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Observations from the Balcony: Directions for Pediatric Health Disparities Research and Policy

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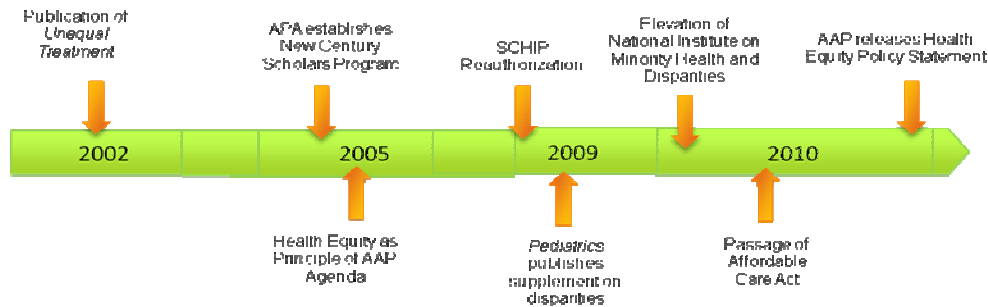
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Introduction

In 2002, the Institute of Medicine (IOM) released the landmark document, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*¹, both transforming and elevating the discourse on health inequities in the U.S. health care system. In summarizing the available medical literature, the report concluded that “the sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, health care professionals, and patients.”¹ With the acknowledgement that more research was needed, *Unequal Treatment* specifically recommended raising public and health care professionals’ awareness of the problem; health system interventions; legal, policy, and regulatory strategies; and education strategies for both patient and providers. At the ten year anniversary of *Unequal Treatment*, the fundamental question for clinicians, researchers, policy makers, and advocates is how to identify and address the barriers to translating current research findings into testable interventions and actionable policy.

A critical challenge to the pediatric community in determining the progress of addressing pediatric health disparities is to avoid mistaking activity for achievement.² A broad examination of the health care landscape for children reveals a number of actions and milestones (Figure 1) that have no doubt imprinted the agenda to address pediatric health disparities – a proliferation of disparities research specific to children, development of academic centers focused on addressing health disparities, creation of the National Institute on Minority Health and Health Disparities, reauthorization of the State Children’s Health Insurance Plan (SCHIP), and passage of the Affordable Care Act. Prominent pediatric academic societies and organizations have also put forth policies to address health disparities among children. The Academic Pediatric Association (APA) established the New Century Scholars Program to mentor minority residents interested in pursuing academic careers focused on addressing racial/ethnic disparities in pediatrics.³ The American Academy of Pediatrics (AAP) has established Health Equity as a universal principle in its AAP Agenda for Children.⁴ Do these efforts represent activity, achievement, or both? With these cumulative developments over the past decade, are we transforming the discourse on pediatric health disparities?

Figure 1: Timeline of Recent Efforts to Address Pediatric Health Disparities



The aim of this paper is to examine the practical challenges of addressing pediatric health disparities in the dynamic context of global changes in health care research, policy, and legislation relevant to children. Using the Adaptive Leadership framework, this paper outlines a conceptual model for assessing the scope of change made in addressing pediatric health disparities, diagnoses the continued adaptive challenges of pediatric health disparities, and provides recommendations for further work and future investment.

Framework of Adaptive Leadership

Ron Heifetz, a leadership expert and physician, provides a framework of leadership that delineates the principles and tools critical to both diagnosing problems and mobilizing resources to effect transformational change in organizations and systems. As defined by Heifetz and colleagues, adaptive leadership is the practice of mobilizing people to tackle tough challenges and thrive.⁵⁻⁷ Within the adaptive leadership framework, an adaptive challenge is a situation for which new strategies are needed. Applying existing methods and expertise does not provide the solutions necessary to address the challenge. Adaptive challenges require an evolution in strategic thinking.⁷

The first step in addressing an adaptive challenge is diagnosing the system. Heifetz uses the metaphor of “getting on the balcony” above the “dance floor” to demonstrate what it requires to gain the distanced perspective necessary to diagnose the system.⁵ In this metaphor, motion makes observation difficult. Engaged in the dance, it is difficult to assess the patterns made by everyone on the floor. According to Heifetz, “To discern the larger patterns on the dance floor - to see who is dancing with whom, in what groups, in what location, and who is sitting out which kind of dance - we have to stop moving and get to the balcony.”⁵ Moving back and forth between balcony and dance floor enables assessment of the scope of the issue and facilitates corrective actions.

