



ISSUE BRIEF #4

LA County Children's Health Disparities

Children and Youth with Complex Medical Needs Transition to Adulthood

How do we facilitate the continuation of critical support when children with complex medical needs age out of care eligibility?

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In Collaboration with

HMA

Introduction

Led by L.A. Care and Children's Hospital Los Angeles (CHLA), and with support from First 5 LA, HealthNet, and Molina, the Los Angeles County Children's Health Disparities Roundtable was convened in November 2023. The roundtable event brought together local leaders to discuss four rising challenges in children's health, with a particular focus on engaging populations that have been historically under-resourced and who often receive services in fragmented care environments.

Local leaders were divided into four working groups to wrestle with a particular challenge facing children and youth in LA County today:

- **Building Resiliency:** How can we improve the systems of care to improve well-being and address children's mental health needs?
- **Vaccine Catch-up and Misinformation:** How can we improve access to and the provision of immunizations to promote children's health?
- **Supporting Children and Youth Involved in the Child Welfare System:** How can we improve the quality, appropriateness of supports, and ease of access to care to address the unique needs of children involved in the child welfare system?
- **Children with Complex Medical Needs Transitioning to Adulthood:** How can we facilitate the continuation of critical support as children with complex medical needs age out of care eligibility?

The four resulting policy briefs present recommendations specific to LA County, recognizing that work in the County has statewide implications and relevance. The workgroup planning and discussions were grounded in the evolving policy and service delivery landscape, particularly for Medi-Cal beneficiaries, and the emerging new opportunities to support children and youth. A consistent theme across the four convenings was the need to engage trusted community partners who can facilitate and promote engagement in care.¹ Recommendations were informed by facilitated workgroup discussions with support from Health Management Associates (HMA) consultants who provided subject matter expertise and drafted policy briefs. Workgroups were charged with developing recommendations that:

- Focus on strategies and actions that are tailored to the specific needs in LA County
- Promote initiatives that can be undertaken in the next two to three years to address gaps and challenges in the current systems of care
- Maximize and reflect opportunities to improve the systems of care, given the known and anticipated changes in the publicly funded systems of care

Members and contributors to each of the workgroup are listed in the Appendix of each report.

¹ Community partners or organizations sometimes are referenced as "backbone" organizations.

Understanding the Evolving Systems of Care

Nationwide and statewide, there has been increased recognition of the need to broadly address children's health following the pandemic. The pandemic highlighted disparities and exacerbated preexisting inequities in access to and engagement in services that promote the physical and mental health of children and youth.

The fact is publicly insured children tend to receive fewer preventive healthcare interventions. The comprehensive benefit package known as Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is available to children and adolescents younger than 21 years old, who have Medicaid (Medi-Cal) or Medicaid expansion Children's Health Insurance Program (CHIP) coverage.² EPSDT requirements are intended to ensure that children and adolescents receive appropriate screening, preventive, dental, mental health, developmental, and specialty services; however, young children insured through Medicaid are less likely to receive regular preventive care than those with commercial insurance.³

A similar pattern of inequity for children in the Medi-Cal safety net exists regarding mental health services. In California, despite more than 30 percent of adolescents reporting feelings of depression and over 10 percent having considered suicide, fewer than 5 percent of children and youth younger than age 21 in the Medi-Cal system have received mental health services.⁴ The recent audit of the California Department of Health Care Services (DHCS) and Department of Managed Health Care (DMHC) issued in November 2023 concerning DHCS's timely access monitoring of specialty mental healthcare and substance use treatment plans found that *significant numbers of County-managed Medi-Cal plans are not in compliance with DHCS standards*. The audit concluded:

“DHCS is missing opportunities to ensure that qualifying children receive the behavioral health care services to which they are entitled.”⁵

² EPSDT is required for Medicaid programs and Medicaid expansion CHIP programs but is not required in states with private CHIP programs.

