THE CHRONIC CARE MODEL:

A Collaborative Approach to Preventing and Treating Asthma in Infants and Young Children

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Nathan is an energetic 13-month-old. For 2 days, Nathan has had a mild cold (which slows him down not at all). However, on the third day when his mother, Jean, picks Nathan up at his family child care home, his child-care provider tells her that Nathan seems to be wheezing. Jean calls Nathan's pediatrician at once. She refers Jean to the local emergency department. After a few breathing treatments, Nathan is sent home with an inhaler and a mask, which Jean finds almost impossible to use, and a liquid medicine that Nathan hates. In the pediatrician's office for follow-up the next day, a tearful Jean asks if Nathan has asstma

Dwayne had an experience similar to Nathan's at about the same age. Now 2½ years old, Dwayne wheezes with every cold, about 6 times in the past year. Nicky, Dwayne's single mother, works full time. She can seldom make it to Dwayne's doctor's office when it is open, so she goes to a local urgent care center when Dwayne is sick. Every time she goes, she is given medicine to use in their home nebulizer machine. The medicine always seems to help his breathing, but the benefits of the medication don't seem to last very long and the medication doesn't seem to

get rid of all the wheezing. Nicky wonders if there is more she should be doing.

Lien is a tiny, bright 3-year-old. She is the youngest of four children who lives with her parents and siblings in an uncle's home with his family of six. The uncle smokes in the home,

at a glance

- No single professional can care adequately for a young child with asthma: Parents and professionals must collaborate.
- By using the transdisciplinary Chronic Care Model, parents and professionals can help children control their asthma.
- Two major barriers to reducing childhood asthma are: (a) failure to implement guidelines for diagnosis and management, and (b) lack of adequate, affordable housing.
- Childhood asthma can be reduced only through ongoing patient education, partnerships among agencies, and continued advocacy for improved housing.



PHOTO: MARILYN NOLT

and the apartment building is infested with cockroaches. Lien has fairly severe eczema, a dry and itchy skin condition. Two of her three siblings have asthma. At her yearly checkup, her father asks the family's nurse practitioner if there is anything that he and his wife can do to keep Lien from developing asthma as well.

athan, Dwayne, and Lien (identifying details have been changed) are representative of the 5.3 million children in the United States who are currently affected by asthma (Centers for Disease Control and Prevention [CDC], 1998; Platt-

Mills & Carter, 1997). Asthma is the most common chronic disease of childhood, yet no single professional—however skilled or well intentioned—can provide a child and family with the medical care, care coordination, legal advice, and advocacy that they need to deal with asthma. When, on the other hand, early childhood specialists from a range of disciplines and settings work together with parents to improve children's health outcomes, such partnerships can achieve significant positive results.

In this article, we argue that the transdisciplinary Chronic Care Model (Wagner, 1998, 2003) offers an effective way for parents and professionals to help children control their asthma and lead an active life. We will use the example of reducing the factors that elicit an asthma response (asthma "triggers") in young children's indoor environments to illustrate the power of such partnerships.

Before describing the challenges involved in reducing indoor asthma triggers and offering guidelines to follow in such an effort, we present an introduction to asthma, its impact on young children and families, the complexities of diagnosis, and the challenges of management.

Asthma 101

Asthma is a chronic disease of the airways (bronchial tubes) of the lungs. In a person with asthma, these airways are always inflamed (Centers for Disease Control and Prevention, 2005). An asthma "trigger," such as cold weather or exposure to tobacco smoke, can cause muscles around the airways to tighten and swell, resulting in wheezing, chest tightening, and difficulty breathing. This experience is commonly known as an "asthma attack." Repeated attacks can cause permanent damage to the lungs.

In the United States, the diagnosis of asthma has increased by 75% since 1980. In preschool children, the diagnosis of asthma has increased by 160% during the same period (National Heart, Lung, and Blood Institute [NHBLI], 1999). Poor children with asthma get sicker and are more likely to die from the disease than are children from financially comfortable families. According to the CDC (1996), African American children are twice as likely to have asthma as are white children and are 6 times as likely to die from it.

