



# Caregiver Perspectives on a Medi-Cal Closed Loop Referral Policy for Effective Implementation

Prepared by Children Now for the Department of Health Care Services

September 2024

## Background and Purpose

The Caregiver Advocacy Circle, a caregiver-driven initiative co-created by Children Now, serves as a platform for caregivers of children with special healthcare needs to identify their priorities, collaborate, and get resources to influence state policies through advocacy. Caregivers possess invaluable firsthand experience and insights into the daily and systemic challenges and needs of children with special healthcare needs. Their lived expertise provides an essential form of thought leadership in the reimagining of more equitable futures for children and families. Their involvement in policy and program design ensures that policies and programs are grounded in real-world experiences, leading to more relevant and impactful outcomes. Despite a wide range of lived and professional expertise, caregivers are rarely fully engaged in shaping the policies, regulations, and service streams that impact their lives on a daily basis.

This memo summarizes key findings from a recent discussion with caregivers on the current state of closed loop referrals and recommendations for the upcoming implementation of a Medi-Cal Closed Loop Referral policy. The memo was informed by perspectives shared by Nancy Netherland, Jenny McLelland, and Susan Skotzke, caregivers passionate about building a better healthcare system for all families. As the Medi-Cal Closed Loop Referral policy gets developed, DHCS should actively involve caregivers in the design and implementation to get diverse perspectives and ensure practical solutions that meet the needs of families. This memo also serves as an invitation to engage in a bi-directional policy development process between caregivers and DHCS. The insights shared in this memo aim to ensure that the Medi-Cal Closed Loop Referral policy is responsive to the needs and challenges faced by families.

## Key Findings and Recommendations

**Efficient and Functional of Referral Systems:** The continued reliance on outdated communication methods like fax machines, wet signatures, and paper forms that can only be filled out by hand hampers the efficiency of the referral process for families. Caregivers can, and do, spend unnecessary hours dealing with these inefficiencies losing valuable parenting and work time for every referral made. Partial functionality and integration with electronic health records and the disconnect between different healthcare providers create significant barriers.

Addressing these systemic inefficiencies is crucial for creating a more streamlined, effective, and consumer-centered referral system. Caregivers highlighted that technology can be used effectively in facilitating referrals. Websites with functional, searchable databases and providers using fully integrated health records systems or platforms can

significantly streamline the referral process. Timely scheduling of appointments, approvals, and dispensing processes can support effective referrals.

**Establish Equitable and Timely Referrals:** Caregivers also pointed out that referrals may be processed more quickly for certain services over others driven by variation in reimbursement rates, which creates further inequities in the system. This is problematic because providers are often incentivized to prioritize services that offer higher reimbursement rates, leaving other essential but lower-reimbursed services delayed or deprioritized. As a result, families seeking care for lower-reimbursed services may face longer wait times, delays in receiving necessary treatments, or reduced access to certain specialists. This inequitable treatment contributes to a fragmented healthcare experience, where timely and appropriate care is not consistently available to all families, exacerbating health disparities and burdening caregivers with additional time and stress in navigating the system.

**Ensure Provider Availability and Suitability:** Ensuring network adequacy, where providers are readily available and accepting new patients, is vital. Caregivers emphasized the need for referrals to connect patients with providers who are appropriately trained and experienced to work with pediatric populations and children with special healthcare needs. It is essential that when referrals are made – that there are 2<sup>nd</sup> and 3<sup>rd</sup> appointments available within a timely manner. Additionally, addressing the difficulties in coordinating cross-county referrals is essential for complex cases involving special healthcare needs, where access to certain pediatric specialists is concentrated in children's hospitals, for example. There is also a significant need to refer families to culturally concordant providers who understand and relate to the diverse backgrounds of the patient population. Matching qualified providers, especially those who are well and sufficiently trained, culturally concordant, and trauma-informed, to the specific needs of children is crucial for effective and equitable healthcare delivery.

**Create Actionable Referrals and Support Systems:** While the ACEs and other screening tools are widely used and evidence-based, there is a lack of a structured framework to translate screening results into actionable referrals. Continuous support and follow-up are essential to ensure that referrals appropriately lead to sustained care with qualified providers. There is also an unmet need for the coordination of referrals and assessments between the entities where children receive care.

Developing robust support systems and resources is key to providing comprehensive care for children, especially those with special healthcare needs navigating multiple clinical delivery systems. Caregivers emphasized the need for active, and informed, involvement of school systems, community organizations, and regional centers in the referral pathways.

**Track, Evaluate, and Improve Referrals:** Collecting data on closed and unclosed referral loops is essential for tracking progress and improving future outcomes. For example, caregivers emphasized that some children have health or social needs that do not meet the criteria for specialized services or existing programs, which lead to unresolved or incomplete referrals. To address this, transparency in the referral and authorization process is critical. It is also necessary to document reasons for uncompleted referrals to maintain accountability and improve systems moving forward.

One significant concern is the lack of consistent terminology and diagnostic codes across healthcare and other providers, causing communication gaps and delays in activating services. Families can be unaware of new diagnoses that could trigger services or assessments, further complicating the referral processes. Despite signing numerous Releases of Information (ROIs), caregivers frequently report that information is not exchanged unless they actively initiate it. This lack of coordination adds unnecessary burdens on families, who must navigate multiple providers to ensure their child's needs are met.

Caregivers also noted that while referrals may appear complete on paper, they often experience significant delays in accessing services. For example, referrals might be authorized and accepted, but families are placed on long waiting lists, sometimes waiting months or even years for an appointment. In these cases, the referral is technically considered successful, but the family does not receive timely care, limiting the effectiveness of the referral system. For instance, some caregivers reported receiving calls for appointments long after the referral was made, to the point that they no longer remembered the reason for the referral or the services needed. These access delays can extend

the time to care by more than a year, creating a system that fails to meet the immediate needs of families, reducing their confidence in the system.

In some situations, particularly in behavioral health, caregivers explained that treatment plans are approved, but services remain unavailable due to a lack of resources. This issue is even more pronounced for families seeking culturally concordant care, where finding appropriate providers can lead to even longer delays. This mismatch between authorized services and actual service availability underscores a critical gap in the current referral system.

To improve the process, it is vital to track several key factors:

1. Were families offered treatment promptly after the intake process?
2. Were they provided with culturally competent care from qualified staff?
3. Did the frequency and type of service align with their child's and family's needs?

Addressing these challenges presents an opportunity to create a more efficient, responsive, and family-centered referral system. Comprehensive policies and frameworks must be implemented to transform screening and treatment data into actionable referrals. Continuous feedback from caregivers, and systematic evaluation of outcomes, is essential for ongoing improvements in healthcare delivery.

## Conclusion

Caregivers envision a Medi-Cal Closed Loop Referral policy that reduces delays and improves the overall efficiency of referrals. A key priority is ensuring that providers are equipped with the necessary skills and cultural competencies to meet the unique health, social, and cultural needs of the children and families they serve. Developing a streamlined and effective referral system is crucial for addressing the needs of children with special healthcare requirements. By incorporating the insights and recommendations shared by caregivers, DHCS can create a more responsive, equitable, and efficient referral process that truly "closes the loop" and better supports families.

## Acknowledgement

*This work is funded by a grant from the Lucile Packard Foundation for Children's Health, Palo Alto, California. The views presented here are those of the authors and not necessarily those of the Foundation or its directors, officers or staff.*