³ Children insured through Medicaid managed care are less likely to receive their recommended well-child visits at 15 months old than children in households with commercial insurance (57% vs. 81%). Source: National Committee for Quality Assurance. Child and Adolescent Well-Care Visits (W30, WCW). Available at: <https://www.ncqa.org/hedis/measures/child-and-adolescent-well-care-visits/>.

⁴ Sources: California Children's Trust. The California Children's Trust Initiative: Reimagining Child Well-Being. November 2018. Available at: <https://cachildrenstrust.org/wp-content/uploads/2018/11/PolicyBriefReimaginingChildWellBeing.pdf>; and California Children's Trust. Data & Backgrounders. Available at: <https://cachildrenstrust.org/our-work/data-backgrounders/#map>.

⁵ Department of Health Care Services and Department of Managed Health Care. Children Enrolled in Medi-Cal Face Challenges in Accessing Behavioral Health Care. Report 2023-115. November 2023. Available at: <https://information.auditor.ca.gov/pdfs/reports/2023-115.pdf>.

California's Medi-Cal system is undergoing substantial changes in response to both statewide and national trends through two major initiatives shaping the health and well-being of children and youth. The first, California Advancing and Innovating Medi-Cal Act (CalAIM), is intended to improve the entire continuum of care, streamline services, and ensure equity across the Medi-Cal program. Integrated with other DHCS preventive and wellness strategies (e.g., 50 by 2025), and with a particular focus on maternal and pediatric care services, CalAIM initiatives leverage managed care plans to ensure assessments and supports for children and youth by addressing the most vulnerable populations through enhanced care coordination and community supports.⁶ Concurrently, the Children's and Youth Behavioral Health Initiative (CYBHI), is a comprehensive, multi-departmental effort to increase the availability and access to behavioral health services for California's children, youth, and families. CYBHI is expanding access points, the behavioral health workforce and services, and reforming reimbursement opportunities, through a significant, one-time investment, new Medi-Cal benefits, and innovative payment strategies.

Additional Acknowledgements

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Note: Each paper will additionally have a list of participants for recognition at the back.

⁶ Bold Goals 50 x 2025 focused largely on children and women's preventive services. Source: Department of Health Care Services. Comprehensive Quality Strategy. 2022. Available at: <https://www.dhcs.ca.gov/services/Documents/Formatted-Combined-COS-2-4-22.pdf>.

Current Context Surrounding Children and Youth with Complex Medical Needs

The population of children and youth with complex conditions includes individuals with a broad range of medical, developmental, behavioral, and social needs. The definition of this group of children and youth also differs by program and health/social service benefit, thereby adding to the complexity of understanding the scope of benefits, the various health needs, and how to track progress.

The Health Resources & Services Administration's Maternal and Child Health Bureau defines children and youth with special healthcare needs (CYSHCN) as *"those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*⁷ Approximately one-fifth of children and adolescents in the United States have special healthcare needs. State-level programs, such as California Children's Services (CCS), provide a range of medical, developmental, and case management services for children or youth with complex conditions. CCS in particular has a more focused list of diagnoses that qualify a child or youth for expanded support. These diagnoses include conditions as varied as cystic fibrosis, cerebral palsy, seizure disorders, and medical needs resulting from traumatic injury, such as accidents or violence. This range of diagnoses highlights the diverse needs and the wide array of specialties that provide essential care to this population. As of July 2024, 44,811 children and youth who live in LA County were enrolled in CCS.⁸ The CCS enrollment rate provides a general indication of the volume of children and youth in LA County with medical complexity; however, not all such people are enrolled in this program, and some CCS enrollees have acute needs that require treatment of limited duration. Hence, the CCS population is likely significantly smaller than the entirety of CYSHCN.

Youth with complex conditions face greater challenges in transitioning from pediatric to adult health systems than the general population. Recent data from the National Survey for Children's Health identified that only 23 percent of US adolescents (between the ages of 12 and 17) with special healthcare needs received sufficient support in transitioning from pediatric to adult healthcare.⁹ This number was lower in California, where only 19.3 percent of this special needs population received adequate transition support.¹⁰ In 2024, approximately 3,000 youth enrolled in LA County CCS will turn 21 years old, necessitating the need for an active transition plan and supports. When expanding the lens to CCS clients between 18 and 21 years old, who are either approaching a transition or who could need to transition to subspecialty care where the pediatric age limit is 18, that number increases to nearly 15,000 (14,369 in 2024).