Asthma is costly—for young children, families, the health care system, and communities. When children with asthma miss time in child care or preschool, they miss important learning opportunities, and their parents miss work when they stay home to care for them. The National Center for Education in Maternal and Child Health estimates that the loss of adult productivity associated with parents staying home from work to care for children who have asthma is equivalent to more than \$1 billion a year (Raskin, 2000). The physical, emotional, and psychological stress caused by frequent asthma attacks can also take a toll on children and their parents.

As the stories of Nathan, Dwayne, and Lien demonstrate, asthma in infants and toddlers poses special challenges in diagnosis and management. ("Management" means both the use of medication and reducing the child's exposure to triggers, particularly in the indoor environment). Diagnosis of asthma is not simple. Although 4 out of 5 children who have asthma acquire the disease before they reach school age, most babies and toddlers who wheeze when they have a viral infection will not continue to wheeze during their preschool years. In trying to predict which wheezing baby or toddler will develop persistent asthma, health-care providers evaluate both the child's history of wheezing and the risk factors in the child's environment.

According to the National Asthma Education and Prevention Program, a young child who is a "frequent wheezer" and whose environment includes one major risk factor or two minor risk factors is likely to have persistent asthma in the school years. To be considered a frequent wheezer, a child must experience:

- More than three episodes of wheezing in a year;
- Wheezing more than 2 days per week or more than 2 nights per month; and
- Severe wheezing episodes less than 6 weeks apart.

Major risk factors for developing persistent asthma include:

- A parent with asthma;
- A history of eczema (chronically dry, itchy skin); and
- Allergies to dust mites, pets, cockroaches, and molds.

Minor risk factors include:

- Allergic rhinitis (a runny nose associated with hayfever);
- Wheezing, apart from colds; and
- Food allergies.

If we revisit our introductory scenarios, we can see that Nathan,

who has wheezed only once, when he had a cold, cannot yet be diagnosed with asthma. Dwayne, however, is a "frequent wheezer." He is clearly at a high risk for continuing to have asthma symptoms at age 6 and beyond. Lien does not yet wheeze, but considering her eczema and her family history of asthma, she is also at high risk. Even with this evidence, we cannot predict the course of any of these children with certainty. Researchers have observed that children with strong family tendencies toward asthma often proceed from eczema in infancy to allergic rhinitis to allergic asthma, but not every child who begins with eczema completes the march to asthma. As pediatric providers and parents frequently remind each other, "all that wheezes is not asthma, and not all asthma wheezes."*

Managing Asthma

A growing body of evidence shows that intervention during the early years of asthma symptoms can reduce later disease (Eid, 2004). The inflammation in the airways of a child who has asthma results in permanent changes—called "remodeling"—in the child's airways. Anti-inflammatory medications—most notably, inhaled corticosteroids—reduce this remodeling. However, pharmacotherapy is not an ideal treatment approach for young children with asthma. Nebulized medication, which involves a machine that transforms liquid into a breathable mist, needs to be administered for several minutes. Inhalers with masks to help small children receive adequate amounts of medication can be tricky for parents to use. As a consequence, caregivers often discontinue treatments unless a child is acutely ill—even though "controller" medications are effective in preventing symptoms only when they are used between episodes.

Looking again at "frequent wheezer" Dwayne, we see a child who exhibits persistent wheezing but is being treated only with "rescue" medications to reduce his symptoms.

A better choice would be controller medications—
anti-inflammatory treatments used to prevent the symptoms

of asthma, including permanent changes to the airways. Dwayne, however, is not getting controller medications. Because he sees a different medical provider each time he goes to an urgent-care clinic in the midst of an asthmatic episode, no one is tracking his disease progression in an attempt to intervene appropriately.

