 3) partnering with community-based organizations in the culturally appropriate delivery of health care and of health-related social supports; and 4) centering community leaders as the backbone foundation to best identify risk and protective factors as well as provide interventions that serve the community needs. Through a series of discussion groups with parents, this report examines the first two levels of engagements — or family engagement — from the perspective of parents themselves. Our forthcoming Equity Through Engagement report will combine these parent observations with a macro-level examination of Medi-Cal health plans’ community engagement, namely the extent to which they are partnering with CBOs to deliver services, and with community collaboratives to design and implement community-based interventions.



Research Methods

During the Spring of 2021, The Children’s Partnership collaborated with **four community organizations** to develop discussion guides, identify participants, conduct focus group discussions and synthesize the findings.²⁰ Eight focus group discussions were conducted by four organizations (two parent discussion groups per each CBO): [Alpha Resource Center of Santa Barbara](#), [San Ysidro Health](#), [Helluna Health/](#)

[Eastern LA Family Resource Center](#) and [California Consortium for Urban Indian Health \(CCUIH\)](#). TCP conducted one additional focus group of parents who participated in health plans’ Community Advisory Committees, for a total of nine parent focus groups. In this report, we will refer to these focus groups as “parent discussion groups.” The collaborating partner organizations and parent participants were financially compensated.

We and our partners were aiming to convene discussions among parents of Medi-Cal children from specific racial and ethnic communities who have been historically marginalized by our health care system, namely Latinx, Black, Asian American and Pacific Islander (AAPI), and Native American parents.²¹ There were a total of 58 participants across the nine discussion groups, including 15 Native American parents, seven

Black parents, 23 Latinx parents, six AAPI parents, and seven white parents. From the 58 participants, 33 were primarily English speakers, 19 were Spanish speakers, and six were Chinese speakers. Fifty-six of the parent participants were female, and two were male.

TCP and our collaborating partners developed the questions for the discussion guide together, which was intended to guide our conversation but not to regiment a checklist of questions to be uniformly answered by all participants. ([See Appendix A.](#)) Parents were asked questions about their experience with their children's Medi-Cal health plan and where they turn for help in navigating health care for their children. In addition, parents were asked to provide their feedback on how Medi-Cal can improve health coverage and the delivery of care for their children.

The additional parent discussion group that TCP conducted was specifically tailored to parents with children with a disability who participate in managed care plans'

Community Advisory Committees. We asked them about their experience participating in these CACs and to share suggestions for both what is working and what improvements could be made. TCP also researched literature on family and consumer engagement fundamentals; interviewed a CBO dedicated to family engagement (Center for Family Voice); and consulted with Ignatius Bau, an independent contractor, who provided TCP with valuable insights into the fundamentals and logistics of direct family engagement for the parent discussion groups that we hosted for this report.

REVIEW PROCESS

On completion of the focus group discussions, we re-convened our collaborating partners to discuss our experiences conducting the parent discussion groups and highlights from what we heard. Each partner drafted a summary of their findings from their parent discussion groups. We then compiled, summarized, and analyzed the findings, categorizing

what we heard into key themes. In congruence with the principles of community engagement, we circled back to our collaborating partners to share a draft of these consolidated findings to get their feedback on the summation and the recommendations. Once in final form, TCP crafted a version that could be helpful to share with the focus group parents themselves to see the product of their engagement and, if they were interested, to share their feedback on what we consolidated.

RESEARCH LIMITATIONS

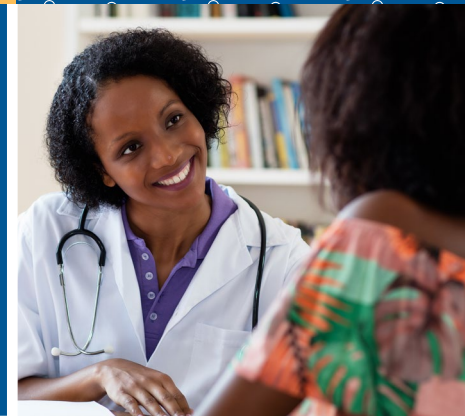
One noted limitation in our methodology was not having the voices of children and youth themselves. Despite our collective attempts to identify youth to participate in our focus group discussions, we were not able to identify youth participants. This is clearly a learning opportunity and responsibility for us in needing to dedicate additional resources to cultivating further partnerships with youth organizations.



Findings



I like that
they're
asking for
my opinion.



Overall, parents wanted to share their opinions and appreciated that what they had to say may be taken into consideration by their insurance plan. Parents in the discussion groups felt like their perspectives mattered, and the parents wanted to know more about how they could more regularly share their feedback with their health plan.

Parents wanted to contribute not only to the improvement of their own children's care but for the benefit of other families, the community and the system as a whole. Moreover, some groups noted that they appreciated discussing their experience with other parents and wanted to get together in similar peer discussion groups again. They liked hearing about others' experience and learning from each other.

In the sections that follow, parents' experiences and observations are summarized into the following topic areas:



The Medi-Cal Program



Parents' Experience With Their Children's Medi-Cal Health Plan



Parents' Experience With Their Children's Health Care Providers



Assistance With Navigating Health Care and Support Services



The Medi-Cal Program

Parents must put excessive effort towards accessing and keeping their children's guaranteed full benefits.

Parents valued the scope of benefits and the affordability that Medi-Cal coverage provides for their children, but, sometimes, parents had to put in excessive efforts to maintain that access. Parents shared that spending a lot of time trying to communicate with the Medi-Cal call center requires them to miss work, which affects their finances and consequently physical and mental health. Parents mentioned that dealing with the Medi-Cal system to secure coverage for their children, even when they already qualify, meant long wait times trying to talk to someone from Medi-Cal support to fix coverage issues that should not be happening. Finding the right information for their needs, doing their own research, and correcting Medi-Cal mistakes on their own felt like a full-time job, which many parents found overly taxing.



I have made multiple, multiple, multiple phone calls. I had to start saying... 'can you please call me back?' and had to keep doing it and keep doing it. And then once you get them on the phone, they're as brief as possible, and they want to get off the phone.



Every time I take my kids to the doctor, I don't know whether or not they're going to be covered, even though my situation has not changed.



PARENT STORY HIGHLIGHT: MEDI-CAL STAFF ERRORS FIXED BY A PARENT

One parent's son's name did not conform to the Medi-Cal system causing extensive issues for her son's coverage, because her son's name included an apostrophe the Medi-Cal software could not comprehend. To fix the issues, the Medi-Cal staff removed the apostrophe in his name from within the system. This ultimately caused the Social Security Administration to flag the issuance of this child's birth certificate and Social Security card. And, although it was an error on Medi-Cal's part, this parent had to do all the labor to correct it. It took nearly two years for this parent to get her child's documents corrected.

A common sentiment across the parent discussion groups was about parents being in constant fear of Medi-Cal discontinuing their child's benefits. A few parents found out their children no longer had Medi-Cal coverage while at doctor visits. Parents feel that Medi-Cal is constantly finding arbitrary reasons to discontinue their children's benefits even when nothing has changed about the family's situation, including the parents' income. Parents have also had to spend hours on the phone with Medi-Cal staff trying to get approvals even when their children clearly qualify for benefits and even after receiving Medi-Cal welcome letters stating their children's eligibility for benefits and patients' rights materials.

Parents often experience rude treatment from Medi-Cal support services, which increases their barriers to finding and accessing health care services for their children.

Parents agreed that customer service representatives lack empathy or patience. Sometimes they were referring to health plan support, but mostly they were referring to the Medi-Cal program support services, such as for enrollment and health plan selection. Some parents noted that whenever they call Medi-Cal support services, staff lack professionalism and genuine care to provide them with the resources, help and information they need. Parents also mentioned that their calls are often unanswered, and calls and voicemails go unreturned. They want customer service to be informative, compassionate and humanistic. They felt disappointed about the amount of work they must do to find support from Medi-Cal assistance lines. Parents felt powerless that they could not identify a process for providing feedback about services received, including feedback on support services.

Families also discussed how their children's academic performance suffers when they are unable to consolidate their doctor's appointments into a single visit since Medi-Cal does not allow children to have more appointments than those previously prescribed. The Medi-Cal system does not allow a kid to have many visits on the same day, therefore parents must take their children out of school for more than one day to see multiple physicians for different reasons.



They want to be treated like a customer, not a nuisance.

