

BMJ Open Conceptualising paediatric health disparities: a metanarrative systematic review and unified conceptual framework

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ABSTRACT

Objective There exists a paucity of work in the development and testing of theoretical models specific to childhood health disparities even though they have been linked to the prevalence of adult health disparities including high rates of chronic disease. We conducted a systematic review and thematic analysis of existing models of health disparities specific to children to inform development of a unified conceptual framework.

Methods We systematically reviewed articles reporting theoretical or explanatory models of disparities on a range of outcomes related to child health. We searched Ovid Medline In-Process & Other Non-Indexed Citations, Ovid MEDLINE, Ovid Embase, Ovid Cochrane Central Register of Controlled Trials, Ovid Cochrane Database of Systematic Reviews, and Scopus (database inception to 9 July 2015). A metanarrative approach guided the analysis process.

Results A total of 48 studies presenting 48 models were included. This systematic review found multiple models but no consensus on one approach. However, we did discover a fair amount of overlap, such that the 48 models reviewed converged into the unified conceptual framework. The majority of models included factors in three domains: individual characteristics and behaviours (88%), healthcare providers and systems (63%), and environment/community (56%). Only 38% of models included factors in the health and public policies domain.

Conclusions A disease-agnostic unified conceptual framework may inform integration of existing knowledge of child health disparities and guide future research. This multilevel framework can focus attention among clinical, basic and social science research on the relationships between policy, social factors, health systems and the physical environment that impact children's health outcomes.

Adult health disparities across sex, race and ethnicity, socioeconomic status (SES), disability status and other social characteristics have been well documented in the USA,^{1,2} and the geographic and temporal trends of these health disparities have persisted over time.^{3–7} Research on child health has also

Strengths and limitations of this study:

- This systematic review was able to identify and synthesise a large number of models with varying constituent parts.
- The search was not restricted by underlying disease, health status and racial or ethnic group and thus the framework can be applied in many types of research in child health disparities.
- This review is limited to models in developed countries.
- Current data limitations may hamper the ability to test the proposed framework empirically, but the framework can guide future work including data collection.

documented a persistence of disparities,⁸ with unequal care or outcomes by race and SES for a range of conditions including asthma⁹ and cancer,^{10,11} and unequal access to treatment.^{12,13} Despite a growing evidence base, disproportionately less attention has been given to health disparities in children compared with adults.¹⁴

Eliminating health disparities is challenging because inequities are driven by multilevel influences including legislative policies, social factors, healthcare availability and access, individual behaviour, biology and genetics.^{6,15} Multilevel interventions, therefore, are required to address social, environmental and organisational factors, as well as individual behaviour.^{16–18} For example, those in lower income strata are exposed to different environmental hazards and social stressors than more advantaged population groups, which may in turn have consequences for health.^{19–21} While associations between race, ethnicity, SES and health outcomes have been identified, the underlying mechanism and causal links are still debated.²²

Theoretical models have been developed to guide health disparities research.²³ Some include environmental or social factors, which may be present at birth or could impact health over the life course.²⁴ Although a life course perspective is critical to understanding child health and the transition from child to adult health, the focus of these models largely remains on outcomes in adulthood. Furthermore, many of the contributors to disparities in child health overlap with and are partially mediated through their impact on the health and well-being of the adults who care for them, making the theoretical and explanatory models developed to explain adult health disparities inadequate for children.¹⁴ There are several characteristics that differentiate child health from adult health, as summarised in the five D's: developmental change, dependency on adults, differential epidemiology, demographic patterns and dollars.^{25 26} Likewise, the development of models focused on child disparities is important because social and developmental forces of child disparities and the strategies to address them may differ from the adult population. The research to develop and refine conceptual frameworks for health disparities that are unique to child populations is just emerging. We aimed to systematically review existing models and identify commonalities that could inform development of a unified conceptual framework for assessing and analysing health disparities in children. While the number of studies on paediatric health disparities has been increasing, they continue to primarily describe existing inequities.²⁷ Conceptual frameworks are needed to guide research on intervention development and testing, thus providing an avenue for eliminating disparities. They also provide a common language and set of definitions/concepts to move the science forward.