Children who are in unstable living situations because of homelessness, their parents' migratory work, or frequent

changes in foster care placement are particularly vulnerable to poor health tracking and follow-up. Yet even children in stable homes may suffer from disconnected, episodic care if their parents are unable to

leave work to take their child to a "medical home" where staff know the child and family. In a transdisciplinary model of health care, as we will describe below, an observant child-care provider who is knowledgeable about asthma can help to monitor a child's course and alert parents to resources for comprehensive care.

Managing Children's Indoor Environments

The story of Lien's living situation provides a glimpse of common indoor asthma triggers and suggests how difficult it may be to protect young children from them. Nevertheless, a family can have an immediate impact on a child's health by focusing on their home, and professionals, working in partnership with each other and with families, can build long-lasting alliances as they collaborate to solve practical problems.

Indoor Asthma Triggers

Contrary to popular belief, indoor air environments actually pose a greater risk to children than outdoor air environments. This elevated risk is a function of the higher levels of toxins that reside in confined spaces and the significant amount of time that people spend indoors (Alliance for Healthy Homes, 2004). Many children, especially those who live in urban areas, spend more than 90% of their time inside (Environmental Protection Agency [EPA], 2003.)

Indoor exposure to dust mites, pests (particularly cockroaches), mold, pet dander, and tobacco smoke can influence the course of asthma (Institute of Medicine, 2000). Although combustible materials from space heaters or wood stoves, paint, perfumes, and cleansers can act as indoor asthma triggers, most experts agree that dust mites, animal pests (particularly cockroaches and rodents), mold, pet dander, and tobacco smoke are the most common triggers. These are substances to which children are exposed daily. Lien, for example, is exposed to environmental tobacco smoke and cockroaches. In her crowded home, house dust mites are also likely. Although Lien does not have asthma, she is at risk. Environmental modifications

Asthma is the most common

chronic disease of childhood.

^{*}Visit www.nhlbi.nih.gov/guidelines/asthma/ for guidelines on the diagnosis and management of asthma, updated in 2002.

would almost certainly help her siblings with their asthma. Even the uncle going outside to smoke would make a difference. However, it is impossible to predict, from the information available, whether Lien's father could protect her from developing asthma.

Reducing Indoor Asthma Triggers

Changing the indoor environment can reduce asthma triggers in the home significantly. In a study supported by the National Institute of Allergy and Infectious Disease (NIAID, 2001), nurse practitioners helped more than 1,000 high-risk families who had children with asthma institute environmental controls in their homes. This intervention led to a striking reduction in asthma symptoms, improved quality of life, and increased school attendance among participating children. More specifically, the intervention group experienced a 30% decrease in asthma-related hospitalizations and unscheduled pediatric and emergency department visits (NIAID, 2001). This study and others like it (Morgan et al., 2004) show that practitioners can effectively work with families to decrease asthma triggers in the home. (See Table 1 on page 24 for specific recommendations on ways to reduce common indoor asthma triggers.)

An evidence base exists to guide practitioners in helping families to reduce indoor asthma triggers. But at least two major barriers interfere with efforts to translate research into practice:

- 1. Practitioners fail to implement the guidelines for diagnosis and management of asthma, published in 1997 by the National Heart, Lung, and Blood Institute. These guidelines stress the importance of patient education to foster a partnership among patients, family members, and clinicians. Yet many pediatric health-care providers remain unaware of or are unfamiliar with the guidelines (Cabana et al., 2000). Other providers think that it is futile to teach families how to reduce indoor asthma triggers. These clinicians maintain that the families who are most affected by asthma must devote all their resources to day-to-day survival. They also point out that such families tend to have limited control over their living environments.
- 2. The lack of adequate, affordable housing in the United States presents a huge barrier to the reduction of indoor asthma triggers (Sandel & Zotter, 2000). In most communities, two parents working full time for the minimum wage do not make enough to rent a safe two-bedroom home at the market rate. And many families whose young children are affected by asthma do not include two adults who are working full time. Families with limited incomes face limited choices about where to live. They often feel helpless to confront landlords—especially if their command of English is fragile—about indoor asthma triggers.



