

COMMUNITY ASTHMA

Community Asthma Initiative PROGRAM REPLICATION MANUAL



Boston Children's Hospital Community Asthma Initiative Replication Manual: Needs Assessment, Implementation and Evaluation

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Introduction

About This Manual

This manual has been developed for individuals or groups considering the creation of a community asthma home visiting and case management program to address the high rates of poorly controlled asthma in their communities, especially among low-income racial and ethnic minority populations. This manual seeks to assist programs with program development, implementation, maintenance and evaluation.

Boston Children's Hospital (Boston Children's) is a tertiary care hospital, but it is also the largest provider of pediatric primary care in Massachusetts. As a non-profit institution, it is required to perform a community needs assessment every three years. In the 2003 needs assessments, asthma was identified by the community as one of four major pediatric health concerns, along with mental health, obesity and injury prevention. In addition, asthma was noted to be the top single admitting diagnosis. African American and Latino children living in Boston were admitted at three to five times the rate of white children, indicating an important health disparity.

In order to address these disparities, Boston Children's initiated the Community Asthma Initiative (CAI) in 2005 to provide enhanced asthma services to children receiving emergency asthma care at the hospital, starting with a pilot intervention in four ZIP codes that encompassed neighborhoods with some of the highest asthma rates among African American and Latino residents. Applying the National Asthma Education and Prevention Program guidelines, the CAI intervention works to reduce the burden of asthma on children and families through a combination of:

- tailored asthma education, case management and home visiting that includes environmental assessments and a moderate amount of remediation for families of children who had been hospitalized or seen in the emergency department (ED) for asthma
- 2. group education and outreach to families, capacity-building in the community and
- advocacy for broad-based changes in health care delivery for people with asthma.

Based on an understanding of the many barriers to good asthma control, the project supports the entire family with respect to culture, language and beliefs through interventions in the home, school and community.

CAI builds on vital partnerships with community-based organizations, health care providers, parent groups, and public health administration and advocacy groups to address the Social Determinants of Health that have led to these health disparities, such as substandard housing and limited access to comprehensive asthma care, including case management and home visiting.

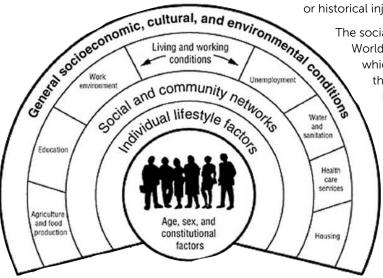
For children needing asthma ED care or hospital admissions, CAI has demonstrated consistent remarkable reductions in subsequent ED visits (58%) and admissions (80 percent). CAI's cost-effective services have demonstrated a return on investment (ROI) of 1.46, i.e., for every dollar spent on CAI, there is a savings of \$1.46 to society. CAI's success can serve as a replicable model of a population-based intervention.

"For every dollar spent ... there is a savings of \$1.46 to society."

Theoretical Framework

Health equity framework, addressing social determinants of health

Health equity is defined by Healthy People 2020 as "achieving the highest level of health for all people...by equalizing the conditions for health for all groups, especially for those who have experienced socioeconomic disadvantage or historical injustices."



The social determinants of health (SDOH)—defined by the World Health Organization as the social conditions in which people are born, live and work¹—underlying these health disparities include poverty, racism, poor

indoor air quality due to cockroaches and rodents, mold and other environmental exposures typical of substandard housing,¹, low health literacy, including low expectations of asthma control, distrust of the medical system and the medications being prescribed, inadequate insurance coverage, and social conditions, such as community violence. Smith et al. reported that low parental expectations for asthma control and competing family priorities (e.g., housing, home/neighborhood safety, job, personal/family relationships, income, or parents' or other family members' health) were associated with suboptimal asthma control and under-use of controller

medications (medications prescribed for people with "persistent" asthma and administered daily on a preventive basis). In addition, under-use of controller medication was associated with parental overestimation of the child's asthma control, no established time to administer medications, and parental concerns about the safety of asthma controller medications.

Figure 1: Reference: Institute of Medicine. (2003). The Future of the Public's Health in the 21st Century. Washington, D.C.: National Academies Press. Original source: Dahlgren G, Whitehead M. 1991. Policies and Strategies to Promote Social Equity in Health. Stockholm, Sweden: Institute for Future Studies

Social-ecological model

The program uses a social-ecological framework, as envisioned by the Institute of Medicine (2003). From addressing the individual child, the program moves to the family, the home environment, the community, including schools and primary care providers, and then moves to the broader health context through advocacy and efforts to impact health policy. Boston Children's intentionally built all three levels into the program model. We believe this framework provides a more sustainable model of prevention and treatment as it reaches beyond individual children to their circles of contact and to the policies that impact them.

Getting Started

Needs assessment

The Office of Child Advocacy (OCA) contains the community benefits effort for Boston Children's. OCA performed a needs assessment (2003–2005) that identified asthma as one of the top issues for the community, using a community-based participatory approach (CBPA). OCA has a community advisory board and strong partnerships in the community with neighborhood health centers, community-based organizations that represent and serve different populations within Boston, and parents who bring their children to the hospital for care. OCA conducts its needs assessments through both a formal and informal process. The formal assessment is performed every three years to meet regulatory requirements (IRS and state attorney general). OCA tries to engage the community residents in this process as much as possible; e.g., the last needs assessment in 2009 included almost 100 participants in focus groups with both adults and youth.

OCA has used an outside consulting group to assist with this process. Consultants are responsible for gathering data, best practices, environmental scans, talking with stakeholders and conducting focus groups. They also pull all the information together in a final report that is user-friendly and is shared with all the stakeholders.

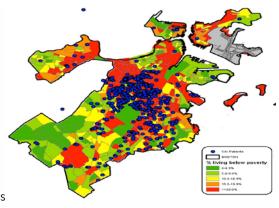
The hospital also worked with its Information Services Department to review hospital admissions (and ED visits) with asthma as a primary diagnosis in the prior five years in the proposed ZIP codes to assess for asthma prevalence.

Planning your needs assessment

Many resources exist to guide organizations on how to conduct a community needs assessment. A good resource for planning is the Web site: chausa.org/communitybenefit.

GIS Mapping

State and city public health department reports with statistical data of numbers and percentage of local hospital admissions attributable to a primary asthma diagnosis, and admission rates by age, race, ethnicity, income, neighborhood and schools were also helpful to further demonstrate the health inequities that we were seeing among our hospital's population. Poverty, race and ethnicity and asthma rates can be mapped together to identify disparities, as well as geographic areas with high asthma incidence. A publicly available resource for mapping is the Web site: communitycommons.org. Mapping can be performed in advance for planning or after the fact to demonstrate where children with poorly controlled asthma live.



69.3% of CAI patients lived in an area where ≥20% of families live below the poverty level Federal Poverty Level (considered "poverty areas")

Identifying model programs

Evidence from national randomized clinical trials, 5.6.7.8 previous models of culturally sensitive care, 8.9.10.11 and National Asthma Education and Prevention Program 2007 guidelines, 12 indicate that comprehensive community-based approaches are most effective in reducing environmental allergens, missed school days and emergency department (ED) visits, and in increasing symptom-free days. Previous literature has shown that quality improvement (QI) evaluation approaches can monitor multifactorial interventions to improve outcomes such as ED visits and hospitalizations for asthma. Multilevel interventions to reduce health disparities can be derived from the socio-ecological model. 14.