METHODS

We developed a study protocol at the beginning of the study (available from authors). The reporting of the manuscript follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement.²⁸

Search strategy

An experienced research librarian, along with the principal investigators, developed the search strategy (online supplementary appendix A). A comprehensive search of six databases (Ovid Medline In-Process & Other Non-Indexed Citations, Ovid MEDLINE, Ovid Embase, Ovid Cochrane Central Register of Controlled Trials, Ovid Cochrane Database of Systematic Reviews, and Scopus) was conducted from each database's inception to 9 July 2015. Controlled vocabulary supplemented with keywords was used to search for theoretical or conceptual models of health and racial/ethnic disparities in children. Systematic reviews and meta-analyses were used to identify additional studies.

Study selection

Studies were included if they reported theoretical models (ie, proposed or derived from theory) or conceptual models (ie, presenting specific relationships between concepts or variables) of health disparities in children aged less than 18 years and were created for use in developed countries. We included studies of any design (randomised or non-randomised, observational, theoretical/conceptual) as long as they presented a new model or empirically tested an existing model. We excluded editorials, erratum, letters or notes. The search was not restricted by underlying disease, health status and racial or ethnic group. Studies published in languages other than English were excluded. Only the first published/original study of a model was included.

For citations identified from MEDLINE, we adopted an advanced text-mining technique to improve the efficiency and reduce the workload of abstract screening.²⁹ The text-mining technique employs three semantics-based relevant ranking metrics (keywords relevance, indexed-term relevance and topic relevance). A total score with a linear aggregation of three ranking metrics was generated to show relevance of each potential study. This method has been tested in multiple systematic reviews and shown to have good performance.²⁹ The 500 highest ranking (most relevant) studies were selected to be screened for full text. A sample of 20 studies was selected to test the performance of the text-mining technique. Of the 20 studies, 18 (90%) were included in the 500 studies, giving us confidence that the technique was valid. Two missing studies from the 20 studies were added to the 500 studies selected through text mining. Reviewers screened the 502 abstracts to identify those that met criteria, and then reviewed the full text. Each abstract and full text was screened independently by two reviewers, and a third reviewer resolved discrepancies. For citations identified from other databases, a traditional screening process was used: reviewers, working independently and in duplicate, screened the abstracts and then full texts, and a third reviewer resolved discrepancies.

Data extraction

A standardised extraction form was developed and tested using a sample of the included studies (n=5). The following were extracted: authors' names, country of study or of lead author, objective of the development or use of the model in the study, population and disparity targeted, and components of the model.

Methodological quality appraisal

We did not find existing tools to evaluate the methodological quality of conceptual models; therefore, we developed our own criteria. Reviewers assessed whether the model was validated (yes/no/unclear/not applicable) and whether it was based on existing theory or was wholly empirical (theory/empirical/both/neither/unclear). Based on this information, reviewers made a global rating of methodological quality as good, medium or low/unclear quality. Models based on empirical

evidence or tested empirically were judged to have good methodological quality, while those based on theory alone were thought to have medium quality. Unclear or poorly reported descriptions of studies were labelled as unclear/low methodological quality.

Analysis

A metanarrative approach guided the analysis process.³⁰ This approach has been evaluated and adopted in multiple studies.^{31 32} It includes six phases: planning, search, mapping, appraisal, synthesis and recommendations. The planning, search and appraisal phases for this study are described above in the Search strategy, Study selection, Data extraction and Methodological quality appraisal sections. The mapping phase included identification of elements in the research paradigm, in this case the study populations, the disparities addressed and the components of the presented models. The synthesis phase involved creating narrative accounts of the dimensions, linking concepts and seeking explanations for contradictory findings. The recommendations phase offers direction for practice, policy and further research. The aim in metanarrative synthesis was to identify domains that could serve as a unified conceptual framework for child health disparities research. This unified conceptual framework can provide an overarching structure (based on a synthesis of many different models' components) that informs empirical testing and enhances understanding of determinants of disparities that, in turn, can guide research and policymaking.