The second step of practicing adaptive leadership calls for mobilizing the system. In this process, interventions are designed help people in the system address challenges. Interventions to mobilize adaptive work take the form of questions, ideas, frameworks, and single-change initiatives.⁷ They also dictate a strategic sequence of efforts that engage different stakeholders in different ways at different points in time. The products of such mobilization include long-term solutions (rather than quick fixes) and strengthening the system’s adaptive capacity to manage future adaptive challenges.

As child inequities occur along a spectrum of systems, organizations, and sectors, the adaptive leadership framework provides a conceptual model for assessing the gains and ongoing challenges in defining the agenda for pediatric health disparities. It focuses on elucidating the relationships between leadership, adaptation, and change. Using this framework, pediatric health disparities function as the core issue with adaptive challenges requiring perspective from both the dance floor (or field) and balcony. The areas for mobilization are represented by research, policy, and legislation.

Methods for Analysis

For this policy analysis, a scientific approach was used to gather key information regarding pediatric health disparities. In selecting research articles, the following criteria were used: (1) empiric research on children; (2) publication in peer-reviewed English language journal between January 1st 2002 and December 31st 2012, corresponding to the decade since the publication of *Unequal Treatment*; and (3) observational, longitudinal follow-up, or randomized controlled trials. The author obtained articles from Pubmed and MEDLINE by entering the following key words: disparities, child, pediatrics, inequality, and inequity. The author searched references of selected articles to identify additional articles. In addition to

research articles, the author additionally reviewed annual reports from the Agency for Healthcare Research and Quality relevant to health disparities: National Healthcare Quality Report and National Healthcare Disparities Report. Lastly, the author searched websites for the major pediatric societies - American Academy of Pediatrics and Academic Pediatric Association - for research and policy briefs focused on pediatric health disparities.

Diagnosing the System

Research. Despite the extensive medical literature reviewed in *Unequal Treatment*, a key recommendation was that further research be conducted. This recommendation was especially relevant to research in pediatrics. Of the literature cited in the IOM report, only five of the 103 published studies specifically addressed disparities in children.¹ The view from the dance floor implies that major advances have taken place in child specific health disparities research. Over the past decade, studies addressing pediatric disparities have dramatically increased and cover a wide range of topics including primary care, health care utilization, chronic disease, and Limited English Proficiency (Table 1 shows a representative list).⁸⁻²⁰ As evidence of the increased volume of research and interest in this field, journals have published entire supplements focused on pediatric health disparities.²¹

From the balcony perspective, it is evident that the advancement in pediatric research relevant to health disparities has stagnated despite the proliferation in research publications. The majority of existing studies are largely descriptive, highlighting a critical imbalance between documentation and intervention.²² They assess a limited array of demographic and socioeconomic variables, either due to limitations of the datasets utilized or methodological flaws in study design and statistical analysis. These studies largely come to similar conclusions – that health disparities are pervasive and impacted by multiple factors including biology, preferences, cultural beliefs, socioeconomic status, cultural competency, and racial discrimination within the health care system.

