



Growing Up Poor: A Pediatric Response

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THE ORIGINAL MISSION of Boston City Hospital, established in 1864, now Boston Medical Center (BMC), was to provide medical care to all regardless of race, ethnicity, or ability to pay. Nationally, health insurance for children has increased, although disparities by race and income remain.¹ However, despite the largest expansion of health insurance in the nation, covering 97% of Massachusetts children and biomedical treatment advances, the low-income and minority children seen at BMC continue to suffer disproportionately from low birth weight, asthma, learning disabilities, and most health problems compared to their nonpoor peers.² While reducing most health disparities are best addressed by state and federal policy changes and expanded public health and community based services, we believe there is an opportunity and obligation to go beyond our traditional health care to make a difference for our patients. In the early 1990s, the Department of Pediatrics decided to initiate efforts to transform our health care delivery system by developing, implementing, and iteratively improving new programs³ to reduce adverse health effects from selected aspects of poverty.

These changes built on Joel Alpert's values and local and national leadership to ensure access through training to high-quality community-based primary care for low-income children. These changes were not informed by a needs assessment or focus groups; rather, we listened to concerns raised by parents of our patients. BMC's new programs were clinician-initiated and multidisciplinary team efforts to enhance access to adequate food and healthy nutrition, early learning, safety, and other basic needs that are necessary for good health. We also engaged parents and patients to improve care for children and adolescents with sickle cell disease (SCD), a group historically adversely affected in the health care arena by race. Data showing effectiveness were generated and published for many of these efforts. Residents and practicing clinicians locally and nationally were trained to identify and/or help families in need. These programs include Reach Out and Read, Medical–Legal Partnership, Project HEALTH (now HealthLeads), a Food Pantry, Child Witness to Violence Project, the Baby-Friendly designation, and the Kids Fund. These efforts have been sustained and in

some cases expanded over the past 20 years, and some have been disseminated nationally. One project, a primary care medical home called Healthy Steps⁴ developed by BMC multidisciplinary faculty, was a national effort but was never implemented at BMC and is therefore not included.

PROMOTING EARLY CHILDHOOD AND BRAIN DEVELOPMENT

BMC pediatric patients frequently enter school not ready to learn, suffer subsequent learning and school problems that are associated with dropping out of school, engage in early drug and alcohol use, and experience teenage pregnancy. Although reading to young children is considered the best way to promote early literacy and school readiness, BMC pediatricians discovered that many low-income parents were not reading to their children. In most cases, parents explained that they grew up in countries without children's books or the tradition of parents reading aloud, and thus they did not have books in their home. Additionally, many lived in areas with no children's bookstores. Some considered books too expensive. Among the most successful efforts of Boston Medical Center's Department of Pediatrics is the Reach Out and Read (ROR) program. Starting in 1989 doctors began giving young children books at each pediatric visit from 6 months to 5 years and explaining to parents the importance of reading aloud to children. Published studies support ROR as an effective strategy that increases parents' report of reading to their children and objective measurement of increased language skills showing ROR as an effective strategy.⁵ These findings corroborated what pediatricians already knew from seeing the joy on parents and children's faces when they received and shared a book. First ladies Hillary Clinton and Laura Bush, and the late Senator Ted Kennedy helped obtain federal funding to scale up the program nationally. Today ROR has almost 5000 clinical sites serving 4.2 million low-income children in the United States. ROR has been awarded the Library of Congress Literacy Award, the Dale Richmond Award from the AAP, and the Unesco Confucius Prize, among others.

Training modules including slides and video modeling anticipatory guidance were developed and are used to train residents and practicing clinicians nationally. Approximately 15,000 residents, medical students, and clinicians nationally have been trained since 1989. A national conference that had 100 to 200 attendees a year was held in conjunction with PAS from 1997 to 2008. A special interest group as part of the APA remains active.

ADDRESSING SOCIAL DETERMINANTS OF HEALTH

BASIC NEEDS

Access to basic needs such as adequate housing and nutrition, appropriate education, and personal safety is well documented to improve health.⁶ We realized we could not afford to ignore them in our assessment and treatment plans if we hoped to improve outcomes.

In the early 1990s, our clinic only had one social worker, who was able to address many, but not all, patient needs. In response, we partnered with lawyers to address legal problems—an important subset of social problems, and one beyond the expertise of the social worker. The need for lawyers was predicated on the understanding that the government has enacted laws and regulations to address the negative health impact of hunger, insufficient income, unsafe housing, and disability. When families do not receive these protections and benefits, health suffers. In 1993, the Family Advocacy Program, now called the Medical–Legal Partnership, was developed and implemented to tackle violations designed to address these upstream causes of illness and protect health.^{7,8} The collaboration of lawyers and doctors, a novel ideal at the time, has spread to more than 220 sites nationwide and now includes helping adult patients. The role for pediatricians and their staff is to identify basic unmet needs as part of their social history⁹ and include them in an individualized care plan. Identification and monitoring is aided by including social determinants in the electronic health record as part of clinical care.¹⁰ We started by developing our own system and subsequently moved it into our commercial system. Beyond case by case legal help, the long-term goal is for doctors and lawyers to use their combined skills to develop population-based strategies.^{11,12} The Medical–Legal Partnership has won the Robert F. Kennedy Embracing the Legacy Award and the VIDA award from the American Hospital Association, among others.

