

# Helping Low-Income Families Manage Childhood Asthma: Solutions for Healthcare & Beyond

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## Introduction

Asthma is the most common childhood chronic illness, affecting more than seven million children nationwide.<sup>1</sup> Managing chronic illness in a child is challenging for any family. Among the challenges is constant fear of an acute episode, a complex regimen of medications given daily or many times each day, frequent changes in prescriptions or dosages, coordinating multiple healthcare providers, and helping a child have as “normal” and active a childhood as his/her condition allows. Low-income children of color bear a heavier asthma burden than their white or more affluent peers.<sup>2</sup> Those low-income children who live in urban areas such as Baltimore, Chicago, Los Angeles, and New York are particularly vulnerable. Families with limited resources struggle to provide their children with asthma the support that these children need.

In recent years, asthma care has grown to recognize the importance of disease management. While asthma is not curable, there are a number of interventions that clinicians, educators, caregivers, patients, and their families can use to control the disease. These interventions, however, can be complex, resulting in high costs and difficulty for families in delivering and/or sustaining effective care. These factors are further complicated as the lives of low-income families are often in flux, with job, housing, and other frequent changes within the family and social structure.

Compared to other locales, the District of Columbia has an especially high prevalence of pediatric asthma. Eighteen percent of children are reported to have asthma.<sup>3</sup> In DC, asthma is three times as common among African American youth as among white youth.<sup>4</sup> Poor asthma management, as indicated by hospitalizations and emergency department (“ED”) visits, is most concentrated in the poorest neighborhoods, which also have the lowest availability of pediatric primary care.<sup>5</sup> ED visits by children in these neighborhoods occur at over 10 times the rate of children with asthma in the more prosperous areas of the city.<sup>6</sup>

Children’s National Health System (“Children’s National”), the Urban Institute, and DC Appleseed teamed up to investigate why there are so many children with poor asthma control and high reliance on EDs for care when doctors and researchers know so much about asthma and effective interventions. Based on that investigation – *District Childhood Asthma Improvement Research* (“DC AIR”) – this policy brief identifies policy challenges and opportunities that could increase the success of low-income families in managing their children’s asthma.

The DC AIR study looked at families whose children had received services through the *Improving Pediatric Asthma Care in the District of Columbia* (“IMPACT DC”) program

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at Children's National. IMPACT DC is a comprehensive, evidence-based intervention that includes extensive asthma education and care.<sup>7</sup> It is located in the EDs of Children's National and focuses on children with high asthma morbidity, especially those with frequent ED visits for asthma. Children are referred to IMPACT DC following an emergency visit or hospitalization for uncontrolled asthma. During a typical 90-minute visit, children and their caregivers are educated about common triggers of asthma episodes, coached on proper technique in administering medication, evaluated by a clinician, and provided resources to help reduce triggers in the home environment. They also are assisted in setting an appointment with their primary care provider. IMPACT DC makes follow-up calls to the family within two weeks of the IMPACT DC meeting to troubleshoot any difficulties.

The DC AIR study was initially designed to distinguish between low-income families who, in the six months following their IMPACT DC visit, were successful in managing their child's asthma, and those whose child continued to exhibit signs of uncontrolled asthma, as indicated by one or more additional asthma-related ED visits within six months. The intended purpose was to identify factors that could lead to improvements in the intervention itself, as well as additional strategies that could support children with uncontrolled asthma. All of the children in the study were covered by Medicaid so health insurance coverage and costs were not contributing factors. Ultimately, the comparative component of the research could not be implemented after the researchers found that even those families who were successful in the six months following the intervention eventually returned to the ED for an asthma

episode. This suggests that even for families who understand and are able to engage in effective asthma management for a period of time, long-term success remains elusive. This further suggests that a successful approach to asthma management needs to go beyond clinically-based interventions into a broader set of supports that address the underlying challenges of caring for a child with a chronic respiratory condition.

The DC AIR research led to a better understanding of the impact on low-income children with asthma of a healthcare system that focuses primarily on diagnosing and resolving immediate presenting symptoms, but not on the ongoing management required for chronic conditions. The research also showed how our healthcare system is ill-equipped to address the ongoing, unrelenting social/emotional as well as financial challenges for low-income families who are trying to protect their children from flare-ups of this life-threatening condition. A system that addresses the chronicity of asthma in children requires involvement of stakeholders outside the traditional healthcare delivery system, as well as attention to issues that are not typically on the healthcare policy agenda. These include strategies to control common triggers of asthma flare-ups in all of the places that children spend time, especially home and school. It also includes ensuring that parents have the time, resources, and tools (such as an adequate supply of medications as well as good information about disability and workers' rights) to manage the disease and prevent acute episodes.

In the DC AIR research report, "Making Sense of Childhood Asthma: Lessons for Building a Better System of Care," the authors cite

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interviews with caregivers of children with asthma, healthcare providers, asthma educators, and school and health system administrators which attest to some of the individual and systemic barriers that prevent families from effectively managing their children’s asthma. Specifically, DC AIR found that in order to effectively support low-income children with asthma, families need: (1) enhanced communication among caregiving parties (families, doctors, school nurses, etc.); (2) access to the appropriate quality and quantity of care; and (3) social and financial supports to address the challenges of managing a chronic illness without economic security.<sup>8</sup>

This policy brief takes these findings about the needs of low-income families facing childhood asthma, as well as the barriers they face to implementing effective asthma management, and identifies specific recommendations to increase the likelihood that they can be successful. The recommendations, based on the interviews and within the framework of the three main research findings listed above, address the following topics:

#### MANAGEMENT OF ASTHMA IN SCHOOLS AND THE ROLE OF SCHOOL PERSONNEL IN ASTHMA MANAGEMENT

There is a wealth of knowledge about how to reduce common asthma triggers in schools, as well as tools to help schools translate that knowledge into action, but schools have not systematically and consistently applied those resources and are typically not held accountable for doing so. In addition, too many schools – including school nurses – lack basic information about who among their students has asthma, what triggers their symptoms, and what medications have been prescribed for them.