⁷The Health Resources and Services Administration. Maternal & Child Health. Children and Youth with Special Health Care Needs. NSCH Data Brief. June 2022. Available at: <https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf>.

⁸California Department of Health Care Services. California Children's Services (CCS) Enrollment by Financial Indicator as of 7/1/2024. Available at: <https://www.dhcs.ca.gov/services/ccs/Documents/CCS-07-2024-Enrollment-Data.pdf>

⁹Data Resource Center for Child & Adolescent Health. National Survey of Children's Health (2022-Present). Available at: <https://www.childhealthdata.org/browse/survey/results?q=10019&r=1>.

¹⁰Ibid.

Systems and Services for CYSHCN

CYSHCN may receive medical services through a variety of channels. These options include private insurance, such as coverage obtained through a parent's employer or purchased via Covered California, as well as public insurance like Medi-Cal, which is based on family income or if the child has a qualifying medical condition or disability. People with Medi-Cal may have fee-for-service (FFS) or traditional Medi-Cal, or they may be enrolled in a managed care plan (e.g., L.A. Care, Health Net, Anthem, Blue Promise, Kaiser, and Molina). Moreover, children who qualify for the CCS program have access to additional services covered by neither FFS Medi-Cal nor managed care. Examples may include payments to certain CCS-paneled specialists, having specific medications or procedures related to the CCS-qualifying condition covered, specific neuromuscular or orthopedic conditions (such as spastic cerebral palsy). People with these conditions may qualify for further services through CCS with the Medical Therapy Program, which provides additional physical and/or occupational therapy and related medical equipment, such as wheelchairs.

CYSHCN who have a qualifying developmental disability with substantial impairment—including autism, cerebral palsy, epilepsy treated with two or more medications, intellectual disability, or a fifth condition closely related in need and services to intellectual disability—may then qualify for services through the Regional Center for children ages 3 and older through the California Lanterman Act. These services are lifelong and intended to provide necessary supports to enable individuals with an intellectual and/or developmental disability (I/DD) to live in the community. The Regional Center serves as the payer of last resort by law, offering necessary medical services, therapies, and equipment related to the qualifying disability if not covered by medical insurance or CCS. In addition, CYSHCN may receive support and therapies through the school district, including access to vocational rehabilitation and transition plans focused on leaving high school.

Mental health services are accessed in a variety of ways as well, including private insurance, Medi-Cal managed care, or county departments of public health; however, navigating the process of obtaining these services, particularly in the transition to adulthood, can be exceptionally challenging. People with an I/DD like autism, who also have co-occurring mental health conditions such as depression or anxiety, may find themselves caught in a cycle of being referred back and forth between entities like the Regional Center and the Department of Mental Health. This dynamic further complicates their ability to access consistent and comprehensive care. As one stakeholder noted, *“Mental health points to the IDD services system and the IDD service systems points to mental health system and the person is caught in the middle.”*¹¹

Thus, at age 17, a CYSHCN may be receiving services to support their mental and physical health, as well as their ability to work toward community-based living, through various channels such as traditional medical insurance (including primary care and specialty care providers like cardiology, gastroenterology, and neurology), CCS, the Regional Center, the school district, and even the child welfare system. They then face a series of changes in care starting at ages 18 through 21 and extending to age 26, which can be highly disruptive given the lack of standardized transition processes and supports.

¹¹ Mirzaian CB, Deavenport-Saman A, Hudson SM, Betz CL. Barriers to Mental Health Care Transition for Youth and Young Adults with Intellectual and Developmental Disabilities and Co-occurring Mental Health Conditions: Stakeholders' Perspectives. *Community Ment Health J*. Published online April 15, 2024. doi:10.1007/s10597-024-01262-x.