— from a collaborating organization conducting a focus group



There was so much information I didn't get [when trying to get out-of-state coverage]. I really had to research it and get the information myself, and present it to the [Medi-Cal] worker and then they let me have it. Like, I had to fight for it.



Medi-Cal materials are not developed with a parent perspective in mind and are difficult to understand.

Parents stated that Medi-Cal written correspondence, including welcome materials, billing statements, and health plan selection packages, are difficult to understand. Regarding bill statements, parents indicated that it is difficult to understand what has been covered by Medi-Cal and what services they need to pay for. Many parents attributed this confusion to the difficulty in understanding Medi-Cal benefits and welcome materials. For example, parents stated that the information contains too much jargon, with technical terms difficult to understand, as if the information is “meant for lawyers.” Parents further mentioned it is extremely difficult to identify important information that applies to their children, as the information and materials they receive is too much to read and process.

Parents feel the Medi-Cal documents they receive are not developed with parents' perspective in mind and in a layout that highlights what is most relevant for parents to know. They want information but prefer one-

on-one discussion over extensive printed material. That said, they also noted having received contradicting information between what written material states and what they hear when they call Medi-Cal support. Thus, parents are seeking someone they trust to help them navigate the information they receive in a compassionate, patient and knowledgeable manner.

Parents stated that although they have received health plan selection packages, it is difficult to discern from all the information in the packages which characteristics of a health plan would be appropriate for the specific needs of their children because the packages contain too much information that is not necessarily applicable to their children. It was stated that going over these materials is time consuming, and parents often do not have the luxury and availability to read everything when choosing a health plan. Parents further mentioned not being aware of certain plan selection forms they should be receiving until they receive a letter saying they have not submitted such forms. This has created a lot of confusion to parents and issues with their children's Medi-Cal access to care.

Receiving materials in their preferred language or receiving interpretation services does not mean parents receive accurate and clear information.

Spanish- and Chinese-speaking parents stated they were able to receive interpretation services and information in their preferred language. However, parents discussed how translations of Medi-Cal materials did not necessarily make information understandable. They noted that materials they receive in their preferred language are often not accurately translated, and they often need to request materials in English as it is often easier for them to understand the information in English. However, because these parents are not fluent in English, there is still a lot of information they miss. Some of the parents believe that Medi-Cal materials are either translated by someone who is not fluent in Spanish or Chinese or by computer software.

Regarding interpreter services during doctor visits, parents mentioned that information gets lost during interpretation, which makes it harder to absorb the information (especially complicated technical medical information) as well as to meaningfully engage with the provider. Parents also mentioned that it is not unusual to receive interpretation assistance from inexperienced interpreters. Finally, Spanish-speaking parents shared that 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.



“ Even with an interpreter, it feels limited because you can't ask all the questions you need to ask. The appointment happens quicker, and the information doesn't always accurately translate.

Parents often know what benefits they want for their children but receive insufficient support when choosing a health plan.

Although parents know what benefits they want for their children, parents across the discussion groups felt they had insufficient support from Medi-Cal in choosing a health plan, including clear explanations about the options available, despite the enormous packet of information provided. For many of the same reasons noted above about support lines and written materials, parents felt they had little to guide them in understanding the distinctions among the various Medi-Cal health plans.

“ In choosing a doctor, [I'd like to know] are you walking with me or are you just trying to get me out of the chair?



Many of the parents indicated that they chose their health plan based on a specific doctor that was recommended by another parent or because of their previous experience with the health plan. Other parents mentioned selecting a plan based on their familiarity and reputation with it, such as choosing Kaiser due to its established presence. Some parents were not aware that there are provider directories and how to access them. Additionally, some parents mentioned receiving misleading information about health plans from doctors' offices.



The best solution [in terms of information about the plan] would be friendly, empathetic front-line people.



As part of the health plan selection process, parents noted that they would value knowing 1) a health plan's patient and customer care service ratings as compared to other plans; 2) which pediatricians in the network have certain specialties; 3) whether the plan offers county-wide coverage; 4) the level of coverage provided for all medications children might need; 6) the variety of special pediatric treatments covered including support services; and 7) the availability of inter-state coverage.

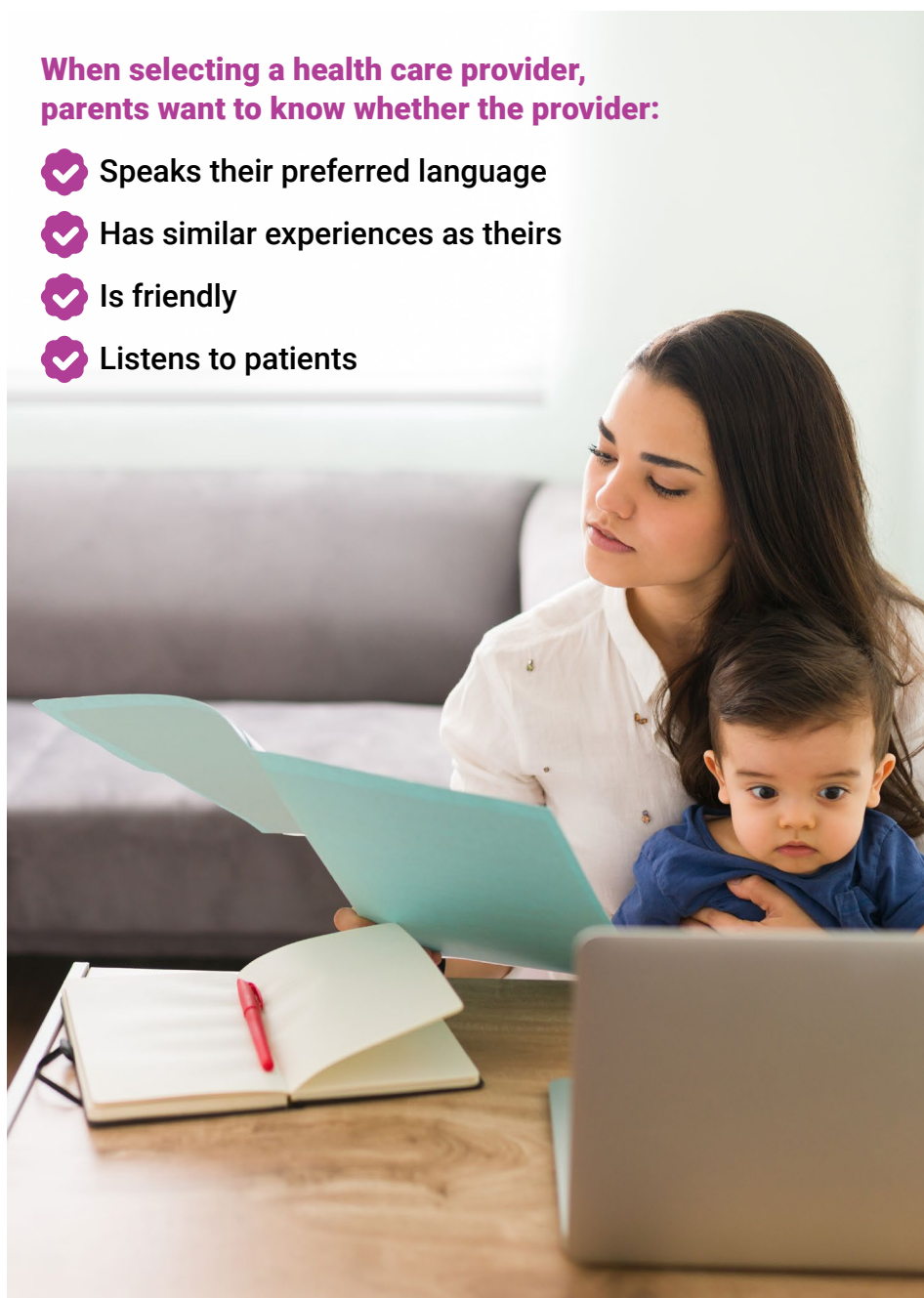
Provider directories do not reflect the relational characteristics that are important to parents when selecting a health care provider for their children.

While parents have seen provider directories, they did not find them sufficiently helpful because they do not have important information about the providers in the directories, such as average office visit wait times;

whether the providers themselves fluently speak their preferred language and have similar lived experiences; or what their demeanor with patients is like. Parents want to know whether the provider is one who will listen to their concerns and whether they will be "holding your hand through a [referral] process." In other words, they would like some rating on whether the provider is a supportive, caring partner in their children's care in addition to providing medical services.