#### INDOOR AIR QUALITY IN SCHOOLS AND RENTAL HOUSING

Children typically spend most of their time indoors at home and school. Indoor air pollution is pervasive, collecting in homes and other buildings from a range of sources including heating fuels, building materials and furnishings, cleaning solvents, pesticides, and other common substances. It contributes to many different illnesses, and has a very clear link to asthma exacerbations. Existing regulation and accountability are insufficient to address the problem. Low-income renters, especially, often lack the leverage and resources they need to address threats to their children’s health in their home environment.

#### ACCESS TO CLINICAL SUPPORT (INCLUDING THROUGH TECHNOLOGY) AND MEDICATIONS

Low-income children with asthma have the least access to and the greatest need for frequent, regular contact with a primary care provider. They also stand to benefit from optimal use of electronic health records (“EHRs”) to preserve continuity of care and keep all of their providers informed and up-to-date about their condition. Barriers to information-sharing limit the ability of schools and healthcare providers to work together effectively to support children with asthma. Children with asthma also need to have access to their medications wherever they are, which can be a challenge when insurers limit patients to a single inhaler at a time.

### GENERAL COMMUNITY KNOWLEDGE ABOUT ASTHMA AND ASTHMA MANAGEMENT

Children depend on many different adults for formal and informal supervision throughout their day, not just their primary caregiver who knows their asthma triggers and medication regimen. Expanding accurate knowledge and reducing the spread of misinformation about asthma, asthma triggers, and appropriate responses to asthma flare-ups could substantially contribute to the well-being of children in high-risk communities.

### ABILITY OF PARENTS TO BALANCE WORK WITH CARING FOR A CHRONICALLY ILL CHILD

Asthma requires frequent medical visits even when it is well controlled. Many low-income working parents lack access to sufficient paid leave to care for their child's chronic condition, and so they prioritize acute over preventive care. This contributes to uncontrolled asthma which manifests as more asthma flare-ups, more visits to the emergency department, more hospitalizations, and more missed work and school. This cycle would be prevented if workers had access to adequate paid leave to care for themselves and their children.

### EXISTING LEGAL SUPPORTS FOR WORKERS AND PEOPLE WITH DISABILITIES

Moderate to severe asthma can be disabling, and children with disabilities – and the people who care for them – are protected by laws that can help shield them from additional consequences, as well as provide families with additional resources. Families need access to this information to determine if seeking disability status is an appropriate choice for them.

The purpose of publishing this policy brief is two-fold:

1. To facilitate interdisciplinary dialogue and collaboration among those concerned about children's health but who may not already be part of the conversation regarding asthma; and
2. To invite an audience of policy makers and thought leaders – who may or may not be aware of their critical role in reducing the burden of asthma on low-income families – to use their leadership in a variety of ways to improve children's asthma outcomes.

Most of the ideas contained here are not original, but clearly need to reach a wider audience. It is our hope that, through this work, communities will have an opportunity to welcome new stakeholders to the children's health table, and that low-income families will find additional resources and support in their struggle to manage this chronic and serious condition.

*A school-wide approach to policy and building maintenance, as well as good communication and information-sharing is essential to protecting students who suffer from asthma.*

# Recommendations to Improve Outcomes for Low-Income Children with Asthma

## 1. Enhance communication among caregiving parties

### Recommendations:

- 1.1: Improve school nurses' access to student health information.
- 1.2: Improve communication between families and the school system so schools have the opportunity to address triggers in the classroom.
- 1.3: Target communities with high prevalence of poorly-managed childhood asthma with general asthma education so as to reach more formal and informal caregivers.

### SHARING HEALTH INFORMATION WITH SCHOOL NURSES (RECOMMENDATION 1.1)

During the academic year, children of school age (as early as age three in DC with universal public preschool, age four or five in most other states) spend almost one-third of their waking hours at school, and for children who participate in before or aftercare, the proportion is even higher. For children with chronic illness, having the school nurse or other designated school personnel included as part of the caregiving team should be standard practice, but it is not. In the absence of this involvement, the burden falls on the parent or guardian to ensure that appropriate personnel receive relevant information about their child's asthma triggers, the current medication regime, recent flare-ups, and other essential medical data.

School nurses who participated in a focus group for DC AIR expressed their discomfort with the lack of information they are given and what they saw as a lack of parental cooperation with school protocols. In fact, schools often have no idea that a student has asthma or what the particular triggers are for that student. Schools may not be informed when a student is hospitalized or when they have run out of medication. According to the nurses, caregivers often do not inform them that their child has asthma, do not provide medical documentation, and permit their child to carry and take unauthorized medication at school.<sup>9</sup> In DC, only 30% of the health information forms that parents are supposed to complete at the beginning of each school year are turned in to DC Public Schools, and the forms that are

turned in may be incomplete.<sup>10</sup> We have no information about how many DC students have written plans documenting their condition and describing their personal management plan ("Asthma Action Plans") on file at their school.

Student health information is in a different legal category than health information retained by healthcare providers and insurance companies, and different privacy laws govern what can be shared with whom and under what circumstances.<sup>11</sup> While it may be relatively easy for a healthcare provider to secure the appropriate releases to share information directly with a school nurse (if such a practice were adopted), there are other barriers to information exchange: the healthcare provider's time is unlikely to be compensated, there may not be a school nurse at all, or the child may not know what school he or she will be attending. In addition, the communication would only flow from the healthcare provider to the school. Communication of information from the school to the healthcare provider would require a separate authorization.

