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

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 color[1], 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 care[2] 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 is intended to provide parents' perspectives about their experience with their children's coverage and their suggestions for improving children's health care and for how health plans can collaborate with families on systems change.**

To learn from parents, we partnered with **four CBOs**[3] who serve families with children enrolled in Medi-Cal to conduct a total of nine parent discussion groups. 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 Children's Partnership (TCP) 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.

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 Georgetown Center on Poverty and Inequality and California Children's Trust 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.

1. Medi-Cal's Strategy to Support Health and Opportunity for Children and Families, DHCS, March 2022

2. California State Auditor, Millions of Medi-Cal Children are Not Receiving Health Services, 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.

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 transiting 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 what families want from Medi-Cal communications.
- 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; and
- 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); and
- 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 customer-friendly trainings for all provider staff.

Conclusion

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, and 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—offer 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

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