The planning team conducted a thorough literature review to identify existing research and model programs. In addition, the team was able to make a site visit to the Harlem Children's Zone's asthma home visiting program prior to program initiation for technical assistance on program design and implementation. Our program also received a great deal of guidance from local partners, in particular the Boston Public Health Commission and their partners conducting Healthy Homes research regarding home environmental interventions and Integrated Pest Management.

Initial planning group

At Boston Children's, the planning group consisted of:

Internal Steering Committee: met monthly

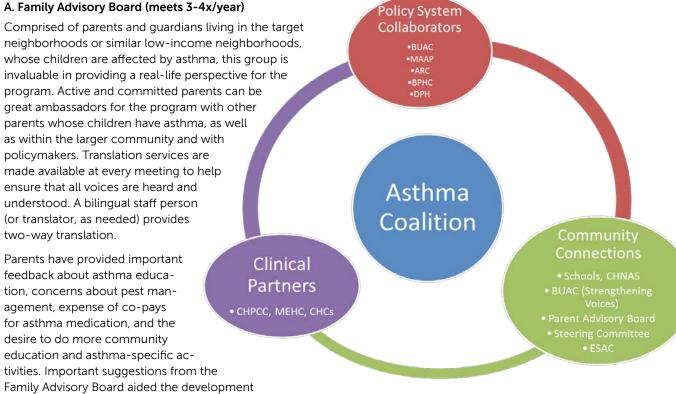
- » Office of Child Advocacy medical director, OCA grant writer
- » Program director
- » Information services
- » Primary care representative
- » Nursing: Asthma clinical nurse specialist and community asthma educator
- » Allergy and/or pulmonary subspecialist
- » Evaluator—establish rigorous evaluation plan at the outset
- » Government Relations
- » Boston Asthma Initiative, a community-based agency already receiving community benefits funds from Boston Children's and Brigham and Women's Hospital, to conduct asthma home visits
 - Program executive director
 - Board members

External partners consulted during planning:

- » New England Asthma Regional Council
- » Boston Public Health Commission Asthma Control program director
- » Boston Medical Center pediatrician/asthma researcher
- » Boston Public Schools Student Health Services

Ongoing community input and feedback

CAI has two advisory boards:



of resource manuals, educational sessions, parent workshops, empowerment training, advocacy training workshops, open forums, and suggestions for additional ways of communication with the larger community about asthma, such as newsletters and public service announcements about future asthma-related events. Two parents from this group also sit on the Community Advisory Board.

B. Community Advisory Board (meets 2-3 x/year)

The Community Asthma Initiative receives advice from a Community Advisory Board, comprised of community collaborators and partners. The Community Advisory Board serves as an expansion of the previous Steering Committee, which met monthly to start up the program. Our current board includes representatives of the local public health department and public health nonprofits that focus on asthma, healthy housing and tobacco and smoke-free policies, as well as representatives from the Boston Public Schools Student Health Services (school nurses), Head Start and the YMCA. Having a multidisciplinary board of external partners allows for a greater focus on the social determinants of health that impact families' ability to control their children's asthma; on where system changes are needed to improve air quality, both indoor and outdoor; and on increasing access to culturally competent primary care pro-

viders, asthma educators and specialists providing care according to national asthma guidelines, as well as access to affordable medications and reimbursement for organizations providing asthma case management and home visiting. Community collaborators are invited to join the Community Advisory Board regularly two to three times a year to address community planning and advocacy issues. We found that this frequency was adequate in Boston, given the very active asthma and healthy housing coalition that exists here and the overlapping memberships in various groups; however, if such coalitions do not exist, the board could serve an even more important role in bringing partners together.

Hospital Information Services Department

During the needs assessment process, the hospital's Information Services provided summary reports of patients seen in the ED or admitted, stratified by age, race/ethnicity, insurance and ZIP code. A system of generating daily reports of admissions and ED visits was developed. Patients are identified weekly and monthly according to asthma diagnostic codes and the ZIP code of their residence.

C. Ongoing Community Partnerships:

- » Asthma Regional Council
- » Boston Public Health Commission
- » Boston Asthma Home Visit Collaborative
- » Boston Healthy Homes and Schools Collaborative
- » Massachusetts Asthma Action Partnership
- » Breathe Easy at Home (BEAH)—participants include City of Boston Inspectional Services Department, Boston Public Health Commission, Boston Housing Authority
 - See Web site: cityofboston.gov/isd/housing/bmc
- » Medical Legal Partnership Boston
- » Neighborhood Health Centers
- » American Lung Association
- » Environmental Protection Agency (EPA) Regional Office
- » Asthma and Allergy Foundation of America

Mission statement

To provide asthma education, case management, home visiting to those from low income communities with poorly controlled asthma; and provide community education to modify social attitudes and norms, and systemic change to address asthma social determinants of health and support a sustainable model of care.

Program Model

The Child and Family

The program identifies individual children through in-patient admission and emergency department (ED) visit records as well as by specialty and primary care provider referrals. Providers identify children at highest risk and in greatest need for asthma intervention services. In the case of CAI, children, the majority of whom are low-income black and/or Latino, who have been hospitalized, as well as children who have been seen in the ED for asthma, are the primary targets of the program. Families are offered the opportunity to participate in the program, and the provider explains the program's benefits to the family and develops a personalized asthma management plan.

Recruitment/enrollment

- » Define enrollment criteria
 - Geographic area: four ZIP code areas in pilot
 - Risk criteria (see referral form in appendix)

Recruitment approach may depend on your setting, as well as cultural norms for the groups you're working with.

- » Establish the relationship with the family
 - culturally and linguistically competent staff
 - non-judgmental approach

For some cultural groups, an introduction from a trusted health care provider or other community member, or a face-to-face meeting in the clinic or hospital must precede the acceptance of a home visit.

- » Hospital-based or clinics affiliated with hospitals—work with information services to access real-time hospital census lists and ED logs, as well as retrospective lists of patients recently admitted/in the ED in the past week or month—we receive an updated list weekly and monthly.
 - We attempt to meet as many families as possible face-to-face during their stay.
 - Eliminates need to wait for provider referrals—on the other hand, you do want to make both hospitalists and community primary care providers aware of your program, so they understand the collaborative nature and don't feel like you are taking over their patient's care.
 - Hospitalizations and ED visits provide "teachable moments," which helps yield high rate of acceptance of program.
 - CAI provides the link from ED visits or hospitalizations to the patient's medical home.
 - More recently, we have also accepted referrals from providers that match the general enrollment criteria of poor asthma control.

- » Other settings—
 - Community-based organizations, including public health departments
 - Medical homes
 - Asthma team with Community Health Worker (CHW)/Patient Navigator integrated into the clinic, supervised by nurse or other clinical provider
- » Payment reform models, such as Accountable Care Organizations (ACO), global and bundled payments, may make this a more financially feasible and cost-effective team approach for comprehensive asthma care through the medical home.
- » Insurers can identify patients with high risk asthma that need additional services.

The Role of Community Health Workers

Employing community health workers (CHW) as members of the underserved racial and ethnic communities in which they work, is one evidence-based strategy for providing culturally competent care. CHWs have been endorsed for their cultural and linguistic competence, their ability to form trusting relationships with patients and mediate between health care providers and their clients, acting as coaches for individuals and families.