DC schools struggle with the specific challenge of having school nursing services provided by the DC Department of Health ("DOH") through a contract with Children's National.<sup>12</sup> While this contract provides benefits in terms of management and quality assurance, there is a lack of communication both between school systems and the health system, and often between individual school leadership and their nursing personnel. Despite the close working relationship among the school



system, DOH, and Children’s National, the current contract does not require DOH to communicate with the schools concerning health conditions and hospitalizations affecting their students. The idiosyncrasies of this system need to be addressed in order to ensure that communication barriers can be removed. School nurses are essential to the well-being of children with asthma, especially low-income children who often rely on the school system to provide sufficient nutrition and other basic necessities.

The process of including nurses in the information loop for children with asthma needs to be simplified, and needs to be accomplished without relying solely on already overburdened caregivers. Better communication through electronic medical data-sharing is one tool that could ensure more continuous care. Using data-sharing and electronic health records, schools would be able to retrieve necessary information from physicians, and vice versa, including the medical forms that schools require. In addition, school health systems that are not already integrated through a centralized care center that uses electronic health systems and other care coordination tools should be, so that student health information can be accessed from different schools within the same jurisdiction, and parents do not have to re-educate their school personnel from year to year.

Though small geographically, DC is served by several different health systems, and District health professionals struggle to find ways to communicate through EHR across proprietary boundaries. Within each given system, however, EHRs have made it easier for providers to access accurate patient histories, avoid unnecessary duplication of tests and other services, and ensure appropriate care. Because health information is highly sensitive, any changes in information-sharing, including those that would make it easier to communicate across different proprietary systems, would require the utmost attention to data security.

#### ADDRESSING COMMON AND STUDENT-SPECIFIC ASTHMA TRIGGERS (RECOMMENDATION 1.2)

Asthma symptoms can be triggered by a range of different conditions and substances, and the triggers will vary from child to child. There are, however, certain common triggers that schools

can and should address through policy and building maintenance practices with particular attention to indoor air quality. These include: tobacco smoke, vehicle exhaust, perfumes and colognes, scented cleaning products, extreme heat or cold, mold, furry animals, and insects. It is important, however, for any information about triggers for individual students to reach the classroom teachers so that any avoidable conditions can be addressed, or potential problem situations anticipated. With identification and communication of students’ triggers, the school can address them specifically and reduce exposure in the classroom. For example, if cold weather is a trigger for a child, a plan should be developed to avoid this exposure during a winter fire drill. Exercise also can trigger asthma flare-ups for some students, so information for physical education teachers is essential. Whether the school nurse is charged with disseminating information to relevant teachers, or that responsibility is assigned elsewhere, a school-wide approach to policy, maintenance, and good communication and information-sharing is essential to protecting students who suffer from asthma.<sup>13</sup>

#### EDUCATING THE BROADER COMMUNITY (RECOMMENDATION 1.3)

Communication and an understanding of asthma also need to penetrate communities, especially those that suffer a high prevalence of asthma. Families rely on their communities for support, and they should be able to find reinforcement of evidence-based practices within those communities. We learned from DC AIR that multiple caregivers, often a necessity for children with working parents, can make consistent asthma care difficult to sustain. While this phenomenon has many causes, in part it results from both formal and informal caregivers not having up-to-date information about asthma management and the best ways to respond to asthma symptoms.

Community education on asthma needs to be a consistent part of a community’s public health strategy. An effective campaign might include public service announcements, billboards, celebrity involvement, advertisements at bus stops and subway stations, and local newsletters and publications as part of social marketing.

## 2. Improve access to the appropriate quality and quantity of care

### Recommendations:

- 2.1: Expand clinic hours to be more convenient for families.
- 2.2: Improve convenience of clinic locations.
- 2.3: Ensure that appropriate billing codes are available for asthma education and other chronic illness support, and facilitate appropriate reimbursement for asthma education.
- 2.4: Develop or expand an asthma-management education intervention that includes schools and homes among their various critical settings.
- 2.5: Increase availability of school nurses, especially at schools with significant student population with chronic conditions like asthma.
- 2.6: Use technology to reach families with asthma education and support during non-work hours.
- 2.7: Eliminate the limits that state Medicaid and any Medicaid MCO may impose on the number of inhalers a child may be prescribed at one time.

Managing asthma effectively requires asthma sufferers to have regular access to a variety of health system professionals, including doctors, asthma educators, pharmacists, school nurses, and others. Yet not all children with asthma have access to either the quantity or the quality of care that they need. The *National Asthma Education and Prevention Program* (“NAEPP”) of the National Heart, Lung, and Blood Institute (“NHLBI”) recommends, for example, that children with asthma be seen by a healthcare provider every two to six weeks while using new medications or new strategies to gain control of asthma symptoms; every one to six months to have symptoms monitored; and every three months if the provider is considering reducing their medication.<sup>14</sup> Many students should visit their school nurse if they need to take medication while in school. In addition, children with severe asthma are likely to rely on daily control medications as well as emergency inhalers, and, if they receive Medicaid, must therefore contact a pharmacy at least every 30 days for a refill. In addition to these medical interventions, families often need help identifying and removing triggers from their home environments and, because of the frequency and complexity of administering the medications, need regular check-ins to support proper technique and consistency. Thus, having convenient access to the appropriate professionals is essential.

