



Making Sense of Childhood Asthma

Lessons for Building a Better System of Care

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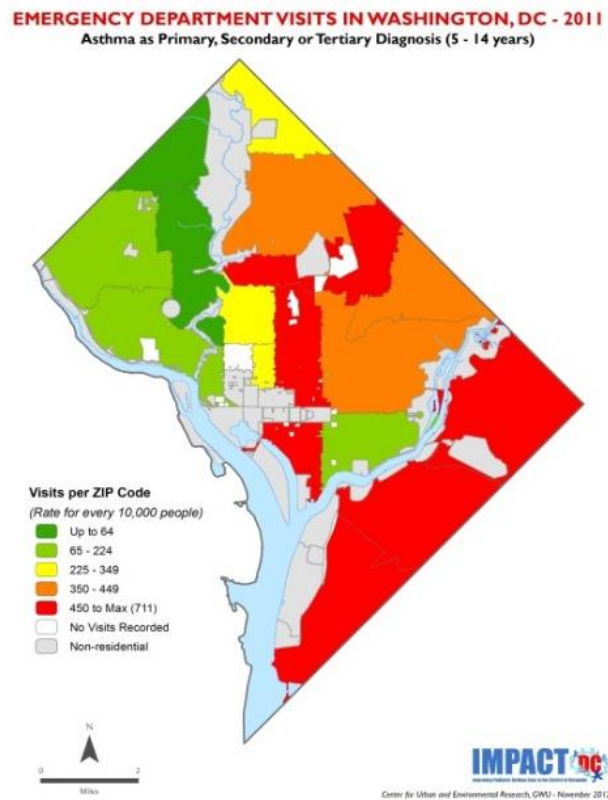
“It’s hard to accept that your child has a chronic illness... We say, take the medicine until you’ve been doing well for multiple months and then we can think about taking it away.... Most other medicines have an end date, and people respond a little bit better to that. It’s really hard to give someone something [i.e., medicine], and say [take it] ‘Every day. Forever.’”—IMPACT DC Asthma Educator¹

Most children do not have a chronic health condition that requires daily medication and constant monitoring. And although the numbers of children with chronic health problems have been increasing (Halfon and Newacheck 2010; Van Cleave, Gortmaker, and Perrin 2010; Park et al. 2013), the vast majority still experience only intermittent or temporary illnesses. With asthma, the most common chronic pediatric disease in the United States (affecting 7 million children under 18 years in 2010; see Moorman et al. 2012), sufferers must avoid potential triggers and take medication daily to prevent dangerous flare-ups (National Asthma Education and Prevention Program [NAEPP] 2007). Unlike most children, those diagnosed with asthma—and their parents or caregivers—must continuously monitor their health.

Dangerous asthma flare-ups can land children in a hospital emergency department (ED). In 2007, children under the age of 18 made 640,000 pediatric ED visits and were admitted to pediatric hospitals 157,000 times for asthma (Akinbami, Moorman, and Liu 2011). Hospital visits and admissions constitute a large share of the disease’s annual direct pediatric costs, which exceed \$3 billion (Wang, Zhong, and Wheeler 2005). Despite the highly effective guidelines for asthma treatment available from the National Institutes of Health (NAEPP 2007; Gupta and Weiss 2009), children’s overall morbidity (attack rates, ED visits, hospitalizations) and mortality have not decreased.² Further, striking racial, ethnic, and socioeconomic disparities persist, with poor and African American and Latino³ children, particularly in urban areas, incurring a disproportionate share of asthma-related problems (Boudreaux et al. 2003; Grant, Lyttle, and Weiss 2000; McDaniel, Paxson, and Waldfogel 2006). The overall ED visit rate for asthma among African Americans from birth to age 17, for example, is 4.1 times greater than among non-Hispanic whites. The asthma death rate is 7.3 times greater. Among Latinos in the same age group, the ED visit rate is 1.8 times greater than non-Hispanic whites, and the death rate is 1.2 times greater (Akinbami et al. 2009).

This report highlights key findings from a qualitative exploratory study about asthma care for low-income African American and Latino children age 4–14 in Washington, DC, which has one of the most severe childhood-asthma problems in the nation. Nearly one in five children under age 18 in Washington, DC, has the condition (American Lung Association 2012). In 2008, asthma prevalence in DC was three times higher among African American youth than among non-Hispanic white youth.⁴ Disparities in outcomes were even more dramatic. Emergency department visits and hospitalizations are heavily concentrated among African American children living in DC’s poorest neighborhoods. In 2010, the ED visit rates for asthma among children in the most disadvantaged zip codes of southeast DC were more than 10 times greater than the more advantaged zip codes of northwest DC (figure 1).⁵

Figure I. Emergency Department Visit Rates for Asthma among DC Children Age 5–14 by Zip Code, 2010



Source: www.impact-dc.org.

Given DC’s troubling asthma record, we explored two central questions: Why, when doctors and researchers know so much about asthma, its treatments, and its disparities, do we continue to see so many children with poor asthma control and high reliance on EDs for care? And, why have we not solved this problem yet? One reason some assert is that our health care system is especially focused on acute—and not chronic—care (National Research Council 2001).⁶ As a result, treatment focuses predominantly on diagnosing and resolving immediate presenting symptoms rather than the ongoing management required for chronic conditions. We examined this hypothesis in interviews with 33 people facing DC’s childhood asthma problem from different vantage points.

About the Study

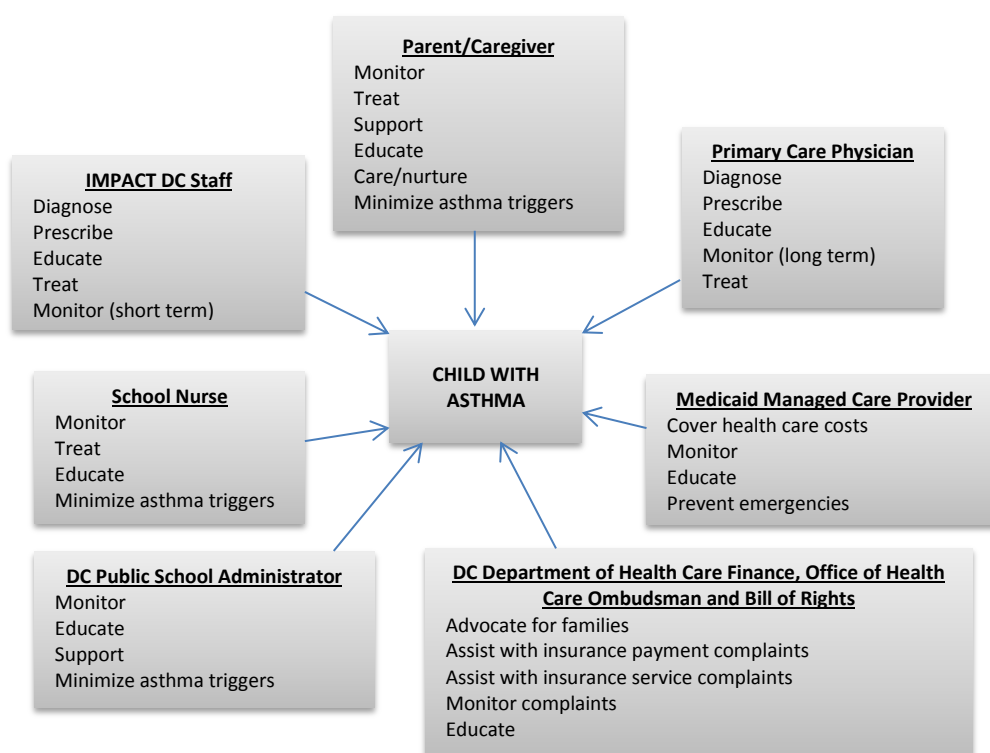
In DC, the emergency department of Children’s National Health System (“Children’s National”) is home to IMPACT DC (Improving Pediatric Asthma Care in the District of Columbia), an intervention that has been shown in clinical studies to decrease unscheduled pediatric ED visits among low-income children and youth with asthma (Teach et al. 2006; Quint and Teach 2009). Despite the intervention’s effectiveness, the leadership of IMPACT DC wanted to better understand why some families who received the intervention continued to visit the ED exhibiting poor asthma control. We began the study in May 2012 with funding from the W.K. Kellogg Foundation to explore the factors that may contribute to less-than-optimal asthma outcomes for low-income children in Washington, DC.