Case management

Each child whose family agrees to participate in the program is assigned to a case manager. The case manager is matched to the family according to linguistic or cultural appropriateness whenever possible. The case manager coordinates services with the primary care provider and assesses what the child and family need to successfully manage the child's asthma. Depending on the results of the assessment, children are either referred to or provided with the necessary services, including home visits tailored to meet their individual needs. Rather than a "one size fits all" approach, this method is tailored to the individuals, ensuring each family has an intervention that will work with their particular circumstances, culture, language and home environment. Services provided may include:

- » Connect to primary care provider, urgent care, asthma specialist
- » Referral to local specialists (allergy, pulmonology) for expert evaluations and care as needed
- » Care coordination between providers and community resources
- » Referral to existing asthma management programs and services available to the family through their own primary care provider, health insurance company, or other
- » One-on-one or group education sessions with a nurse to discuss proper use of medications and devices
- » Reminders and referrals for influenza shots.
- » An Asthma Action Plan to be shared with the family, school nurse and primary care provider

- » A home visit and environmental assessment to identify and reduce asthma triggers in the home
- » Advocacy assistance with landlords and housing authorities and others
- » Assistance with enrollment in health insurance or assistance around co-pays (supplemental Medicaid available in some states or Healthwell Foundation)
- » Connection to resources for educational, support and physical activity programs in the family's neighborhood.

Also, patients and their families receive follow-up to review asthma management techniques and answer questions; assess adherence to the Asthma Action Plan; identify progress on overcoming barriers; assess new barriers; and receive referral to other services if needed.

It is important to note that while the individual child referred to the program is the target of the intervention, other family members benefit through increased knowledge about their own asthma management and environmental changes. Very often more than one family member, including parents and caregivers, has asthma and is in need of education, asthma supplies and referral for services. On average, two family members have asthma in this population. This increases the reach and the impact of the program on this population.

The Home Visit¹⁵

Asthma education in the home is an interactive process and tailored to the child's and family's needs.

Things to consider:

- » Parental low expectations of asthma control, e.g., parents may believe it is normal for a child with asthma not to be able play sports or to end up in the ED multiple times a year
- » Fears about inhaled steroids, due to myths and misconceptions, that lead to non-adherence

Assessment of control and risk:

Asthma Control Test (ACT) (see Appendix 1) or other asthma control tool: This is a great way to introduce the concept of asthma control. This tool does need some explanation initially, in particular to correct the misconception that the child's asthma is under control if he needs frequent Albuterol use or if keeping the child quiet is necessary to keep him/her out of the ED. The ACT is an excellent teaching tool that allows patient/family, home visitor and provider to track control over time. The ACT asks about symptoms and asthma control over the previous four weeks. Documentation of daytime and nighttime symptoms is also becoming a common quality measure tracked by payers.

Other programs find it more useful to use a two-week recall, since people are more likely to accurately remember the previous two weeks, rather than four.

Other asthma control tools available online are:

- » The Asthma Therapy Assessment Questionnaire (ATAQ)
- » Test for Respiratory and Asthma Control in Kids (TRACK), which is an alternative for younger children, since it is designed for children under 5, whereas the ACT is only validated for children over 4.

In addition, we ask specifically about:

- » Missed school and work days by patient or parent
- » Limitations in physical activity
- » Courses of oral steroids
- » Number of hospitalizations and ED visits

This is also an opportunity for the client and family to identify their own specific goals for asthma control, e.g., the child wants to participate in sports.

Assess family's knowledge of asthma basics, role of medications

- » Step 1: "Tell me what you know about what asthma is." Generally, this will lead to a basic explanation/review of asthma anatomy and physiology, using graphics and models. We use a graphic with a normal airway, one that is mildly inflamed and constricted and one with severe inflammation and bronchoconstriction (which, conveniently, aligns with the Green, Yellow and Red Zones of their AAP). (See Appendix 2.)
- » Step 2: Relate this back to the individual client's asthma control, e.g., if someone was recently hospitalized for an asthma exacerbation, you can identify what the airways looked like when they were in the ED in the red zone, where they are now and what the goal is in terms of control of inflammation, mucus and bronchoconstriction.
- » Step 3: Bring in the Asthma Action Plan and relate the different roles of controller and quick relief medications to the symptoms and graphics.
 - Review early signs of exacerbation, when to start yellow zone medications, when to call the clinic.
 - Importance of routine asthma follow-up at clinic based on severity and even when well-controlled to re-assess plan, anticipate seasonal changes, etc.
- » Step 4: Parents need to understand what it means to have wellcontrolled asthma.
 - While assessing the child's current asthma control, based on the Asthma Control Test or a similar instrument, the home visitor, the child and family members can discuss current thinking about asthma control. This includes the ability to exercise without limitation, few or no missed school days due to asthma, no more than 1 course of oral steroids/year, no or rare ED visits and no hospitalizations. We also use an easy to remember guide for the frequency of asthma symptoms or the use of Albuterol that should prompt a parent to call the clinic to re-assess a child's asthma control, called the "Rules of Two". Using this tool, parents learn to call their child's provider if the child requires:
 - Albuterol more than 2 times a week during the day,
 - wakes up with asthma symptoms more than 2 times a month at night,
 - or needs more than 2 refills of Albuterol in the course of a year.

- We encourage feedback to providers if the child's asthma is not in good control before symptoms worsen. This also allows us to discuss the concept of parents being partners with the health care team in managing the child's asthma, as outlined in the NAEPP guidelines. By communicating with providers if the child's asthma symptoms increase or the prescribed medicines aren't controlling the child's asthma. This is particularly important, because some people stop controller medicine because it doesn't seem to be helping, rather than giving feedback to the provider, who could then adjust the Asthma Action Plan.
- Scheduling routine asthma visits every 3-6 months based on the child's asthma severity, seasonal triggers, etc. is another important measure in maintaining good asthma control.

Medication review and evaluation of adherence

We request a copy of the Asthma Action Plan or list of current medications as part of the referral process in order to compare this with the medications the family has on hand. We bring along a copy of the AAP (and a magnet to put it on the refrigerator!), in case the family can no longer find theirs. Also, it is helpful to assess literacy level of the parent/guardian before the visit, since it may be necessary to create a pictorial AAP for these clients (See appendix).

Check what medications and devices are present, where they are stored, how long it takes to find them, understanding of how each medication works, routines for administration, how they are actually being givenand by whom, as well as refill dates and counters.

Review device technique with repeat demonstration at each visit. Bring additional spacers in case the child's has been misplaced.

Sometimes this involves going through bags of old and expired medications, and with the families' permission, discarding multiple empty or expired medications, or those no longer being used, to reduce confusion. We also provide a shoebox-size plastic box to use as med box where only current meds and devices are stored (Sterilite 6-quart storage box, model #: 16428012) as well as a daily medication container with labeled days of the week if the medications are in pill form.

Assess adherence with open-ended questions and acknowledge that it is often difficult to remember to take a medication every day or twice a day.

Assess barriers to adherence (fears about medicine, complicated family schedule, e.g., parent works nights and child goes to different family member's house after school, can't afford medicine, no insurance/Medicaid, inactive due to not responding to request from Medicaid for updated information, has insurance but can't afford co-pay, competing demands, unrealistic expectations of child being in charge of medication administration, didn't understand or believe in importance of continuing controller.

- » Where are medications stored?
- » Who is administering the medications?

- If a child, is the parent reminding the child? Observing the administration? (Reality check if refill date or counter doesn't reflect consistent use).
- Assessing parents' beliefs about when a child is ready to take on this responsibility
- Normalize need to continue to be involved with medication administration with most children to some extent through adolescence.

