



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 and youth with special health care 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 and youth with special health care 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 health care 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Efficient and Functional of Referral Systems: The continued reliance on outdated communication methods like fax machines, wet signatures, and paper forms that can only be filled out by hand hampers the efficiency of the referral process for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 health care 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 health care 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 and youth with special health care needs. It is essential that when referrals are made, additional appointments or follow-ups are also available in a timely manner. Additionally, addressing the difficulties in coordinating cross-county referrals is essential for complex cases involving special health care needs, where access to certain pediatric specialists is concentrated in children's hospitals, for example. Referring families to culturally concordant providers who understand their diverse backgrounds is essential. Connecting children with well-trained, culturally responsive, and trauma-informed providers is key to ensuring effective and equitable healthcare delivery.

Create Actionable Referrals and Support Systems: While the Adverse Childhood Experiences (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 and youth, especially those with special health care 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 health care 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?

By addressing these gaps and consistently tracking key factors such as timeliness, cultural competency, and service alignment, the referral system can become more responsive and equitable, ensuring that children and families receive the care they need without unnecessary delays or burdens.

Conclusion

The recommendations presented in this brief offer a roadmap for creating a more efficient, responsive, and equitable Medi-Cal Closed Loop Referral system. By addressing the current inefficiencies, reducing delays, and ensuring culturally competent care, the system can better meet the needs of children with special healthcare needs and their families. The active involvement of caregivers throughout the design and implementation of this policy is essential, as their lived experiences offer invaluable insights into the practical challenges families face. A system that prioritizes timely, coordinated, and culturally relevant care will not only improve health outcomes but also restore confidence in the referral process. Through continuous feedback loops with caregivers and a commitment to addressing disparities, DHCS can establish a referral system that truly "closes the loop" and delivers meaningful, accessible care for all families.

Acknowledgement

Nancy Netherland founded Kids and Caregivers; a nonprofit that provides wellness and navigation resources for families, caregivers, and providers of children living with chronic illnesses. She also works with the California Children's Trust on caregiver engagement and serves on a variety of committees including; the California's Medicaid Children's Health Advisory Panel (MCHAP), CCS Monitoring Workgroup, the Cal-AIM Workgroup for Foster Youth and Families, and the Family Advisory Council at UCSF Benioff Children's Hospitals.

Susan Skotzke serves on the Whole Child Model Family Advisory Committee, passionate about securing access to quality health care for children and youth with special health care needs. She also advocates in various other areas such as education, improving the design of classrooms and bathrooms for fragile students.

Jenny McLelland serves on the Medi-Cal Members Advisory Committee (MMAC), works closely with Little Lobbyists, a national group that advocates for medically fragile, technology dependent children and disability justice, and writes for the California Health Report on issues that affect children and youth with special healthcare needs.

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.