Methods

We interviewed caregivers whose children had visited the IMPACT DC clinic between 2009 and 2012, and other key stakeholders involved with day-to-day medical care, policy, or advocacy for children with asthma in DC. We wanted to generate hypotheses about the primary barriers, challenges, and opportunities for improving asthma treatment for DC's low-income children and youth. We held three focus groups and spoke with 15 caregivers from neighborhoods with the highest asthma rates in the city. We also held a focus group with six school nurses from public schools and public charter schools, as well as a focus group with five IMPACT DC asthma educators. We spoke one on one with four primary care physicians from four community health clinics, one administrator from DC Public Schools, and one administrator with a Medicaid managed care organization. Within the DC Department of Health Care Finance, we spoke to a representative from the Office of Health Care Ombudsman and Bill of Rights who handles citywide grievances around consumers' health care services (see appendix A for additional descriptions about the sample and study methods).

Figure 2 shows the constellation of stakeholders we interviewed and some of their roles and relationships to children with asthma.

Figure 2. Stakeholders Interviewed for the Study



Our original research strategy was to learn about challenges and effective approaches for controlling children's asthma from caregivers who had gone to the ED or inpatient ward at Children's National for their child's asthma and had had a follow-up visit at the IMPACT DC Asthma Clinic. We intended to speak separately to families whose children age 4–14 met our criteria for having “well-controlled asthma” and to families whose children age 4–14 appeared to have “poorly controlled asthma.”⁷ Our goal was to better understand the circumstances or practices that may have contributed to different outcomes. We recruited families who had been

treated at the asthma clinic between 2009 and 2012 to allow sufficient time following their visit to observe later asthma outcomes.

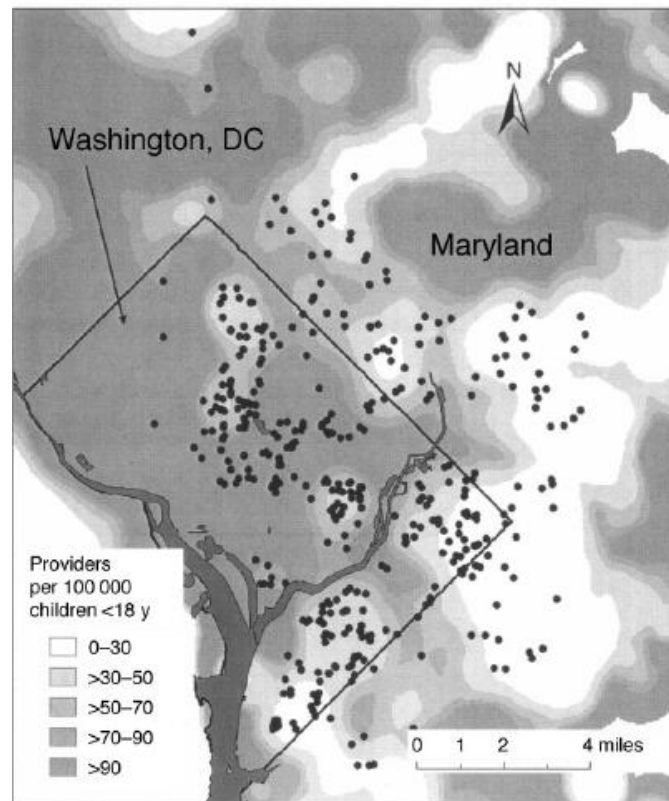
Despite attempting to identify families whose children had well-controlled asthma (i.e., had not returned to Children's ED within six months after their IMPACT DC appointment), we did not find *any* who had not visited the emergency department in the past year. Some children met our initial criteria of not having an ED visit within six months of their IMPACT DC appointment, but nearly all had at least one relatively recent ED episode, and all were still taking emergency inhaler medications regularly. While our groups were small and not statistically selected to represent all families seen by IMPACT DC, our difficulty locating families that had not been to the ED in the prior year was telling. Consistent with the research on barriers to proper asthma care, many families may not be achieving adequate long-term asthma control. This may stem from the present health care system's emphasis on short-term solutions for families with long-term needs.

Childhood Asthma in Washington, DC

Like many other large cities, Washington, DC, provides a useful local case study of a region struggling with high asthma rates. African Americans and Latinos make up 60 percent of all DC residents,⁸ but they account for over 95 percent of all pediatric ED visits for asthma. In the pivotal research trial of the IMPACT DC intervention described below, 62 percent of families recruited on the basis of repeat ED visit reported that the ED was their usual source of asthma care, *not* their primary care providers. And in a recent study of 188 patients age 2–12 years discharged from the ED at Children's National after care for asthma, only 24 percent returned to their primary care provider within 30 days. Because emergency departments do not focus on long-term aspects of care, such as trigger identification/control and controller medications (Thomas et al. 2001), many of these children develop unhealthy patterns of repeat ED visits.

Like elsewhere, low-income children with asthma in DC face challenges accessing ongoing care. An analysis⁹ of the geospatial accessibility of pediatric primary care across metropolitan DC highlights the very low density of providers in its poorest neighborhoods, which are also the neighborhoods with the greatest concentration of underserved children with asthma (figure 3). Primary care providers, in turn, are stressed by the quantity and complexity of asthma-related care they must deliver. Asthma and its treatments are complex, and devices that deliver medication are sophisticated and difficult for patients to master. Most clinicians' knowledge of guideline-based care remains suboptimal (Finkelstein et al. 2000; Garbutt et al. 2007); this shortcoming is a focus of improvement efforts by the National Asthma Education and Prevention Program of the National Institutes of Health (NAEPP 2008).

Figure 3. Density Map of the Geographic Distribution of FTEs of Pediatric Providers



Black dots represent residential addresses of children who made ED visits to Children's National for moderate to severe asthma exacerbations.

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FTE = full-time equivalent

High Asthma Burden despite High Rates of Health Insurance Coverage

DC is an important case study location for another reason. The city has one of the highest rates of health insurance coverage in the nation for children (Chandra et al. 2009), nearly half of whom are covered by Medicaid.¹⁰ Despite this extensive coverage, DC still has distressing child health outcomes: high rates of obesity, hospitalizations for sickle cell anemia, HIV infection, sexually transmitted diseases (three times the national rate), and untreated emotional disturbance (Chandra et al. 2009). Thus, while other cities and states work to increase rates of insurance coverage among low-income as well as African American and Latino youth, DC's experience demonstrates that insurance coverage alone will not necessarily reduce the challenges of managing asthma or other chronic childhood illnesses. Increasing health insurance coverage is an important goal, and it contributes to DC's ability to serve children with asthma and other illnesses. But until the health care and other systems adapt to the needs of children with chronic illness and their families, these health problems will not abate.

A Terrifying Condition

I just want this asthma to get under control. People die from asthma.—Caregiver

Behind the disproportionate numbers of emergency department visits for low-income African American and Latino children living in large cities are parents' and caregivers' very real and urgent fears about their children's health. "There was one time when I was calling 911... one of these times she's not going to make it," one grandparent told us about her 11-year-old granddaughter.

Asthma attacks are terrifying, causing caregivers stress, anxiety, and lost sleep. As this mother told us, "She doesn't wake up in the middle of the night wheezing. She'll sleep through an attack and I'll put the mask on her face while she's asleep. I'll put her in my bed with me so I can monitor her better."

It's scary! It's really scary because we have to constantly watch her. She has an attack and we may not know.—Caregiver

Others described their anguish when their children are weak and struggling to breathe.

It hurts when you can see her not breathing, but there's nothing I can do except give her the medicine.—Caregiver

"It worries me," a caregiver told us in Spanish, "and I wonder if when she's older... who will take care of her when I'm gone. I won't be around forever."

Parents and caregiver's fears about uncontrolled asthma led many to seek information from health care providers and their peers. Even in the focus groups, parents and caregivers were swapping tips and strategies. "[Asthma] scares the hell out of me. I don't know about you guys and how you treat your children, but I try a bunch of things," one caregiver explained. Remedies such as breathing into a bag, taking a steam bath, and breathing cold air from the freezer were discussed and debated. As described later below, these same remedies are often interventions health care providers discourage because they are contrary to medical advice. But, as we learned from families desperately looking for immediate solutions, many will try whatever they feel might work.

Poor Housing, Lack of Providers in Low-Income Neighborhoods

Despite wanting to do what was best for their children to keep them healthy, caregivers faced barriers to effective asthma management, many of which were tied to poverty. The families invited to participate in the study lived in zip codes with fewer primary care providers, as shown in prior research (Teach, Guagliardo, et al. 2006). The caregivers described work schedules that could not flexibly accommodate appointments during standard 9:00 a.m.–5:00 p.m. business hours. They also talked about having little control over environmental triggers in their homes, such as mold on carpets or overheated apartments that could not be adjusted. Low-income families are less likely to own homes and can be at the mercy of their landlords. This situation can result in families needing to move over seemingly trivial issues.

