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EXPERT PERSPECTIVES ON CHILD HEALTH POLICY ISSUES

COMMUNITY HEALTH WORKER SUPPORT FOR PEDIATRIC PATIENTS AND FAMILIES

Community health workers (CHWs) are a skilled and trusted workforce who often share a background and lived experiences with the individuals they serve and are therefore uniquely equipped to provide patients and families with social care, health education, and care navigation, among many other roles. CHW roles are designed to serve as a bridge between health care institutions and the communities they serve and to enhance the efficacy of clinical care teams with patient support that extends beyond the health care setting.

Recognizing the many ways CHWs can support patients and families, improve health outcomes, and promote health equity, there has been momentum around health care payment reforms and policies that could expand access to CHW services and help scale and sustain this workforce in the United States.

However, at present, the CHW workforce remains fragmented and under-resourced in many settings, and looming cuts to Medicaid could threaten the progress states have made towards payment models and policies that support sustainable CHW programs. At the same time, as changes to Medicaid and other public benefit programs like the Supplemental Nutrition Assistance Program (SNAP) take effect, the core functions of CHWs—including supporting families in navigating complex health and social service systems and accessing needed resources—are more important than ever.

There is a robust body of literature showing that CHW support can improve health outcomes among adults with chronic conditions, and there is a growing body of literature supporting the impact of CHWs on child and young adult health outcomes and their potential role in pediatric health care delivery.

What Are Community Health Workers?

Community health worker is an umbrella term, and CHWs can hold many different job roles and professional titles. Some examples include health promoters (or *promotores de salud*), community health representatives, community health navigators, and community health advocates or advisors. Core competencies for the CHW role include strong communication and relationship-building skills, care navigation skills, and knowledge about resources available in their communities.

Children's Hospital of Philadelphia®
PolicyLab

Madison Langrin, MSPH

Tanisha Belton, DrPH, MPH

Aditi Vasan, MD, MSHP

Elizabeth Odunaiya, MPH, CHES

Rebecka Rosenquist, MSc

In this brief, we discuss evolving financing and care delivery models for CHW programs, review research from Children's Hospital of Philadelphia (CHOP) and elsewhere on the use of CHWs to serve pediatric patients and their families, and highlight some examples of how CHWs have been integrated into care delivery at CHOP. We also (1) discuss areas for future research to help better understand how to optimally deploy and support CHWs serving pediatric patients and families; and (2) examine policy and payment reforms needed to scale and sustain this key workforce.

EVOLVING FINANCING AND CARE DELIVERY MODELS FOR PEDIATRIC CHWS

Historically, many CHW roles have been funded through time-limited philanthropic or grant support. This patchwork of funding mechanisms has made it challenging to scale and sustain CHW programs, sometimes leading to unstable employment for CHWs and inconsistent support for patients and families they serve.

During the COVID-19 pandemic, federal funding for CHWs **increased** **rapidly**, and many health systems relied on CHWs to connect with the communities that were most impacted by the pandemic. And in recent years, **Medicaid funding** has become an important strategy for CHW program sustainability, particularly for CHWs serving pregnant individuals and children.

A **growing number of states** are also moving on programs and policies that specifically support the CHW workforce in pediatric care settings. These programs vary in their focus, Medicaid reimbursement requirements, and care delivery settings. However, emerging themes include using CHW services to support perinatal maternal and child health, children with special health care needs, and children and adolescents with behavioral health needs.

Delivery models often span clinical and community contexts: pediatric CHWs may be embedded in primary care or subspecialty clinics, hospital care teams, home visiting programs, schools, or community-based organizations. Across these settings, pediatric CHWs frequently serve multiple roles, supporting both caregivers of pediatric patients and adolescent and young adult patients with health system navigation and transitions, social needs screening and referrals, health education, and care coordination for children with special health care needs.

In these roles, CHWs benefit from close collaboration with social workers, physicians, nurses, case managers and other members of a child's care team. Effective collaboration between CHWs, social workers, and pediatric clinicians can allow all care team members to prioritize tasks at the top of their scope of practice while ensuring the families they serve are able to have their health and social needs identified and addressed. In a recent **multi-center qualitative study** led by CHOP researchers, CHWs and social workers emphasized their complementary skill sets and highlighted the benefits of working together closely to meet families' needs.

WHAT THE RESEARCH TELLS US RELATED TO CHWS IN PEDIATRICS

A growing body of evidence suggests that CHWs can have a positive impact on both caregiver and child health outcomes, including by **increasing** families' receipt of anticipatory guidance in pediatric well child care, **reducing** children's acute care utilization, and **improving** chronic disease management and health-related quality of life among children with chronic conditions and their caregivers. There is also **evidence** to suggest that CHW programs in pediatric health care settings can **improve well-child care visit attendance and enhance caregiver experiences** interacting with care teams.