Service Changes in the Transition to Adulthood

Though important work is ongoing to ensure a safe and satisfactory transition from pediatric to adult providers, significant obstacles remain for this vulnerable population. At age 18, individuals become legally responsible for scheduling medical appointments, interacting with their insurance company, and completing necessary paperwork, unless they have a family member with documented power of attorney, a healthcare agent, or conservatorship properly obtained and filed with the court. Their Medi-Cal and Supplemental Security Income (SSI) shift toward being directly issued to them, rather than their family.

Regional Center services may be minimally affected, but the individual must be able to prove that the condition started before the age of 18 to qualify for lifelong services. The individual's primary provider of care may need to change depending on the specialty and practice policies. For instance, pediatricians may continue to see the individual until age 18 or 21, depending on the practice. Family practice physicians may be able to continue providing primary care, whereas many providers of pediatric specialty care are likely to stop seeing people at age 18, with some exceptions extending to age 21. For individuals with managed care, access to adult specialists will require a referral from a primary care physician. The lack of systems of information exchange and universal health records adds complexity to this transition.

Many patients seeking to transition from pediatric to adult healthcare report difficulty finding a primary care provider who is willing and able to provide care given their underlying medical or developmental condition. Exacerbating this challenge is the fundamental differences in pediatric and general adult medicine. These differences begin with the transition from caregivers making the patient's decisions to the expectation that the patient is now autonomous and fully capable of assuming responsibility for healthcare decision making.

Adult providers are less likely than pediatric providers to approach the patient from the lens of needing care coordination and case management. For example, the provider might expect the patient to schedule, attend, and report back about specialty care appointments. Furthermore, adult providers are less likely than pediatric providers to operate as subspecialists than pediatric providers, creating the need for additional specialty care referrals. Pediatricians are likely to manage problems further along the continuum before referring a patient to a pediatric subspecialist. Families of CYSHCN frequently report being unable to find an adult specialty care provider appropriate for their child's medical needs. Access to specialty care is further complicated by significant workforce issues both in California and nationally. A variety of programs to assist in the transition process are already in place in LA County, though these reach a small minority of the total transitioning population. For example, at UCLA, a transition consultation clinic staffed by medicine- and pediatrics-boarded physicians assists families in planning for all aspects of transition.

Fortunately, CCS can continue until age 21, bridging coverage and continuity of care for youth who need to change medical providers at age 18. However, despite many of the CCS-qualifying conditions persisting into adulthood with the same or greater support needs, no equivalent program is in place for adults. The Genetically Handicapped Person Program covers a very limited number of diagnoses, and there are significant gaps in the number of teams available to serve the adult population. Simultaneously, individuals may be transitioning out of their supportive school environment at age 18 or 22 and now face the additional challenge(s) of seeking employment, higher education, and/or appropriate day programs. The myriad changes in care, support, and services during this time, coupled with barriers to access (including transportation and economic challenges), can create significant stress and result in an inability to access necessary medical care or durable medical supplies and equipment. Qualitative studies on healthcare transitions for CYSHCN have noted that the transition process can be “objectively terrifying” to youth with special needs and worrisome for their families.^{12 13}

Recommendations

As a starting point, the following recommendations are offered to improve care for CYSHCN transitioning to adulthood in LA County. It is critical to systematically evaluate and study needs in LA County related to the lack of primary and specialty care providers willing and able to care for our CYSHCN as they reach adulthood. Of equal importance are the lapses in documented care, increased healthcare costs resulting from barriers to seamless transitions, and appropriate access to healthcare. Understanding where critical lapses in care (e.g., examining data by specific specialty needs, access to durable medical equipment, etc.) will expand our capacity to develop solutions that address the challenges identified here.

Health plan data—potentially linked to CCS data—may be particularly useful in this domain. It would be particularly helpful to characterize the proportion of patients who aged out of CCS in the prior year for specific conditions and have an appointment with a specialty provider in the year following transition.

Recommendation 1: Increase access to an appropriate care network.