We had to move because there was something in the carpets [that was triggering asthma attacks].—Caregiver

We don't have a thermostat to control the heat in the basement apartment. It gets so hot in there and we have to keep the windows open all the time.—Caregiver

When asked about systemic solutions that could better help families cope with asthma, an administrator from the DC Department of Health Care Finance echoed caregivers' concerns about housing, explaining that DC government can play an influential role in ensuring that landlords have ethical practices and are providing housing that is not harmful to families. "They need to make sure they [landlords] put in air conditioning for the children too," she added. As she explained, low-income families may not complain when their housing is in poor condition if they are worried a landlord might displace them.

NAEPP and IMPACT DC: Bridging the Gap between Acute and Chronic Care

The National Asthma Education and Prevention Program (NAEPP) published updated, evidence-based best-practice asthma education guidelines in 2007. Their recommendations include four central instructions to care providers: monitor and assess asthma severity regularly, provide continuous and consistent education about proper asthma care, teach families to attend to environmental triggers, and prescribe proper medication (Gupta et al. 2009; NAEPP 2007). These strategies prevent hospitalizations and emergency department visits (Coffman et al. 2008) and school absences for asthma (Fox et al. 2007).

Because proper long-term asthma management is critical, NAEPP recommends regular doctors' visits every two to six weeks when patients are beginning care or are increasing their children's medication, and monthly to biannual visits once the asthma is under control. NAEPP emphasizes constant, ongoing education at every opportunity. The program recommends that asthma patients and families receive self-management education from "multiple points of care," including from pharmacists and schools (NAEPP 2007, 97). The guidelines give specific recommendations to schools in particular to provide regular and comprehensive asthma education to students, principals, teachers, and other staff.

IMPACT DC is a local intervention that articulates NAEPP best practices within a hospital ED setting. It was designed to address families' preferences for hospital settings while also providing a bridge to better ongoing services. IMPACT DC's objective is to address gaps in the continuum of care a family receives. It aims to bridge the medical attention families receive at the ED with the ongoing care they should receive at their regular primary care providers' office (Quint and Teach 2009). Families are referred to the clinic in three ways: following an ED visit, after an overnight hospital stay, or through a doctor's or nurse's referral. Once referred, a clinic staff member contacts the family in person or by phone and schedules patients for a 90-minute appointment. The appointment with the child and his or her primary caregiver focuses on asthma education, environmental triggers, and care coordination to ensure the family's primary care provider and school nurse are included in the asthma action plan.

The IMPACT DC Asthma Clinic is staffed by a clinic manager, asthma educators, and a physician or nurse practitioner. Asthma educators are typically recent college graduates who receive training in asthma treatment protocols. Many become Asthma Educators—Certified (AE-C) as soon as they qualify (e.g., by working as an asthma educator for 1,000 hours). The asthma educator discusses the child's asthma history, spends time discussing the illness and how to manage it effectively, and coaches the child and family on proper asthma technique using asthma devices for medication delivery. The physician or nurse practitioner conducts a physical examination and answers any medical questions the family may have. The clinic also gives the family free items to help with asthma care such as a "spacer" (a device used with aerosol

medication such as inhalers to ease its administration, especially for children) or allergy barrier pillow covers in addition to other asthma resources.

Families are generally seen once or twice at IMPACT DC, and are then encouraged to follow up with their primary care provider for ongoing care. Two weeks after the visit, the asthma educator calls the family to see how they are doing and to ensure the family has made a follow-up appointment with their child's primary care provider.

Emphasis on Asthma Education

According to IMPACT DC asthma educators, the intervention addresses some of the impediments that prevent some families from benefiting from services at a primary care office or clinic. Their model addresses key issues related to short appointment times and asthma education.

The 90-minute appointment means families have more time with the asthma educator and clinician to review critical information and guidelines—time that most primary care providers are unable to spend.

I think time is a huge factor. I think in most primary care visits you have 15 minutes to cover the entire health of the child and you're looking for such big things and the amount of time physicians have for health education is almost none.... We have more time and can provide additional information and support.—Asthma educator

That additional time can be spent on increasing asthma education, which can counteract false messages or beliefs the family may hold.

There's a concept that their [kids] are ... on too much medicine. That "this is just too much medicine for them and it's not good for them!" There is another fear that the child's body will start to get used to a certain dose and will need to increase the dose or volume of their prescription.—Asthma educator

"Is their body going to need more and more and more?"—Asthma educators, describing parents' questions

If you have a good way of explaining asthma and the way the different medications work, you are really able to inform a family in a way that helps them be their own advocates in terms of their child's asthma care It's so nice [as an asthma educator] to be able to combat that ... information imbalance that often exists between physicians and patients; because we have the time to talk to them, and we have the time to explain, "Now, here's why your doctor prescribed this."—Asthma educator

Limits to IMPACT DC's Reach

While IMPACT DC staff attempt to address many barriers to effective asthma care for low-income families, they acknowledge many challenges. Among their concerns, the techniques they teach are not always sustained at home, and families' other life stressors can push a child's asthma management to the wayside.

I think for a lot of families they have so many barriers to face in their immediate life—like having enough food at the end of the month, or keeping their electricity on ... whatever it is. They're living very moment to moment to a point where, if the asthma's ok, "It's ok now." And then they don't think about what's going to happen next winter or next spring. —Asthma educator

Complex Lives: Why Proper Asthma Management May Take a Back Seat

There's a cultural perception about ...[whether or not] asthma can be controlled. It's so endemic in some communities and so uncontrolled that for a lot of kids having these symptoms is normal. There's just sort of a normalcy to mild, persistent asthma symptomsThere is a major disconnect between what a healthy [child actually] is and what [the parent] thinks a healthy child is.—Asthma educator

In focus groups and interviews with caregivers and other key stakeholders, we asked about families' lives and factors that may contribute to better or worse asthma outcomes. Caregivers and other stakeholders described challenges treating asthma as a chronic condition that requires daily maintenance even when a child is not experiencing symptoms. In a parallel way, the health care system and the school system appear to operate in an acute-care, treat-and-fix model—jumping into action when a child is in crisis. The prevailing tendency is to focus on “sick care” rather than “health care.” While the system can generally catch and treat children in an emergency and prevent a complete fall through the cracks, our key stakeholders acknowledge that the system has not done a good job filling up the cracks that lead to emergencies. Families must navigate those hazards themselves.

Stress: Juggling Family, Work, and Health Challenges

In clinic I sometimes feel like I'm competing with all the at-home stresses the family has.—Asthma educator

I think a lot of the time we talk about low-income families and all the stresses of their lives, but I think personally, it's probably stressful to have children—especially [more than one]. And keeping everything in order is probably exhausting. Every parent comes with some barrier; otherwise, they wouldn't be there [at IMPACT DC]. They would have never made it to IMPACT. They would have [received care] somewhere upstream.—Asthma educator

Among the caregivers who participated in the focus groups were several grandparents raising their grandchildren. In at least three instances, the child's parent, aunt, or uncle (the grandparent's son or daughter) had passed away. In addition to the stress of asthma, families and their children were facing the trauma and pain of death and loss. Several parents and grandparents had chronic health conditions of their own, and so were coordinating and prioritizing their own treatments as well as managing their child's medications. One had cancer; another had chronic obstructive pulmonary disease. Others had asthma themselves or a spouse, partner, or other children with asthma. As this grandmother put it,

Whatever has to be done I'm willing to do. When I was in the hospital with cancer I was asking about “How's her asthma?” “Does she need her pump?” I was always worried about that child. She has so much going on.—Caregiver

Parents and caregivers also spoke about the stresses that come from juggling work while caring for a chronically ill child. Several had jobs that lacked flexibility or paid sick leave, and some reported they had to stop working in order to manage their child's illness.

It affected me because I had to stop my job.—Caregiver

I had to quit jobs before because she had an asthma attack three days in a row; and they won't let me take time off, so I quit.—Caregiver

*It's affected my job... I have to take off [time from work] every time he gets sick.
—Caregiver*

I will be working [when an attack happens]. It's good that [Children's National has] the things to excuse me from work.—Caregiver

Coping: Relying on Family Resources That May Not Support Best Asthma Care

We asked families how they managed their children's asthma and what resources and strategies they use to cope with the condition. Two common responses were social support networks (e.g., family members and friends) and children. Family members and friends were important resources and integral to how caregivers managed their households. Caregivers also said their children who had asthma had to take more responsibility for the condition by a certain age. Caregivers generally viewed both strategies positively and as a vital resource for managing their child's asthma in addition to other work and life demands. However, providers and other stakeholders we spoke to held more negative views about these coping strategies. From their perspective, multiple caregivers and children managing their own illnesses in many cases meant poor asthma control.