In this section, we highlight some potential areas of opportunity for CHWs in pediatrics, based on research from CHOP and elsewhere. While the research we highlight on health impacts of CHW programs is largely positive, much of this evidence comes from small observational studies rather than randomized controlled trials, and there remains a lot we do not know about how pediatric CHW programs should ideally be designed and implemented to maximize their clinical effectiveness and support cost effectiveness and return on investment. Later in the brief, we highlight key focus areas for future research to help fill these gaps.

CHWs can provide family-centered education and support to children with chronic conditions and their caregivers

Several studies have examined the role of CHWs in providing health education and addressing social and structural determinants of health among children with chronic conditions. Much of the available research at CHOP and across the country has focused on CHW support for caregivers of **children with asthma**.

CHW Support for Children With Asthma

There is robust evidence to support the role of CHWs in improving health outcomes for children with asthma. Across three systematic reviews, CHW programs focused on providing health education, social support, and assistance with environmental remediation to children with asthma and their caregivers have been shown to reduce the frequency and severity of asthma symptoms, increase symptom-free days and improve health-related quality of life, and decrease rates of emergency department utilization and inpatient admissions.

Research examining the role of CHW support for children and adolescents with other chronic conditions and their caregivers includes studies on CHW support for caregivers of **children with type 1 diabetes** and CHW support for **adolescents with sickle cell disease** and **type 2 diabetes** as they transition from pediatric to adult care. In the **study** focused on adolescents with sickle cell disease, CHW support was shown to be more effective than mobile health interventions or enhanced usual care in improving young adults' quality of life.

Collectively, these studies find that CHWs can be **effectively integrated as members of the pediatric health care team** and can deliver a range of services to children with chronic conditions and their caregivers. These services include liaising between families and their health care teams, supporting families in accessing needed medical care and social services, assisting with care coordination needs like scheduling appointments and filling prescriptions, providing families with social support through regular check ins, and helping families overcome structural barriers impeding patient care through interventions like home remediation to reduce asthma triggers.

Studies of CHOP's CHW programs have found that they are **feasible** to implement, **acceptable** to patients and families, and **effective** in providing family-centered education and support, **helping** families connect with resources, and, in some cases, **improving** chronic disease management.

In studies of children with chronic conditions in other health care systems, many of which have focused on asthma, CHW support has been linked to **reductions** in acute health care utilization, **improvements** in medication availability and medication adherence across **multiple chronic conditions**, and **increased** knowledge about asthma with improved asthma management.

Less research has examined the relationship between pediatric CHW programs and caregiver outcomes, although emerging evidence is promising. **One study** that focused on providing CHW support to caregivers of children with special health care needs found that completion of the program was associated with decreases in caregivers' reported distress scores and increases in their self-reported understanding of their children's diagnoses. Caregivers in this study were also less likely to report unmet food and housing needs following the intervention.

Collectively, these studies suggest that tailored CHW support may help fill gaps in care and promote the provision of more equitable care among children with chronic conditions.

CHWs can provide culturally concordant health education and systems navigation support to children in immigrant families

Children in immigrant families, along with their caregivers, often face **unique challenges** navigating the health care system and getting access to the care and support they need. These challenges may include difficulty accessing health insurance coverage, understanding their eligibility for government benefit programs and completing enrollment paperwork. Children whose families speak a language other than English may face additional barriers to accessing needed services and completing eligibility and enrollment paperwork. Furthermore, immigrant children and their families may face discrimination within and outside of health care settings and may benefit from support in understanding and adapting to how health care and health insurance coverage function in the United States.

A recent national survey found that **1 in 3** pediatricians in the United States reported feeling unprepared to care for children in immigrant families. CHWs, who often have similar cultural backgrounds to the families they serve along with lived experiences navigating these health care and social services, can play an integral role in bridging this gap.

CHW programs designed to meet the specific needs of children in immigrant families, such as **Family Bridge** at Seattle Children's and **Health Focal Points at CHOP**, have been shown to **improve** parents' knowledge of their children's care and of the health care system, enhance communication with the medical team, **increase patient's health care self-efficacy** and **parent-reported ability to navigate the health system**, and **decrease** patients' likelihood of forgoing medical appointments due to barriers.

Collectively, these studies suggest that support from CHWs may help children in immigrant families access the health care, benefit programs, services and supports that they need to stay healthy.