The County should consider strategies for increasing access to appropriate care networks for CYSHCN transitioning into adulthood. These approaches could include the expansion of existing Medi-Cal Centers of Excellence, which are certified by the State to provide comprehensive, disease-specific care, similar to the CCS Special Care Center Model. At present, these facilities cover limited conditions, including sickle cell disease and transplants. Los Angeles County has a vast network of federally qualified health centers (FQHCs) that are geographically suited to serve all areas of the County, most of which are contracted to serve as enhanced care management (ECM) providers under the California Advancing and Innovating Medi-Cal (CalAIM) program. Primary care professionals who staff these FQHCs should be trained in care coordination and case management of complex diseases and facilitate referral to subspecialists who also serve the FQHCs.

¹² Cleverley K, Lenters L, McCann, E. "Objectively Terrifying": A Qualitative Study of Youth's Experiences of Transitions Out of Child and Adolescent Mental Health Services at age 18. *BMC Psychiatry*. 2020;20(1):147. Available at: <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-020-02516-0>.

¹³ Young-Southward G, Rydzewska E, Philo C, Cooper SA. Physical and Mental Health of Young People with and without Intellectual Disabilities: Cross-Sectional Analysis of a Whole Country population. *J Intellect Disabil Res*. 2017;61(10):984–993. Available at: <https://onlinelibrary.wiley.com/doi/10.1111/jir.12422>.

Another option for youth with physical disabilities, a need for ongoing therapy, and access to durable medical equipment would be extended coverage at existing CCS medical therapy units. LA County houses 22 of these units that serve the adult population and are staffed with appropriately trained adult providers. Specific attention is needed for the mental health and dental needs of this population, making use of resources under the Department of Mental Health and expanding Denti-Cal eligibility to adults with special healthcare needs.

Recommendation 2: Improve payment models for CYSHCN transitioning into adulthood.

To address the financial obstacles that CYSHCNs face when transitioning to adult care systems, eligibility for, and coverage by, existing healthcare programs and reimbursement for specific services under those programs need consideration. Eligibility for CCS could be legislated to expand the age limit from 21 to 26 years old, in alignment with private insurance industry standards. The GHPP program could be legislated to include additional complex diseases. Continuous Medi-Cal coverage could be provided when CYSHCNs become eligible to apply on their own, alongside assistance with accessing other public programs, such as SSI. Finally, some CYSHCNs with Medi-Cal are eligible for participation in programs within Medi-Cal, such as ECM, which provide access to benefits that are unavailable to the general Medi-Cal population. Because eligibility criteria for adults differs from that of the pediatric population, these beneficiaries risk losing that benefit when they reach 18 years of age. Extension of this eligibility into adulthood could be considered. Of note, ECM is a program for eligible high needs populations that are enrolled in managed care; to ensure continuity of care, eligible CYSHCNs may need to be enrolled in managed care prior to aging out of current benefits. Providers of care coordination services receive additional payment under ECM.

Recommendation 3: Invest in the case management infrastructure.

The availability and effectiveness of care management and patient navigation programs needs to be increased to assist individuals and families through this incredibly challenging time. Options for consideration include replicating the model and best practices of existing navigation hubs. For example, at Children's Hospital Los Angeles (CHLA), transition activities and information exchange between the patient and pediatric and adult providers are centralized, possibly through Medi-Cal managed care plans. Exploring the role of ECM services for CYSHCN transitioning to adulthood may provide one avenue for this support.

Recommendation 4: Improve communication and data exchange.

The communication/data exchange between related systems need improvement. State-level leadership and financial support are necessary to build a data-sharing framework that would link CCS, Medi-Cal managed care, Medi-Cal providers, and non-medical stakeholders, such as the Regional Centers, school districts, and adult day programs, among others.

Conclusion

CYSHCNs face substantial obstacles and gaps in support when transitioning from pediatric to adult care systems, which could have far-reaching consequences for their continued health and well-being. To address such obstacles, action is needed at the local, regional, and State levels. Generally, this effort will require financial and legislative support, as well as the identification of an organized body of key stakeholders to review and implement recommendations.

Appendix

Members of the Complex Conditions Workgroup

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