Multiple caregivers

Several people we interviewed, including caregivers and other stakeholders, described scenarios where a caregiver's family members would pitch in and help when the primary caregiver was not available. "Multiple caregivers" included the second parent, grandparents, older siblings, and other friends and relatives who helped care for the child. Sometimes children would stay with the caregivers during the day or overnight. In addition to caregiving, surrogate caregivers provided emotional support, transportation, and guidance.

Typically caregivers described these resources as vital for managing their child's illness.

*Right now it's me and my husband. If we're not home, my mother and brothers know what to do. I write down a list, and the oldest kid knows what medication to take. If it's about to get bad, I leave wherever I have to go. Everybody has to know [what to do].
—Caregiver*

Despite often relying on their support networks, some caregivers gave examples of when the additional hands were not always helpful. For example, sometimes the family member or friend may not understand the medicines and when they should be administered. Asthma educators generally shared this concern and felt the arrangements could be detrimental to a child's health in some cases. The caregiver most responsible for the child may not have been present for the IMPACT DC visit or may not properly relay the information to other adults caring for the child throughout the week.

*[Having] multiple caregivers is a strong indicator of poor adherence—for obvious reasons. Usually only one caregiver comes [to] the visit, and frequently it's the caregiver with the most time on their hands—so it's grandma who's not working. But it's not necessarily the one with the most power in the family dynamic... Usually the mom has the most power... especially when it comes to health decisions.
—Asthma educator*

Frequently what I've noticed with low-income families, mom has some unpleasant work schedule that requires her to be up really early or stay up really late at night. So the kid might even sleep in multiple homes during the week... and you're never really sure if you're going to keep your medicine at home. There's your adherence problem right there.—Asthma educator

The primary care physicians we interviewed also discussed the challenges with multiple caregivers or reliance on siblings for care. As mentioned by the asthma educators, physicians also told us that the child's medication might be with one caregiver when the child is staying with another.

We have people who have multiple caregivers. Mom may have asthma medications but the neighbor or grandma may be the caregiver.—Primary care physician

*The younger kids are being taken care of by older siblings who don't know how to take care of their medicine. For younger kids the baby-sitter is the one who spends most time with the patient and the mom doesn't want to give medicine responsibilities to [the] baby-sitter.... Related to baby-sitter, there are multiple caregivers and they [the caregivers] are passing around medication, and the child ends up not taking it.
—Primary care physician*

Children responsible for their own care

Just as children with many caregivers may have more trouble receiving their daily medicine consistently, children with more responsibility and less supervision may also take their medicine less regularly resulting in poor asthma control. We heard this concern mostly from caregivers as they described reasons that managing asthma can be challenging.

He's had asthma all his life, so you'd think he's used to it. So, I have to remind him. Sometimes he'll do it on his own, but sometimes I forget to ask him. For two days he'll stop taking it. I have to remind him but sometimes I forget. I think because he feels okay he won't take it. But it's preventative so he has to remember... [otherwise] he'll have to go to the hospital.—Caregiver

Another common challenge is that children resist taking their medications.

*She [her granddaughter] is not trying to help herself. She takes this asthma as a joke... She is 11 and she is not taking medicine. She's saying she doesn't need the pump.
—Caregiver*

My problem is he doesn't think he needs it.—Caregiver

Other caregivers were proud of their child's competence. One parent praised her 7-year-old son for knowing what to do with his inhaler:

[He] is so good. He knows what he is supposed to do. He has to tell [his school nurse] he needs four puffs or two puffs.—Caregiver

A second caregiver added:

*When I am at work then she call[s] me. "Mommy, it's time for medicine," and I say, "Okay, go do your thing." She turns it on and uses it. You have to rinse it out and she knows what she doing.... But my son, I can't trust him with nothing! He's only 4.
—Caregiver*

Parents and caregivers expected and encouraged their children to monitor their asthma symptoms and medication. This responsibility is also reinforced by schools, which permit students with proper permission and doctors' orders to hold and administer their own emergency inhalers. Similarly, an important aspect of IMPACT DC's educational component is to ensure both the child and caregiver understand and practice proper technique. With very young children (perhaps less than 9 years old, depending on the child's maturity), the asthma educator will primarily talk to the caregiver. With older children, the asthma educator talks directly to the child, but directs some questions to the caregiver.

As part of the training we also try to focus on making sure we engage kids when they get to an age where they can be engaged in the program, which gives them a little bit more responsibility in taking care of their asthma at a younger age... which I think is important especially considering a lot of families are juggling a lot of different kids in the family, a lot of different sort of responsibilities. So sometimes kids have to take a little more initiative in their own care.—Asthma educator

From providers' perspectives, however, the children should be well-supervised by an adult. While providers hope children increasingly take more initiative as they get older, the stakeholders we spoke to did not encourage children's complete independence. For schools, children's independence can also become an issue. School nurses were troubled when caregivers did not inform them that their children have asthma, did not provide medical documentation, and permitted the children to carry and take unapproved medication at school.

You have a lot of children who come and they have medicine in their backpack. And the teacher brings the kid in to you... and you call the parent and they say, "Yes, he has it [asthma]." And if they haven't brought you a new health certificate, I say, "I need documentation. How often is he taking it?" And some of them [parents] cuss you out. Then you take a deep breath and you ask how often is Johnny taking it at home. Then they say, "My son is 12 years old and he can take it himself!"—School nurse

Children taking responsibility for their medication is an important resource from a caregiver's perspective. But it may contribute to less consistent daily care. For some caregivers, the school policy requiring an up-to-date health certificate may feel like another hurdle, although unintended, to keeping their children's asthma under control in school.

Additional Barriers

Families with multiple stressors, multiple caregivers, or less supervision over their children's asthma care are likely to have trouble maintaining a daily treatment routine. On top of these challenges, parents/caregivers and stakeholders described other barriers that are often also reported in research literature. These barriers included poor transportation, few providers (Teach, Guagliardo, et al. 2006), inconvenient office hours or difficulty scheduling appointments (Crain et al. 1998; Mansour et al. 2000), medication costs, inadequate or confusing information (Mansour et al. 2000), the stress and burden of constant vigilance and regular struggles with children about taking their medication (Bender and Bender 2004), competing household priorities and not believing medication is effective (Smith et al. 2008), preference for nonmedical treatment techniques, strong personal and cultural beliefs against medication use, or not feeling their children's asthma is severe enough to require daily medication (Bender et al. 2004; Mansour et al. 2000).

Research on school nurses points to additional obstacles including not having medication in school, not being able to reach parents, not having students' medical forms, school staff not having adequate asthma education, and school buildings with dust, mold, and excessive heat

(Forbis et al. 2006). Table 1 lists all the barriers the stakeholders we spoke with raised. One barrier families named that other stakeholders did not concerned triggers. Caregivers talked about learning what triggers their children’s asthma. For them, missing a trigger or not knowing how it could affect their child was a constant worry and intensified their uncertainty about how to avoid and treat flare-ups.

Table 1. Barriers to Asthma Control

Barriers mentioned by parents/caregivers and nonfamily stakeholders	Barriers mentioned by parents/caregivers only	Barriers mentioned by nonfamily stakeholders only
Remembering daily medication	Learning new triggers that affect the child (sometimes the hard way)—remaining vigilant for new triggers	Not enough time with the doctor or provider
Multiple caregivers		Families not “taught to be patients” (e.g., advocate for themselves, bring appropriate information to appointment, ask certain questions)
Getting child to take responsibility		Caregivers don’t want to believe that child has a chronic illness
Limited control over environmental triggers (e.g., heat or mold in rented apartment)		Caregivers swayed more by personal anecdotes than by medical evidence
Concern about possible medication side effects		Caregivers wait until child is extremely sick to get medical care
Language barriers (among Spanish speakers)		Not having insurance
Health care provider’s demeanor or attitude toward family		Switching clinics and not alerting prior doctor
Health care provider’s hours and location		Lack of transportation and parking
Stop taking medicine when feel better		Schools/primary care physicians not having current contact information
Too many other stressors to focus on		
Not understanding medicine instructions or techniques		
Smoking cigarettes or marijuana		
Having more severe asthma		
Difficulty getting in touch with doctors or long wait times (especially for Spanish speakers when they go to the hospital)		

Lessons for Improving Asthma Care for Low-Income Children

School nurses, primary care physicians, asthma educators, and administrators from the Department of Health Care Finance, the DC Public Schools, and a Medicaid managed care organization each felt their school, clinic, agency, or department had a role to play in improving services for low-income children with asthma. They recognized that many challenges were system-related.

An asthma care model that takes the condition’s chronicity as well as its acute episodes into account would ideally emphasize daily management and strategies to ensure ongoing and consistent care. Three major areas where caregivers and stakeholders described system breakdowns were poor communication among the many caregivers, providers, and other stakeholders; inadequate access to both the quality and quantity of care needed to manage a child’s asthma; and scarce long-term support to address both the social-emotional and financial burdens created by managing a chronic childhood illness.