Table 1. Health Disparities Research at a Glance					
Primary Author (year), Study Design	Study N	Findings	Notes	Control Group	Reference No.
Primary Care					
Hambidge (2007) Cross-sectional	2,892	Black and Latino children less likely to receive preventive counseling	Black children also less likely to receive preventive screenings	White race	10
Seid (2003) Cross-sectional	3,406	Asians and Hispanics reported lower quality primary care	Adjusting for language attenuated results	White race	11
Stevens (2002) Cross-sectional	413	Racial/ethnic concordance between parent and provider not associated with parent report of primary care experiences	Adult studies on concordance show mixed findings	N/A	12
Health Care Utilization					
Coker (2009) Cross-sectional	5,147	Black children had lower odds of using mental health services	Differences between Hispanic and White children fully explained by socio-demographic variables	White race	13
Javier (2010) Cross-sectional	1,404	Children with special health care needs in immigrant families experienced reduced access to health services and decreased health care utilization	Disparities according to immigrant status attenuated when insurance status, race/ethnicity were included in analysis	Non-immigrant status	14
Raphael (2009) Cross-sectional	35,301	Black children with special health care needs had higher odds of ED utilization	Disparities were attenuated with access to a medical home	White race	15
Chronic Disease					
Flores (2009) RCT	220	For minority children with asthma , parent mentor program reduced wheezing, asthma exacerbations, ED visits, and missed work days	Only African-American and Latino children enrolled	N/A	16
Raphael (2012) Cross-sectional	150	Children with sickle cell disease had poor access to medical home components	Only assessed African-American children	N/A	17
Taveras (2003) Prospective cohort	1826	African-American and Hispanic children exhibited a range of risk factors related to childhood obesity	Inadequate power to assess interactions between race/ethnicity and SES	White race	18
Limited English Proficiency					
Arauz-Boudreau (2010) Cross-sectional	462	Parent-primary care provider language concordance not associated with parent reported well child care quality	Providers' self-reported cultural competency correlated with higher scores parent scores in how content was delivered	N/A	19
Cohen (2006) Retrospective cohort	38,793	Infants of parents whose primary language was not English were less likely to receive all preventive care visits	Disparity not seen in Asian-American infants	English as primary language	20
Flores (2008) Cross-sectional	102,353	Children in non-English primary language households had high odds of unmet medical needs, not having a usual source of care, and problem obtaining specialty care	Some disparities were specific to certain minority groups	English as primary language	21

ED =
Emergency
Department
N/A = Non-
applicable
RCT =
Randomized
Controlled Trial

The critical mass of research documenting pediatric health disparities would seem to dictate a sequential progression towards intervention science and solutions. However, a recent systematic review on racial/ethnic disparities in children's health and health care found that only two of 111 articles evaluated interventions to reduce disparities.²² The need for intervention studies is further highlighted by unyielding trends in disparities among children. The current evidence indicates that racial/ethnic disparities are persisting or worsening over time in key areas, including overall mortality rates, elevated blood lead concentrations, and asthma prevalence, mortality, and hospitalizations.²² According to recent reports published by the Agency for Healthcare Research and Quality (AHRQ), racial/ethnic disparities among children persist for receipt of recommended vaccinations, emergency care visits for asthma, and untreated dental caries.^{23, 24}

While there are numerous studies and reports describing health disparities, other works show more mixed data. Multiple studies have shown that rates of well-child care do not differ according to race/ethnicity.^{9, 24, 25} Differences have not consistently been found in overall ratings of well child providers.²⁵ In one study, a higher proportion of minorities relative to Whites reported that their medical provider followed up on specialty care.²⁶ Some disparities are attenuated when socioeconomic status is accounted for in analyses.^{25, 27} In one study on asthma, processes of asthma care including ratings of provider and asthma care and use of preventive visits and specialists were equal or better for minority children compared to White children with all factors considered.²⁸

Despite the persistence of inequities, contradictory findings in the literature, and notable lack of intervention studies, conduct of more cross-sectional studies with large databases continues to define the field of health disparities research as a default response. This approach fails to address the full range of factors influencing health outcomes and may not foster the development of new strategies. Several factors explain why cross-sectional research dominates this field. First, this ecological approach reflects much of the research conducted in health disparities over the past decade. The methods for this research are well documented and accepted. Large datasets offer substantial numbers of minorities not available from other data sources. Second, such work is relatively inexpensive and time-efficient compared to intervention trials. Third, while the numbers of pediatric health disparities studies has grown, this research historically receives significantly less funding than adult disparities research. Therefore, pediatric researchers have been limited in

their efforts towards intervention research. Funding agencies are still just beginning to understand the central role of pediatric health disparities in the downstream occurrence of adult health inequities. While there is continued consensus that more longitudinal studies in pediatric health disparities should be conducted, these studies are more costly than other forms of research and therefore difficult to get funded. Overriding the defaults of disparities research necessitates new strategies focused on intervention that carry risk – developing new methods, obtaining resources to conduct complex research, creating infrastructure for clinical trials, recruiting and retaining minorities in research, and funding agencies investing in work that will not yield immediate results.

