Forgone Health Care is one of twelve Maternal and Child Health (MCH) **Standardized Measures (SMs)** for the Title V MCH Services Block Grant to States Program. This SM is focused on decreasing the percent of children, ages 0 through 17, who were unable to obtain needed health care in the past year.

For Forgone Health Care, there are 11 evidence-based strategies from MCHbest and 8 field-based practices from Innovation Hub (see page 3)

The **What Works Evidence Accelerators** provide background information and a summary of effective strategies to advance each of the SM topic areas. The strategies support increased access to needed health care services for children and adolescents to prevent and treat health conditions.

Overview. Health care can influence children's physical and emotional health, development, and growth, as well as their capacity to reach their full potential as adults. ***Forgone health care*** is described as parents or caregivers not using health care for their children despite perceiving a need for it.[1] It stems from issues such as lack of adequate coverage, financial barriers, logistical challenges, or cultural beliefs. All children are at increased risk of developing preventable conditions if appropriate care is not provided to them when needed.[2] All children need access to coordinated, effective, and age-appropriate preventive services, acute care, ongoing care for children with chronic medical conditions, rehabilitative care for children with disabilities, and care and special support services for children and youth with special health care needs (CYSHCN).[2]

In the U.S., forgone care is an issue for over 2.3 million children.[3] According to data from the 2022 National Survey of Children's Health (NSCH), forgone mental health care was the most frequently reported (1.5%),[4] followed by dental care (1.3%),[5] medical care (0.9%),[6] vision care (0.4%),[7] and hearing care (0.2%).[8] When asked about the reasons for forgone health care, problems getting an appointment was the most frequently reported reason (63.1%),[9] followed by cost (45.0%),[10] lack of availability in the area (32.9%),[11] lack of eligibility (25.0%),[12] clinic or doctor's office was not open when the child needs care (18.8%),[13] and problems getting transportation or child care (14.1%).[14] Children who were older,[15] had a greater number of health conditions,[16] were non-Hispanic Black,[17] were CYSHCN,[18] were uninsured,[19] and had family incomes < 200% of the federal poverty level (FPL)[20] were more likely to have any reported forgone care. Efforts to reduce forgone care need to address financial and non-financial barriers to care and the factors associated with delaying care.[21, 22]

Barriers that Contribute to Forgone Health Care. Families are forgoing needed care for their children due to health care-related financial burden:

- *Financial barriers* refer to the costs imposed by a coverage plan that prevent children from accessing the care they need. This can include high copays, high deductibles, and unaffordable prescription drug prices.
- *Provider-based financial barriers* exist wherein clinics and providers are not incentivized to participate with certain insurance plans, such as Medicaid or CHIP.

Non-financial barriers leading to forgone care include:

- *Access barriers,* such as lack of coverage, difficulty getting an appointment, limited office hours, lack of a usual source of care, lack of transportation, and provider shortages, can inhibit care options.
- *Family-level barriers,* such as lack of child care and difficulty taking time off work, can impede the ability of families to obtain needed care. Cultural factors can also influence care-seeking behaviors.
- *System- and provider-level barriers,* such as racism and discrimination, language and communication difficulties, and lack of culturally responsive care can decrease the likelihood that families will seek care.[2, 21, 22, 23]

In addition to efforts to expand insurance coverage, strategies are needed to address the multiple types of barriers associated with forgone care, and ensure timely access to needed health care for children.[21]

Data. This SM is measured through data collected from the NSCH. In 2022, 3.2% of children did not receive needed health care.[3] By race and ethnicity,

3.6% of Black children, 3.4% of Other, non-Hispanic children, 3.2% of Hispanic children, and 3.1% of White children did not receive needed health care.[17] When looking by special health care needs, 8.4% of CYSHCN did not receive needed health care while 1.9% of non-CYSHCN did not receive needed health care.[18]

Social Determinants of Health (SDOH).

Health care access and quality is one of the five key areas of [SDOH] in Healthy People 2030 with a goal of increasing access to comprehensive, quality health care services.[24] Race and ethnicity, income, gender, and geographic location all play substantial roles in a family's ability to access high-quality, equitable, and affordable health care.[25] Children, particularly those with disabilities and chronic health needs, children experiencing poverty, and children from racial and ethnic minority groups have more health problems and less access to health care than their higher socioeconomic status cohorts.[26]

With increasing recognition of the impact of racism, ableism, and other social and economic factors on child health, many pediatric health systems are undertaking interventions to address SDOH. Value-based payments, expansion of Medicaid funding resulting from policy changes and delivery system reform, along with health system philanthropy and operating revenues, will all be needed to meet mission-based goals of addressing SDOH while supporting financial sustainability.[27]

Health Equity.

Children and families need a health care system that services their unique needs and supports opportunities for life-long health and well-being.[28, 29] The current system fails too many children, especially Black, Indigenous, Latino, and other children of color.[28, 30] Racism, a driver of health inequities, is experienced in the health care system by children, families, and providers and is reinforced by policies, practices, and interpersonal relationships.[11] The Center for Health Care Strategies identified three key strategies for child health care transformation:

- Adopt anti-racist practices and policies to advance health equity.
- Co-create equitable partnerships between families and providers.
- Identify family strengths and health-related social needs to promote resilience.[28]

CYSHCN.