Communication among Stakeholders

As we learned, many stakeholders play a role in helping a child manage asthma. These include the primary caregivers in the home setting; secondary caregivers, such as neighbors, extended family members, and baby-sitters; ED staff; primary care providers; school nurses; and insurance companies. A potential consequence of poor communication and poor hand-offs across systems and service providers is fractured care for children. In addition to inadequate asthma control, inadequate coordination may lead to further discouragement and disillusionment about the treatment's effectiveness.

We highlight examples of communication across stakeholder groups and how the information they relay (or miss) can affect children's asthma care. The first concerns doctors' communication with families, school nurses, and hospitals. The second concerns caregivers' communication with schools. The third focuses on communication between schools, the department of health, and hospitals.

Primary care providers' communication with caregivers, hospitals, and school nurses

Primary care providers and families must be able to communicate effectively. One reason is to ensure children receive the correct diagnosis and treatment. As an asthma educator explained, children with temporary illnesses take medication and generally get better. When they get better, they associate it with the treatment and believe it was effective. With a chronic disease that may never go away, families need the positive reinforcement and evidence of success even more. With poor doctor-patient communication, parents/caregivers and children may not receive the right medicine or dosage (in part because providers may not know the child's health history or have access to their medical records, or because families may not provide the appropriate information), or families may not take the medication as prescribed. As a result, families may not believe the treatment works, which can adversely affect their adherence to or trust in their doctors. According to the asthma educators, this happens frequently with the families they see. One educator saw this miscommunication as a two-way street.

By the time they [families] get to us, they're shut off because they're so frustrated with bad care, but they [families] also aren't giving the right information.—Asthma educator

Another important communication path is between primary care physicians and other providers, EDs, hospitals, and schools. Better communication through electronic medical-data sharing is one tool stakeholders thought could ensure more continuous care. Using data sharing and electronic medical records (EMR), schools would be able to retrieve necessary information from physicians, and vice versa (e.g., medical forms that schools require). Data sharing would also allow primary care physicians to access the medical information of patients who change clinics without notice. Unfortunately, stakeholders told us that data sharing is only extended to primary care physicians and hospitals, and not to schools.

We communicate with Children's [National] on Michigan Avenue and ... UMC [United Medical Center]. We have EMRs that let us see if they've been in the ER, we're all connected. It is very easy to see if a physician is particularly concerned, and they can speak directly with the doctor.—Primary care physician

Although doctors can access health information from the EMR, they also noted some limitations. For example, a doctor may access the information only if he or she is listed as the patient's primary care physician. This could mean other doctors in the same practice may not be able to access the record if the primary care physician listed is not available; or, if patients visit a different clinic, their new doctor may not be able to access their health records. School nurses also noted how they are affected when doctors have incomplete information about children's

medical histories. A child's current doctor may not know the child has asthma, and therefore the school is not aware—even if the school has received the required health certificate from the family.

I think we miss a lot of asthma kids. Parents go from doctor to doctor and they don't take their records, and that is how the health information does not get shared with the new provider. And the new provider has no idea they have asthma.—School nurse

Caregivers' communication with schools and school nurses

Stakeholders gave several examples of how poor communication between caregivers and schools affects children's care. A school administrator explained how information is supposed to be shared from the family doctor to the family, and then to the school nurse, but how that process did not always happen.

Another challenge is the doctor-family-school communication... The child is diagnosed and the provider gives the meds. They [doctors] give the inhaler and nebulizer, and there's [also] the asthma action plan. They [parents] have to bring [a medical] form and meet with [the] school nurse. There's supposed to be a face-to-face meeting. They [nurses] really want [a] face-to-face meeting. That is an area of breakdown. The parent might not bring [the form] in. There will be things on the [medical] order, and the parent hasn't always gotten them [the nurses] what they need. The nurse needs to be able to train the staff. There are lots of moving steps and lots of people who need to be involved.—DC Public Schools administrator

And as nurses echoed:

We are paralyzed by incomplete [asthma action plan] orders.—School nurse

Several stakeholders suggested that direct communication between physicians and schools via EMRs could minimize the miscommunication and reliance on caregivers to ensure doctors' forms are filled out correctly.

Sometimes the school policies and practices were extremely frustrating and confusing to parents and caregivers. One caregiver described an emergency incident when her son began wheezing at school, and how his care was delayed while they waited for her to arrive at school:

[The school] called the ambulance and common sense says to meet at Children's [National]. And [the school] called me and said, "Where are you? The ambulance can't leave until you are there." I said, "What?! He could die!"—Caregiver

Schools' communication with the Department of Health and Children's National

Better communication also includes better capacity for schools to monitor and track how many of their students have asthma. An administrator from DC public schools explained that the schools' ultimate objective is to "manage asthma in the building; not send kids to the ER [emergency room]. When there are breakdowns, then we have to send kids to the ER." We asked the administrator how effective the school has been with this goal, and she responded:

I can't say whether it's effective. We don't have data from the Department of Health about trips to the ER. We've asked for the data. We asked for that kind of utilization data and we want to know the effectiveness of the programs. Sometimes we get "That's not in the contract".... Access to data would improve the program. The Department of Health or Children's [National] would be able to say if it's effective.—DC Public Schools administrator

In general, better coordination and collaboration among DC Public Schools, the Department of Health, and Children's National would improve pediatric asthma care in Washington, DC.

Sometimes when I hear other school districts talk I get jealous. There are places where this works more seamlessly. For parents these walls are really frustrating. Sometimes when it comes to communication and collaboration we hit walls too. I was emailing head nurse at Children's [National] and the Department of Health asked me to send request to them and they will give it to them. We are not supposed to talk to Children's [National] directly. I feel like it is not about following some chain of command. So being able to work more collaboratively would be huge. The communication is such a challenge.—DC Public Schools administrator

Access to Appropriate Quality and Quantity of Care

With a chronic health condition, patients need ongoing care fully supported by sufficient numbers of well-trained staff at various contact points, including doctors' offices, emergency departments, and schools. Staffing and training were topics that physicians, school nurses, school administrators, and asthma educators raised. Stakeholders held the general view that families did not have enough access to health care providers and that many do not have as much expertise for managing asthma as they need. Both physicians and IMPACT DC asthma educators felt one solution would be to have more asthma educators in the community.

Having health educators in primary care offices and in the community and employing people who are actually members of the community as health educators. And I think that's a model that's worked tremendously well in other countries that have lower access to medical care, and I think that... it would be such an efficient, low-cost way to combat the multiple barriers we have of primary care visits not being long enough, there not being enough providers for communities, and people really believing their neighbors more than they believe their doctor.—Asthma educator

One physician described steps they are taking to offer more asthma education at their clinic.

I think the big thing we really need to work on is education. That's what IMPACT [DC] does so well. They have long appointment times; they get asthma educators, and they have the time to do that [provide education]. We are trying to make that happen here. We are doing training for medical assistants and nurses to feel empowered to give advice. Having appointments with me will make them better, but they need to reinforce [the information they learn].—Primary care physician

The providers' suggestions to increase asthma education in different settings matches the NAEPP recommendation described earlier about providing constant education from "multiple points of care."

From the schools' perspective, their staffing needs centered on the challenges of training staff to administer asthma medication whenever a school nurse is unavailable. DC Public School policy requires that at least three staff members in addition to the school nurse be certified to administer medicine. While school administrators feel three is the right number, "It's hard for us to get three." This is due in part to the length of time required for training and the budget requiring trainings to occur during the school year—and not as paid overtime.

I would say the medical training program could be improved. It is a four-day training. It's four days out of the building. We have seen cuts to the budgets—the fewer people you have in the building—it makes them even harder to send them away to a training. We struggle with our schools to release them to the training. It's during the school year.

We tried to do it during the summer but our premium got cut and so we could no longer do it during the summer. But now during school year it means they are gone for four days.

We have asked the department of health to move the training to online. I know it's frustrating for the department of health or Children's [National] to run a training and not have the room full. That's an expressed frustration, and we sympathize and feel that too.—DC Public Schools administrator

The school administrator also described parents' frustrations about the steps required to ensure school staff members are properly credentialed to administer medication. As she told us, "One parent told me, 'My 8-year-old has to self-administer their asthma medication,' but an adult has to go to a four-day training?" The administrator went on to say that policies and decisions like those are not in the school's hands. The Department of Health and Children's National Health System would have to change that policy. The administrator acknowledged the hospital's constraints while explaining that hospitals are understandably risk averse, which is another reason they are resistant to shorter and online training options.