Policy

Over the past several years, U.S. health care policy has focused on the reorganization of systems of care to be more directly oriented toward the needs of patients and families. As one of its major goals, Healthy People 2020 aims to achieve health equity, eliminate disparities, and improve the health of all groups.²⁹ From the field, many of these policy innovations have the potential to create more equitable care for minority children.

Long advocated by the American Academy of Pediatrics, several models of patient-centered medical homes (eg, “primary care homes”, “health homes”, “medical neighborhoods”) have emerged as potential care delivery innovations.^{30, 31} The medical home model is an integrative systems approach to care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.³² With research and demonstration projects documenting improvements in care with a medical home³³⁻³⁵, policy makers have increasingly focused on establishing the medical home as a centerpiece of health system reform and reimbursement.³⁶

From the field, it appears that this movement towards patient-centered care will have clear and significant impacts on reducing health care disparities among children.^{37, 38} The conceptual tenets of the medical home model show clear opportunities to advance health equity. From the balcony, however, there is limited evidence to indicate that national efforts of medical home implementation will ameliorate disparities for children. A large body of research exists assessing medical home components and associated outcomes for children.^{33, 39-41} With regard to health disparities, many studies have found inequities in access to a medical home.^{26, 42-45} However, very few among the cross-sectional studies have examined whether the medical home reduces disparities among children.^{14, 46, 47} Among these studies, the medical home was associated with only a partial reduction in racial/ethnic disparities or no change at all. Consequently, the

pediatric research to date does not provide a clear evidence base demonstrating how medical homes will enhance the care of minority children.

The focus of ongoing demonstration projects for medical home implementation has further constrained efforts to understand the implications of the medical home for minority children. Many of the demonstration projects have been adult-focused given a larger potential for cost savings.⁴⁸ Pediatric health care accounts for less than 15% of total health care spending.⁴⁹ Therefore, the investment in medical demonstration projects for children has been small relative to that for adults. Data on the impact of the medical home for pediatric disparities may have to be extrapolated from adult medical home initiatives in safety net clinics and community health centers.⁵⁰ A significant percentage minority children receive care in these settings.²⁴ This historical approach of treating children as “little adults” represents a default response where the needs of children are assumed to be similar to adults in implementing policy, when in fact, this failure to address the specific needs of minority children for medical home implementation may undermine long-term outcomes.

In addition to expanding care delivery models, policy efforts have also centered on improving cultural competency as a means of ameliorating health disparities. Cultural competence is defined as “the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients’ social, cultural, and linguistic needs.”⁵¹ In 2001, the Department of Health and Human Services (DHHS) Office of Minority Health published standards for culturally and linguistically appropriate services (CLAS) for healthcare organizations.⁵² The National Quality Forum has since endorsed 45 practices to guide health care systems in providing culturally effective care and developed a comprehensive framework for measuring and reporting cultural competency.⁵³ The National Committee for Quality Assurance (NCQA) now offers a voluntary program that awards distinction to health plans that meet rigorous requirements for addressing CLAS standards.⁵⁴ In addition, The Joint Commission has developed policy level approaches to create hospital accreditation standards to promote and incentivize the provision of culturally competent care.⁵⁵

For children, the emerging emphasis on cultural competency brings both award and risk. Provision of culturally effective and appropriate services has the potential to improve care for minority children. However, caution should be used in implementation of CLAS standards for pediatrics, given that children’s cultural experiences can be different from

that of their parents.^{53, 56} Over the course of time, the child's cultural experience and orientation may gradually shift from those of their family to those of their own. Therefore, among children, culturally competent care must address the needs of the family and developing child.⁵³ Furthermore, cultural competency must be distinguished from linguistic competency such that interventions based on improving cultural competency go far beyond translation of materials and hiring of bilingual staff.