RESULTS

We identified 7477 citations through database searching (figure 1); 3115 abstracts were screened (502 MEDLINE and 2613 non-MEDLINE) and 210 met criteria for full-text assessment. Forty-eight of those citations met inclusion criteria and were included in the qualitative synthesis. Forty-eight different theoretical or conceptual models were presented, 41 of which were developed in North America (37 in the USA and 4 in Canada), 3 in Europe (Netherlands, Ireland and the UK) and 4 in other regions. Seventeen models were intended to address general health disparities, 5 oral health disparities, 5 racial/ethnic disparities and 21 other topics. Eleven models targeted the general paediatric population while 37 targeted specific paediatric populations.

Eighteen out of 48 (37.5%) models were developed from empirical evidence while 19 (39.6%) were developed from theory alone. Eighteen (37.5%) of the models were empirically evaluated. The methodological quality was judged to be good in 10 (20.8%), medium in 17 (35.4%) and low/unclear in 21 (43.8%) of the models. The detailed characteristics of the studies describing these models are provided as online supplementary appendix B.

Components of the unified conceptual framework

This systematic review found multiple models guiding the assessment of childhood health disparities. There was no consensus on one approach or validation of a unified

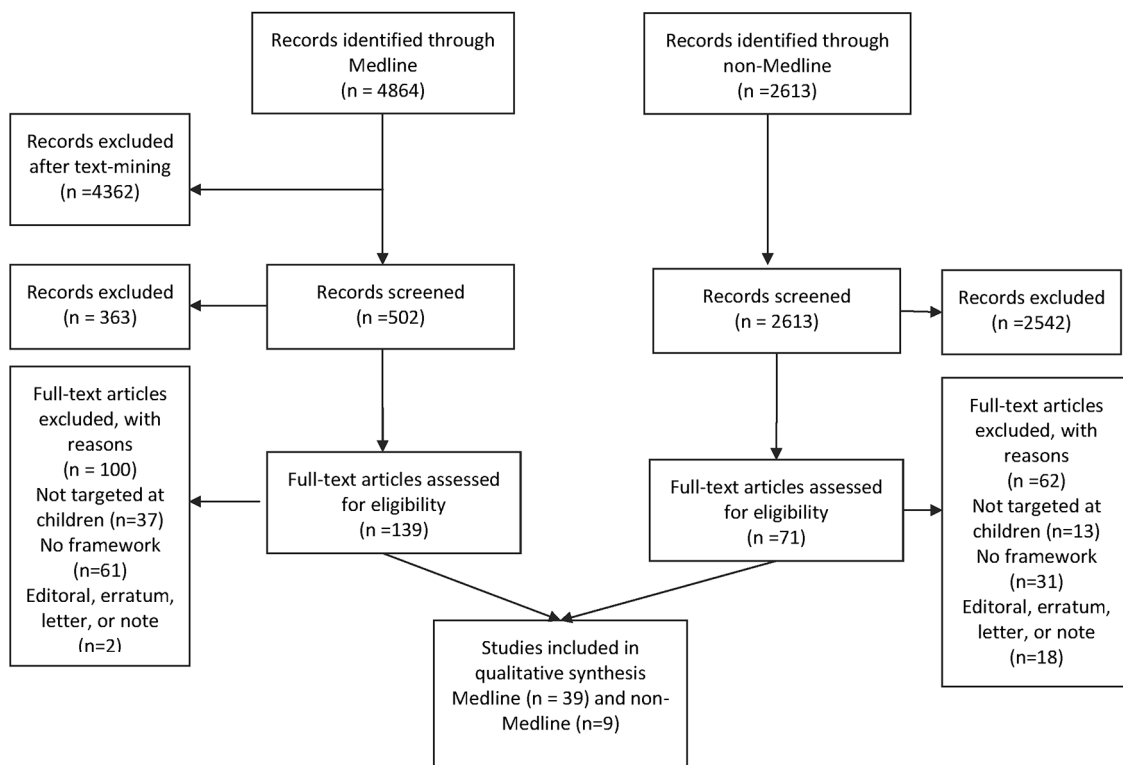


Figure 1 Process of study selection and screening using the PRISMA flow diagram.²⁸ PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

model, but analysis using the metanarrative approach found convergence along four domains or levels of influence: individual characteristics and behaviours, healthcare providers and systems, environment/community, and health and public policies. We describe the levels below, along with themes representing the types of variables included in each level. These themes may guide future work to operationalise what we propose as a unified conceptual framework.