Adolescents

- » Empirically, one recommendation that's been successful is to put meds in a med box that is kept in the kitchen rather than the youth's bedroom.
- » Engaging adolescent in plan, exploring their feelings about controller meds (do they believe they help? Which ones do they "like" or not like and why—taste, delivery method, doesn't fit in with routine? Would once a day regimen help?)
- » Transition to control of administration by adolescent gradually with goal of independence by late teens
 - Identifying goals for asthma control, relationship to adherence
 - Tools, e.g., setting phone alarm, text messaging

Known or suspected triggers

After reviewing what parents/child perceive as triggers, we review potential or known triggers that they may not be aware of, using low-literacy materials with pictures.

Has child been allergy tested?

While allergy testing is not always necessary, the NAEPP guidelines recommend assessing all patients with persistent asthma for allergies by history and, as indicated, allergy testing. In particular, indoor allergies to pests, pets, house dust and dust mites and molds are difficult to diagnose without testing. Allergy testing can steer clinicians to more aggressive management of allergies in their overall medical management of a child's asthma.

We have found that allergy test results, when available, have been very helpful to our work, as well, in targeting the most important triggers for parents to focus on. Families, in general, are eager to learn more about their children's allergies and are often surprised by the results and feel empowered to take measures to control triggers, once they have this new information. A confirmed allergy to the family pet is often necessary before a family considers giving the pet away.

Some payers also require evidence of allergies to dust mites or other indoor allergens in order to justify provision of bedding encasements or HEPA vacuums. In addition, documented allergies to mold, mice or cockroaches can be a powerful argument to convince a landlord to provide more effective pest management or repairs, or if the problem cannot be easily solved, for a housing authority to approve a transfer to a better apartment as a reasonable accommodation.

Home environmental assessment

We generally conduct the initial home environmental assessment towards the end of the first visit after the education, since at that point we have, hopefully, established the foundation of a trusting relationship.

We assess for common triggers—mold, pests, clutter/dust, smoking, harsh cleaning products and air fresheners, pets

Clutter and dust

We explain that we are not there to judge someone's housekeeping, but to help identify together some possible triggers and ways to create a more "asthma-friendly" environment, e.g., we talk a lot about reducing dust collectors, whether clutter, curtains, uncovered toy boxes, as general ways to create an asthma-friendly home. We place particular emphasis on the child's bedroom.

Likewise, when realistic, we attempt to normalize conditions, e.g., a lot of people have clutter because they don't have enough storage space, and offering simple, inexpensive solutions (we provide plastic storage bins to help with clutter).

Environmental Tobacco Smoke

Children come into contact with secondhand smoke in many settings, including their own homes, apartment buildings, extended family and friends' homes, parks and neighborhoods. Within our population 18.3% of our patients lives with a family member that smokes cigarettes. We also specifically ask if there is other smoke exposure, such as neighbors in their buildings or other places where they spend a lot of time.

Home visitors assess for smoking at every visit and may employ a brief intervention, such as the 5 A's, to identify all patients/parents for smoking status and their readiness to quit.

Beyond this, we use a non-judgmental "motivational interviewing" (MI) approach in talking about smoking cessation and other behavioral change with parents/clients, promoting self-efficacy and building on the person's own motivations to change over time. Through this process many parents accept a referral to the state Quitline. Seattle-King County Health Department and the Massachusetts Department of Public Health have both incorporated MI modules into their Community Health Worker trainings.

In addition parents or other family or household members who are not ready to quit are advised to institute a smoke-free home and car policy. Begin by assessing current smoking practices in the home. Many people believe that by smoking only in their bedroom, hallways/stairwells, or only when the child with asthma is not at home, they are employing safe practices.

- » Tobacco smoking in household or extended family
- » Assess all families—use 5A's
 - Ask—systematically identify all tobacco users at every visit

IPM Supplies

We provide every family with the following supplies, unless they already have them:

- » HEPA vacuum cleaner
 - » For families with carpeting: Eureka 4870MZ Boss Smart upright vacuums with two additional filters and additional bag of 9 bags, \$211 total
 - » For families with hard surface floors (wood, tile): Eureka 3684F Mighty Mite Pet-lover Compact canister vacuums, \$103/each
 - » Another inexpensive model used by other local home visiting groups: Bissell Cleanview Helix Bagless Upright Vacuum, \$90/vacuum
- » Dust mite-proof bedding encasements that are cloth and washable: we provide one mattress encasement, two pillows and, optionally, one box spring encasing (vinyl)
- » Plastic storage bins (for clutter and to reduce harborage for pests)

IPM supplies offered to families

- » Covered kitchen trash can (Sterilite, Hefty, or Rubbermaid 52-quart spring top trash container)
- » Copper Gauze to fill in holes mice can squeeze through, e.g., around pipes coming through walls or floors (other related supplies are expanding foam and caulk, though we don't currently provide these, since these are easier to find in hardware stores)
- » Sticky traps for rodents and insects
- » Some programs provide cleaning supplies, such as mops and sponges or green cleaning materials, such as baking soda and white vinegar; we provide an empty spray bottle as a "starter kit" to try some of the green cleaning mixtures (See Appendix 4)

Three-visit schedule for home-visit protocol:

- » Initial visit: As soon as possible after triggering event or referral
- » Second visit: No more than four weeks after the initial visit
- » Third visit: no less than six weeks after baseline and up to 12 weeks from baseline
- **» Follow-up phone call:** Twelve months after baseline¹⁶

The Seattle-King County Public Health Department's Healthy Homes program recommends four visits, also with interval phone calls and additional visits as needed.¹⁷

- Advise—strongly urge all tobacco users to quit
- Assess—determine willingness to make a quit attempt
- Assist—aid the patient in quitting
- Arrange—schedule a followup contact

We discuss the Smoke-free Home Pledge with all families and utilize tools through the Boston Public Health Commission

bostonsmokefreehomes.org/Pages/default.aspx

- » Motivational Interviewing, Third Edition: Helping People Change (Applications of Motivational Interviewing) [Hardcover] William R. Miller Phd (Author), Stephen Rollnick PhD (Author)
- » Refer to state or federal Quitline

Integrated Pest Management (IPM)—

"Integrated Pest Management (IPM) is a multidisciplinary approach to pest management that uses a range of pest control methods, including pest exclusion, sanitary practices, and minor structural alterations rather than relying on just one approach, such as pesticide application. Targeting pests in a variety of ways greatly reduces the dependency on the use of chemical. There are four fundamental IPM principles:

- 1) Monitoring pest populations with sticky traps to find out where pests are living and hiding.
- 2) Blocking pest access and entryways.
- 3) Eliminating food and water.
- 4) Selectively applying low-toxicity pesticides to address problems."
 - » Ref: asthmaregionalcouncil.org/healthy-homes/IPM.html

IPM educational materials

There are excellent English/Spanish information sheets on IPM that we provide residents, as well as information for landlords/property managers at the following Web sites:

- cityofboston.gov/isd/housing/bmc/default.asp
- asthmaregionalcouncil.org/healthy-homes/IPM.html
- asthmaregionalcouncil.org/uploads/IPM/asthma_ipm_guide.pdf
- asthmaregionalcouncil.org/uploads/IPM/IPM_FINAL_2009.pdf

(See Appendices—data collection forms used in home visits)

Mold and Moisture

We often encounters problems with mold, which can range from a little mold on the caulking around the tub, to major leaks from outside or inside the building, leading to very extensive, rapidly developing mold.