CHWs can support the delivery of high-quality well-child care and help promote early childhood development

CHWs have also proven beneficial in promoting healthy early childhood development and helping caregivers access the services and supports their children need. For example, CHWs have been **integrated** into the provision of preventive care and developmental support during and after well-child care visits and used to help **connect families to early intervention services** that can help manage developmental delays. Studies also suggests that CHW programs can **improve** childhood vaccination rates, **particularly in early childhood**.

Well-child care visits often cover a wide range of topic areas including assessing caregiver psychosocial needs and child safety, conducting development and behavioral screenings, and screening for social and community resource needs. **HealthySteps**, an evidence-based dyadic care model that integrates a child development expert into the primary care team, **saw** a higher rate of successful referrals to community resources when a CHW, in addition to the child development expert, was part of the primary care team. Another program that integrated CHWs into the early childhood well-child care team saw **increased adherence to** the well-child care visit schedule. CHW integration in pediatric primary care may help ensure that caregivers can receive and retain key information provided during these visits and can subsequently access resources critical to promoting early childhood health.

CHW support may be particularly helpful for families with children who are experiencing developmental delays. Prompt identification of developmental delays and use of early intervention services can improve developmental outcomes, particularly for low-income and racially minoritized children. Researchers at CHOP found that support from a patient navigator, who was a CHW, led to **high rates of referral completion** among children referred to early intervention, and to **expedited completion** of evaluations and subsequent diagnoses among children referred for developmental evaluation.

This evidence underscores the vital role CHWs can play in patient navigation supportive of healthy development and in ensuring children with developmental delays can access the services and support they need.

CHW Programs at CHOP: Case Studies

Program Name	Program Description	Case Study
Community Asthma Prevention Program (CAPP)	CAPP supports families in improving children's asthma outcomes by providing asthma education and trigger-remediation resources. CAPP CHWs help caregivers gain the knowledge, tools, and confidence to effectively manage their child's asthma and advocate for their care.	When a caregiver shared that her toddler's frequent asthma flare-ups were not improving with a rescue inhaler, a CAPP CHW supported her in communicating these concerns to her child's primary care provider, leading to the addition of a long-term control medication and improved asthma management.
Community Health Worker and Mobile Health for Emerging Adults Transitioning Sickle Cell Disease Care (COMETS)	CHWs in the COMETS program work with adolescents and young adults with sickle cell disease to strengthen self-management skills, address barriers to care and support progress toward personal goals.	When a young adult shared that they felt overwhelmed while preparing for their first adult hematology visit, a CHW helped them organize questions for the visit and practice communicating directly with the care team. With this support, the young adult felt more prepared to attend the appointment and was able to take a more active role in managing their own care.
Karabots Primary Care Clinic CHW Program	CHWs provide families of children seen at the Karabots Pediatric Primary Care Center with support through empowerment, advocacy, and community resource navigation and education. In the primary care office and in the community, CHWs focus on meeting and supporting families where they are.	When one mother of several Karabots patients, who was a refugee who recently arrived in the United States, shared that she was unsure how to travel to her child's medical appointments, two CHWs went to her home, rode the bus with her to her child's appointment, and helped her identify recognizable landmarks and ways to navigate the city that did not require English language literacy. They stayed with her through her visit and then accompanied her as she navigated the bus ride back home, helping her build confidence and independence.

WHAT ELSE WE NEED TO KNOW—A RESEARCH AGENDA

The research summarized in this brief offers a snapshot of the many roles CHWs can play in supporting children and caregivers, particularly caregivers of children with chronic conditions, children in immigrant families and children at risk for developmental delays. However, more research is needed to understand how CHW programs should ideally be designed and implemented to benefit pediatric patients and families.

In particular, key focus areas for future research include: (1) optimizing CHW program design, (2) ensuring adequate support for and sustainability of the CHW workforce, and (3) evaluating CHW programs' clinical effectiveness and cost effectiveness across a range of outcomes.

In terms of program design, future research can make CHW programs more effective and efficient by defining *how much support* families need (dose) and *for how long* (duration) to reliably improve child health and well-being. While **several studies** have characterized effective CHW program doses and durations for supporting children with asthma, it is less clear how pediatric CHW programs should ideally be designed to address social needs, support children in immigrant families, support children with chronic conditions other than asthma, or support adolescent and young adult patients in their transition between pediatric and adult care.

To support the CHW workforce, future studies should focus on identifying best practices for effectively **integrating CHWs into pediatric care teams**. This includes exploring strategies for social work supervision and support, promoting CHW workforce sustainability through standardized CHW training and peer support, and implementing standardized processes for promotion and pathways for career advancement.