Fortunately, legal strategies are not always needed to help families obtain needed resources. Project HEALTH, now HealthLeads, started with Harvard undergraduate volunteers in primary care clinics to connect families with basic community resources. The doctor's role was to identify problems, such as lack of food, heat, or safety, and write a "prescription" for the college volunteers to fill by working with the parents to secure the needed resources in the community. HealthLeads developed a technologic infrastructure, including a Web-based resource landscape database for the community that is searchable and updatable in real time. Their care management system is integrated with

clinic electronic medical records. Metrics regarding number and types of needs identified and how many were successfully met are reviewed quarterly (data of program outcomes are available at <http://www.healthleadsusa.org/>). This student opportunity resulted in a pipeline of physicians with insight into problems faced by low-income families. Today, HealthLeads operates in 22 sites in 6 US cities.

Lack of money prevents many parents from buying small but important necessities that other families take for granted. The Kids Fund was established to provide assistance to parents. Whereas charitable contributions in pediatric departments commonly support research and other academic activities, the Kids Fund focuses on providing items such as winter coats, special formulas, summer camp, eyeglasses, and breast pumps for families. Any member of the pediatric staff, including doctors and nurses, can request support for their patient.

ADEQUATE FOOD AND HEALTHY NUTRITION

Ensuring that low-income children have adequate nutrition is a long-standing challenge. BMC Pediatrics opened the first hospital-based preventive-care food pantry in 2003. It provides families in need with 2 bags of groceries prescribed by their doctor, and it conducts eligibility screening to assist individuals that need to apply for food stamps. The food pantry provided food for 250 individuals per week when it opened, and it now helps more than 1600 individuals per week. In addition, food pantry nutritionists hold cooking classes.

As with other urban inner-city hospitals, most newborns at BMC were missing out on the nutritional benefit that breast-feeding provides. In 1997, a physician-led multidisciplinary effort was launched to encourage skin-to-skin holding, especially in the first hours of life, and babies rooming with their mothers. Doctors, nurses, and other staff members learned about strategies to make breast-feeding successful, and the hospital refused free supplies of formula from manufacturers. In 1999, BMC became the first hospital in Massachusetts and the 22nd in the country to achieve Baby-Friendly status, a title conferred by the World Health Organization and UNICEF to hospitals that meet the highest standards for promoting breast-feeding.^{13,14} In 2002, the assistant secretary of health at the US Department of Health and Human Services picked BMC as the Best Practice model for the nation. Breast-feeding rates increased dramatically. In 2013, 95% of women initiated breast-feeding, and 85% fed their babies more breast milk than formula during their hospital stay. The exclusive breast-feeding rate increased 6-fold compared to the years before Baby-Friendly status.

Premature babies in the neonatal intensive care unit (NICU) especially benefit from human milk. BMC pediatrics promoted breast-feeding in the NICU¹⁵ and developed a program so neonates in the NICU can also receive human donor milk from the nearby Mothers' Milk Bank Northeast.^{16,17} Although banked milk is not uncommon in NICUs, it is less common in NICUs in safety net hospitals.¹⁸ In addition, the Kids Fund–sponsored program

Pumps for Peanuts provides breast pumps for mothers of NICU babies.¹⁹

FREEDOM FROM EFFECTS OF VIOLENCE

Our clinical experience showed that many of our patients were suffering by witnessing violence in their community and, more tragically, in their home.²⁰ Ten percent of our patients under age 6 had witnessed a knifing or shooting the previous year, and 18% witnessed moderate violence.²¹ Although we were trained to treat physical trauma associated with violence, treating emotional trauma after witnessing violence first involved a recognition of its importance, then referral for other treatment measures.^{22,23}

The Child Witness to Violence Project was started in 1992 to provide counseling and therapeutic interventions for the affected children and mothers (<http://www.childwitnessstoviolence.org>). The program also trains front-line professionals, police, and family court officials to be aware that even if children are not physically hurt, they may be significantly harmed emotionally and will view their world as dangerous. The front-line providers were also taught to recognize the signs children show when they have witnessed violence. Police officers and pediatricians are the biggest sources of referral and support. In addition, the Good Grief Program (<http://www.bmc.org/pediatrics-goodgrief.htm>), one of the first in the nation in the early 1990s, provides education to school officials, teachers, and others to help children cope with the death—violent or otherwise—of classmates, relatives, and neighbors.

SPECIAL CASE FOR CHILDREN WITH SCD AND NICU GRADUATES

Although not innovative, we have implemented selective efforts to improve care for children with SCD and NICU graduates. Although generally absent from discussions of disparities because it predominantly affects patients of one race, SCD has a special place in the history of race and health in the United States. Available evidence suggests a history of relatively fewer resources for research, health care delivery, and improvement of care for SCD compared to many other diseases.^{24,25}

When we asked parents or patients with SCD what their biggest concern was about the care we provided, the most universal response was the length of time it took in the emergency department (ED) for their pain to be treated.²⁶ We looked into this problem and found that the average time to treat pain ranged from 1 to 2 hours, due in part to work flow barriers. We introduced a time-delivered protocol outlining the care steps to be provided and incorporated use of intranasal fentanyl as the first opioid provided, and we were able to reduce the time to pain treatment to less than 30 minutes.