For smaller mold issues we review simple preventive measures, such as:

» Drying off damp walls after showering

- » Venting bathrooms, dryers, and other moisture-generating sources to the outside
- » Checking the exhaust fan (if there is one) in the bathroom to make sure it's drawing air (a simple trick is holding up a piece of tissue to the fan to see if it holds it up), and running the fan for 15-30 minutes after a shower to remove the humidity. If there is no fan or vent, a window should be opened for a similar amount of time.
- » Fixing (or reporting) leaks as soon as possible, so that mold doesn't have time to grow
- » Avoiding laying carpet directly on cement floors
- » Maintaining indoor humidity at 30-60%;
- » Using air conditioners and de-humidifiers;
- » Using exhaust fans whenever cooking, dishwashing, and cleaning

For living areas prone to mold and moisture, like basements (we encourage people to avoid basement apartments, if at all possible!), we do provide a humidity gauge (also called hygrometer), which is an inexpensive item that they can use to track the humidity and report excesses to the landlord. In Massachusetts, the state sanitary code specifies the acceptable range of humidity. This may vary from state to state.

For mold clean-up in small areas, we recommend using non-chlorine bleach (e.g. 1 cup non-chlorine bleach in 1 gallon of water). Clean-up of large areas often involves first removing the walls, carpeting or flooring affected by mold, making repairs, so that the leak or other source of water is eliminated and having someone experienced in mold clean-up, wearing the appropriate protective gear, do the clean-up in a way that seals the affected area off, as much as possible, from the rest of the house and protects all household members.

An excellent source of information about mold is the EPA.

Number and timing of visits

Our program is designed to follow a child over a 12-month period. Initially, we planned visits at baseline, three and six months. Since the program is tailored to the family's needs, we have maintained a degree of flexibility in terms of the number of visits families receive, with some families receiving fewer than three visits and some more. The average number of visits has been two overall within the range of one to 10. We also provide a significant amount of case management and care coordination over the phone, so contact with families often goes far beyond the number of home visits.

More recently we have participated in the Boston Asthma Home Visit Collaborative, which collectively designed a home-visit protocol with a three-visit schedule (with additional visits as needed), see sidebar.

Visit content

We (and the home visiting collaborative) have taken the approach of having a long first visit tailored to the individual, which covers asthma basics, med-

ication and environmental assessment and education. We have chosen this approach, since most families have significant issues in all areas, i.e., understanding of what asthma is, how the medications work, adherence and environmental triggers. This makes for a long first visit of approximately one and a half hours.

The timing and content of subsequent visits is largely determined by the issues identified during the first visit, e.g., issues with adherence may call for a shorter follow-up interval, such as two weeks, to assess presence of meds, number of doses administered based on the counter.

We currently use a loose-leaf binder that has educational materials in plastic sleeves in the order that we, generally, walk through during the initial visit, as described in this manual. This notebook was developed as part of the Boston Asthma Home Visit Collaborative so that we all would use the same materials. It is a combination of educational materials and resources and contains:

- » Asthma Control Test_(Also available in Spanish)
- » Asthma Control Goals (page 4 of Boston Children's Health Fund guide)
- » Graphic of airways (Krames Patient Education) Also available in Spanish.
- » Controller vs. quick relief medication comparison
- » Rules of Two (see Appendix 3)
- » Blank Asthma Action Plan
- » Devices—we use NHP flyers
- » Triggers—general education sheet with all kinds of triggers: allergic, irritant, weather, illness
- » Safe cleaning handout (Also available in Spanish)
 - Ref: Handout re: other products with Volatile Organic Compounds (VOCs) and alternatives
- » Smoke-free housing pledges and other materials
- » Smoking cessation literature
- » Referral forms to smoking quit line
- » Integrated Pest Management materials (Also available in Spanish, see Appendix 5)

We minimize handouts and provide them selectively, as relevant. In general, all families receive a handout regarding safe cleaning methods, and then others at the discretion of the home visitor.

Educational materials

There are several good published asthma materials, some of which are in multiple languages.

» Children's Health Fund Family Asthma Guide (free download in English and Spanish)—this is long, but you are able to pick and choose which pages you want to reproduce childrenshealthfund.org/publications/health-education-groups/family-asthma-guide

- » The Environmental Protection Agency also has free literature on many asthma topics
- » Devices—Great multilingual low literacy materials produced by Neighborhood Health Plan of Massachusetts nhp.org/pages/providers_clinicalresources_asthmatoolsdownload.aspx
- » Provide feedback in written reports to primary care providers and specialists regarding findings from home visits and other patient contact. This will include observations related to patient/family's understanding of asthma and medications, as well as adherence, home environmental triggers and other social needs.

Community Outreach and Group Education

A nurse educator provides educational sessions throughout the city at:

- » Schools—teachers, coaches
- » Head Start, other day care
- » Health fairs
- » Health centers
- » Day camps and recreational organizations—afterschool staff and camp counselors
- » Asthma Basics in English and Spanish

Social marketing campaign in 2006 with community partners

» Arthur Campaign: Kids with Asthma Can!

Physical activity

For children living in urban centers, physical activity is problematic; a recent increase in community violence has left many parents concerned that allowing their children to play outside is unsafe, and indoor, organized recreational activities may be cost-prohibitive. Rates of childhood obesity and elevated body mass index, with their concurrent health problems, are on the increase. Not all recreational programs have staff that are aware of and educated about asthma. Providing additional asthma education to recreational programs may help increase access to exercise opportunities for children with asthma in the target neighborhoods.

» Asthma Swim at YMCA, Boys & Girls Club, Boston recreational facilities City of Boston

Systemic change

Role of Community Benefits

CAI resulted from a process of community needs assessments and planning through the Office of Child Advocacy, the community benefits department at Boston Children's. An interview with the vice president for Child Advocacy at Boston Children's Hospital, Laurie Cammisa, describing this process, can be found at: rwjf.org/en/blogs/new-public-health/2012/02/laurie-cammisa-childrens-hospital-boston.html.

Advisory Boards

Program planning process included consultation with partners working on asthma advocacy and consideration of broader system issues—in particular, those of sustainability through reimbursement of comprehensive asthma programs, including home visiting, by payers.

Demonstrating cost-effectiveness or cost-savings was identified as an important evaluation focus.

Working in coalitions

- » Work with existing asthma coalitions, as we did in Boston, or if one does not exist, begin to reach out to others working in the field to create a local or state coalition.
- » Identify champions in:
 - Health care institutions
 - Public health agencies
 - Housing agencies—e.g., community development corporations, tenant groups, local and state public health departments, public housing authorities (both leadership and at the property manager level), inspectional services, IPM contractors (identify those who practice a comprehensive IPM approach)
 - Legal services agencies that are working with low-income clients around housing, income support, etc.
 - Community health centers
- » Identify policy issues for the coalition, employing focus groups and needs assessments of the populations most impacted by asthma health disparities. Some of the issues that coalitions have addressed include:
 - Smoke-free housing
 - Housing and Urban Development (HUD) is also actively encouraging public housing and other subsidized housing developments to transition to smoke-free housing. As an example, the Boston Housing Authority (BHA) after over a year of preparation just implemented their smoke-free policy for all public housing developments.
 - BHA lease addendum (also available on their Web site in Spanish and Chinese):
 - Ref: bostonhousing.org/pdfs/Non-Smoking%20Lease%20Addendum.pdf

- » Effective, safe pest management. This will include policies around the use of Integrated Pest Management in public and subsidized housing.
- » Strengthening the state sanitary code to support healthy housing efforts
- » Sustainable funding for asthma home visiting through reimbursement directly by payers or integration into the medical home and health care payment reform efforts.
- » Support for certification and recognition of community health workers as critical members of the health care workforce in order to provide culturally and linguistically competent care.