Caregivers of CYSHCN have to navigate complex and inefficient health care and insurance systems to access needed health care.[31, 32, 33] Over 40% of caregivers of children with more complex needs reported spending time coordinating their children's care each week, and the administrative burdens fall disproportionately on Hispanic, lower-income, and publicly insured or uninsured caregivers.[31] The increased time spent coordinating care was associated with an increasing probability of forgone medical care: 6.7% for children whose caregivers spent no weekly time coordinating care versus 9.4% for < 1 hour; 11.4% for 1 to 4 hours; and 15.8% for ≥ 5 hours.[31] To promote equitable access to health care for CYSHCN, health care and health insurance systems need to be streamlined and innovative models of care coordination support need to be implemented.[31, 32, 33]

Key Resources.

Efforts to expand health insurance coverage, increase access to a pediatric medical home, improve resources in communities that are medically underserved, and strengthen cultural competency in health care settings can help reduce unmet needs for children.[33, 34, 35]

Search the [Established Evidence database] for peer-reviewed research articles related to strategies for addressing lack of health care.

Find [field-based resources] focused on addressing lack of health care relevant to Title V programs in the [MCH Digital Library].

Partnership and the Role of Title V.

To reduce forgone health care, Title V can:

- Partner with Medicaid programs to utilize Medicaid managed care (MMC) and expand access to Medicaid for all CYSHCN.[33, 36]
- Leverage Title V CYSHCN care coordination services and expertise to ensure that families have sufficient choice of services based on need and that administrative burdens are low.[31, 32, 33]
- Reduce out-of-pocket health care costs, improve health coverage, and expand social support for children and their families to alleviate financial burdens and the need to delay care.[1, 37]
- Engage in community outreach and education to inform families about available services and the importance of seeking health care for children.[38]

Forgone Health Care Strategies. This page summarizes the latest strategies and practices that have emerged as potential approaches for decreasing the percent of children, ages 0 through 17, who were unable to obtain needed health care in the past year. It provides a framework to identify, understand, and implement "what works" in creating new Evidence-based/informed Strategy Measures (ESMs). Use the links below to access strategy and practice details, approaches, supporting evidence, outcomes, and examples of how Title V agencies are either using these strategies directly or adopting components of the intervention that address this SM.

Evidence-Based/Informed Strategies. 11 strategies have emerged from studies in the scientific literature as being effective in advancing the SM. They can be adopted or adapted to meet your program needs. More information on these strategies can be found in the MCH Evidence Center's MCHbest database. In addition, see Evidence Accelerators in support of related measures: Adequate Insurance (34 strategies) | Uninsured (8 strategies).

Field-Based Practices. 8 practices from state-/community-based programs have emerged as potential approaches for advancing the SM for specific communities or populations. They can be used as models to meet your program needs. More information can be found in the Association of Maternal and Child Health Program's (AMCHP's) Innovation Hub.

Key Findings.

The following are key findings emerging from the literature:

1. Clinic-based enhancements[39-43] can address barriers to care and SDOH to create more convenient, supportive, culturally competent, inclusive, and affirming healthcare environments for preventive and acute care, including care for vulnerable populations, such as LGBTQ+ youth, to improve the health and well-being of children and their families.
2. School-based health programs[44-47] can increase access to preventive and other routine care leading to increased receipt of essential health services, including reproductive health services, and improved management of disease conditions for children and youth with unmet health care needs who may not have otherwise accessed care.
3. Medicaid and health insurance enhancements, such as continuous eligibility policies,[48] Medicaid managed care,[49] and a Medicaid Buy-In program,[50] are associated with improved utilization of primary and preventive care for children, including children with disabilities and children in foster care, by making services more accessible and affordable.
4. Expanded access to healthcare services through a mobile health clinic[51] or transportation assistance[52] can reduce the likelihood of missed or delayed medical care enabling more children to receive necessary health care services.
5. Technology-based initiatives, such as a digital health platform[53] or a mobile phone app,[54] can increase knowledge and awareness to better enable children, youth, and their families to seek and obtain health care when needed.
6. Home visiting programs[55, 56] providing education, support, and referrals to families can encourage timely use of health care, including well-child and sick care, vaccinations, screening, and early intervention to promote healthy development in underserved pediatric populations and prevent the need for more extensive and costly care later.

Discussion: Research, Practice, Partnership.

Research. Multiple strategies are emerging as potential approaches to advance this SM, but they have not been studied with enough rigor to be included in the evidence-based continuum. Additional research is needed to verify outcomes, but initial studies have shown promise of these strategies in MCH settings:

- Engaging community organizations, nonprofits, and faith-based groups to identify and support families with limited access to health care.[57]
- Collaborating with schools to facilitate health insurance enrollment for eligible children.[58]
- Improving the health literacy of parents and caregivers to promote optimal child health.[59]

Practice. The following tools can be used to translate evidence to action to advance this SM:

- Barriers to Care Questionnaire (Cincinnati Children's Hospital Medical Center). This tool developed for parents of children with chronic health conditions measures health care access.
- Find Coverage for Your Family State Map (InsureKidsNow.gov). This tool helps families find health care coverage in their state.

Partnership. The following organizations focus efforts on addressing lack of health care:

- Child Health Transformation Resource Center. Supports improvements in pediatric practice.
- National Center for a System of Services for CYSHCN. Advances the system of services for CYSHCN by supporting implementation of the Blueprint for Change for CYSHCN.

Frameworks and Tools for "What Works."

Use this accelerator to strengthen current or new programs that align with multiple MCH frameworks across domains and settings. Access toolkits related to these frameworks for additional resources:

- MCH Evidence Framework
- Blueprint for Change for CYSHCN
- Maternal Health Toolkit
- Life Course and Social Determinants Brief

Need More Help?

Contact us for training and technical assistance customized to your needs.

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