It is also essential that these professionals are up-to-date on best practices in managing and caring for children with asthma, and that the messages that caregivers and children are receiving about asthma care are consistent and accurate. Penetration of best practices, according to researchers, is sub-optimal among primary care providers,<sup>15</sup> and while resources and information on asthma are available, many healthcare providers bemoan the lack of time available to them to implement best practices with their patients.<sup>16</sup> Barriers to accessing the appropriate quantity of high-quality care need to be addressed if low-income families are going to be successful in getting their children’s asthma under control.

In our investigation, caregivers described work schedules that could not flexibly accommodate appointments during standard 9 am-5 pm business hours, as well as difficulty taking time off from work for what they considered lower-priority prevention-related appointments. They also described their preference for the ED, which is not only available whenever they need it, but where they could be assured that their child would get relief. In addition, the District, like many cities, has an imbalance in the geographic availability and distribution of care:<sup>17</sup> the families who participated in DC AIR resided in the zip codes with highest asthma prevalence and also where fewer primary care providers were located. These barriers to access

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and concerns about quality contributed to families prioritizing acute episodes and relying on the ED for care, rather than using primary care services in the community.

#### AVAILABILITY OF MEDICAL SERVICES (RECOMMENDATIONS 2.1, 2.2)

Federal Medicaid regulations provide some guidance on access to care, and state programs typically mirror that guidance with some variation – *e.g.*, in DC, for certain patients (such as children with disabilities) care must be available no further than 30 minutes or 30 miles away, and patients must be required to wait no longer than one hour to be seen for a scheduled visit.<sup>18</sup> These standards, however, are insufficient to motivate low-income families to choose community care over the ED, and fail to recognize the time demands placed on low-income families caring for a child with a chronic illness like asthma. If children are to receive the quantity of preventive care necessary to manage asthma and prevent life-threatening flare-ups, reliable and appropriate care must be available at times that make it easy for families to get there. States must therefore consider how to use the leverage available through their Medicaid State Plans, Certificate of Need procedures, and licensing and other regulatory tools to incentivize and support the availability of primary and urgent care during non-standard hours, especially services targeted toward management of chronic illness.

Similarly, disparities in the geographic distribution of care have a disproportionate impact on low-income families, not only because they are often the ones who must spend more time and resources to get to locations where care is available but also because they can least afford it. They also can least afford to spend the extra time away from their jobs, where they are less likely to have sufficient paid sick leave to cover

all of the care their child with asthma requires. Though economic forces largely determine where many providers choose to locate, governments must use all of the tools at their disposal to incentivize providers to locate where low-income families can most easily reach them.

#### ALIGNING MEDICAID WITH CHRONIC CARE (RECOMMENDATION 2.3)

The *Early Periodic Screening, Diagnosis, and Treatment* (“EPSDT”) Program in Medicaid is meant to ensure that low-income children will receive services necessary to ensure their physical, mental, and developmental health.<sup>19</sup> Yet economic realities and the pragmatic demands of running a medical practice or clinic can interfere with providers’ ability to deliver optimal care to low-income patients. For example, primary care providers interviewed for DC AIR reported frustration at having too little time during a standard office visit to cover all of the important components of managing asthma. Primary care providers will not be able to fulfill their role in managing this condition unless they can be appropriately compensated for all of the critical components of such an intervention: clinical exam; education about triggers; training in administering medication; and coordinating care with school health providers, specialists, and pharmacists. Primary care providers, especially those serving low-income populations, need resources to staff their practices with educators and other non-clinical staff to be able to better serve the chronically ill.

Each state chooses what billing codes are accepted and included in the Scope of Covered Services under its State Medicaid Plan. Without an approved billing code, services cannot be reimbursed. States need to ensure that their Medicaid billing codes and reimbursement rates support asthma education and care coordination, and that per-enrollee rates paid



to managed care providers are sufficient to provide case management, care coordination and other centralized preventive services for the large number of children on Medicaid who have asthma. States should also take advantage of a recently changed Medicaid rule that allows non-licensed health personnel to deliver reimbursable preventive services that have been recommended by a physician or other licensed healthcare practitioner.<sup>20</sup> These preventive services can be provided in a clinical or non-clinical setting, such as a home.

#### IMPLEMENT COMPREHENSIVE APPROACHES TO ASTHMA MANAGEMENT (RECOMMENDATION 2.4)

The NAEPP recommends that asthma patients and families receive self-management education from “multiple points of care.”<sup>21</sup> They also recommend teaching families to attend to environmental triggers. In the District of Columbia, IMPACT DC articulates these NAEPP best practices within a hospital setting. In the District’s adoption of the comprehensive and nationally acclaimed Healthy Schools Act of 2011, however, the District rejected the proposal that all school nurses seek certification as asthma educators, a proposal that would have expanded the “points of care” available to low-income children.<sup>22</sup>

By contrast, programs in other parts of the country provide models for strong asthma education. New England Asthma Innovation Collaborative delivers cost-effective prevention-oriented care in clinics and at home; and is piloting reimbursement methodologies with payers.<sup>23</sup> Boston Children’s Hospital Community Asthma Initiative provides a series of home visits tailored to each family’s needs and questions; includes, with the family’s permission, a walk-through of their home along with suggestions about how to make their homes more “asthma-friendly”; and provides case management to help families improve housing conditions and access health insurance or other services.<sup>24</sup> The San Francisco Asthma Task Force breaks its interventions down by setting: childcare, clinical, community, school, and housing.<sup>25</sup>

#### GETTING CARE AT SCHOOL: THE IMPORTANCE OF SCHOOL NURSES (RECOMMENDATION 2.5)

The District of Columbia is required to provide at least 20 hours per week of registered nursing services at each elementary and secondary school in the District.<sup>26</sup> Nurses are distributed through the public school system based on the ratios recommended by the National Association of School Nurses (“NASN”) and Healthy People 2010, whereby one full-time nurse is provided for every 750 students.<sup>27</sup> In practice, however, because many schools have fewer than 750 students, and because many of the District’s public charter schools do not meet physical layout requirements in their buildings, many District students have only part-time or no access to a school nurse. And because the NASN/Healthy People 2010 ratio is based on the health needs of the student population, the District, with its disproportionate number of students with asthma and the concentration of high-risk students in certain schools, is underserving students with asthma in terms of access to a school nurse.