Individual characteristics and behaviours

The majority (42 or 88%) of models in this review included factors consistent with individual characteristics and behaviours of the parent and/or child. The factors in this level can be summarised in three overlapping themes: sociodemographic factors; genetic, biological and psychological factors; and knowledge, attitudes and behaviours. The first theme, sociodemographic factors, extends beyond personal socioeconomic factors and includes issues such as race/ethnicity, immigration status, language and language acculturation, age, birth order, employment status (parent/guardian as well as child/student) and gender.^{14 33–57} It also includes socioeconomic factors related to the family, including parents' support network, parental involvement in school or monitoring of peers, maternal hardship, household size and family structure.^{34 35 37 38 41 44 45 48 49 55 58–62}

Models in the second theme, genetic, biological and psychological factors, represent a range of disparities.^{36 40 57 63} Issues discussed within the genetics and biological theme ranged from associations between variants of the ADAM33 gene and asthma in Caucasian and Latino Americans and the presence of the Arg16 allele and asthma severity,³⁶ to the factors involved in the pathogenesis of diseases and how they might vary by race and ethnicity.⁴⁰ Psychological factors addressed in this theme include resilience,⁵⁸ emotional, cognitive and social isolation,⁵⁹ perceptions of and locus of control,⁶⁴ personality,¹⁴ stress,⁵³ trauma⁶⁰ and developmental delays.⁶⁵

The third theme focuses on relevant knowledge, attitudes and behaviours, especially those of parents. Knowledge included understanding of diseases or treatments and the healthcare system, as well as general understanding of the consequences of poor health, media use, and health literacy and numeracy.^{11 14 36 43 46 51 52 66 67} Attitudes included perceptions of the affordability and acceptability of healthcare, belief in the value of preventive versus acute care, spirituality and religiosity, distrust of healthcare providers or systems, and cultural beliefs about health.^{36 43 45 48 51 52 64 68 69} Parent behaviours were seen as heavily influenced by other levels of influence and included smoke exposure, bedtimes or mealtimes, safety practices like seat belt use, child-proofing of homes, and use of home remedies, illness management and adherence to treatment recommendations. Child behaviours were seen to be heavily influenced by both parental behaviour and other levels of influence and include diet, sleep, exercise, personal

and dental hygiene, and alcohol, tobacco and other drug use.^{11 14 38 41 44 52 53 58 60–63 70–72}

Healthcare providers and systems

Issues pertaining to the healthcare providers and systems level of influence were mentioned in 30 (63%) of 48 models. Two overlapping themes emerged. First, access to healthcare included the supply/shortages of providers, affordability, health insurance coverage, having a usual source of care, access to specialty care, ancillary services (eg, translation services, patient health education, and so on), system fragmentation/integration, office hours, referral practices, hospice supply and managed care models.^{11 14 33 36 37 39 41 45 52 56 58 61 63–65 67 68 70 72–76} Second, quality of care included: lack of care coordination, diagnosis delays, gaps in the use of evidence-based medicine, delayed or foregone care, wait times; use of emergency care versus primary care, a variety of problems with the cultural competence/sensitivity, lack of diversity of the healthcare workforce, the presence of unintentional bias or stereotyping, language barriers, poor patient-provider communication and shared decision making, power and authority differentials, intimidation, prejudice, patient-provider race/ethnicity concordance, and physician workload or burnout.^{11 14 33 35–42 44–46 52 64–68 72 74 75}

Environment/Community

Twenty-seven of the identified models (56%) included factors consistent with an environment/community level of influence. We found this level of influence to include three themes. First was the impact of social class or SES on child health disparities. As environmental factors, these speak to the opportunities available to children and their families. Examples included the detrimental impact of foreshortened economic opportunities, experiences of discrimination and potential for beneficial social connections.^{11 14 33 38–40 51 57 60 62–64 66 72 75}