Related to access, outreach, and follow-up, stakeholders voiced concerns about problems families have scheduling doctors' appointments, making time for the appointments once scheduled, finding transportation to appointments, and having enough time to fully address their health issues.

[For low-income families in poor neighborhoods] getting to the doctor is harder. Once you get to the doctor you wait longer, so you're less likely to go to the doctor.... Of course they [families] don't go to the doctor. It's not nice. It's hard. And you lose an entire day of work. And these are the families who also tend to have the least flexible work schedules.—Asthma educator

An administrator from the Department of Health Care Finance lamented that such disregard for families schedules was unjustifiable and required a system change:

That is where we have to get the system to change. What changes are we talking about in health care besides payment? But are you opening up the system? If I work 11-7am, are you opening and making it convenient for me to go? No. My appointment has to fit in. Private doctors close their doors. They are not open on holidays. Maybe some of the people we're trying to get have a day off, or trying to go in the evening. And in southeast [DC], you have a transportation problem. Children's [National] has a center there. That center is a long way from major transportation, and how do I get them there? When we look at that, no one is addressing true access to care. You and I can take off and go to the doctor; [we're] not going to be docked. The people who come and clean, they can't afford to take it off. To have true improvement in care the way we deliver care needs to change.—DC Department of HealthCare Finance administrator

The administrator added:

I had a young lady in a program and she said she would no longer be taking her children to preventative programs. That meant time off from her work so she said from now on she will just have to take them to the emergency room when she gets out.—DC Department of HealthCare Finance administrator

Long-Term Support to Address the Social-Emotional and Financial Burdens of Managing Chronic Illness

I think we as a society undersell the psychological aspect of medicine, and medical care giving.... if you think about how much money we put into coming up with new cures for everything and then our absolute failure to figure out how to get people to take that medicine, it's unbelievable. If you were to spend that much money and time figuring out what you need to do in a 15-minute visit to make somebody feel like they should take their medicine—obviously human psychology is complicated, but it's not that complicated. I mean the things we are coming up with medicine for—now that's complicated.... If we were to invest at all in what makes a good care [provider], what makes a good visit... I think it's probably not all that complicated.—Asthma educator

Managing a chronic disease like asthma takes a toll on patients' and families' social-emotional and financial resources. Whether dealing with the strain of constant vigilance, or having to find new housing with fewer triggers, the impact of asthma on families is significant. An asthma care model that attends to the illness's chronicity might provide special care and support to patients around the unique challenges of managing a chronic condition—including both financial and social-emotional aspects. One suggestion several gave was that families with asthma might benefit from support groups focused on managing the chronic illness.

The biggest obstacle really is the education piece and having parents understand their problems. Most chronic illnesses have case managers, specialists who deal with those issues—like diabetes, there's a team to help manage the illness and the patient gets extra time to see those different specialists. Even HIV patients, they have a social worker who explains how to take medication. With asthma, children don't have those resources. The only thing we really have are health educators who are mainly located with IMPACT DC.... If we had a health educator trained in medical issues, that would be something we could do to help a little bit. She or he could help with parents.
—Primary care physician

Maybe a family support system would help. A group of parents form a group for themselves. This is done for a lot of genetic or chronic conditions. But one for parents with asthma [doesn't] exist. We could have a system to have parents talk about how they care for their children.—Primary care physician

Parents and caregivers we spoke to would welcome the support. When asked how her child's asthma affects her life, one caregiver remarked: "I think it affects everything—financially, spiritually... because if you never prayed, now you are praying! And if you did pray, now you're praying now. It affects all forms, and all standards we have in life."

A responsive chronic-care service model could also find creative ways to work with families' available resources, including multiple caregivers, or more regular ways to reinforce and remind children about taking their medicine. Caregivers appreciate follow-up and outreach from their doctors and other health care providers, as several families told us.

[IMPACT DC] be calling us—IMPACT DC checks in. I like someone to call and check in.
—Caregiver

My doctor will remind me if I have to refill a prescription or if a medicine is about to expire.—Caregiver

Among those with the ability to impact both the social-emotional and financial burdens of asthma, insurance providers—especially public programs—have significant potential to help families more than they do. Children with a chronic health condition need consistent and regular access to their medication. For children who are not always in control of where they are or where they will be, several stakeholders felt it was important for them to keep multiple medications in different locations.

Families and doctors alike felt constricted by insurance companies when trying to adjust asthma care plans. For example, insurance can delay families filling prescriptions on time, accessing enough medication, and accessing asthma accessories needed for daily controller medications.

One of the big challenges is that not all of the payers are allowing kids to have two inhalers at the same time. We have one for home; one for at school, and they don't pay for both inhalers.... Making sure there is something clear on health insurance policy that for kids you can have more than one kind of inhaler. There needs to be a way for me to not have to fill out a medical authorization form. That could be a nice policy piece—so that insurers pay for multiple medications.—Primary care physician

One thing Medicaid has access to is claims so they know what medications are prescribed.... One of the things they could do better is managing claims and hiring educators to look at claim to see who is filling what prescriptions and when and how often. They could then work with those families when they see prescriptions are not being filled.—Primary care physician

The same doctor also described what he considered differences between some private health insurance plans and the services offered by Medicaid plans:

Some insurers reach out to children for some other reasons, like immunizations. They have quality measurements—they have to make sure the child goes in for annual physicals, and the families get incentives for doing so. Private insurance have begun the process of chronic disease management a little better. We get notifications from those private insurances that say the patient isn't filling medication—but that's for a small population because we don't have a lot of patients with asthma who have private insurance.

It's much more cost-effective for insurance to keep child out of the ER. There's a lot of benefit for the insurance. The form will say, "Patient X has a diagnoses of asthma based on this code in ER form, and we noticed the child filled prescription for X but has not been prescribed a controller medication/has not filled the prescription."—Primary care physician

Conclusions: Getting Serious about Children's Asthma Outcomes

Asthma is a serious and chronic health condition. But the experiences and risks to many low-income children, especially African American and Latino children in metropolitan cities such as Washington, DC, are far worse than they need to be. What's more, expensive ED and hospital-based care remains far too common.

Our findings suggest that the system of care low-income children in our study received was often poorly suited to reach them and not consistent with NAEPP recommendations.

Appointments were at inconvenient locations and hours; doctor's visits were inadequately short; ongoing asthma education, outreach, and follow-up was insufficiently provided; and medical records were not easily accessible, updated, or communicated across systems and providers. Despite families' concerns and fears about their children's health, many held false beliefs about proper treatment; they were also simultaneously juggling concerns about housing, employment, and other pressing health issues. The complexity of low-income families' lives coupled with a care system ill prepared to offer consistent, ongoing care contributes to children with poor asthma control living in constant threat of the next serious flare-up or exacerbation.

Getting serious about the health of low-income children with asthma will require involvement from the health care system as well as nonmedical institutions and systems.

- **Improving communication:** Recognize and enhance communication across health systems and providers who come in contact with children, including primary care physicians, school nurses, pharmacies, hospitals, insurance companies, and caregivers. This also means better using technology and electronic medical records to ease the transfer of information.
- **Improving access:** Take seriously the problems of access to care— increasing both the quality and the availability (and quantity) of care available to families. For a chronic condition without a known cure, like asthma, care must be accessible, available, and ongoing.
- **Improving support for the social-emotional and financial challenges of chronic illness:** Barriers to asthma control extend beyond the reach of health care systems. Families grappling with poverty, unhealthy and unstable housing, poorly resourced schools (e.g., few staff trained to support children's health needs), and other risks, may have difficulty benefiting from even the best health care system improvements. An effective system should be highly integrated and support communitywide collaboration among the many stakeholders and systems that affect children's health and well-being. The integrated system should be focused on best practices and have the capacity to disseminate those practices broadly and rapidly.

Study Methodology

The study was designed to understand why some low-income families in Washington, DC, struggle to achieve good asthma outcomes. The study was completed through focus groups with parents and caregivers, asthma educators, and school nurses, as well as one-on-one interviews with primary care physicians and key stakeholders from DC Public Schools, the DC Department of Health Care Finance, and United Health Care, a Medicaid managed care organization. The data were collected from June 2012 to May 2013.

Parent and Caregiver Eligibility

Parents and caregivers that were recruited for focus groups cared for children who were patients at IMPACT DC between 2009 and 2012; they were identified by our partners at Children's National. Recruitment involved contacting families with a letter describing the study and following up with phone calls to gauge interest and confirm participation. Parents or caregivers who were eligible to participate in focus groups had to meet the following criteria: the parent or caregiver had at least one child age 4–14 who visited the IMPACT DC clinic between 2009 and 2012; the parent or caregiver's child or children was African American and/or Latino; the family lived in a zip code designated as an at-risk community in Washington, DC, based on the frequency of ED visits for asthma; the child received public health insurance; the child was prescribed a daily asthma controller medication at an IMPACT DC clinic visit (indicating persistent disease); the child had met the study criteria for either poorly controlled asthma or well-controlled asthma;¹¹ and the parent agreed to participate in the focus group.