When selecting a health care provider, parents want to know whether the provider:

- ✓ Speaks their preferred language
- ✓ Has similar experiences as theirs
- ✓ Is friendly
- ✓ Listens to patients





Parents' Experience With Their Children's Medi-Cal Health Plan

Health plans often do not communicate important information to parents regarding their children's eligibility for certain services and supports, including care coordination, and are not up to date with policy changes impacting children.

In general, parents felt that their health plan provided coverage for the services that their children needed. Parents often experience long wait times to receive pre-authorizations for certain specialists or prescription approvals, and, in some cases, find out that the medications they need are not covered by the plan. One parent requested help from their health plan with a referral but got no response. When it came to care coordination and accessing support or community services, parents did not feel like their health plans have played a role in providing and connecting them to support services. Parents turn to trusted local entities such as family-led or community-based organizations, schools, regional centers or clinics. In some cases, parents are more knowledgeable about recent policy changes than the health plans, and it takes time for the updates to "trickle down" to plans. Parents must push to catch their children's plan up on the latest policies.

Parents do not feel that their health plans have played a role in providing and connecting them to support services.

Communication using newsletters and mailed letters are often not as useful to parents' specific needs.

Parents would prefer more personal interaction, such as groups and learning experiences, with content specific to children's health and children with disabilities. They noted that information on raising pre-teens, peer supports, healthy nutrition, and mental health care would all be useful to them. They did appreciate the reminders health plans send about well-child visits because, for those with children who are relatively healthy, those reminders help parents keep up to date on preventive care like vaccinations.

Parents would like to provide their feedback on providers; however, the grievance process seems more geared toward denial of services than to substandard care.

One parent indicated she does not see the plan as the barrier but more the individual people or doctors with whom she is seeking care. She has wanted to complain about the process and the service provided by an individual staff member, but she was not able to figure out how to give that feedback for the health plan to address the issue. Other parents have had negative experiences with their doctors and other staff but have not found a way for the health plans to address their concerns and provide a solution.



Parents' Experience Participating in Health Plans' Community Advisory Committees

As explained earlier in this report, Community Advisory Committees (CACs) should offer patients and parents of children enrolled in Medi-Cal the opportunity to raise their voice in how health care systems handle their concerns. In addition, it is particularly critical to obtain information from and get the participation of parents of children with disabilities. These parents need more advanced services and specialized knowledge to adequately care for their children, and these interactions are crucial to shape the delivery of services to which their children are exposed.



Referring to their experience participating in our parent discussion group, a parent said the following:

"The health plans should organize these kinds of discussion groups!"

Although some non-CAC parent members stated not being aware of what a Community Advisory Committee is, what it does, and how to join one, they also showed interest in knowing more about CACs and the opportunity to be able to participate as members. Parents said they would like to join a CAC to learn more about health plan resources available to members, to receive updates on topics that might benefit their children, to have concerns about their children's health care addressed, and to advocate for other families.

The CAC members with whom we met had similar reasons for why they decided to join a committee, including to have more awareness, information and involvement with their children's health plan. CAC members stated they did not

receive enough information from their health plans before joining the CAC. Some mentioned that it would have benefited them if their health plans would have provided more information about the advisory committee before their first meeting to better understand its process and structure in addition to their role and expectations for involvement. One CAC member said that they were given sufficient information in preparation for joining the CAC.



Referring to their experience with CACs, a parent said the following:

"We trust our parent group [parents active in their CAC] the most, because they are not doing it for money."



CAC Parent Members' Feedback Regarding Their Participation in Their Respective Committees:



Despite being CAC members, parents expressed not receiving enough assistance and information from health plans.

CAC parents believe health plans lack knowledge on processes and available resources. Similar to the parents in the other discussion groups, the CAC members felt that health plans lack an understanding of processes and resources available for children and children-centered settings as well as where to refer parents for support (despite being CAC members and having a forum to raise their concerns about their lack of understanding). CAC members also expressed dissatisfaction with the type of assistance received from staff answering phone calls and from social workers. Parents expressed that these types of situations prolong the time for their children to be able to access and receive the resources they need.



According to CAC parents, CAC membership has privileges that should be granted to all health plan enrollees.

Parents expressed how their membership on the CAC did open access to services and get resources approved while they and other parents were not getting a response through the regular health plan channels. These CAC members expressed concern that parents should not have to join a CAC to get access to services that the health plan should be providing to children.



CAC members reported varying committee structures and objectives, which were often determined by the health plan and not the CAC members.

For example, there were frequent changes to which representatives from the health plan served as a liaison to the committee. One member noted that their committee chairs first met with the representative from the medical division. Then the health plan wanted the committee to shift its focus to communications, and the plan representative to the committee was changed to the director of services. The plan representative then shifted again to the plan's community liaison staff.

Nonetheless, some CAC members noted they could review future meeting agendas and raise potential topics of interest to include. They could assign responsibilities to each member of the committee to provide updates on specific topics during meetings. However, if the scope and objectives of the CAC were not clear, meetings could be restructured arbitrarily without full notification and involvement of the committee members. For example, one CAC member noted that because there is no specific mandate indicating how their plan's committees should be run or what they should entail, it is uncertain whether the committee will continue or be dissolved. As a result, their committee meetings were not necessarily conducted to address families' concerns but seemed to be more related to what the plan wanted to discuss.



While only CAC parent members can vote to establish a quorum, sometimes health plan staff and non-consumer representatives of other agencies can also vote, which can skew the consumer representation and control.

Parents expressed their dissatisfaction in the voting structure and process of their CACs, noting that CAC leadership who are not patients or parents of Medi-Cal children themselves often end up leading the CAC direction including determining the topics of discussion and how concerns are addressed. One CAC member noted that their regular meetings were canceled after CAC staff voted to reschedule meetings to once every three months without any advance notification about such a vote in the upcoming agenda. As a result, she did not have the ability to object because she had to miss that meeting and didn't know such a vote was taking place. That member noted that the infrequency of meetings caused a delay in following up from previous meetings' action items and on updates. This discourages parents from further participation since they seem to have little input into the committee process and feel that the committee is not meeting their needs.

CAC members felt that the health plan staff organizing the meetings do not have a clear understanding of what kind of issues should be addressed by the CAC, with staff asserting the committees are "running out of ideas" to talk about during meetings. Members considered this claim unacceptable, as there are still a wide range of issues that children face and that parents want addressed in their health plan. Committees in which members are involved in setting agendas can address other issues even if the committee has a specific focus.



Although virtual meetings have allowed parents to attend meetings more often, technology is still a barrier to other parents.

CAC members noted that the pandemic has provided them and others with the opportunity to be more involved with their committees as meetings have mostly been held through virtual platforms. One parent mentioned having difficulty in the past attending CAC meetings in person due to transportation issues and hopes virtual meetings continue. However, CAC members also noted the lack of access to technological devices to join virtual meetings might be a potential barrier for other parents joining advisory committees.



CACs' diversity, outreach and representation are still barriers for parents to become aware of and participate in CACs.

Two CAC members stated their committees are "pretty diverse." However, one parent mentioned that her committee is not a good representation of the diversity of her neighborhood. There were also comments regarding a health plan's willingness to provide appropriate translated materials and interpretation for Spanish-speaking parents in order to be able to join CAC meetings. The scheduled times for meetings were also identified as a barrier for members.





Parents' Experience With Their Children's Health Care Providers

Parents' individual experience varied: Some responded they were "happy" with their children's care, most notably when they were young, but faced more challenges as their children got older. Below are some common themes across the focus group discussions, reflecting parents' experience with their children's health care.

Children's care requires a holistic and "whole-child" approach that addresses the myriad issues children and families face that impact their well-being.

Several parents wanted their children to be treated as a whole, particularly when they have a disability: Having the appropriate care — head to toe — and including the family in their relational role to the children is important. Other parents mentioned their desire for a health care system that is more inclusive of holistic approaches to healing and with more focus on prevention rather than treatment. They also mentioned wanting a whole-person approach to health, where the health care system doesn't look at a health condition as an isolated occurrence and in which intertwined societal and physical events are also considered. With this approach in mind, the parents expressed a desire for more supportive programs and treatments that integrate mental, social and physical health services.



Some of the different social issues parents mentioned have impacted their family's health overall included:

- 1 Lack of resources on healthy nutrition.
- 2 Lack of family support services for alcohol or substance abuse.
- 3 Food and housing insecurity including limited housing accepting Section 8 Vouchers.
- 4 Social isolation due to COVID-19, which was a concern mentioned among Native American parents in particular.
- 5 Lack of access to technology including devices and a secure internet connection.