Second were characteristics of the neighbourhood. These include crime rates, unemployment rates, school quality, public service availability, access to healthy stores, positive neighbourhood attributes (eg, sidewalks, play areas, recreation centres, libraries/bookmobiles), negative neighbourhood attributes (eg, higher concentrations of pollution-emitting buildings, litter, dilapidated housing, vandalism) and neighbourhood instability (eg, low home ownership).^{36–38 40 41 43 51–54 60–63 65 69–71 74} Last was the relevance and importance of environmental exposures. Six of the models reviewed included such elements as indoor and outdoor allergens, pollution exposure, environmental stress and fluoridation in the water.^{36–38 41 61 63 70}

Health and public policies

Eighteen (38%) of the 48 models included health and public policies. Policy factors included those targeting the formation and activation of community health partnerships,⁷⁷ the design of and access to health insurance, public sector nutritional programmes (eg, Special Supplemental Program for Women, Infants, and Children (WIC)), policies aimed at health behaviour (eg, soda and tobacco taxes), and employment, economic development

or income policies.^{11 33 36–38 40 48 50 60 61 64 67 68 70 72 73 78} Some of these models noted the potential of public policies to reduce or increase health disparities by virtue of their ability to create access to programmes. The most commonly included factor was health insurance access/coverage. Public policies were also conceived of as having the potential to influence behaviour, for example, restricting the types of beverages that can be purchased using food programmes to change consumption patterns.⁶¹

DISCUSSION

The elimination of health disparities has been the focus of research and policymaking for decades.^{79–85} Despite this history, the research agenda for child health disparities is just emerging, and there exists a paucity of work in the development and testing of theoretical models specific to child health disparities, even though they have been linked to the prevalence of adult health disparities including high rates of chronic disease,^{22 86} and practitioners and advocates have called for addressing poverty and other factors in childhood that affect both child and subsequently adult health.^{87 88}

While we did not find consensus with one approach, we did identify a fair amount of overlap of factors that can be organised into four domains. Functionally, the four levels of the proposed framework are consistent with the socioecological model and other ecological models that conceptualise a complex nested set of factors and relationships that impact health and health

disparities (figure 2).⁸⁹ The socioecological model focuses on understanding multiple and interactive personal and environmental factors that influence health outcomes, portrayed as levels of influence on individual human development.^{16 17 90 91} Influence is also applied by the larger health and social service systems, the environment or neighbourhood in which individuals live, and the greater cultural and political conditions. In fact, disparities in healthcare, educational and other systems play a critical role in resulting health disparities among children and their communities and families.⁵³ This can be seen in the historical influence of health and education systems on child disparities in the American Indian and Alaska Native communities.⁹² In this framework, we portray the underlying role—explicitly or through more subtle channels—of health and public policies on the other domains of paediatric disparities, as well as the reciprocal influence of environment/community and individual characteristics and behaviours.

Among the papers reviewed, the model portrayed by Raphael and Beal¹⁴ highlights how disparities models created for adult health, like that by Warnecke and colleagues,¹⁸ need to consider aspects specific to paediatric patients. Our study largely coincides with the Raphael and Beal model but its broader attention to conceptual models being used in a range of disparities—expanding beyond race and ethnicity to include studies of disparities based on sexual orientation or disability status—may demonstrate that similar constructs are salient to other areas of paediatric disparities research. Although the number of these