Boston Asthma Home Visit Collaborative

In Boston, we have a unique situation with multiple agencies conducting asthma home visits. This led to a collaborative, facilitated by the Boston Public Health Commission and funded by the Environmental Protection Agency to create a more coordinated approach.

The mission of this collaborative is to provide a coordinated CHW asthma home visiting program with potential outcomes that include:

- » Standardization of home visiting protocols
- » Centralized referral system
- » Coordination of training, purchasing, referrals
- » Data sharing and evaluation
- » Coordinated negotiations with payers
- » Culturally and linguistically competent workforce
- » Access regardless of health insurance or health care provider

Progress thus far has included:

- » Development of a standard home visiting protocol, which required everyone to make some changes in what they were doing
- » Standard educational materials
- » Electronic data collection and de-identified data-sharing; the forms were initially created as an Access database on Netbooks. Boston Children's is currently moving to a Web-based data collection system (REDCap).
- » Development of an evaluation plan

Role of Government Relations

The hospital's Office of Government Relations (GR) has been critical to our progress around policy and reimbursement issues.

GR was part of the program's initial planning group and they assigned a member of their team as the asthma champion so that they stayed informed of the program's accomplishments, as well as, the barriers that stood in the way of implementing a successful model. As the program began to demonstrate success, the hospital looked for ways to expand CAI's reach to benefit more children. In 2007 GR partnered with the Asthma Regional Council to develop a white paper, Investing in Best Practices for Asthma: A Business Case, for cost

effective asthma interventions.

After several years of strong advocacy activities related to affordability of asthma medications, and reimbursement for asthma management, GR was successful in persuading the Massachusetts legislature to earmark \$3M in the FY11 Medicaid budget to fund and evaluate a demonstration project that would provide case management services for children with poorly controlled asthma. The RFR for this project was released in April 2013 and strongly resembled all of the positive accomplishment from the CAI program.

Engaging your Government Relations department in the beginning of your programmatic efforts will allow them to be informed and ready to move on any policy or legislative action that can support your work.

Funding and sustainability of the program

While we work with insurers and policymakers to identify sustainable payment models to fund home visiting and case management programs, rather than be dependent on grants and philanthropy, community health initiatives must be long-term in nature in order to demonstrate results and work effectively with community partners for system change.

Programs that exist within non-profit hospitals and other agencies should work with the community benefits efforts and fund-raising arm of their institutions to help support these efforts. The current climate represents additional challenges for funding with federal budget cuts and limitation on grant opportunities. However, additional funds can be identified from private foundations that do not represent a conflict of interest, to expand case management and home visiting services. In order to ensure sustainability of the community health initiatives, programs should: 1) ensure that programs are of high quality and demonstrate meaningful results; 2) attract mission-designated funds, which can be allocated where they are needed; 3) find creative ways to fund programs through third-party billing, whenever possible; and 4) try to build a philanthropic base or an endowment to provide ongoing programmatic support. The health outcomes and cost analysis results from the program will help to expand funding sources.

- » New programs should develop an approach to identifying potential funding sources, such as:
- » Collecting appropriate data to demonstrate the level of savings generated by the program in order to appeal to insurers and legislators. Work toward policy and system change to establish permanent improvements in care.
 - Develop a convincing business case that can be made to insurers about the cost-effective nature of the services provided.
 - Work with insurers to develop innovative payment systems.
 - Educate legislators about health disparities, disease specific issues and need for health care funding.
- » Build capacity and skills of staff at community-based organizations to

provide asthma education services and guidance to children with asthma and their families.

- Many primary care sites may integrate care coordinators and home visitors as part of primary care redesign.
- » Attract media attention to educate insurer, legislators and the public about the extent of health disparities related to asthma in your region and success of your program in addressing them. This will in turn call attention to the need for innovative payment systems to support your progarm and similar programs that provide services that are not traditionally reimbursable in a fee-for-service system.
 - Disseminate information about the program model in peerreviewed publications.
 - Speak regionally and nationally about the program.
 - Work with local and regional partners on system changes concerning the disease process.
 - Use social marketing approaches to change attitudes and norms about the disease process.
- » Private foundations and corporate foundations frequently provide funds for community programs.
 - Programs will need to work with institutional fund raisers to identify foundations and corporate foundations that may be interested in your program.
- » Develop subcontracts from collaborators:
 - CDC, Healthy Tomorrows and other HRSA agencies have sported some collaborative program development grants that are directed towards specific disease processes, populations, or addressing health disparities using community-based participatory approaches.
 - Work with local partners and insurers to develop Center for Medicaid and Medicare Services Innovation grants to show cost-effectiveness and develop innovative payment systems.
 - Replicate the program model through funding from societies and institutions focusing on new models of care and replication in other states and regions.
- » Try to build a donation fund or endowment fund to provide for ongoing programmatic support.
 - Ongoing support is critical to complement specific funding sources, complement the federal and other time-limited funding, and tide over funding between grant efforts.

Roles/Job Descriptions/Staffing

The Community Asthma Initiative team is multidisciplinary and includes both funded and in-kind staff. We will describe the members of our team as a way to identify the various roles that may be important to your program's success and mission, while appreciating that funding, patient population, cultural and linguistic competency and other factors will determine your staffing configuration.

Staff mix of clinical staff (may be MD, RNs, social workers, respiratory therapists, etc.) and CHWs; mix will depend on multiple factors, e.g., funding, language needs, etc. In our experience, it is best to have all staff under one roof for supervision and team work.

The CAI Program Director/Principal Investigator (PI) 0.4 FTE (0.2 Basic Program, 0.2 Grant Related), is a pediatrician with an MPH and experience directing community health programs for medically underserved youth, as well as expertise in Quality Improvement initiatives throughout the hospital. She oversees all aspects of the program including program development, implementation, grant-writing and reporting, budgetary management and contracts, dissemination of information and development of program products, and program evaluation.

The Clinical Director 1.0 FTE, in our program is a nurse practitioner, but may also be a nurse, respiratory therapist or other clinician who has clinical asthma experience, experience with community or public health projects and the ability to supervise the clinical staff. She/he provides case management and asthma education for families and community providers, and supervises the nurse case managers and home visitors. She/he and the nurse case manager will contact families, complete case management questionnaires, set up a patient tracking system with tickler files, and see children and families in person, when possible, in the hospital setting and home environment. She/he will supervise the home visiting staff, including conducting weekly supervision meetings to discuss cases, share resources. The clinical director, along with other team members, also meets on a monthly basis with the asthma team in the hospital's primary care clinic in order to review shared cases and discuss new referrals. She/he, along with the case manager and CHW, will assist in connecting children and families to health care providers, insurance, and asthma resources and activities in the community.