To facilitate quality improvement in the health care system, policy makers have increasingly advocated performance-based incentives such as pay-for-performance programs. The motivation behind such programs is that tying a provider's financial incentives to provision of high quality health care will improve performance and adherence to evidence-based guidelines.⁵⁷ On the surface, it would seem that such programs would play a central role in reducing health disparities among children with the assumption that improving care for all children would eliminate inequities. In this scenario, quality improvement initiatives should disproportionately aid those who have historically experienced disparities. From the balcony, however, there are theoretical concerns as well as concrete evidence that performance-based systems could have the opposite effect of improving health care quality. They may actually widen existing disparities in quality.⁵⁸⁻⁶⁰ If primary care providers believe that such programs do not account for patients' characteristics and adherence, they may avoid caring for vulnerable populations, including racial/ethnic minorities.^{60, 61} In addition, incentive-based programs may further worsen disparities by increasing the resource gap between high- and low-performing health care providers.^{58, 59} Based on the findings of previous studies, improving the resources available to care for minority populations while also maintaining performance-based payments will be critical to preserving health equity during implementation of incentive-based programs.⁵⁸

Legislation

Passage of the Affordable Care Act (ACA) created a significant platform for addressing health disparities. While eliminating health disparities was not a core goal to begin with, the ACA includes numerous provisions that directly or indirectly address the needs of minority children.⁶² Expansion of Medicaid will have a substantial impact on minority children who disproportionately rely on public insurance and whose families have been most adversely affected by unemployment and erosion in employer-sponsored health insurance.⁶³ Key questions will be whether there is a sufficient supply of physicians to adequately care for newly insured children, and whether the workforce reflects the diversity of the patient population. Another concern will be unintended consequences for safety-

net providers who already care for minority children. If private providers are better positioned to recruit newly insured children, safety-net providers could be left with insufficient revenues with which to manage panels of high-risk, minority children.⁶⁴ Care in such lowly resourced settings may compromise quality for these children, further exacerbating disparities.

The ability to identify and monitor disparities over time has been limited due to inconsistencies in the quality and reporting of data collection. The ACA requires that all federally funded population surveys collect data on race, ethnicity, and primary language. Another provision mandates that the Medicaid program and SCHIP collect and report data on disparities. While the ACA provisions on data collection mandate adherence to race/ethnicity reporting, they do not provide guidance on how data should be collected (eg, categories to be used) or reported.⁶²

The ACA also makes a significant investment in health disparities research by elevating the National Center on Minority Health and Health Disparities to Institute status within the National Institutes of Health and creating more funding academic Centers of Excellence focused on disparities. Additionally, the ACA created the Patient-Centered Outcomes Research Institute (PCORI) to conduct comparative effectiveness research and examine health care services outcomes according to diverse populations. However, the success of these provisions will all be reliant on appropriations and consistent funding over time.

Recommendations for Mobilizing the System

Making the Intellectual Leap from Documentation to Intervention

While studies assessing the root causes of disparities should remain a fundamental component of pediatric health disparities research, intervention science should define the next stage of addressing inequities in child health. This transition carries risk for researchers, given declines in available research funding and the complexity and time involved in conducting clinical trials. However, intervention symbolizes the work required to start targeting pediatric health disparities in a meaningful way. Although disparities-specific intervention trials are routinely conducted in adult care, they are only now gradually becoming more widely adopted in pediatric research. In a study by Flores et al, a parent mentor intervention was utilized to improve asthma outcomes for minority children.¹⁵ The results of this randomized controlled trial demonstrated that parent mentors can reduce wheezing, asthma exacerbations, emergency care visits, and missed parental work days among minority children. In a randomized control trial conducted by Mendoza et al, a walking school bus intervention improved active commuting to school and daily moderate-to-

vigorous physical activity among low-income children.⁶⁵ Building on the large body of work research documenting pediatric disparities, studies such as these ones should provide momentum for future investment in pediatric intervention trials. These studies will ultimately inform policy and legislation relevant to reducing disparities among children.