The Chronic Care Model Applied to Childhood Asthma

Childhood asthma has become a condition that challenges a multidisciplinary array of health care practitioners. No single professional, however well-trained and dedicated, can provide the necessary level of medical care, care coordination, legal services, family support, and advocacy that an overburdened family requires in order to care adequately for a young child with asthma. In contrast, the Chronic Care Model, developed by Ed Wagner (1998) and his colleagues at Group Health Cooperative in Seattle offer a transdisciplinary, systemic approach to high-quality care for patients with chronic disease.

Originally developed as an approach to the care of diabetes, the Chronic Care Model can be applied to other chronic diseases, including asthma (Improving Chronic Care Illness, 2003). The model consists of six elements: (a) the community, (b) the health system, (c) delivery system design, (d) decision support, (e) clinical information systems, and (f) self-management support.

1. In the Chronic Care Model, community members advocate for policies that will improve patients' lives. For example, families who have children with asthma might participate in local smoking cessation programs and become involved with tenant and neighborhood associations. Early childhood professionals who work with the family might collaborate with the local lung association to provide smoking cessation classes in the languages spoken by people in the community. Pediatric health-care providers and lawyers can work

TABLE 1: How to Reduce the Five Most Common Indoor Asthma Triggers: Recommendations for Providers to Use With Families

Trigger	Definition	Recommended Practical Reduction
Dust mites	Tiny insects that eat dead skin and collect on anything fluffy, such as beds, stuffed animals, and furniture. Their droppings are the asthma trigger.	 Use allergen-proof bed and furniture covers.* Wash and dry bedding frequently in hot water. Limit the presence of fluffy objects, such as pillows, carpets, and stuffed animals, in the house.
Animal pests	The body parts and fluids of animal pests, particularly cockroaches and rodents, are known triggers for indoor asthma. These triggers include the body parts and droppings of cockroaches and the hair, skin, urine, and saliva of rodents.	 Reinforce to families that they are not dirty and that is not why they have pests. Aggressively and regularly clean areas of the house in which food is eaten, cooked, and stored. Wash and dry dishes immediately after use. (Do not let dirty dishes sit on counters and tables.) Keep trash bins tightly closed at all times. Store all food, including pet food, in closed containers. Throw out stacks of newspapers.
Mold	A superficial growth that forms on damp or decaying organic matter or on moist surfaces (such as those found within the home).	 Circulate the air. Use exhaust fans. Dry clothes in a dryer that is appropriately vented. Repair leaks. Use air conditioning to help control humidity. Wipe shower and tub toys dry. Use washable towel style bathmat instead of rubber backed mat. Empty refrigerator and air conditioning drip pans Avoid standing water in plants and flowers.
Pet dander	The skin flakes, urine, and saliva of furry pets are all asthma triggers.	 Do not allow pets in sleeping area. Vacuum and clean pet areas frequently. Consider finding another good home for the pet or keeping the pet outdoors.**
Secondhand smoke	Secondhand smoke, also known as environmental tobacco smoke, is a strong irritant and asthma trigger.	 Keep sleeping areas smoke free. Understand that smoking cessation is a complicated process and may not be culturally, logistically, and financially appropriate for all families. The goal is smoking cessation, but if that is not possible, smoking in a room where the child is not present—or smoking outdoors—is recommended.

^{*}Be sure you know how much these allergen-proof covers cost before recommending them to low-income families. Often, church or community groups can lead a campaign to purchase them for families in need.

Source: Environmental Protection Agency, 1998, 2003.

^{**}Even after removing a pet from one's home, it may take months to reduce the allergens in the home.

together to reduce health problems that are related to substandard housing. Home visitors can identify potential indoor asthma triggers and teach families how to reduce those triggers. A home visitor might discover, for example, that a young child sleeps on the sofa where her father likes to smoke a cigarette after work. The home visitor can inform the team that is working with the family about opportunities and limitations to reducing asthma triggers.