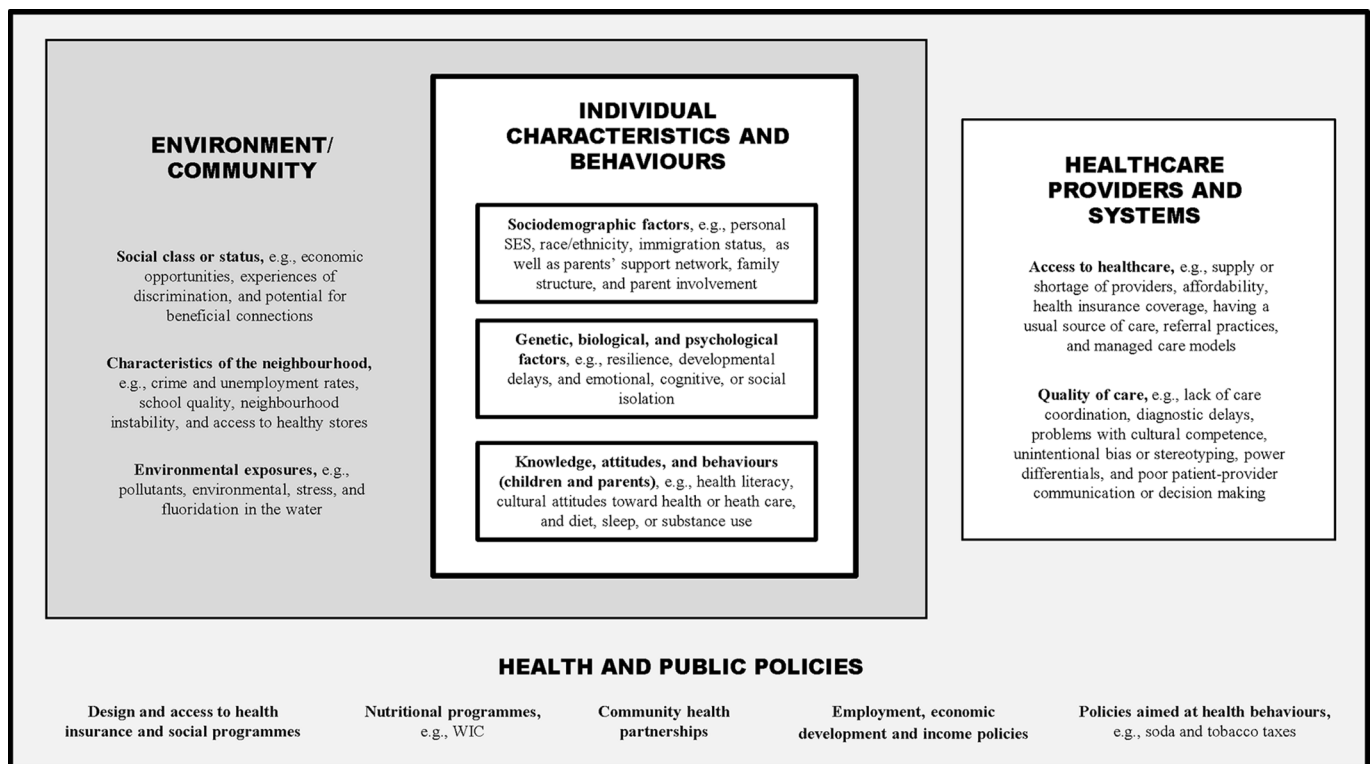


Figure 2 This unified conceptual framework presents a multilevel view of factors related to paediatric health disparities. SES, socioeconomic status; WIC, Special Supplemental Program for Women, Infants, and Children.

studies in our review was small, future research should aim to assess how a paediatric disparities framework can be expanded to be more inclusive of factors relevant to other vulnerable paediatric populations.

It is notable that while disparities and socioecological models stress the importance of multiple interacting levels of influence, only 10 of the 48 models reviewed for this study included items in each of the four domains described herein. Furthermore, while 42 of the 48 models included constructs related to individual characteristics, only 27 included environmental or community characteristics. This is a critical issue for paediatric disparity research and the potential to address disparities through intervention. Children spend their time in different ways and in different settings. For example, children in the USA spend an average of around 1200 hours in school each year⁹³ with significant implications for health and health disparities.⁹⁴ However, explication and understanding of the various features of school exposures (and protective factors) for child health disparities has been vastly underdeveloped as compared with the explication and understanding of the various features of occupational settings on adult health disparities. In addition, the kind, intensity and impact of psychosocial and environmental exposures may differ greatly for children as compared with adults, not least because of their impact on healthy child development.^{95 96} The environmental, developmental and social determinants of child and adolescent health-related behaviour are distinct in several respects from the environmental, developmental and social determinants of adult health-related behaviour. Resilience and protective factors need to be considered differently for children than adults; as one example, the way social networks and social ties (structure, features and functions) influence child health may differ greatly from the ways in which social networks and ties affect adult health.⁹⁷ Inadequate conceptualisation of the determinants of child health and health disparities limits our ability to develop effective remedies.