Though not meant to serve as a substitute for appropriate primary care, nurses have the potential to play a key role in helping low-income children manage their asthma. In addition to providing clinical intervention in case of asthma flare-ups, nurses can provide education and information for children, parents, and school staff; can lead trigger reduction policy development; and can liaise with primary care providers when necessary.<sup>28</sup> In the District and elsewhere, research is currently under way exploring the impact of having school nurses oversee the administration of one dose per day of controller medication for children with persistent uncontrolled asthma.<sup>29</sup>

In practice, however, many school nurses are overburdened and under-resourced. As described above in the section on “Sharing Health Information with School Nurses,” they lack the information they need about their students, and are often kept busy administering routine first-aid for bumps and bruises. In the District, where school health records are still kept in paper files, they lack computer access to student health information. While it may not be viable to open full school health clinics everywhere they are

needed, increasing the availability of school nurses and empowering them may serve as an intermediate intervention by expanding access to health professionals – especially in schools in communities with the highest prevalence of asthma and other serious health conditions.

#### USING TECHNOLOGY TO EXTEND SUPPORT (RECOMMENDATION 2.6)

During DC AIR interviews, caregivers and other stakeholders described challenges treating asthma as a chronic condition that requires daily maintenance even when a child is not experiencing symptoms. We discuss those challenges above in terms of access to clinics, but some of the support that families may need does not necessarily require the presence of an asthma expert. A study from the Netherlands in 2012, for example, found that sending electronic reminders to patients is a simple yet effective way to improve at least short-term medication adherence by patients with chronic conditions.<sup>30</sup> This research points to the potential for using technology in innovative ways to support adherence to a complex and time-intensive preventive regime. Such an intervention could be developed through a partnership between a public health department and health provider, or administered more generally to the broader community, but in either case does not require that a child have face-time with a clinical professional to have the desired impact.

#### ACCESS TO MEDICATION (RECOMMENDATION 2.7)

Children with a chronic health condition need consistent and regular access to medication. Asthma educators and primary care providers who were interviewed for DC AIR noted that

children with multiple caregivers often have a harder time controlling their asthma. Parents who were interviewed reported that their children did not always have their emergency or controller medications when and where they needed them because the children left the medication in one place when transitioning to another.<sup>31</sup> Because children are not always in control of where they are or where they will be, and because children cannot be expected developmentally to anticipate every eventuality, several stakeholders felt it was important for them to keep multiple medications in different locations. This would help ensure that, whether they sleep at home or elsewhere, they can use their controller medication morning and evening, and can have emergency medication whenever and wherever their symptoms occur.

State Medicaid plans often use limits on prescriptions as a cost control measure, and some insurers, while not banning multiples, institute barriers to obtaining multiple prescriptions – barriers that are surmountable but time-consuming.<sup>32</sup> Given the importance of the medication regime to managing asthma and how difficult it can be to promote medication adherence under the best of circumstances, it may be short-sighted to limit a child's access to asthma control and emergency medication. An exception to prescription limits should be carved out for children's inhalers, and healthcare providers should be educated to discuss with parents an appropriate number of inhalers for their child given their schedules and common behaviors.

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### 3. Improve support for the social/emotional and financial challenges of chronic illness

#### Recommendations:

- 3.1: Educate families on the protections available for students with asthma through anti-discrimination laws including (1) Section 504 of the Rehabilitation Act; (2) Title II of the Americans with Disabilities Act (“ADA”); and (3) the Individuals with Disabilities Education Act (“IDEA”).
- 3.2: Improve families’ access to information and legal support to encourage use of available labor protections for ongoing non-emergent medical care/attention. These include local and federal family and medical leave laws, and paid sick leave laws.
- 3.3: Improve families’ access to legal support to address asthma triggers in rental housing.
- 3.4: Create an Asthma and Housing Task Force to focus on provider compliance with codes including the Fair Housing Act, Common law’s implied warrant of habitability, and (for public housing) Section 504 of the ADA.
- 3.5: Establish a fund for making legal modifications in rental housing.
- 3.6: Increase access to high quality affordable housing with clean indoor air.
- 3.7: Empower the federal Environmental Protection Agency to set standards and regulate indoor air.

Among the most striking findings of the DC AIR study was the level of daily stress that families experience from having a child with a chronic, potentially life-threatening condition. Parents described losing sleep listening for their child’s wheezing, or trying to care for a child from their own hospital bed while dealing with cancer or other serious illness. This stress only compounds what low-income families must contend with on a daily basis: food insecurity, poor and/or unstable housing conditions, jobs with low pay and limited benefits, poorly-resourced schools, and unreliable transportation. The healthcare system alone cannot contend with the many social, emotional, and financial challenges that low-income families face, yet these challenges have a clear relationship to families’ ability to manage their children’s asthma. While the health system has moved forward in recognizing the value of social support for managing certain diseases, like diabetes, it has been less effective in creating and making those resources readily available to the primary caregivers of children with asthma.

Because this is a multi-faceted issue, it requires a multi-faceted policy response. Policy efforts that go beyond the healthcare system but have

a recognizable impact on the ability of families to meet the needs of a child with asthma should be included on the agenda of anyone concerned with helping to improve asthma management.