Checklists for indoor asthma triggers are available from the EPA (2003), among other sources.

2. In the Chronic Care Model, the health system leadership

must create an organization and a culture that promotes high-quality care. The senior leadership must identify care improvement as an institutionalized goal and encourage an open system to handle errors and quality problems, and to seek support to improve care.

- 3. Delivery system design ensures clear assignment of roles and efficient use of resources within a transdisciplinary model. In a clinic setting, for example, the medical assistant, the nurse, the pediatrician, and the social worker could all be working with the family and asking about circumstances in the home. Practitioners must talk with one another about who will ask which questions and then inform one another of the answers so that important information is gathered and shared appropriately.
- 4. Decision support is designed to ensure that all health-care providers know and can adhere to the best evidence-based medical practices that are currently available. Studies listed in the references section of this article describe programs that have successfully reduced indoor asthma triggers. To continue to change practice as new knowledge emerges, professionals need access to continuing education. They also need practical reminders, such as the asthma tool card on page 26. Teachers, home visitors, health-care workers, and lawyers can use this tool card to provide early childhood specialists and families with constant educational reminders about ways to reduce indoor asthma triggers. Because complexities arise when dealing with families who have children with asthma, front-line providers may need specialists to help them bolster families' knowledge of asthma. For example, a respiratory therapist may give an in-service training for home visitors on the treatment of severe asthma, which the home visitor can discuss with a family in terms of their child's situation. A legal professional might inform the staff of a clinic or a child-care center about the legal rights of renters and housing law. (See sidebar on page 27 for

- a description of the Association of Clinicians for the Underserved [ACU].)
- 5. Clinical information systems document data on individual patients and populations of patients. A computerized system can provide reminders to all providers about the treatment plan for the patient and the services that the patient needs. Families who receive services in a large system—such as a clinic or

social service agency—have no guarantee that they will consistently see the same provider, who will get to know them over time. A system that offers reminders and summaries to health-

care professionals can stimulate follow-up and discussion of treatment beyond the health-care setting. In addition, the refunding of many grant-based projects depends on regular monitoring of outcomes and consistent quality improvement measures.

6. Self-management support, the central component of the Chronic Care Model, is a strategy to empower families and prepare them to take on the management of their child's asthma. This approach involves educating the family about the disease, offering them self-management options, and helping them set their own goals. Ongoing support, problemsolving, and follow-up are essential.

Steven's Family, the Doctor, and the Asthma Educator

Steven is a 2-year-old boy who has recently been discharged from the hospital following a 3-day stay for an asthma exacerbation. This was his third hospitalization in 6 months. His asthma grew worse after the family had to move in with his paternal grandparents. His grandfather smokes. There are two cats in the home. Steven and his parents are staying in a bedroom in a finished basement with carpeting on the floor and mold in various places.

Steven's doctor asks an asthma educator to talk to the family about their home environment. The doctor feels that she has maximized medication for Steven, with little improvement.

The asthma educator, Erica, discusses the asthma triggers in the home with Sharon, Steven's mother. Triggers include environmental tobacco smoke, cats, dust mites, and mold. Erica asks Sharon what she would like to address first. Slowly, Sharon says she should ask her father-in-law to smoke outside the house. Erica writes down this goal, then asks how confident, on a scale of 1–10, Sharon is that she can accomplish this goal. Sharon points to 3 (10 is "most confident"). Erica wonders if there might be another goal that Sharon would feel more comfortable addressing. After more discussion, Sharon picks the option of using bleach to rid the room of mold.

Intervention during the early

years of asthma symptoms can

reduce later disease.

PEDIATRIC ASTHMA AND INDOOR ENVIRONMENTAL TRIGGER MANAGEMENT

Tip: The 6 "Cs" of pediatric asthma case management can be helpful to document and monitor the status of indoor environmental triggers.

Cover Collaboration

Clean Cultural and Linguistic Competency

Clear Community Connection

Goal: Control of environment—Partnering with families can improve environmental control of the indoor air environment.