Experimenting with New Models of Health Care Delivery

Over the past several years, new models of care have emerged with a focus on enhancing care delivery mechanisms for minorities. In adult care, lay worker interventions based on individualized assistance have provided new insights on how to facilitate timely, high quality care for those with chronic conditions. More specifically, patient navigation has become a central strategy in reducing disparities in cancer care. Patient navigators are non-health workers who target at-risk populations such as racial/ethnic minorities and those from low-income populations for delays in care.⁶⁶⁻⁶⁸ Positive outcomes associated with patient navigation have included timeliness of diagnosis, faster initiation of primary therapy, patient satisfaction, quality of life, and cost-effectiveness.⁶⁹⁻⁷² While patient navigation models have predominantly been implemented in adult chronic care, such programs may have major impact in pediatrics, where a whole family may benefit from navigation around the care of children with a chronic condition.

Avoiding Unintended Consequences from New Health Care Solutions

As demonstrated in the case of pay-for-performance programs, there is potential for new health care solutions and strategies to adversely impact pediatric health disparities. While these innovations warrant further investment given their potential to improve health care delivery, policy makers must assess and monitor how implementation of these programs affects minorities. Researchers and policy makers must anticipate all the possible outcomes of new interventions to ensure that equitable care is maintained, if not advanced.

Exploring Sectors Outside the Health Care System

While considerable intellectual and financial resources have gone towards improving the health of individuals and the operation of the health care system itself, efforts focused solely on this sector miss opportunities to address determinants of health and health care in other sectors.⁷³ A significant number of studies and interventions focus on individual risk behaviors. Other interventions concentrate on changing how the health care system responds to the needs of patients. These approaches, if

solely used, may marginalize the role of social and structural factors that give rise to risk behaviors and health.⁷⁴ Poor and minority children often live in “food deserts” with limited access to healthy foods.⁷⁵ Waste sites, bus depots, and factories are often located near low-income and minority neighborhoods, where they create significant allergen and toxin exposure.⁷⁶ Advertisements that promote consumption of alcohol, tobacco, and high-calorie foods frequently target minority neighborhoods.⁷⁵ Therefore, researchers and policy makers must overcome the assumption that health disparities can only be addressed through health care. More solutions must focus on the environments in which children live – families, neighborhoods, schools, and built environment. Increasingly, policymakers are advocating a “health in all policies” approach in which governments and businesses consider the consequence to health and health disparities, of proposed policies in housing education, transportation, taxes, and land use.⁷⁴ Within this approach, decision makers conduct health impact assessments to determine the health consequences of policies. A “health in all policies” should become a core strategy in addressing local social and environmental conditions that perpetuate health inequities among children.⁷⁴

Funding the Future

Allocating resources largely to adult research may represent an unbalanced, inefficient, and consequently inadequate strategy to eliminating pervasive inequities. Funding agencies must more strongly embrace a more life course approach to disparities such that addressing pediatric health disparities becomes a core strategy for reducing and eliminating disparities in adult health.⁷⁷ Reviewers of health disparities research must be better educated regarding the importance of pediatric research and how the environment of the child influences future outcomes in adult health. Specific areas for focus should include pediatric research that emphasizes social and structural determinants of health, cross-disciplinary collaborations with sectors outside of health, longitudinal data collection, and intervention.

Conclusion

In the decade since the publication of *Unequal Treatment*, the field of pediatric health disparities has experienced unprecedented growth in opportunities to reform the care of minority children through research, policy, and legislation. While there has no doubt been a great deal of activity in the field, the activity has not significantly altered the course of

health inequities experienced by children. Transformative change and achievement will require adaptive leadership. In order to move forward, stakeholders must get on the balcony, diagnose the challenges, make interpretations, and effectively mobilize the system. The challenges of pediatric health disparities extend well beyond the health care system into neighborhoods, families, environments, local economies, and politics. It is imperative that those invested in advancing health equity among children undertake the work necessary to pose new questions, innovative strategies, and impactful solutions.

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