Lastly, future studies exploring the short-term and long-term clinical effectiveness and cost effectiveness of CHW programs using a range of relevant process and outcome measures are needed. Prior evaluations of pediatric CHW programs have focused primarily on evaluating their impacts on health-related quality of life, medication adherence and health care utilization. The SIREN Social Care Logic Model (see callout at right) points to other outcomes that may be important to consider, including rates of connection to community-based resources; caregiver emotional well-being, stress, and trust in the health care system; caregiver-reported access to needed health care; and patients' and caregivers' self-efficacy in managing chronic conditions.

Social Care Logic Model

The Social Interventions Research and Evaluation Network's (SIREN) Social Care Logic Model highlights the many pathways by which social care interventions, like community health worker programs, could improve health outcomes, including by connecting families to community resources, providing patients and caregivers with emotional support, connecting patients with needed health care services, and changing or tailoring care plans to improve disease self-management.

In addition, understanding the impact of CHW programs on health care provider outcomes, including rates of burnout and provider turnover, could help health systems and payers understand how CHWs impact provider satisfaction and well-being and support high-functioning interdisciplinary care teams.

WHAT ELSE IS NEEDED—FINANCING AND POLICY

As states navigate changes to Medicaid and other social service programs, investing in CHWs offers a family-centered strategy that could help families preserve access to needed benefits while potentially generating cost savings for state governments in the long-term. Accordingly, there is an urgent need for payment models that encourage a long-term financial commitment to retaining CHWs and support sustainability of the CHW workforce.

There has been **national momentum** around Medicaid reimbursement for CHW services through several different mechanisms. As of April 2025, **33 states** provide reimbursement for some CHW services through Medicaid, either through permanent addition of CHWs to the state's Medicaid plan, time-limited Section 1115 demonstration waivers, or managed care contract requirements. Each of these mechanisms represents an important approach to advancing CHW payment and program sustainability, but these strategies also each have some **drawbacks and limitations**. However, the introduction of the Rural Health Transformation Program (RHTP) may present an opportunity; some states plan to **leverage these funds** to continue financing and developing CHW programs serving rural communities.

Medicaid Financing for CHWs in Pennsylvania

Pennsylvania's current strategy for financing CHW services through Medicaid focuses on leveraging Medicaid MCO contracts to promote CHW utilization by setting baseline expectations for CHW staffing and services within MCOs and aligning payment and quality incentives to support these investments. The state requires all of its Medicaid MCOs to employ or contract with CHWs as part of their Community-Based Care Management Programs. While leveraging Medicaid MCO contracts has allowed for reimbursement for some CHW-provided services, there is variation in the specific services and supports provided by these programs and in the patient populations they serve. Pennsylvania has also previously indicated its intent to pursue a Medicaid state plan amendment, which could allow for standardized reimbursement for a broader range of CHW services in the future.

There are several challenges that health system-based CHWs and CHW programs currently face, including restrictive entry criteria for accessing CHW support and limited opportunities for reimbursement. Health systems could consider broadening eligibility criteria for CHW support, rather than relying on disease specific criteria, in order to better support all children and families in need. Additionally, there may be benefits to financing and policy approaches that allow CHWs to work with individuals and families across multiple systems, as this could help ensure CHWs can support patients in their transition from pediatric to adult health systems and can support both pediatric patients and their adult caregivers.

Sustainable financing remains a challenge for the CHW workforce and many CHW initiatives, making it challenging to measure the enduring impacts of these programs on families and communities. Health systems will need to explore multiple funding streams and continue their own investment in CHW programs. State leaders can continue to explore available funding streams—including within Medicaid and through initiatives such as the Rural Health Transformation Program—to support the stability and sustainability of this essential workforce. Stable funding would enable both the scaling of effective models and additional long-term, rigorous evaluation, strengthening the evidence base and clarifying how CHWs can be optimally deployed to support child health.

FOR QUESTIONS OR FURTHER DISCUSSION, CONTACT:
Rebecka Rosenquist, rosenquisr@chop.edu

THE AUTHORS

Madison Langrin, MSPH, is a policy and communications coordinator at PolicyLab.

Elizabeth Odunaiya, MPH, CHES, is a clinical research coordinator at PolicyLab.

Tanisha Belton, DrPH, MPH, is the senior manager of research initiatives at PolicyLab.

Rebecka Rosenquist, MSc, is the deputy director of policy and strategy at PolicyLab.

Aditi Vasan, MD, MSHP, is a faculty member at PolicyLab and an attending physician with the Division of General Pediatrics at CHOP.

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PolicyLab

Children's Hospital of Philadelphia
2716 South Street
Roberts Center for Pediatric Research,
10th Floor
Philadelphia, PA 19146

PolicyLab@chop.edu
policylab.chop.edu

@PolicyLabCHOP