The Nurse Case Manager 1.0 FTE (again, in some programs this role may be filled by someone other than a nurse, such as a respiratory therapist or Certified Asthma Educator) will work closely with the clinical director and outreach home visitor to provide care. She/he provides case management and asthma education for families and community providers, and works closely with the CHW. She/he will contact families, complete case management questionnaires, set up a patient tracking system with tickler files, and see children and families in person, when possible, in the hospital setting or home environment. She/he will supervise the home visiting staff for care for those families, and will provide medication and personalized asthma management plans for patients.

She/he will assist in connecting children and families to health care providers, insurance, and asthma resources and activities in the community.

The Community Health Worker/Health Educator/Home Visitor 1.0 FTE (one or more) works closely with both the clinical director and the asthma nurse case manager to provide home-based services to high-risk pediatric asthma patients and their families through health education on asthma anatomy and physiology, medications, home environmental triggers and other related topics. She/he will perform home environmental assessments and provide education on environmental remediation as needed. She/he will reinforce instruction provided by health care providers, including the primary care provider, specialists, clinical director, and asthma nurse case manager. She/he will assess client/family needs and will develop intervention plans in conjunction with the family and other involved persons. She/he will provide case management and serve as a liaison, case manager and advocate for clients in interactions with health, government and social service agencies. She/he will contribute to future growth and development of the program and provide training around case management to other staff. She/he will serve as part of the health care team.

As part of providing asthma education, community health workers will explain medications prescribed by health care providers and will teach patients how to take them. The CHW will assess the patient's asthma control, using specific data collection tools that will both guide the visit and document the findings. Questions about whether or not they should be on a medication, or whether the dosage should be changed will be referred to the health care providers as well as the clinical supervisor.

The Program Coordinator provides support to the program, facilitates program communication, performs administrative duties and assists with the evaluation of the program. She/he will order supplies, track expenditures, arrange meetings and provide needed administrative support to the program, PI and staff. She/he coordinates the Family Advisory Board and Steering Committee meetings including scheduling room, ordering food, contacting members, mailing flyers and preparing minutes. She/he assists in writing reports, disseminating information and producing products for the program. She/he works with the evaluator to set up data management systems, enter data and help track patients and products for the program.

The Community Asthma Nurse Educator 1.0 FTE works closely with program collaborators to provide the community education and activities for the program, helping children with asthma to lead healthy, active lives. She/he organizes asthma workshops for parents, teachers and coaches, provides educational support as well as asthma-related supplies to school nurses, disseminates asthma education materials in the community, and acts as a liaison with community partners, including schools, daycares and recreational organizations (e.g., Boys and Girls Clubs and YMCAs).

The Evaluator 0.2 FTE (0.1 FTE in Basic Program, plus varying amounts for analysis and grant tasks) is an employee of the Office of Child Advocacy and

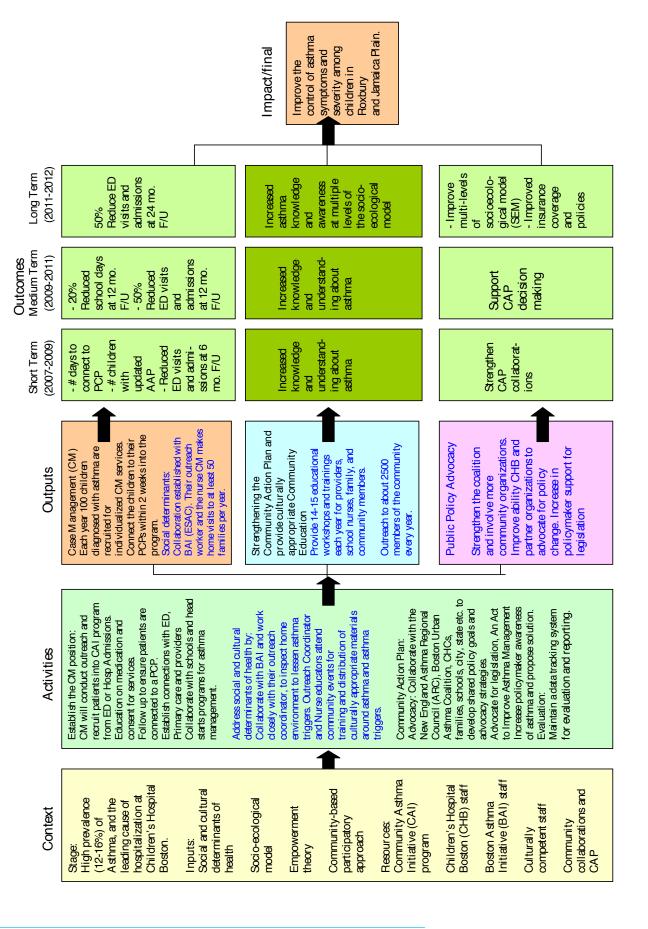
evaluates all OCA's community programs. She/he assists with evaluation design, questionnaires and data management systems (see Evaluation).

Information Services Department: Close relationships are developed to produce regular reports of patients seen for care, and access to hospital databases.

Responsibilities of all Asthma Team members

- » Work with team to identify barriers to asthma management and to create solutions and prioritize needs.
- » Participate in weekly or biweekly team meetings to discuss feedback from community advisory board and family advisory board meetings, discuss funding strategies, opportunities for expansion and/or improvement, data collection, data management, evaluation and the status of structural change initiatives.
 - Weekly supervision meeting by clinical director and/or nurse case manager to review cases with CHWs.

Community Asthma Initiative Program Logic Model



Training

There are many resources available for staff to gain both the asthma and healthy homes knowledge they need for a successful program.

The National Heart Lung Blood Institute's National Asthma Education and Prevention Program guidelines-Expert Panel Report 3 is by far the best resource available for clinicians, nurses and asthma educators.

Other training resources we are aware of include:

Planning and

Developing

Program

The Partners Asthma Educators Institute offers Becoming an Asthma Educator course online as a series of 10 video modules with related, exam-type questions and answers at asthmalearning.org.



Engage Stakeholders For those who are interested in pursuing certification as an asthma educator, the National Asthma Educator Certification Board has developed a certification exam. To

learn more about this process, go to naecb.com/ index.php. This certification is designed for li-

censed or credentialed health care professionals, such as nurses, respiratory therapists and pharmacists, but non-licensed providers, such as health educators and community health workers are also eligible to take the exam by providing direct patient asthma education, counseling or coordination services with a minimum of 1,000 hours experience in these activities. This is verified through a letter from a supervisor.

There are review courses available throughout the country, including one that is sponsored by the American Lung Association: lung.org/lung-disease/asthma/for-health-professionals-and-volunteers/asthma-educator-institute/



Gather Info

Analysis and

Results

Evaluation Design

There is also an online Basic Skills for Working with Smokers course through the University of Massachusetts Medical School.

The National Center for Healthy Housing holds trainings at locations throughout the country and, in addition, has an online Integrated Pest Management course.

You may also want to contact your regional Environmental Protection Agency office for other training opportunities in your area.

All regions also have Area Health Education Centers (AHEC) that provide courses and networking opportunities for community health workers.

Program Monitoring and Evaluation

Logic Model

A logic model (also known as a logical framework) is a tool used commonly by managers and evaluators of programs to evaluate the effectiveness of a program. Logic models are usually a graphical depiction of the logical relationships between the resources, activities, outputs and outcomes of a program. While there are many ways in which logic models can be presented, the underlying purpose of constructing a logic model is to assess the "if-then" (causal) relationships between the elements of the program. For example, if the resources are available for a program, then the activities can be implemented, if the activities are implemented successfully, then certain outputs and outcomes can be expected. Logic models are most often used in the evaluation stage of a program; they can, however, be used during planning and implementation.