#### INCREASING FAMILY AWARENESS OF DISABILITY PROTECTIONS AT SCHOOL (RECOMMENDATION 3.1)

Some school systems do a better job than others in developing and implementing policies to support children with asthma.<sup>33</sup> For schools that have not been proactive in school health, building maintenance, and policy development, students may need access to additional resources to assist them on an individual basis. In some cases, depending on severity and other factors, asthma can be defined as a disability. To help improve asthma control in school, it would be beneficial for families to have a better understanding of disability law and anti-discrimination protections. While there may be very good reasons for a parent to choose not to have a child designated as disabled, in many instances the value of the protections may outweigh the negatives.

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The Federal laws that provide some level of protection at school for children with disabilities include:

1. Section 504 of the Rehabilitation Act (“Section 504”);<sup>34</sup>
2. Title II of the Americans with Disabilities Act;<sup>35</sup> and
3. The Individuals with Disabilities Education Act.<sup>36</sup>

Section 504 and the ADA prohibit discrimination in educational settings. Schools must eliminate barriers and provide reasonable accommodations to allow disabled students to fully participate in the school’s general curriculum. Under Section 504, a “504 plan” would be drafted to describe the specific accommodations that a child needs, including any environmental modifications, in order to fully participate. The school is legally responsible for implementing the plan.

To receive protections through IDEA, the disability must have an adverse effect on a student’s educational performance. There are many different types of disabilities, including but not limited to health impairments, that can qualify a child for services under IDEA. Under IDEA, a student would have an Individualized Education Program (“IEP”) that describes the educational supports and related services required for that student to receive an appropriate education. IDEA also provides a number of procedural safeguards, including periodic assessments and dispute resolution options.

For students whose asthma is legitimately classifiable as a disability, these existing protections may help ensure that school personnel are aware of and accountable for implementing measures that would otherwise

be left to the school’s discretion. DC AIR research suggests that families may not be fully aware of these legal protections, and should have the opportunity to decide if pursuing any of these options might be in their child’s best interest.

#### **INCREASING UNDERSTANDING AND USE OF FAMILY LEAVE AND PAID SICK DAYS (RECOMMENDATION 3.2)**

In the DC AIR research, caregivers described demanding employers and work schedules and the stresses of juggling work while caring for a chronically-ill child. Several parents had jobs that lacked flexibility or paid sick leave, and several reported having to stop working or change jobs in order to manage their child’s illness.<sup>37</sup> One agency administrator heard from a parent who planned to stop taking off work for preventive appointments, because she simply could not afford to miss that much work. Even in DC, which is one of a few jurisdictions in the United States to mandate paid sick leave for workers, few have enough paid leave to attend all of the preventive appointments recommended by the NAEPP, much less combine that with taking off time for the typical acute illnesses that all children suffer.<sup>38</sup>

Even when employers are willing to allow their employee to take unpaid leave, most employees cannot afford to lose the income. Nearly 80% of workers who are eligible for unpaid leave under the federal Family and Medical Leave Act (“FMLA”) report not taking leave due to its financial cost.<sup>39</sup> Research on the potential benefits of paid sick leave for Philadelphia workers found that mandating paid sick leave – which would allow employees to make better use of primary care during standard working hours – would prevent over 12,000 ED visits and reduce healthcare costs by \$10.3 million.<sup>40</sup> Current conditions essentially pit the health

*The healthcare system alone cannot contend with the many social, emotional, and financial challenges that low-income families face, yet these challenges have a clear relationship to families' ability to manage their children's asthma.*

needs of a chronically-ill child against the parent's need to provide income.<sup>41</sup> It is vital that the healthcare industry, and not just individual providers, support these worker protections which, while focused on adults, are absolutely necessary to the health of children.

Like the disability protections described above, many families – and employers – are not aware of the job protections applicable to them under federal and local law and they should be.<sup>42</sup> The FMLA, for example, applies when an immediate family member has a “serious health condition,” and the Department of Labor specifically recognizes asthma as an example of a “chronic serious health condition” for which FMLA leave could be used.<sup>43</sup> Under FMLA, 12 weeks of job-protected, unpaid leave can be taken continuously, intermittently, or on a reduced-hours basis. Some jurisdictions, including DC, have additional family leave protections. For example, employers in the District cannot require employees to first use accrued paid sick or vacation leave before taking DC FMLA leave. DC FMLA also expands the definition of family to include foster children, domestic partners, and other domestic relationships either excluded from or not contemplated by FMLA. Many families of children with asthma would benefit from education on their rights as employees so they can choose whether to take leave to which they are entitled.<sup>44</sup> These families would benefit from new or existing medical-legal partnerships that include and are prepared to address labor issues as an important component of their work.<sup>45</sup>

In the absence of federal protection, paid leave laws are currently enacted or under consideration in a number of states and cities. As of January 2014, three states had statewide paid leave policies, and several cities, including Jersey City, NJ, New York, NY, Portland, OR,

Seattle, WA, and San Francisco, CA, provided paid leave protections for workers. Eligibility, rate of accrual, and other provisions vary. The success of state and local efforts should increase the likelihood of federal action. Bills to provide paid sick leave standards and a national paid family and medical leave insurance program have been introduced in Congress. These activities, whether local, state, or federal, should be on the policy agenda for asthma advocates.<sup>46</sup>

**IMPROVE UNDERSTANDING AND ENFORCEMENT OF LEGAL PROTECTIONS FOR SAFE, AFFORDABLE HOUSING (RECOMMENDATIONS 3.3, 3.4, 3.5)**

Like worker protections, safe, affordable housing is a children's health issue. DC AIR interviews revealed families with little control over environmental triggers in their homes such as mold on carpets or overheated apartments that could not be adjusted. Because low-income families are less likely to own their homes, and because affordable housing can be so difficult to find, families are hesitant to risk losing their housing by challenging unsafe conditions. Or they may move because they don't know they have the right – or may not have the resources – to modify their living unit to better accommodate their child's health. In the District, funds are available for low-income homeowners to bring homes into compliance with housing codes and/or make modifications for disabilities, such as installing a ramp for a wheelchair, or widening doorways or installing grab bars.<sup>47</sup> These same resources are not currently available to most tenants.