Although we attempted to recruit families with both well-controlled asthma and poorly controlled asthma, all but one caregiver who participated in the focus groups had children with asthma that was considered poorly controlled. Although some families met our criteria for well-controlled asthma and had not had an ED visit within six months of their IMPACT DC appointment, all caregivers except one had visited the ED or an urgent care center for asthma within 12 months of the focus group. Based on that criterion, most caregivers in the focus groups cared for children with poorly controlled asthma.

Methods

We held three focus groups and spoke to a total of 15 parents. Two groups were held in northwest Washington, DC (one in English, one in Spanish), and one was held in southeast Washington, DC (in English).

In addition to parent focus groups, we spoke with five asthma educators in the IMPACT DC Asthma Clinic, six school nurses, four primary care physicians, one administrator from DC Public Schools, one administrator from the DC Department of Health Care Finance, and one administrator from United Health Care.

Focus groups and interviews were semi structured covering topics related to what families and other stakeholders saw as key and potential barriers for managing children's asthma (see appendix B for focus group and interview discussion guides). Two Urban Institute research staff conducted all interviews and focus groups. One staff member moderated the focus group or interview while the other staff member took detailed notes and audio-recorded the meeting.

Analysis

The Urban Institute research team coded the interview notes and analyzed them using NVIVO, a qualitative analysis software program. The team compared and contrasted key themes raised by

parents and caregivers and other key stakeholders, and organized each theme into a single document that included related quotes. Research team members reviewed and discussed key themes and summary documents.

Appendix A. Study Sample, Recruitment, and Lessons Learned

Between June 2012 and May 2013, the Urban Institute (in partnership with Children’s National Health System and DC Appleseed) interviewed parents and caregivers of low-income children with asthma, asthma educators, primary care physicians, and key stakeholders from DC Public Schools, the Department of Health Care Finance, and a Medicaid managed care organization. The study was designed to understand why some low-income families in Washington, DC, have poorly controlled asthma. Table A1 lists the key stakeholder groups and number of respondents. At least two Urban Institute researchers were present at all one-on-one and focus group interviews; one to moderate the interview or discussion and the other to take detailed notes on a laptop. Each focus group and interview was simultaneously recorded on a digital recorder to verify accuracy of quotes and other information. Notes taken during the focus groups and interviews were then analyzed using NVIVO software.

We detail how we recruited participants for the study below, and present some lessons learned through the process.

Table A1. Key Stakeholder Groups and Number of Respondents

Respondent group	Number
English-speaking parents and caregivers	13
Spanish-speaking parents and caregivers	2
IMPACT DC asthma educators	5
School nurses	6
Primary care physicians	4
Key stakeholders ^a	3
Total	33

a. Key stakeholders included an administrator for DC Public Schools, the Department of Health Care Finance, and a Medicaid managed care organization.

Parents and Caregivers

The research team submitted detailed study procedures to the Institutional Review Boards at both Children’s National Health System and the Urban Institute before initiating research activities. Once the study procedures were approved, IMPACT DC reviewed medical records of over 170 English- and Spanish-speaking families who met initial criteria for study participation, including having a child between the ages of 4 and 14 in 2010 who had been to the IMPACT DC clinic between 2009 and 2012 and living in one of 10 high-risk zip codes in Washington, DC. Families’ contact information (name, address, and phone) were shared with Urban Institute research staff who mailed families a letter inviting them to participate. The Urban Institute staff followed up the letters with phone calls. Families who called in or were reached by phone were screened further to verify whether the child self-identified as African American and/or Latino and received health insurance through Medicaid. Urban Institute staff also determined whether the parent or caregiver’s child met criteria for well-controlled asthma or poorly controlled asthma (see definitions in study methodology). The original intention for the study was the hold separate focus groups for parents and caregivers caring for children with poorly controlled asthma and well-controlled asthma. However, virtually none of the families recruited met the criteria for having well-controlled asthma. The original sample size of families was whittled down from 176 to approximately 70 families after going through the eligibility screening guides and removing families with incorrect addresses (i.e., mail returned by the post office) and/or

phone numbers. The Urban Institute team reached families over the phone, making several phone calls to ensure contact was made and to determine interest and eligibility for the study.

Table A2. Parent/Caregiver Recruitment and Participation

Focus group sample	Number
English-speaking parents	
Total sample screened	170
Total respondents unreachable	108
Total respondents ineligible	8
Respondents uninterested in/refusing participation	17
Respondents who confirmed attendance	24
Respondents who participated in focus group	13
Spanish-speaking parents	
Total sample screened	18
Total respondents unreachable	14
Respondents uninterested in participating	1
Ineligible respondents	0
Eligible respondents unavailable during focus group time	2
Respondents who confirmed attendance	1
Respondents who participated in focus group	2

At the end of recruitment and confirmation, the Urban Institute team held three focus groups for parents: two in northwest Washington, DC (one for English speakers, one for Spanish speakers), and one in southeast Washington, DC. Overall, 15 parents or caregivers participated in the focus groups. Families that participated in the focus groups were compensated for their time and transportation to and from the focus group. Light refreshments were also provided. The average age of the children in focus was 8 years, and about half were girls (table A3). The bulk of children were in first, second, or third grade. Although we did not have information from parents or caregivers who participated in our Spanish-language focus group, all but one caregiver from the English-language focus group reported that his or her child had either been to the ED or an urgent care center for asthma in the past year. Among the 9 children who had been to the ED in the past year, they averaged three total visits. Three children had been admitted to the hospital for asthma. Nearly all caregivers in the English-language focus groups reported that their child with asthma had visited their primary care provider in the past year for asthma. The children averaged three visits.

Table A3. Focus Group Participants' Child's Characteristics

Participant number	Child's age	Child's sex	Child's grade in school	Number of ED visits for asthma in past 12 month	Number of hospital admissions for asthma in past 12 months	Number of urgent care visits for asthma in past 12 months	Number of visits to primary care physician for asthma in past 12 months
1	6	F	1	N/A	N/A	N/A	N/A
2	7	F	2	1	0	1	1
3	11	M	5	6	2	10	6
4	6	F	2	5	0	0	4
5	7	M	1	0	0	1	1
6	11	F	6	1	0	2	2
7	9	F	3	0	0	0	0
8	7	M	2	4	0	4	4
9	14	N/A	7	3	0	2	0
10	8	F	3	2	2	0	3
11	8	M	3	2	1	2	2
12	7	M	3	4	0	4	4
Spanish-speaking parent participants							
13	6	F	1	N/A	N/A		
14	7	M	2	N/A	N/A		

IMPACT DC Asthma Educators

IMPACT DC employs between 5 and 8 asthma educators each year. At the start of the study, IMPACT DC provided the Urban Institute research team with the names and contact information of current and former IMPACT DC asthma educators living in the Washington, DC, metropolitan area with between one and three years of experience as asthma educators. The average time working with IMPACT DC for this group of educators is 2.1 years. Urban Institute staff emailed the educators inviting them to participate in a focus group held in June 2012. Five asthma educators were available and agreed to participate. The focus group was held at Children's National. IMPACT DC asthma educators were compensated for their participation in the focus groups. Light refreshments were also provided.

School Nurses

IMPACT DC staff mailed letters addressed to the school nurse at all elementary and middle DC Public and DC Public Charter Schools located in 10 zip codes designated as an "at-risk community" in Washington, DC, based on the frequency of ED visits for pediatric asthma. The letters invited nurses to participate in a focus group to be held at a school in one of the high-risk zip codes. Urban Institute research staff followed up the letter with a phone call to each school nurse. The research team made several rounds of recruitment calls. Several nurses expressed interest but needed to first get approval from their nurse manager employed by Children's National. IMPACT DC contacted the nurse managers to tell them about the study. The nurse managers approved the study and contacted the school nurses to confirm that they were able to participate if they chose to. Once school nurses were aware that they could participate, several called the Urban Institute team to learn more about it. Five school nurses representing several schools in Washington, DC (some worked at more than one school), participated in the focus group. They represented both DC Public and DC Public Charter Schools. The nurses all had experiences with children with asthma, some diagnosed and some undiagnosed. The nurses had been practicing for an average of 15 years. The focus group was scheduled during after-school hours, and nurses were compensated for their time.

Primary Care Physicians

IMPACT DC provided the Urban Institute with the contact information for primary care physicians located in community clinics in Washington, DC's high-risk zip codes. The Urban Institute team mailed letters and followed up with phone calls to physicians. The Urban Institute team had to make several phone calls before reaching doctors at their respective clinics. The team ultimately relied on the help and connections of Children's National Health System to get in touch with four primary care physicians who agreed to participate in the study. Primary care physicians received compensation for their time.