The lack of cultural awareness, understanding and sensitivity among Medi-Cal providers causes fissures and distrust among families and the health care system.

Parents noted that Medi-Cal providers often assume things about a child based on a family's circumstance, appearance and ethnicity. Parents of color noted having experienced unnecessary scrutiny from doctors based on racial bias, such as doctors assuming that women of color do not understand the responsibility of having a child and the importance of family planning. Such experiences were deeply demeaning, particularly at times of vulnerability and need of care.

“Black women are invisible, until we open our mouths then they make assumptions: 'here is another angry Black woman.'”



I change [doctors] if the wait time is too long, or if the doctor is not paying attention to me as a parent or not being proactive or positive about my child's condition.



Parents stated that some doctors misdiagnose children due to their lack of awareness about common conditions in certain cultures. One parent shared how their child was initially diagnosed with cleft lip, but doctors then informed them that it was only the child's "Native features." Another parent shared that doctors confused her child's dermal melancytosis — a common skin condition in certain populations which causes bluish spots — with bruises, and they, the parents, were treated as if they had beaten their child.

PARENT STORY HIGHLIGHT: RACIAL BIAS



A parent of color nervously shared that she had a miscarriage and then had to endure the medical staff treating her unsympathetically. She explained that she was unsure why the doctors treated her this way: "Maybe because I'm Medi-Cal, maybe because I'm a person of color. I don't know." She shared that it was an unfortunate experience for her.

Some parents mentioned that when they try to change doctors to receive care from a pediatrician who has experience treating children of color, they experience long wait times — which hampers their intention to change doctors because their child's care cannot be delayed.

Parents are not recognized as experts in their children's condition or care and feel doctors don't take their concerns seriously.

Several parents from various racial and ethnic backgrounds expressed frustration trying to convey their concerns and observations about their children to medical professionals who often did not give parents' opinions much medical importance. One parent raised concerns that her child was suffering from reflux, but her concern was dismissed. The parent was persistent (and ultimately proven correct), and the doctor eventually apologized for not taking her concern seriously. Another parent relayed her experience trying to raise a concern to her child's doctor despite the provider's apparent indifference. Not until she described the condition in medical terminology did the doctor show interest. When the doctor then asked if she had a medical background, she replied that she did not. She simply knows her child and her child's condition very well.



[Parents] want to have a relationship not gatekeepers with someone who could inform them.

— from a partner organization on their focus group discussion



Parents have a tough time finding and accessing mental health services and resources for their children.

While some parents had succeeded in connecting to mental health services, many parents expressed that they would like more support in accessing mental health care. One parent reported that she called about 25 different psychologists/psychiatrists in the area, and she was still unable to find help. She would like to see a point of contact for people struggling with mental health added to Medi-Cal. The isolation resulting from the pandemic was noted as contributing further to the need for mental health services.

The lack of assistance for parents throughout the transition from child care services to adult care produces anxiety and uncertainty for families.

Parents expressed not feeling supported during transition periods as their children with complex health care needs move from pediatric care to adult care including not receiving enough information from providers. Parents in the focus group that went through this transition often experienced anxiety as they were forced to do their own research to find resources regarding transition requirements and processes. They

also expressed that their children experience disruptions in treatment and care due to the difficulties in transitioning their children's coverage to adult care. Parents also mentioned feeling that Medi-Cal staff does not have the knowledge to easily transition their children's coverage in a way that they could keep their check-ups, treatments and therapy. Parents also shared that after transitioning, providers do not consider the communication needs of those individuals who still need representation even when they are legally considered adults, such as individuals with autism.

“Autism doesn't end at 19, although service providers can make it seem like it does.”





Assistance With Navigating Health Care and Support Services

Despite health plans' contractual responsibilities to offer assistance in navigating social support services, assisting in coordinating care, and providing health care information and answers to parents' questions, parents often rely on local and community organizations as trusted resources that offer that relational and caring connection. (See examples of trusted partners parents noted below.)



ORGANIZATIONS OR AGENCIES PARENTS RELY ON:

- ▶ Family Resource Centers, which serve families with children with special needs, such as Alpha Resource Center
- ▶ California Children's Services (CCS)
- ▶ Teddy Bear Cancer Foundation, which provides financial, educational and emotional support to families
- ▶ Food banks
- ▶ Schools, which parents rely on for referrals
- ▶ Health centers, where parents obtain information about social services including referrals

PEOPLE PARENTS RELY ON:

- ▶ Pediatricians
- ▶ Health plan representatives
- ▶ Health workers/promotoras
- ▶ Social workers
- ▶ Friends
- ▶ People from their own community or people from their same culture or similar backgrounds to obtain information about resources and ask questions about Medi-Cal

Recommendations: The Path Forward

In our discussions, parents suggested improvements for Medi-Cal, health plans and providers to better assist parents in taking care of their children. Parents' recommendations reinforced our analytic research and compilation of existing resources on effective family engagement strategies in the health care delivery system.²²

First and foremost, families' input needs to be authentically centered in all levels of the system from the individual care level in the doctor's office to the systems level in how care is managed as well as in the health care policies set forth.

Using the framework for the fundamentals of authentic consumer engagement shared in this report's introduction, *Figure 1* below outlines the operational building blocks for managed care plans' activities for engaging families. These building blocks can also apply to DHCS' Medi-Cal family engagement strategies.

AUTHENTIC FAMILY ENGAGEMENT BUILDING BLOCKS¹⁶



1 Representation: Does the health plan fund and partner with community-based organizations and family-led organizations to help identify, support and mentor family participation? Do family participants reflect the community (e.g., race, ethnicity, income, language, geography)?

- ▶ Participants reflect the Medi-Cal community (race/ethnicity, language, income, immigration, gender identity, geography, age) with multiple and varying engagement strategies given communities are not monolithic.
- ▶ Health plan partners/contracts with CBOs to support their capacity and infrastructure to help recruit, cultivate family leadership development and mentor family participation.
- ▶ Health plan trains families in leadership skill-building.

2 Transparency and inclusivity: Does the health plan provide supports and information families need to be informed participants in providing input? Are they partnering at each stage of the process?

- ▶ MCP provides families the necessary supports to reduce barriers to participation in family engagement activities (e.g., compensation, transportation, child care, translation, varying levels of participation, flexible and accessible meeting times and locations).
- ▶ MCP engagement strategies clearly communicate to families how, when, and the extent to which their participation and feedback will play a role in decision-making.

3 Involvement: What is the health plan doing differently because families were involved?

- ▶ MCP incorporates family input into organization decision-making.
- ▶ MCP monitors and shares back with families the demonstrable impact their participation has had on how the MCP does business. (Process and outcome measures showing a difference made as a result of families' input.)

4 Commitment: Is leadership involved and incorporating family input into decision-making? Does the health plan educate and inform all staff about the importance of engaging families at all levels of the system, valuing families' time, and respecting their contributions?

- ▶ MCP secures a long-term commitment from and involvement of institutional leadership.
- ▶ MCP trains all staff in the importance of family engagement, valuing the expertise and input families offer and approaching collaboration with humility and patience.
- ▶ MCP dedicates skilled staff, funding and time to family engagement strategy.



The following recommendations are to operationalize and improve Medi-Cal's family engagement strategies to advance child health equity. Recommendations are organized according to the entity to which they are directed.



DHCS: Seeking Input From Families Themselves

- ▶ Direct input into DHCS policies and programs.
- ▶ Setting family engagement standards for contracted plans and providers.



Managed Care Plans: Engaging Families as a Quality and Equity Strategy and Leadership Priority

- ▶ **Managed Care Plans** collaborate with community on family engagement strategy.
- ▶ **Managed Care Plans' CACs** work best when co-run with community consumer members and input is channeled to organizational leadership.



Managed Care Plans: Improvements to the Delivery of Care for Children

- ▶ Implementation of a whole-person approach to children's care, care coordinators and transition teams.
- ▶ Improve information shared with families and include support services for the whole family.



Providers: Partner With Parents as Experts in Their Children's Care and Lived Experience

- ▶ Improve provider directories.
- ▶ Cultural and customer-friendly trainings for all provider staff.