Some of the same laws that provide protections for students with asthma in schools also apply to publicly-funded housing. There are also anti-discrimination and safety provisions in housing-specific law. The federal Fair Housing Act prohibits discrimination in private housing



with four or more units, and permits tenants to make necessary modifications.<sup>48</sup> State and local jurisdictions can add additional protections to Fair Housing requirements, such as lowering the number of units required for applicability, or increasing the landlord's responsibilities for modifications. In the context of a residential lease, the implied warranty of habitability requires that landlords provide housing that is livable and up to local housing codes. This warranty empowers tenants to demand repairs to make the housing livable, such as providing heat and running water or addressing pest infestations. It could potentially be used to argue that environmental conditions, such as mold, make the housing unlivable. In federally-funded public housing, Section 504 and Title II of the ADA require reasonable accommodations at the landlord's or housing authority's expense.<sup>49</sup>

Where affordable housing is limited, and landlords are allowed to violate housing codes, tenants may feel powerless to protect their health. It is therefore necessary to ensure both that families have access to free and low-cost legal services to enforce their rights, and that local jurisdictions use their authority and resources to require property owners to maintain safe, healthy housing free of common asthma triggers. The asthma advocacy community needs to reach out to and/or advocate for new resources in legal services and housing advocacy in order to ensure that efforts to improve housing and empower tenants extend to those who are caring for a child with asthma.

The Fair Housing Act requires that landlords allow tenants with disabilities to make reasonable modifications to the housing unit at their own expense, as long as it doesn't

make the unit unrentable to a future tenant.<sup>50</sup> Depending on the specific modification, tenants could be required to restore the housing unit to its original state when the tenant leaves. If restoration will be required, the landlord may require the tenant to pay into an (interest-bearing) escrow account the amount estimated for the restoration.<sup>51</sup> Thus, if a tenant needs to remove carpeting because it traps dust and causes asthma flare-ups, the tenant not only would have to finish the floor underneath or provide some alternative floor cover, but may have to put up money to replace the carpeting upon termination of the rental agreement. The costs associated with such an accommodation would likely be prohibitive so the tenant will either move, or live with the threat to the child's health. For this reason, there is a need to financially support low-income renters, not only with rental subsidies and other on-going costs, but also with the one-time cash infusions necessary to make housing free of asthma triggers. Programs like the one in DC that serve homeowners should be developed for low-income tenants who need modifications to make their homes healthier for children with asthma.

#### IMPROVE ACCESS TO CLEAN INDOOR AIR AND COORDINATE FEDERAL OVERSIGHT OF INDOOR ENVIRONMENTAL QUALITY (RECOMMENDATIONS 3.6, 3.7)

With the general concern about environmental sustainability growing among policy makers and communities in the last three decades, "green buildings" and "green product certifications" have become increasingly popular. More and more buildings are being built to standards such as the Green Building Council's *Leadership in Environmental and Energy Design* ("LEED") which provides guidance

*There is a wealth of knowledge about how to reduce common asthma triggers in schools, as well as tools to help schools translate that knowledge into action, but schools have not systematically and consistently applied those resources and are typically not held accountable for doing so.*

on everything from building materials, to heating and cooling systems, to windows, to plumbing fixtures. Most states, along with hundreds of cities and counties, including Washington, DC, are making policies that require some new construction to meet these standards, and consumer preferences are also driving demand.<sup>52</sup> The good news is that new construction built to the standards of LEED, *Green Globes*, and other similar programs have much improved indoor environmental quality. Research has demonstrated, for example, that LEED Platinum-certified residential buildings can improve asthma outcomes for residents, including reduced symptoms, fewer emergency room visits, and improved attendance at school and work.<sup>53</sup> The bad news is that these standards are coming more slowly to affordable multi-family urban housing.<sup>54</sup>

In the meantime, most of the current housing stock – along with many schools – is aging, and was not built to high standards for indoor air quality. Homes in inner-city areas, in particular, have higher levels of indoor air pollutants than suburban homes.<sup>55</sup> Poor indoor air quality is a distinct concern in cold and unsafe environments because people spend more time indoors.<sup>56</sup> In addition, in multi-family dwellings, families can suffer from irritants like cigarette smoke and strongly-scented cleaning products that reach them through shared walls or ventilation systems.<sup>57</sup> Housing codes for private residential construction have not kept pace with public buildings and the commercial market.

Despite some progress, indoor air quality remains an orphan in terms of federal regulation and leadership. Different agencies, including the Environmental Protection Agency

(“EPA”), and Housing and Urban Development (“HUD”), each contribute components of oversight and action. HUD, for example, regulates manufactured homes, and homes built for use in HUD programs, and the Consumer Product Safety Commission can take action on consumer products that create toxic exposure in homes or schools, but no agency has the power to regulate indoor air the way that the EPA, through the Clean Air Act, regulates outdoor air pollution. The result is that much of the action is advisory and compliance is voluntary. EPA, for example, has a program called *Tools for Schools*,<sup>58</sup> which provides a framework and action plan for organizing around, inspecting, and remediating indoor air quality in schools. In DC’s Healthy Schools Act, language requiring schools to undertake the *Tools for Schools* process was changed in the final version to language requiring promotion of *Tools for Schools*.<sup>59</sup> The result is that no one has been assigned responsibility and no specific actions to promote school indoor air quality have been undertaken. Congress needs to take action to consolidate authority over indoor air quality and to allow EPA to set standards for the presence of known indoor air pollutants.