Likewise, few models included items related to the healthcare provider and systems domain (n=30) or the health and public policy domain (n=18), although these factors have potential to exacerbate or intervene to eliminate health disparities. While the process of creating or modifying policies and addressing structural inequities in the healthcare system is difficult, these efforts are necessary to make a large-scale impact on health disparities and disrupt persistent patterns in inequities. Recent work in the field of paediatric bioethics highlights the role of healthcare providers in being attentive to what is already known about the social determinants of child health disparities.⁹⁸

This review also found that research on child disparities includes constructs that are familiar in life course models, including the model proposed by the National Research Council and the Institute of Medicine.⁹⁹ Children's dependency on adults, their interactions with physical and social environments, and their capacity to develop resiliency are not static over their development, and there are critical time points for dynamic change, for example, birth, entrance to school and puberty.⁹⁹ Our framework does not

explicitly demonstrate a life course perspective but these findings point to the fact that there are many points across the life course where disparate conditions bifurcate what would otherwise be a healthy trajectory for children. This may contribute to future efforts at finding points of intersection between life course models, which posit a dynamic view of child health and the influence of many factors over time, and disparities models, which provide a platform for understanding population-level inequities in health.

There are limitations to this study. First, although the figure suggests nested relationships among the components, little effort in the extant literature has been directed at ascertaining how the components interact functionally (eg, interaction between genes and environment). Our analyses did point to potential constituent parts of the different components and ideas for how the four components might interact. For example, at the policy level of influence, alterations to medical insurance programmes for children that are aimed to contain costs may directly impact the access to and the quality of healthcare received by limiting the number of paediatricians willing to accept public pay clients. Moreover, an individual's genetic characteristics can interact with the environment. For example, autism may be triggered by a mother's exposure to environmental agents such as air pollution or pesticides while pregnant.¹⁰⁰ These exposures, in turn, could cause or contribute to autism development. Two models, by Canino and colleagues³⁶ and by Raphael and Beal,¹⁴ show promise in identifying how domains in the models interact. Nonetheless, more research that explicates the relationships between the components is needed.

Second, the search was limited to studies published in English due to feasibility. It is possible that models published in other languages may have different elements or offer different inferences. Likewise, our focus is on models published for use in developed countries. Health disparities in other countries may require different approaches and warrant further exploration of appropriate theoretical models. Other limitations inherent to metanarrative systematic reviews are also possible, including challenges in identifying sources of evidence and thematically appraising and analysing evidence. Future reviews with expanded search headings, like the new health equity MeSH heading, may identify more publications, including those relevant to the health and public policies domain. The search is also limited in its reference period. Future review may identify new ways of conceptualising paediatric health disparities that were lacking at the time of this review.

CONCLUSIONS

While the literature on child health disparities is growing, we found that few studies are guided by a multilevel model, and those that are multilevel vary in their constituent parts. A unified conceptual framework specific to child health disparities, which is inclusive of multiple levels and applicable to a diverse range of health-related

studies, could have broad applicability and set the foundation to integrate existing knowledge of child health disparities and guide future research. It could also provide definitional and conceptual clarity that allows the science to move forward using a common language. Because the framework is multilevel, it can facilitate the combination of clinical, basic and social science research to examine the relationships between policy, the social environment and the physical environment, while guiding data collection and intervention development that address factors at the individual and population levels.

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Contributors JLR reviewed articles, extracted data, critically reviewed and revised the manuscript, and approved the final manuscript as submitted. ZW designed and conceptualised the study, developed the search strategy, designed the data collection instruments, coordinated and supervised data extraction and review, reviewed and revised the manuscript, and approved the final manuscript as submitted. LJFR, MVR and JMG reviewed articles, extracted data, reviewed and revised the manuscript, and approved the final manuscript as submitted. MHM designed and conceptualised the study, developed the search strategy, reviewed and revised the manuscript, and approved the final manuscript as submitted. GBA and JSE reviewed articles, extracted data, critically reviewed the manuscript, and approved the final manuscript as submitted. TJB designed and conceptualised the study, developed the search strategy, carried out the initial analysis, drafted the initial manuscript, and approved the manuscript as submitted. TJB is the guarantor. All authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

Competing interests None declared.

Patient consent This research did not include data collection from human subjects.

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Data sharing statement Additional data are available by emailing the corresponding author at beeb026@umn.edu.

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