Questions to Assess Environment:

(Reminder: Think of a child in more than one environment on any given day.)

- a. Where does the child spend time, in what settings, and with whom?
- b. Are there changes that can be made in any of these places?
- c. What are the families' beliefs and values in relation to the needed changes?
- d. What kind of assistance does the family/caregiver need to improve the environment?

Suggestions to Assist Family/Caregivers:

- The Asthma Management Team can review and monitor self-management techniques.
- Home visits may complete and monitor environmental assessment.
- Use pictographs to explain location and control of asthma triggers.
- Document trigger management plan as part of overall case management.

3 Cs of What to Do:

- 1. Cover—Cover bedding and food.
- **2. Clear**—Clear the air of environmental tobacco smoke, rugs, and stuffed animals.
- **3. Clean**—Clean the home environment regularly, especially bedding, toys, and areas where mold, dust mites, and pet dander can accumulate.

3 Cs of How to Implement Indoor Air Trigger Plans.

4. Collaboration

Work in partnership with families and community agencies. Recognize and solicit their knowledge and experience

5. Cultural and Linguistic Competency

Learn about the values, beliefs and the social context of the family in a nonjudgmental way.

Ask about cultural, social, and financial barriers to implementing changes.

Provide information in the language and formats preferred by families.

Use trained interpreters appropriately.

Document cultural beliefs and practices to impact case management.

6. Community Connections

Identify and partner with resources in the community.

underserved

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Conclusion

how everything is going. Sharon is excited about ridding the room of mold. Now, more confident, she decides to discuss with her in-laws the possibility of having the cats live elsewhere until the family can move.

Erica likely had different priorities for this family, but a allowed the mother to begin to take charge of man-

Two weeks later, Erica checks back with the family to see

Erica likely had different priorities for this family, but she allowed the mother to begin to take charge of managing her child's asthma. The mother first chose the goal she thought she *should* choose, instead of what she felt she could do. When Erica asked her about her confidence level, she was able to choose a more realistic goal. Success with one goal empowers a family to address other goals.

Solving the problem of housing-related health hazards—including the presence of asthma triggers—requires collaboration from health-care and child-care professionals across the disciplines. Service providers from many settings who have strong relationships with families can support them in self-managing their children's asthma by controlling their child's environment and thereby reducing the number and severity of asthma attacks. However, getting the word out to families is a monumental effort. In order to build community and institutional support for the management of a chronic disease such as asthma, professionals should know what other professionals can offer and what the families can realistically do. Ongoing patient educa-

THE ASSOCIATION OF CLINICIANS FOR THE UNDERSERVED (ACU)



The Association of Clinicians for the Underserved (ACU) is a national transdisciplinary network of health professionals. ACU's mission is to improve the health of underserved

populations and to enhance the development and support of healthcare clinicians serving these populations. As part of this mission, ACU is working with the Environmental Protection Agency (EPA), Division of Indoor Air, to help providers improve the quality of life for their low-income pediatric asthma patients by reducing indoor asthma triggers that can aggravate asthma attacks.

ACU has developed a curriculum targeting a multidisciplinary team of health professionals ranging from physicians to social workers to lay health advisors. This curricu-

lum provides practical strategies to reduce common indoor asthma triggers along with culturally and linguistically sensitive methods in which to address them. The curriculum focuses on training providers how to integrate the assessment of environmental factors as part of a comprehensive asthma management plan to complement the medical management of asthma.

The "Pediatric Asthma Indoor Air Quality Improvement Project" has completed two pilot sessions and hopes, by 2006, to reach between 380 and 400 providers working with the homeless, migrant, rural, immigrant, uninsured, and minority families. This 1½—2-hour continuing education program offers a professional tool kit, including a patient resource guide and clinical tools. Professional organizations who are interested in hosting this program should contact Jennifer Sheen at jsheen@clinicians.org.

tion, partnerships among agencies, and continued advocacy for improved housing and living conditions can reduce the risks to development of this common, chronic, and costly children's disease.

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