We also developed a special registry of patients with SCD so we could systematically identify those patients who were not receiving the recommended preventive efforts, including flu shots, immunizations against pneumococcus, and annual transcranial Doppler imaging for

children older than 2 years.²⁷ As of March 2014, 91% of children with SCD received their annual flu shots, 84% were up to date with pneumococcal conjugate vaccine (PCV13) and pneumococcal polysaccharide vaccines (PPV-23), and 85% of eligible children had been screened via transcranial Doppler imaging in the past 15 months. Finally, hydroxyurea has recently been proven safe and effective in children.²⁸ In response, we expanded the criteria for use in children 2 years and older, developed explanatory visual materials, and spent time with each family addressing their questions and concerns about hydroxyurea. Currently 79% of eligible children have initiated treatment with hydroxyurea.

The care of NICU graduates is usually focused on primary care and newborn follow-up clinics, resulting in many appointments. In 1998, we combined these clinics and added case management and selected specialty care, creating one of the first primary-care medical homes for NICU graduates.

ONGOING EFFORTS

Newer and ongoing efforts undergoing evaluation include a randomized trial of a standardized cognitive behavioral intervention to prevent depression among low-income mothers, family navigation to help parents get services for their child diagnosed with autism, use of visual media to explain diseases and treatment for patients and parents with low health literacy, giving e-readers to 4-year-olds to promote school readiness, and a reinvented resource center (bWell Center) next to the clinic that goes beyond health information to connect families to libraries, schools, nutrition, exercise, and activities. Other efforts include Project DULCE, which builds on components of Healthy Steps and the Medical–Legal Partnership to support low-income families and their newborns.²⁹ Finally, a systematic effort to identify and address unmet basic needs, the WE CARE Project, has been shown to increase provider referrals and families' receipt of community-based resources.^{30,31} This effort will now be tested as an effectiveness trial in an urban pediatric clinic.

FAILURES AND LESSONS LEARNED

Successful initiatives for patients are satisfying and seem easy in retrospect, but failed efforts must also be considered. Some efforts never get off the ground. Over 15 years ago, we initiated an effort called Learning Not Waiting, which placed computers in the specialty waiting room so patients and parents could look up information either before or after their medical visit. Although many colleagues thought this was a good idea, there was never a physician or other champion on site to prompt and guide parents, and the effort never took. The computers are gone, but we have included this idea into the bWell Center, along with other activities described above.

Other efforts were implemented but not sustained after a few years. This includes a 4-year effort starting in 1996 called Pain-Free Pediatrics,³² which was a department-wide effort to reduce pain, especially for common medical

procedures. At its peak, depending on the service, 60% to 80% of all children getting a needle stick, sutures, and so on in the nursery, NICU, wards, clinics, and the ED received either an evidence-based pharmacological or behavioral intervention to reduce pain. We also developed a post-NICU discharge home visit program to improve care and train residents.³³ Residents conducted a home visit 3 to 5 days after discharge for one of their patients. Unfortunately, this effort ended this year after 4 years because of a crowded NICU curriculum; it became an issue of priorities for resident time. Finally, we developed a Woman and Infant Clinic with an addiction counselor as part of the primary care team for neonatal abstinence syndrome infants and their mothers.³⁴ This small clinic lasted only 3 years, but it served as a model for a Substance Abuse and Mental Health Services Administration (SAMHSA) national effort. Our contribution was to show it could be implemented.

What are the lessons learned from our successes and failures? First and foremost, an on-site physician or nurse clinical champion is an absolute necessity. All of our failures were due in part to the loss of or lack of a champion on site. The champion does not have to do much work on the project, but their commitment and passion motivates and supports their colleagues. Other key components include the existence of an understandable, concrete benefit to patients and families, especially before evidence is obtained. Contrast this to efforts directed from above to improve efficiency or productivity. It is hard to mobilize passion for such efforts. Another key component is that the idea behind the effort should be relatively simple to implement into the work flow of the setting and relatively inexpensive. In the case of lawyers, a new collaboration may need to be implemented, but because of synergy of missions, the collaborators may have their own funding. In the case of food, new donors are attracted to the specific activity and are not competing with donors who are targeted for research donations.

CONCLUSIONS

It is important that pediatricians work at the policy level and community level to reduce health disparities, but we also need to lead change in our own homes, which is sometimes harder than looking outward. The best example is advocating for better childhood nutrition at the policy level but not promoting breast-feeding by achieving Baby-Friendly status at one's own hospital. By extending the boundaries of traditional health care to address socioeconomic determinants of health, BMC pediatrics provides whole child and the whole family care targeted to the neediest children in the community. These efforts provide a model for our trainees and for other pediatrics departments to encourage clinician-led efforts to reduce health disparities for the patients they serve.

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