DHCS: Seeking Input From Families Themselves



DHCS and the Medi-Cal agency have a few different roles to play in consumer engagement, such as directly seeking beneficiaries' experience of and feedback about the DHCS and Medi-Cal operations. Engagement in Medi-Cal operations would include county enrollment/renewals, health plan selection, and health plan and health care provider availability and quality of care, as well as DHCS' own direct services to beneficiaries such as assistance lines, outreach/notices, and translations. Another DHCS family engagement responsibility is providing clear directives and guidance to Medi-Cal contractors like counties, Health Care Options, and contracted managed care plans on consumer engagement requirements essential in their Medi-Cal lines of business.

Over the past few years, DHCS has noticeably increased its engagement with stakeholders through the creation of stakeholder workgroups and advisory committees based on

various areas of focus. Examples include the consumer-focused stakeholder workgroup on specific consumer issues, which mostly relates to eligibility and enrollment, and the Stakeholder Advisory Committee, which keeps consumer and provider organizations updated on Medi-Cal reforms and seeks their feedback. For the development of the new CalAIM reform package, DHCS held several workgroups with stakeholder organizations at which DHCS sought feedback on specific policy and operational issues for several of the CalAIM proposals. Most recently, DHCS has engaged children's organizations in thinking through how to design the CalAIM programs like the Enhanced Case Management benefit and the Population Health Management requirement from the perspective of child-specific needs, health care and care settings.

Over time, DHCS has broadened its engagement reach from stakeholder input in the form of formal comment periods on almost-final policies

to a more iterative feedback loop in the design of its initiatives. The next stage in DHCS' consumer engagement is to seek the direct input from beneficiaries themselves, not filtered through organizations representing their positions and not filtered through the contracted entities serving them such as counties or managed care plans.

DHCS' Quality Strategy puts forth as one of its four Quality Strategy Goals "Engaging members as the owners of their own care."²³ Toward this goal and as part of DHCS' Health Equity Roadmap, DHCS intends to solicit feedback from families directly on Medi-Cal policies and require beneficiary representation from health plans' Community Advisory Committees to participate in DHCS' own consumer advisory committees. During the writing of this report, DHCS released the managed care RFP and the accompanying template contract included many features of the recommendations listed on the following page.

RECOMMENDATIONS FOR DHCS SEEKING INPUT FROM FAMILIES THEMSELVES:

(See [Appendix B](#) for more details).



Build a family engagement infrastructure by meaningfully supporting families' engagement and including their input into DHCS decision-making.

- ▶ Fund — and partner with — local CBOs to help recruit, mentor and support consumer engagement participants in DHCS' engagement strategies.
- ▶ Compensate families for their participation.
- ▶ Create and support peer-to-peer mentoring programs through CBO partners.
- ▶ Create an office of consumer engagement within DHCS leadership.
- ▶ Promote and increase capacity in DHCS' ombudsman program.
- ▶ Establish DHCS Consumer Advisory Committees, including representatives from the managed care plans' CAC members.



Require Managed Care Plans to integrate authentic family engagement strategies into decision-making.

- ▶ Require managed care plans to demonstrate the impact of family input on organizational decision-making.
- ▶ Co-develop, with family representatives, a family engagement performance measure as part of managed care plans' equity improvement measures.
- ▶ Provide managed care plans with guidance on claiming family engagement expenses and technical assistance in developing and implementing family engagement strategies.



Center the Family Experience: Incorporate in communication materials the information that families want to receive from Medi-Cal and help them navigate the Medi-Cal program.

- ▶ Contract with trusted local partners and peer-to-peer programs to help families navigate Medi-Cal (i.e., enrollment, benefits, health plans) and provide classes to help parents understand Medi-Cal.
- ▶ Promote grievance processes and make the process easier for parents to register concerns about a plan, Medi-Cal staff and health providers.
- ▶ Increase awareness about the rights of parents to request interpretation services and to receive paid care coordination covered by their child's health plan.
- ▶ Design information materials with the parents' interest in mind, and in collaboration with them (with compensation), and highlight what information is relevant for a child's specific needs.
- ▶ Ensure information materials are concise, consumer-tested and translated by a native speaker.





Managed Care Plans: Engaging Families as a Quality and Equity Strategy and Leadership Priority

As mentioned, the recently released DHCS' Comprehensive Quality Strategy and Medi-Cal managed care RFP and sample contract²⁴ have prioritized centering the patient in care delivery, including new channels for family engagement in the systems operation, particularly regarding managed care plans' Community Advisory Committee. The contract clarified the role members and families should play in various managed care plans' responsibilities such as in its Population Health Management program and in developing its Quality Improvement activities.

For both health plans and DHCS, it cannot be overstated how pivotal ongoing partnerships with and support for local community-based and local organizations will be for the success of their family engagement strategies. CBOs are effective because family trust and relational engagement are the cornerstone of their operation. Medi-Cal and managed care plans can benefit from that relational trust that CBOs have with families, but CBOs need to be sufficiently compensated for assisting health plans, given CBOs' limited staff capacity and resources.



MANAGED CARE PLAN RECOMMENDATIONS

In addition to meeting Medi-Cal contractual requirements, there are approaches managed care plans can take that will differentiate authentic family engagement from a “check box” compliance exercise. Below are suggested activities and approaches that could yield greater meaningful input.



Set consumer input as an organizational and leadership priority.

- ▶ Incorporate family input into leadership and decision-making processes.
- ▶ Have leadership directly participate in family engagement activities.
- ▶ Provide a feedback loop, sharing back the changes made based on family input.
- ▶ Train all managed care plans’ staff in family engagement principles.
- ▶ Train managed care plans’ support line staff on cultural competence and humility.
- ▶ Partner and contract with local community consumer organizations to train families in leadership skill-building and assist in recruitment.
- ▶ Provide classes and training to members and community partners on Medi-Cal, the health plan’s care delivery models and policies, as well as background on managed care plans’ potential engagement approaches.



Develop with consumers an organization-wide consumer engagement strategy.

- ▶ Develop the strategy in collaboration with consumers and CBOs.
- ▶ Involve a multidisciplinary managed care plan’s team including leadership in the strategy development and implementation.
- ▶ Develop specific family engagement activities including CACs, listening sessions, interactive workshops and focus groups.
- ▶ Assess current organizational family engagement practices.
- ▶ Provide a budget for this strategy.
- ▶ Establish an organizational leadership commitment.



Implement a family engagement strategy feedback loop and outcome monitoring.

- ▶ Establish an ongoing, multi-disciplinary engagement team to implement the strategy.
- ▶ Establish processes and channels of accountability for incorporating family input into decision-making across organizational sectors.
- ▶ Develop outcome measures and track the impacts family input has on managed care plans’ practices.
- ▶ Invest in supporting family participation, such as travel reimbursement, on-site child care, and compensation for their participation.
- ▶ Share back to participating families the impact their input has on managed care plans’ practices.
- ▶ Provide staff time to participate in developing and implementing the strategy.



Actively recruit for family engagement participation and open communication channels.

- ▶ Create an outreach campaign to connect with members for education and recruitment in the managed care plans’ family engagement activities.
- ▶ Partner with and fund local CBOs to assist with recruitment and leadership development.
- ▶ Partner with CBOs to educate members about the managed care plans’ organizational structure and Medi-Cal coverage benefits.
- ▶ Provide channels for communication among members, creating forums for parents to discuss shared issues about their children’s health.
- ▶ Open more opportunities for parents to share suggestions outside of set family engagement activities.



RECOMMENDATIONS FOR MAKING CACS WORK:



Co-develop CAC charter and governance with community/consumers.

- ▶ Develop a 100% consumer/member committee that includes family caregivers and advocate representatives.
- ▶ Ensure members are representative of Medi-Cal community for geography, race/ethnicity, language and gender identity diversity.
- ▶ Co-design CAC goals and scope to reflect the needs of the managed care plans and family.
- ▶ Restructure CAC's governance with consumers (e.g., voting process, agenda setting, subcommittees and co-chairing meetings).
- ▶ Share leadership over the operation of the CAC.
- ▶ Develop process for sharing input in managed care plans' decision-making.
- ▶ Provide feedback loop to share how CAC input impacted managed care plans' practices.



Make it easier for parents to participate in CACs.

- ▶ Provide compensation, transportation stipends, interpretation and child care services for CAC members.
- ▶ Provide an overview of the CAC purpose and process as well as managed care plans' orientation information prior to joining the committee.
- ▶ Provide digital access resources to join virtual meetings.
- ▶ Set regular meetings at times parents can attend.
- ▶ Clarify process for follow-up on next steps for each agenda item.
- ▶ Post CAC meeting agendas, materials, meeting notes and contact information on the health plan website and provide opportunity for public comment.