*Research has demonstrated that LEED Platinum-certified residential buildings can improve asthma outcomes for residents, including reduced symptoms, fewer emergency room visits, and improved attendance at school and work.*

## Conclusion

### Broad spectrum of players who need to be involved and how they can help

The recommendations in this report are based on findings and observations from the DC AIR investigation into disparities in families' management of pediatric asthma. For those working on or living with pediatric asthma, the information presented is not likely to be new. This report aims to inform and engage a broader audience who play critical – though perhaps less obvious - roles in asthma management in their communities.

The optimal care-delivery model for managing asthma goes beyond the typical medical office visit; it requires communities to step in and manage contributing factors that are outside the control of many low-income urban families. For example, indoor air quality and access to medication at school are well-documented and significant factors in helping or hindering management of children's asthma. School leaders, however, must take the steps necessary to consistently implement safe and healthy school policies.<sup>60</sup> If school leadership is slow to take on this challenge, state and local policymakers must step in to provide the necessary incentives and consequences to ensure that implementation occurs.

We hope that this document provides a blueprint that communities can use to identify and bring together the key players necessary to address the communication, care, and support challenges that are obstacles to successful management of asthma among low-income and disadvantaged children. We need leadership from government officials and policymakers to make sure the steps outlined in this document are implemented and responsible parties are held accountable. For low-income children with asthma, not only does their chronic condition impact their lives, but the challenges in their families' lives have an additional impact on their asthma. Tackling this problem requires involvement beyond families and clinicians – it takes a broad range of community members using their authority to provide safe and healthy environments and access to appropriate care, and to ensure that families have the support they need to care for their chronically-ill children.

*For low-income children with asthma, not only does having a chronic condition impact their lives, but the challenges in their families' lives have an additional impact on their asthma.*

Audience	Recommendations for Improving Asthma Management
<p><b>Federal Lawmakers</b></p> <p><b>State and Local Legislatures/ Policy Makers</b></p>	<p>3.7 Empower the EPA to set standards and regulate indoor air.</p> <p><b>General Recommendation:</b> Use authority and leadership to hold responsible parties accountable to implementation of steps to reduce the burden of asthma on low-income families.</p> <p>2.2 Improve convenience of clinic locations.</p> <p>2.5 Increase availability of school nurses, especially at schools with significant student populations with chronic conditions like asthma.</p> <p>3.4 Create an Asthma and Housing Task Force to focus on provider compliance with codes including the Fair Housing Act, Common law's implied warranty of habitability and (for public housing) Section 504 of the ADA.</p> <p>3.5 Establish a fund for making legal modifications in rental housing.</p> <p>3.6 Increase access to high quality affordable housing with clean indoor air.</p>
<p><b>School Systems</b></p>	<p>1.1 Improve school nurses' access to student health information.</p> <p>1.2 Address triggers in the classroom.</p> <p>2.5 Increase availability of school nurses, especially at schools with significant student populations with chronic conditions like asthma.</p> <p>3.1 Educate families on the protections available through anti-discrimination laws.</p>
<p><b>Departments of Health</b></p>	<p>1.3 Target communities with high prevalence of poorly-managed childhood asthma with general asthma education so as to capture more formal and informal caregivers.</p> <p>2.4 Develop or expand an asthma-management education intervention that includes schools and homes among various critical settings.</p> <p>2.6 Use technology to reach families with asthma education and support during non-work hours.</p>
<p><b>Community Clinics and other Healthcare Providers</b></p>	<p>2.1 Expand clinic hours to be more convenient for families.</p> <p>2.2 Improve convenience of clinic locations.</p> <p>2.4 Develop or expand an asthma-management education intervention that includes schools and homes among various critical settings.</p> <p>2.6 Use technology to reach families with asthma education and support during non-work hours.</p>
<p><b>State Medicaid Programs</b></p>	<p>2.1 Expand clinic hours to be more convenient for families.</p> <p>2.2 Improve convenience of clinic locations.</p> <p>2.3 Ensure appropriate billing codes are available for asthma education and other chronic illness support, and facilitate appropriate reimbursements for asthma education.</p> <p>2.7 Eliminate limits state Medicaid and any Medicaid MCO may impose on the number of inhalers a child may be prescribed at any one time.</p>
<p><b>Legal, Social, and Financial Support Service Providers</b></p>	<p>3.2 Improve families' access to information and legal support to encourage use of available labor protections for ongoing non-emergent medical care/attention.</p> <p>3.3 Improve families' access to legal support to address asthma triggers in rental housing.</p> <p>3.4 Create an Asthma and Housing Task Force to focus on provider compliance with codes including the Fair Housing Act, Common law's implied warranty of habitability and (for public housing) Section 504 of the ADA.</p> <p>3.5 Establish a fund for making legal modifications in rental housing.</p> <p>3.6 Increase access to high quality affordable housing with clean indoor air.</p>

## End Notes

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- 3 Am. Lung Assoc., *Trends in Asthma Morbidity and Mortality* (2012), available at <http://www.lung.org/finding-cures/our-research/trend-reports/asthma-trend-report.pdf> (accessed February 4, 2014).
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- 5 McDaniel et al., *supra* note 1.
- 6 *Id.*
- 7 Evidence-based, as defined by the Department of Health and Human Services Agency for Healthcare Research and Quality, means the application of the best available research results (evidence) when making decisions about healthcare. For more information about IMPACT DC, see [www.impact-dc.org](http://www.impact-dc.org)
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