Road to the Future: Priorities for Child Health Services Research



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The authors declare that they have no conflict of interest.

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ABSTRACT

BACKGROUND: Prior health services research (HSR) agendas for children have been published, but major ones are now over 15 years old and do not reflect augmented understanding of the drivers and determinants of children's health; recent changes in the organization, financing, and delivery of health care; a growing emphasis on population health; and major demographic shifts in the population. A policy-relevant research agenda that integrates knowledge gained over the past 2 decades is essential to guide future child HSR (CHSR). We sought to develop and disseminate a robust, domestically focused, policy-oriented CHSR agenda.

METHODS: The new CHSR agenda was developed through a series of consultations with leaders in CHSR and related fields. After each round of consultation, the authors synthesized the previous experts' guidance to help inform subsequent discussions. The multistep process in generation of the agenda included identification of major policy-relevant research domains and specification of high-value research questions for each domain. Stakeholders represented in the discussions included those with expertise in child and family advocacy, adult health, population health, community development, racial and ethnic disparities, women's health, health economics, and government research funders and programs.

RESULTS: In total, 180 individuals were consulted in developing the research agenda. Six priority domains were identified

for future research, including both enduring and emerging emphases: 1) framing children's health issues so that they are compelling to policy-makers; 2) addressing poverty and other social determinants of child health and wellbeing; 3) promoting equity in population health and health care; 4) preventing, diagnosing, and treating high priority health conditions in children; 5) strengthening performance of the health care system; and 6) enhancing the CHSR enterprise. Within these 6 domains, 40 specific topics were identified as the most pertinent for future research. Three overarching and crosscutting themes that affect research across the domains were also noted: the need for syntheses to build on the current, and sometimes extensive, evidence base to avoid duplication; the interrelated nature of the domains, which could lead to synergies in research; and the need for multidisciplinary collaborations in conducting research because research studies will look beyond the health sector.

CONCLUSIONS: The priorities presented in the agenda are policy-oriented and include a greater emphasis on how findings are framed and communicated to support action. We expect that the agenda will be useful for immediate uptake by investigators and research funders.

KEYWORDS: child health services research; framing children's health; policy; poverty and social determinants; research agenda

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AN ACTIONABLE AND POLICY-DRIVEN research agenda is indispensable to optimally guide child health services research (CHSR). The timely development of broad policy-relevant health research agendas helps to identify critical gaps in knowledge and infrastructure. Research agendas can encourage funders and investigator communities to focus on consensus-driven key questions and research approaches, the results of which can provide evidence to inform health policies and programs.

Recent child health focused research agendas have been proposed for topics such as adverse childhood events/toxic stress, child and adolescent mental health,² Latino children,³ children's oral health,⁴ school mental health,⁵ devel-

opmental/behavioral pediatrics, ⁶ preterm birth, and others. ⁷ However, stakeholders concerned about children have not developed a broad, nationally relevant CHSR agenda since the late 1990s. Those late 20th century agendas were helpful in orienting research to children's unique characteristics relative to adults as well as in shaping research on how to improve health care quality. ^{8,9} The agenda developed by Forrest, Simpson, and Clancy, published in 1997, was critical in building the emerging field of CHSR, in large part by presenting a framework that accounts for ways in which children are different from adults, as captured by the "4 D's"—developmental change, dependency, differential epidemiology, and

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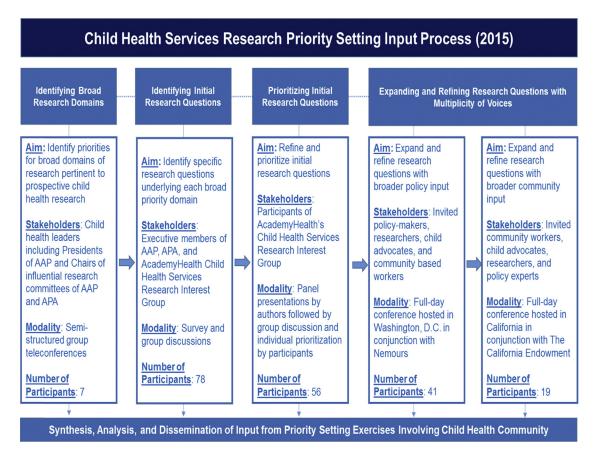


Figure. Process for setting child health services research agenda. Some individuals were engaged in more than one stage of priority setting process, and therefore sum of number of participants in all of stages (n = 201) is not equivalent to total number of individual experts engaged (n = 180).

demographic patterns.⁸ Similarly, a major effort led by Halfon, Schuster, Valentine, and McGlynn resulted in an agenda, published in 1998, that focused on improving the quality of care for children and enhancing the related research enterprise.⁹

These agendas have been cited frequently and have been instrumental in both the framing and conduct of CHSR. ^{10–14} However, they objectively cannot reflect recent understandings of the drivers of children's health and the health policies that support optimal child health. Of note, the prior agendas focused primarily on the health care delivery system, rather than on broader determinants of health and so no longer align with changes in health care financing, organization, and delivery, including efforts to integrate health care and population health. ^{15,16} Nor do they fully capture priorities in light of major racial/ethnic and age-based shifts in the population and the emergence of a life-course perspective as a major driver of thinking about children's well-being. ^{17,18}

Here we present a robust CHSR agenda developed through consultation with diverse groups of child health research experts, practitioners, system leaders, policy makers, and child and family advocates. The agenda is intended to be a starting point for funders, researchers, and advocates and to spur debate and discussion as we collectively work to improve children's health and wellbeing.

METHODS

The CHSR agenda was developed through a series of consultations with leaders in the CHSR community and a multiplicity of perspectives beyond CHSR. Our agenda setting approach was aligned with that of several prior agenda setting exercises across a range of health conditions, topics, and populations not limited to child health. The specific, iterative steps, described more fully below and in the Figure, were aimed at defining broad research domains, identifying initial research questions for each domain, prioritizing these initial research questions, and expanding and refining the research questions with experts beyond CHSR. Semi-structured consultations were held by telephone, electronic survey, and face-to-face meetings over the course of 9 months. After each consultation, the input was summarized, shared, and discussed with the next group, thus iteratively and cumulatively refining the input and priorities.

Our approach to setting research priorities by attaining input first from child health researchers and then intended users of the evidence is consistent with other priority setting initiatives. For example, we followed the guidance of the Child Health and Nutrition Research Initiative to consult first with senior researchers in the field because these people are best able to comment on the state of available knowledge and its use. ^{1,19–23}

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