CACs work best when co-run with community consumer members and input is channeled to organizational leadership.

As mentioned, the effectiveness of a CAC comes from how these structures are implemented.²⁵ The managed care plans' sample contract outlines several specific requirements for the role and function of the CAC and its member composition, as well as requires managed care plans to provide support for CAC members in order to maximize participation and involvement. Establishing and maintaining authentic family engagement in the CAC requires substantial time and effort. Therefore, it is vital to have buy-in and involvement from both health plan leadership and community members.



Managed Care Plans: Improvements to the Delivery of Care for Children

Parents provided feedback on how they believe their health plans could improve the services provided to their children, including the types of support they would like to have access to. In addition, the information and communications they receive from health plans could be improved to highlight what is most relevant for their children's health.

RECOMMENDATIONS:



Improvements on Health Care Delivery

- ▶ Implement a whole-person approach to health for all children.
- ▶ Provide special training for Medi-Cal eligibility workers to ease children's transition of coverage from child to adult care.
- ▶ Improve preventive services.
- ▶ Provide training, support and incentives for providers to include parents in treatment teams.
- ▶ Implement a transition team for children who will be transitioning into adult care.
- ▶ Provide a care coordinator to each family that knows a child's specific case and that can help parents coordinate follow-ups, treatments, medication authorizations, surgeries, etc.
- ▶ Implement training for interpreters to provide friendly and high-quality services to families.
- ▶ Provide self-advocacy trainings for parents.
- ▶ Provide the flexibility to parents to consolidate their child's doctor appointments into a single day visit if a child needs to be seen for multiple issues.



Improvements on Information Shared

- ▶ Highlight information pertinent to their child's care in health plan welcome packets.
- ▶ Provide important information verbally to parents that is pertinent to their child, including contact information to reach social/care coordinators.
- ▶ Provide more personal interaction, such as groups, webinars and interactive workshops on child-specific topics.
- ▶ Make benefit and provider directories more accessible (online) and searchable for specific information (e.g., by provider language and specialty).
- ▶ Improve tailored information for teenagers to navigate their health plan.



Support Services for Children and Their Families

- ▶ Provide classes for parents on stress reduction, parenting and nutrition.
- ▶ Assist families in identifying mental health care providers and resources so that children and their families can access such services in a timely manner.
- ▶ Provide more resources and increase awareness about family counseling options for children and families.
- ▶ Provide mental health support for parents including sharing information and appointment assistance with available mental health providers.





Providers: Partner With Parents as Experts in Their Children's Care and Lived Experience

Throughout the discussion groups, parents shared their feedback regarding ways in which they believe health care providers could improve and better help their children while also considering the parent role in the process. For example, one parent suggested a “continuous improvement plan” in which medical services make sure they’re meeting the needs of the people they’re serving and making sure they’re going through the correct steps to fix what is not working. It was also suggested for hospitals to be staffed with health care professionals that are from the community they’re serving, as a way of ensuring that medical providers are people who understand their patients and truly want the best for them. Additionally, one parent noted that if doctors knew the patient and were part of her same community, they would treat her as one of them and care about how she would want to be treated.

RECOMMENDATIONS:



Improvements on Partnering With Parents as Experts

- ▶ Include in provider directories the doctors’ specialties, as well as their familiarity delivering care to people of color, including a page for parents to see reviews about the doctor.
- ▶ Implement cultural- and customer-friendly trainings for all provider staff.
- ▶ Improve preventive services.
- ▶ Send reminders via text message for appointments as well as recommended vaccinations by age group.



Conclusion

Our conversations with parents/ caregivers revealed several opportunities to improve how Medi-Cal, managed care plans, and providers can collaborate with families to move toward shared decision-making on behalf of children's healthy development and well-being. Key to engagement is ongoing feedback, earnest collaboration and the ability for input to impact decision-making.

To be authentic, and thus effective, family engagement cannot be transactional. Rather, it must be relational and iterative, which requires time and resources. The research revealed this finding, but, more directly, conducting these parent discussion groups was a teachable moment for us in exactly what it takes to be authentic as opposed to transactional in our own engagement. It required a significant investment of time, sharing back what we heard to make sure it reflected what the parents wanted to convey, and making sure that we provided the parents with materials outlining their findings and suggestions. Namely, the parents were not only the research subjects but our partners and audience as well.

Health care providers and systems of care have made some progress in building meaningful engagement into

their operations, such as community clinics with patient representatives on the board of directors²⁶ and health systems creating specific community advisory boards.²⁷ With regard to health plans, local initiatives have ordinances about member inclusion in their governing boards.²⁸ More broadly, authentic family engagement in Medi-Cal health plans is a relatively new endeavor, but the recent DHCS managed care RFP and template contract requirements as well as the new Comprehensive Quality Strategy and Equity Roadmap indicate that Medi-Cal intends to move in that direction.

It is reassuring that Medi-Cal is embracing the goal of child health equity in its recent policies and strategies, but disrupting structural racism means fundamentally shifting the framework, namely health systems collaborating and sharing in decision-making on behalf of children's health. Medi-Cal and its contracted health plans could adopt the operational recommendations presented here. However, without a fundamental reframing of leadership to embrace a shift to shared power and collaboration with families and community, much of the strategies aimed at advancing health equity will be a paper exercise.

Family engagement is one aspect of a larger strategy of community collaboration. In addition to family voice, the community itself needs to be centered in determining health interventions for its population. **Community leaders, community-serving organizations and families know the social factors that are compromising their community and the protective factors strengthening it.** When it comes to population health management and social determinants of health, the community should be setting the table at which health care payers and decision-makers participate rather than health plans determining which community interventions are worthy of investment.

Further exploration of the impacts of community engagement for advancing child health equity will occur as part of our Equity Through Engagement project. In this effort, TCP partnered with the California Children's Trust and the Georgetown Center on Poverty and Inequality to examine the role of Medi-Cal managed care plans in advancing child health equity through community partnerships. A forthcoming report will build upon this family engagement body of work to explore population health needs of children and the needed partnership between Medi-Cal health plans and accountable communities of health and local CBOs.



Endnotes

1. [Medi-Cal's Strategy to Support Health and Opportunity for Children and Families](#), DHCS, March 2022.
2. [Millions of Medi-Cal Children Are Not Receiving Health Services](#), California State Auditor, March 2019.
3. The four CBO partners were: Alpha Resource Center of Santa Barbara, San Ysidro Health, Helluna Health/Eastern LA Family Resource Center, and California Consortium for Urban Indian Health (CCUIH).
4. Throughout this report we refer to the discussion group participants as "parents" because they all were parents of Medi-Cal children. Otherwise, we use the term "caregivers" to reflect all those who have responsibility for raising children, such as parents, guardians, foster parents and grandparents.
5. [CAHPS ECHO Survey Measures](#), Agency for Healthcare Research and Quality, May 2018.
6. [Millions of Medi-Cal Children Are Not Receiving Health Services](#), California State Auditor, March 2019.
7. Throughout this report we refer to the focus group participants as "parents" because they all were the parents of Medi-Cal children. More generally, however, in our discussion of family engagement, we use the term "caregivers" or "families" to encompass parents, guardians, adoptive parents, foster parents, grandparents and others who have or share responsibility for raising children.
8. [2020 Preventive Care Utilization Report](#), DHCS, December 2020.
9. [2020 Health Care Disparities Report](#), DHCS, December 2021.
10. [Medi-Cal COVID-19 Vaccinations](#), (data charts comparing Medi-Cal to all Californians by race/ethnicity), DHCS, February 2022.
11. [In Their Words: Black Californians on Racism and Health Care](#), Linda Cummings for California Health Care Foundation, January 2022.
12. [2021 Edition – Health Disparities by Race and Ethnicity in California: Pattern of Inequity](#), California Health Care Foundation, October 2021.
13. This slogan is often used by marginalized groups seeking to raise their voice and be included in decision-making on issues directly affecting their community. The slogan originated from the work of disability rights activists. <https://www.nytimes.com/2020/07/22/us/ada-disabilities-act-history.html>
14. [Issue Brief: A Framework for Assessing Family Engagement in Systems Change](#), Family Voices, April 2018.
15. [Definitions of Family Engagement](#), Children's Bureau, U.S. Department of Health and Human Services, accessed March 2022.
16. [Center for Consumer Engagement for Health Innovation](#), [Center for Health Care Strategies](#), and the [Center for Family Voice](#).
17. PlanH – an organization that facilitates local government learning, partnership development and planning for communities – [adapted the IAP2 spectrum of public participation](#).
18. [Convening a Consumer Advisory Board: Key Considerations](#), Center for Health Care Strategies, December 2019.
19. [MMCD Policy Letter 99-01: Community Advisory Committee](#), DHCS, April 2019.
20. One of these partners was ultimately unable to fully participate due extremely intensive COVID-19 response activities at their clinic.
21. Throughout this brief 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.
22. [Center for Consumer Engagement for Health Innovation](#) and the [Center for Family Voice](#).
23. [Comprehensive Quality Strategy](#), DHCS, 2022.
24. Medi-Cal Managed Care RFP, Primary Contract Exhibit A Attachment III Scope of Work; Section 5.2.11.
25. [Consumer Engagement in Medicaid Accountable Care Organizations: A Review of Practices in Six States](#), Center for Consumer Engagement for Health Innovations, September 2016.
26. [Health Center Program Compliance Manual, Chapter 20: Board Composition](#), Health Resources & Services Administration, August 2018.
27. [Patient Engagement in Community Health Center Leadership: How Does it Happen?](#), A. Sharma, et. al., Journal of Community Health, May 2018, and [Who Governs Federally Qualified Health Centers?](#), B. Wright, Journal of Health Politics, Policy and Law, February 2013
28. Some local initiatives have ordinances requiring consumer representatives on their governing boards.
29. The [CAHPS ECHO survey](#) specifically asks questions including:
 - Q11 Clinicians listen carefully
 - Q12 Clinicians explain things
 - Q13 Clinicians show respect
 - Q14 Clinicians spend enough time
 - Q15 Feel safe with clinicians
 - Q18 Involved as much as you wanted in treatment
 - Q19 Talk about including family and friends in treatment
 - Q20 Told about self-help or consumer-run programs
 - Q21 Told about different treatments that are available for condition
 - Q27 Care responsive to cultural needs