Key Stakeholders

Research team members from DC Appleseed identified key administrators from DC Public Schools, the Department of Health Care Finance, and a Medicaid managed care organization that serve or otherwise work with low-income families whose children have asthma. The Urban Institute team emailed the administrators inviting them to participate in the study. Administrators were relatively easy to reach and readily agreed to participate in the study. We interviewed three administrators: two interviews were face to face, and one was conducted by phone. The administrators did not receive any compensation for their time.

Lessons Learned

Our study focused on identifying challenges, barriers, and opportunities for improving asthma outcomes for low-income children in Washington, DC. We were interested in low-income African American and Latino children in particular given DC's large racial and ethnic disparities in asthma outcomes. We intended to interview a small number of caregivers and other key stakeholders as we explored hypotheses and potential themes, but the challenges we encountered recruiting reduced the total families interviewed to even fewer numbers than anticipated. Our original design included between four and six focus groups, but instead we held three groups and took additional time to locate and recruit families. We note these challenges as they parallel some of the barriers providers described about reaching low-income children, especially when addresses and phone numbers may change frequently.

IMPACT DC medical records were the best available source for identifying families who had visited the clinic, but we learned early on that the short-term medical intervention was not designed for long-term follow-up with families. Recruiting families from IMPACT DC's medical records dated between one and three years prior revealed many addresses and phone numbers were no longer current. We were therefore unable to reach and invite about half the families initially identified to participate in the groups. We were not surprised by the challenge but recognize that it typifies obstacles key stakeholder described as a challenge to long-term support.

Among families with up-to-date contact information, the Urban Institute team had greater success reaching the parents or caregivers when IMPACT DC staff called them first to tell them that researchers may be contacting them. In general, families spoke very highly about the asthma clinic and its staff and appeared more willing to participate when they were invited by IMPACT DC staff whom they trusted.

Our challenges reaching potential study participants were not limited to parents and caregivers. To reach primary care physicians, the Urban Institute team called each clinic several times. Depending on how the automated-answering-system prompts were organized, the team had varying degrees of difficulty getting transferred to a physician's voice mailbox. Several clinics did not have a live staff person answering the phones at the times we called (during clinic business hours). And the automated-operator choices rarely included an option to speak with

the physician we were trying to reach. The Urban Institute team had much greater success contacting physicians when our partners at Children’s National made personal calls or emails to them first. Much like the families, physicians—whose days were extremely busy and left limited office hours for general administrative duties—were much more likely to respond to a request from a trusted source.

Although our reasons for calling the clinic were quite different than a typical patient’s reasons (and, understandably, the answering system is set up to address health-related questions), our attempts to contact physicians demonstrated a barrier we heard from caregivers and other key stakeholders about challenges reaching providers.

Our recruiting efforts illustrate how access and communication between families and providers may be challenging, and how it may affect the consistency in care a child may receive. The families that participated in our study described complex lives, juggling multiple demands in communities with few providers and services. The providers in our study similarly described juggling multiple demands with few resources with limited time and ability to contact families (who may not be reachable). The result can be highly fractured care. These observations return us to the study themes and three top challenges a large metropolitan city like DC will need to address in order to improve outcomes: communication among families, providers, and other key stakeholders; access to the appropriate quality and quantity of care; and support for the social-emotional and financial challenges of chronic illness.

Appendix B. Focus Group and One-on-One Interview Discussion Guides

The following questions guided each focus group or one-on-one interview.

Parents of Children with Asthma

1. We are interested to know how having a child with asthma affects or has affected your life/your family's life/your child's life. What are some ways it affects your life?
2. What kinds of things do you do or does your family do to care for your child with asthma?
3. What are some other things, in addition to what you've already told us, that affect the care your child gets for asthma? Let's talk about doctors, nurses, health care providers, medications, and asthma triggers.
4. What about your child's school? What experiences or interactions, if any, have you had with schools about your child's asthma?
5. And finally, please tell us what we've missed. Are there any other things we may not have talked about already that make it easy or hard to keep your child with asthma well?

Asthma Educators

1. What do you like best about working with families and children with asthma?
2. Of the children and families you've seen at IMPACT DC, what determines who has a good outcome? Can someone give me an example of a family or two that had a particularly good outcome?
3. What does a bad outcome look like? Can someone give me an example of a family or two that did not have a good outcome?
4. In your experience, what are some of the main reasons the children and youth you've seen keep coming back to the emergency department for asthma—or have poorly controlled asthma?
5. What do you think would help these children, youth, and families with poorly controlled asthma do better?
6. Are there things that IMPACT DC could do better to help these families in particular? What does IMPACT DC *not* do very well?
7. Are there things outside the control of IMPACT DC that could help children and families with poorly controlled asthma do better?
8. You've shared a lot with us today. Are there any final thoughts about your work and what families need? Anything we missed—that we should have asked, but didn't?

School Nurses

1. To start, we'd like to hear about the work you do and your role as school nurse.
2. Could someone walk us through the protocol at your school—beginning with the ways you find out a student has asthma. What happens at that point? What paperwork or forms are required—what about for students/families receiving Medicaid (EPSDT)?
3. Based on comments you shared earlier, it sounds like asthma [is/is not] a big issue at your school(s). Let's talk about students with asthma. First, though, would you say asthma is a controllable disease? Why or why not—what makes you say that?
4. Let's talk a little about school policies. In your opinion, how effective are your school's procedures around asthma? How good a job does the school do in caring for children with asthma? What do schools do well, what do they struggle with?
5. Is there any communication or coordination between your school and family providers?

6. Is there any communication or coordination you have with the Medicaid system regarding students with asthma? If so, what's the nature of that communication? If not, is that something that would be useful or beneficial—why or why not? What type of communication or coordination would be helpful? How feasible would it be to implement?
7. Do children have a hard time having extra medicine at school due to insurance or other barriers?
8. Are there other things within or outside the control of schools that could help children and families with poorly controlled asthma in DC do better? For students with poorly controlled asthma, what would you say are the main barriers to them receiving the care they need?
9. You've shared a lot with us today. Are there any final thoughts about your work and what families need? Anything we missed—that we should have asked, but didn't?

Key Stakeholders and Primary Care Physicians

1. To start, please tell us about the work you do as [ROLE]? How long have you held this position? How long have you worked [OFFICE]? What is your educational background and training?
2. Would you consider asthma a big health problem in DC—why or why not?
3. What is the department's role and your role with respect to policies and services around asthma in DC?
4. Are there challenges in implementing these policies and services for low-income families and children with asthma, specifically? If so, what are they?
 - Do you currently collect information on children with asthma? What kind of information do you track, and what do you use it for?
5. We're interested in the broad system of care for children and families in DC—including interactions and communication/coordination you may have with [hospitals, schools, families, physicians, insurance companies]. Are there other systems or agencies you work with—including other departments in DC government?
6. Are there any other things that we haven't covered that could help children and families with poorly controlled asthma in DC do better? For children with poorly controlled asthma, what would you say are the *main* barriers to them receiving the care they need? (This could include barriers discussed earlier, or new ones we haven't discussed)

Notes

1. All quotes in the report are taken directly from interview recordings or detailed notes taken during the interviews and focus groups.
2. See Moorman et al. (2012).
3. The terms Latino and Hispanic are used interchangeably and refer to the same group in this report.
4. Behavioral Risk Factor Surveillance System. Centers for Disease Control and Prevention, 2008.
5. Available at <http://www.impact-dc.org>, last accessed September 9, 2013.
6. See also R. Priester, R. L. Kane, and A. M. Totten, “How the Current System Fails People with Chronic Illnesses,” unpublished working paper, Society of Actuaries, 2005.
7. For the purposes of our focus groups, children age 4–14 who had not returned to the ED for asthma within six months after visiting the IMPACT DC clinic and were still taking their daily medication as prescribed were considered to have well-controlled asthma. Children age 4–14 who had returned to the ED within six months and were no longer taking their daily medication as prescribed were considered to have poorly controlled asthma.
8. Data found at <http://www.quickfacts.census.gov>, last accessed September 9, 2013.
9. See Teach, Guagliardo, et al. (2006).
10. See “Health Insurance Coverage of Children 0–18,” Henry J. Kaiser Family Foundation, <http://kff.org/other/state-indicator/children-0-18/>, accessed February 24, 2014.
11. Children were considered to have well-controlled asthma if they had no ED visits in the six months following their IMPACT DC visit. Children were considered to have poorly controlled asthma if they had one or more ED visits following their IMPACT DC visit.

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