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Appendix A:

Parent Discussion Groups Discussion Guide

INTRODUCTIONS

- ▶ This discussion group is being hosted by {*your organization*} and The Children's Partnership; we are community organizations working to make sure that everyone gets the best health care available, especially our children.
- ▶ We have invited you to share about and discuss the experiences with your child's/ children's health plan and how that health plan might better meet the needs of our children.
- ▶ We will listen to what you share and discuss so that we can make recommendations to health plans throughout California about how they might provide better health care to families like yours.
- ▶ Nothing you share or discuss will be identified with your name, or shared with your health plan or doctors, e.g., we won't say, "Mr. Lee said that he usually has to wait on hold for 10 minutes whenever he calls his health plan."
- ▶ We are recording this discussion for our own notes; we will not share the recording publicly.
- ▶ As a thank-you for your participation, we will be sending you a \$100 gift card after we finish the discussion.

GROUP AGREEMENTS

- ▶ We want to hear from everyone in the group; after you are finished talking, please give others in the group their turn to talk.
- ▶ Everyone has different experiences with their child's health plan, so there are no "right answers"; we want to learn from each other, especially good experiences that we could recommend as examples for health plans to follow.
- ▶ You can ask each other questions or add to what others say.
- ▶ You can talk about your participation in this discussion group with your family and friends, but please don't share personal information that you might learn about others in the group. For example, if someone in this group shares with us that their child has a certain medical condition, please don't tell others, "I found out that this person's child has this disease!"
- ▶ Can we agree to these agreements as a group? Are there any other agreements that you want to add?
- ▶ Do you have any questions before we begin our discussion?

OVERVIEW OF MEDI-CAL HEALTH PLANS

- ▶ Our discussion today will be about Medi-Cal and the Medi-Cal health plans in California. Can each of you share which Medi-Cal plan your child/children is on? *[From now on, will just say "child" but always mean to include all your children on Medi-Cal.]*

EXPERIENCES WITH YOUR CHILD'S MEDI-CAL HEALTH PLAN

- ▶ If you remember, how did you choose your child's Medi-Cal health plan? (e.g., recommended by doctor, other family members, friends) *[PROBE for auto-assignment.]*
- ▶ Can you say what was most important in how you chose a Medi-Cal health plan for your child? (e.g., because my child's doctor/ clinic was part of the health plan network, language access, heard good things about the health plan, heard that the health plan provided good customer service)
- ▶ Did you have enough information to make a good choice for a Medi-Cal health plan for your child? What type of information did you look at? What type of information would have been helpful?
- ▶ Did you have help in choosing a Medi-Cal health plan for your child? Who helped you?
- ▶ Have you ever received a provider directory (a listing of all doctors and clinics included in your child's Medi-Cal health plan)?
- ▶ Have you ever used the online provider directory on your child's Medi-Cal health plan's website? How easy or difficult was this online provider directory to use? Is there any other information about doctors and clinics that you would want?
- ▶ Did you know that you could change your child's doctor or clinic? What might be some reasons that you would want to change your choice? Do you know how you would change your doctor or clinic with your child's Medi-Cal health plan?

- ▶ When you have questions about your child's Medi-Cal health plan or about your child's health insurance more generally, how easy is it to get answers from your child's Medi-Cal health plan? *[PROBE about translation/interpretation if primary language not English or other communication barriers.]*
- ▶ Are there others that you reach out to with your questions about your health insurance? *[PROBE about doctors, clinics, CHWs/promotoras, family, friends, community-based organizations, faith-based organizations, etc.]*

PROGRAMS AND SERVICES OFFERED BY MEDI-CAL HEALTH PLAN

- ▶ Does your child's Medi-Cal health plan have any health education programs or classes that you have used? (e.g., parenting class, stress reduction class)
- ▶ If you attended any of these programs or classes, what was your experience with them? (e.g., convenient, helpful, too short, not enough information)
- ▶ Are there any other supports or services that your Medi-Cal health plan provides to your family? (e.g., drop-in center, referrals to social services, community health fairs)
- ▶ If you used any of these supports or services, what was your experience with them? (e.g., convenient, helpful, not easy to access)
- ▶ Does your child's Medi-Cal health plan offer you any support in navigating the health care system? (e.g., patient navigators, CHW/promotoras, doulas, peer support, etc.)
- ▶ If you have used any of these supports, what was your experience with them? (e.g., convenient, helpful, not easy to access)

- ▶ Are there any classes, programs or services that you would want from your child's Medi-Cal health plan?
- ▶ What do you like the best about your child's Medi-Cal health plan?
- ▶ What do you like the least about your child's Medi-Cal health plan? How could it improve?

COMMUNICATIONS WITH MEDI-CAL HEALTH PLANS

- ▶ Has your child's Medi-Cal health plan asked you what language/dialect you speak? Whether you want written information in your primary language [other than English]? Whether you need materials in alternate formats? Whether you had difficulty reading or understanding forms or written materials that your child's health plan sends to you?
- ▶ Has anyone ever explained to you that you have the right to a free interpreter [at no cost/charge to you] when your child sees the doctor/goes to a clinic, or when your child has to go to the emergency department or hospital? If yes, who explained this to you?
- ▶ Do you use any of the following to communicate with your child's Medi-Cal health plan: email, text, video online/patient portal? If no to any of these, would you want to use them? *[PROBE about translation/interpretation if primary language not English or other communication barriers.]*
- ▶ Do you use an online/patient portal or an app on your phone to make appointments with your child's doctor? To refill prescriptions? To check/see test results, e.g., a blood test or x-ray? To review your medical record/notes about your child's visits to your doctor/clinic, emergency department, or hospital? If no, would you want to use them?

[PROBE about translation/interpretation if primary language not English or other communication barriers.]

- ▶ Would you say that the written information that you receive from your child's Medi-Cal health plan is easy or difficult to understand?
- ▶ Which written materials are the easiest to understand? (e.g., notices/bills about your monthly premiums, notice about your annual renewal, etc.)
- ▶ Which written materials are the most difficult to understand? (e.g., explanation of covered benefits, bills for services/copayments/deductibles, etc.) *[PROBE: in which language(s)/formats?]*
- ▶ Have you ever received a "member handbook" from your child's Medi-Cal health plan? Have you ever read or used this member handbook? How easy or difficult was it to understand?
- ▶ Does your child's Medi-Cal health plan send you an email or newsletter with general information or reminders about health, e.g., about flu shots, COVID-19 vaccines, etc.?
- ▶ How often do you get this email or newsletter from your child's Medi-Cal health plan?
- ▶ Do you read all, some or none of the information?
- ▶ How useful would you say the information is? (e.g., very useful, somewhat useful, not very useful)
- ▶ Is there any information about your child's health, or your family's health, that you would want from your child's Medi-Cal health plan? (e.g., ideas for healthier eating or more physical activity, parenting classes, stress reduction, mental health services)

COLLECTING INFORMATION ABOUT YOUR CHILD AND GIVING YOU INFORMATION ABOUT YOUR RIGHTS

- ▶ Has your child's Medi-Cal health plan asked you what your child's race or ethnicity is? About any disabilities your child might have? Has your child's health plan ever raised issues of sexual orientation or gender identity with you/your child? If yes, did your child's Medi-Cal health plan explain why they asked you these questions?
- ▶ Has your child's Medi-Cal health plan asked you about your child's or your family's social needs, e.g., about your housing, food needs, transportation, difficulty paying bills, etc.? How did they ask about these social needs? Did your health plan offer you any assistance or referrals for these social needs?
- ▶ Has your child experienced any barriers to accessing health care?
- ▶ Has anyone ever explained to you how to make a complaint about your child's Medi-Cal health plan?
- ▶ If you knew how make a complaint, and had something to complain about *[REFERENCE any experiences shared that could have been something to complain about]*, would you feel comfortable and confident in making a complaint? Why or why not?
- ▶ Has anyone ever explained to you that it is against the law for your child's Medi-Cal health plan to discriminate against your child or you, or treat your child or you differently because of your child's or your race, ethnicity, language, disability, sexual orientation or gender identity?
- ▶ Have you ever felt that your child's Medi-Cal health plan might have discriminated against your child or you, or treat patients differently because of their race, ethnicity, language, disability, sexual orientation or gender identity?

PROVIDING FEEDBACK ABOUT YOUR EXPERIENCES WITH YOUR CHILD'S MEDI-CAL HEALTH PLAN

- ▶ Have you been asked to give your feedback about a phone call or other communication with your child's Medi-Cal health plan? How have you been asked for your feedback? (e.g., survey at end of call, online survey, survey by mail)
- ▶ If you were to be asked for your feedback, which ways are you most likely to respond to? Why? *[PROBE about translation/interpretation if primary language not English or other communication barriers.]*
- ▶ Some health plans ask patients and patient family members to serve as "patient and family advisors" or on a "community advisory council" to give feedback about how to provide better health care on a regular basis. Have you heard about these roles?
- ▶ Would you ever want to serve as such a patient and family advisor or on a community advisory council? Why or why not? What would make it easier to participate? *[PROBE for convenience, accessibility, language needs, transportation/parking, child care, etc.]*
- ▶ If your child's Medi-Cal health plan invited you to a discussion group like the one we are having now to give feedback about your experiences with your child's health plan, would you agree to participate? Why or why not? What would make it easier to participate? *[PROBE for convenience, accessibility, language needs, transportation/parking, child care, etc.]*
- ▶ Do you think that your child's Medi-Cal health plan should organize these types of discussion groups?

- ▶ Do you have other feedback for your child's Medi-Cal health plan to improve your child's health care experiences or the health care experiences of families like you?

TRUSTED SOURCES OF HEALTH INFORMATION

- ▶ Finally, I want to ask about how each of you gets information about your child's health and about any treatments or medicine that your child might need. Besides your child's doctor or clinic, where do you get this information? *[PROBE for sources: family, friends, other health care providers that you know, internet/online, news, social media, etc.; in which language(s)/formats?]*
- ▶ Discussing each of these sources of information *[LIST: family, friends, other health care providers that you know, internet/online, news, social media, etc.]*, which ones do you trust/depend on the most? Why do you trust these sources of information?

Thank you for participating in this discussion group!

Appendix B:

Recommendations for DHCS for a Family Engagement Strategy

- ▶ **Include managed care plan contract requirements with the following features:**
 - + Develop a family engagement strategy through an inclusive, multidisciplinary team (demonstrating consumer and community leader inclusion in the strategy development) with the features listed above.
 - + Establish a Community Advisory Committee based on the features listed above with directed scope on community and consumer needs but flexibility for CAC.
 - + Include additional engagement strategies such as consumer listening sessions, focus groups and surveys, each with ongoing feedback loops and demonstration of how input is impacting decision-making.
 - + Plan for creating a culture of consumer engagement throughout the managed care plan's organization, demonstrating commitment at the highest leadership and monitoring how feedback is incorporated and impacting decision-making.
 - + Designate managed care plan budget for investing/contracting with community-based organizations to recruit and train consumer leaders; provide compensation and support to consumers for their participation (as well as to internal staff to organize the infrastructure, monitor implementation and analyze data).
- + Report to DHCS consumer family input and impact on managed care plans' decisions.
- + Designate a CAC member to participate in a DHCS Consumer Advisory Committee.
- ▶ **Include managed care plans' consumer engagement strategy in RFP rating structure.**
- ▶ **Develop community engagement measures to include in quality performance requirements, including performance payments for consumer engagement quality improvements.**
- ▶ **Provide managed care plans with guidance, best practices and technical assistance in developing and implementing a family engagement strategy.**
- ▶ **Collect and use more data from validated patient experience surveys such as [CAHPS ECHO](#), including specific questions about family experiences of respectful and culturally sensitive care.²⁹**
- ▶ **Create an office of consumer engagement within DHCS that is an integral part of the department's decision-making and quality improvement and develops a DHCS consumer engagement strategy.**
- ▶ **Promote and increase capacity in DHCS' ombudsman program to effectively respond to concerns with providers/health plans, including training in referring cases to OCR.**
- ▶ **Establish a DHCS Consumer Advisory Committees (distinct from stakeholder committees), including one consisting of managed care plans' CAC members, and other consumer engagement strategies such as listening sessions and focus groups to provide feedback to the participants about the impact of their input.**
- ▶ **Fund and partner in an ongoing manner with local CBOs to help recruit and train consumer engagement participants in DHCS' engagement strategies.**
- ▶ **Require contract with an independent entity to conduct an evaluation to assess CAC effectiveness, outcomes and potential improvements and provide evaluation reports to committees. This could be both what DHCS should do itself in addition to a requirement for health plans.**

Appendix C:

Recommendations for Health Plans — Building Blocks for Family Engagement

- ▶ **Plan for an organization-wide family engagement strategy by establishing a workgroup to develop the strategy.** The workgroup would consist of consumers, community leaders, consumer organizations, and a multidisciplinary team of managed care plans' staff including leadership.
- ▶ **Assess current organizational practices and consult family engagement experts including local community consumer voice organizations.**
- ▶ **Establish ongoing organizational leadership commitment and a budget for this strategy.**
- ▶ **Partner and contract with local community consumer organizations to train families in leadership skill-building and assist in recruitment.**
- ▶ **Develop the family engagement strategy.**
 - + Set goals.
 - + Develop specific family engagement activities (Community Advisory Committee, listening sessions, focus groups, interviews, surveys, webinars).
 - + Provide staff time for participating in the development of the strategy.
 - + Develop processes and channels of accountability for incorporating family input at various levels of organizational decision-making.
- + Develop process and outcome measures for and monitor impact of input on organizational practices.
- + Develop feedback loops to share back to families the impact of their input.
- + Create an outreach campaign to connect with members to educate and recruit participation in the managed care plans' family engagement strategy.
- ▶ **Establish an ongoing multi-disciplinary engagement team to implement the strategy (which may mirror the representation of the planning workgroup, with 25% community/consumers).**
- ▶ **Designate staff to coordinate the activities of the family engagement strategy and support the engagement team in their implementation of the strategy plan.**
- ▶ **Resource investments in supporting family participation, such as travel reimbursement, on-site child care, and compensation for their participation; training (staff and participants), recruiting, outreach, functioning of CACs and other engagement strategies (e.g., listening groups, interviews, testing translation materials with families, etc.); and data analysis.**
- ▶ **Train staff in the organizational values of family engagement and incorporating engagement and input into their line of work and processes.**
- ▶ **Train managed care plans' support line staff on cultural competence and humility.**
- ▶ **Train members and community partners on Medi-Cal, the health plan's care delivery models and policies, and background on managed care plans' potential engagement approaches.**
- ▶ **Incorporate listening and family input at the leadership/decision-maker level.**



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

The California Children's Trust (The Trust) is a statewide initiative to reinvent our state's approach to children's social, emotional, and developmental health.

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