A logic model is an integral part of program planning and evaluation. It serves as a helpful visual representation of a program, and aids the development of a program's evaluation plans. Developing a logic model in the early stages of a program helps ensure that goals, objectives and data indicators are recognized from the beginning. The logic model represents a flow chart of what resources are available for the program, what the program plans to do and what it expects to achieve. The major components of a logic model are:

- » Inputs—what resources go into a program
- » Activities—what activities the program hopes to undertake
- » Outputs—what is produced through those activities
- » Outcomes/impact—the changes or benefits that result from the program

A logic model is developed in response to conversations and feedback with various stakeholders that include local partnering agencies and organizations, as well as information provided from the organization itself. Arrows represent the associations between program activities, outputs, short-term outcomes, intermediate outcomes, long-term outcomes and the final impact goals.

Logic models can be developed for specific aspects of the program. See the logic model for the Community Action plan for CAI.

Process indicators are monitored on a monthly basis and outcome indicators every six months. The following are core health indicators to be measured:

Monitor Monthly

- » Number of patient face-to-face meetings
- » Number of patients receiving case management
- » Number of home visits
- » Number of days to follow-up with primary care
- » Number of community programs and meetings
- » Number of training sessions
- » Number of patients who have Asthma Action Plans

Monitor every 6 or 12 months

- » Number of emergency department visits of patients managed (6 months or 1 year) and visits before the program (6 months or 1 year)
- » Number of hospitalizations (6 months or 1 year) and hospitalizations before program (6 months or 1 year)
- » Number of missed school days (last 6 months or 1 year) and missed school days before the program (6 months or 1 year)
- » Number of parent/guardian missed work days (last 6 months or 1 year) and missed work days before the program (6 months or 1 year)
- » Cost/patient for patients in the program compared to those not in the program

Tip: sections that follow are most useful for Evaluators and Program Directors.

Evaluation Plan

Evaluation is based on the CDC's framework for program planning and evaluation.

It is based on the basic evaluation framework:

- » Formative evaluation: identifying need, target population, ZIP codes for intervention, areas needing improvement
- » Process evaluation: number served, reached, referrals made, triggers identified
- » Outcome evaluation: environmental and health results.

An evaluation plan should be built into the asthma program during program formation. The program goals need to be clearly defined and have agreement from all the required stakeholders. The objectives should next be created and they should be SMART objectives, i.e., they should be specific, measurable, attainable, relevant and timely. The objectives will help frame the process and outcome measures as listed below.

The evaluation will be guided by a series of questions:

Process Questions

The process evaluation will answer two basic questions, what was done? and how was

it done?

How many clients are served by the initiative (i.e. case management, community education) and what are their characteristics?

To what extent are the program and its components implemented as planned? How, if at all, does the program deviate from the plan and why?

To what extent are the participants or the families satisfied with the program?

Are the participants satisfied with the education workshops?

How the program is staffed, and is the staffing adequate, in terms of training, expertise, language and FTE?

What are the highlights of the project?

What are the challenges and facilitating factors implementing this project?

Outcome Questions

The outcome evaluation will answer the primary question what measurable change is detected as a result of this program?

To what extent does the asthma ED visits and hospitalizations and the missed school days change between before and after intervention?

To what extent does case management increase client connection with the required services?

To what extent does participating in the community education events increase knowledge of health risks, enhance advocacy techniques and increase awareness of available resources? How do we measure this?

To see the extent of disparity in asthma as related to being Black, White, Latino, Asians and Others over the three-year period? What are the next steps?

How many clients are there at the end of 1 year after recruitment into the Case Management services? (not lost to care or follow-up)

For the CAI program, data collection utilizes parent report at baseline, 6 months and 12 months, as well as hospital billing and administrative data for emergency department visits and hospitalizations before and after program intervention. Questionnaires should be designed to provide clinical and case management information to program staff and to assess asthma control through the number of hospitalizations or emergency department visits, day or nighttime symptoms, limitations in physical activity, missed school and parental work days, medication costs, adherence, and triggers. The program also uses pre- and post- evaluations at workshops and training sessions.

Data will be collected on an ongoing basis. Results of the project will be shared with the staff on a quarterly basis. Halfway through and at the end of the first project year the Advisory Board will review all results of the project and make recommendations.

The goal of evaluation of the program will be:

- » To determine the effectiveness of the program
- » To assess the achievement and progress toward reaching program objectives
- » To investigate components of the program that are performing optimally so they can be expanded, and also to share what works and does not work with others
- » To determine whether the funding is adequate and ensures sustainability
- » To ensure accountability
- » To build community capacity by including the voice of the community
- » To involve all partners and stakeholders from the beginning and onward
- » To allocate resources appropriately (cost/benefit)

Present value results formula

NPV= Present Value of Direct and QOL Benefits- Present Value of Program Costs

ROI= Present Value of Direct / Present Value of Program Costs

SROI= Present Value of Direct and QOL Benefits / Present Value of Program Costs

Hospital Quality Dashboard: Program Effectiveness

CAI tracks quality measures of effectiveness, the number of ED visits and hospitalizations from asthma related causes; and efficiency, the cost of ED visits and hospitalizations from asthma related causes.

For the analyses:

- » CAI patients were compared to children from four similar ZIP code neighborhoods (not statistically different): similar diverse low-income communities (Black; Hispanic), male sex, mean age, and socio-economic status (% Medicaid) with ED visits or hospitalization during the same study period. The comparison study group receives no case management services, home visits or follow-up by the CAI staff.
- » From hospital administrative data for the CAI and comparison community, the number of hospitalizations and ED visits and costs are assessed the year before the baseline visit, and at one and two years of follow-up. The number of ED visits and hospitalizations are extracted from hospital administrative data.
- » The cost data is obtained from the hospital administrative database. The hospital cost calculations include both expenses that are attributed to a patient care department such as labor and supplies, as well as overhead costs such as depreciation and building costs; however, they do not include physician costs that are submitted separately through provider foundations.
- » The number of missed school days and number of missed workdays over the past 6 month period are based on self-reported data recorded by CAI Case Managers at intake, 6 months, and 1 year for the intervention patients only.
- » CAI ED visits and hospitalizations are also obtained from case management data to reflect visits and admissions at any hospital.

Social Return on Investment calculation

The cost of instruction for each student per day is computed using the annual budget for the local school districts for money spent on instruction divided by the number of enrolled students and divided by 180 (assuming that 180 days of classes are held each year).

The income from the savings in missed workdays is based on wage data obtained from average annual household income from CAI case management data. The CAI demographic data are obtained from the Case Management data set, while the demographics data for the control group are obtained from hospital administrative data.

IRB Involvement

Boston Children's Internal Review Board waived the need for consent for the enhanced clinical care program, and approved access to case management data and hospital administrative databases for intervention and comparison groups with waiver of informed consent for the evaluation.

HIPAA compliant clinical releases were obtained to share information with providers and school nurses as needed.

Health Outcomes

The effectiveness of the intervention is assessed using the change in the number of ED visits and hospitalizations per patient between one year before and one and two years after the intervention.

For the comparison group, changes in the number of ED visits and hospitalizations per patient are similarly determined between the year prior and one year and two years after an index date. Since there is no intervention in the comparison group, an index date is chosen as the first date a child either visited the ED or is admitted to Boston Children's during the study period.

Since QOL data is only available for the intervention group this analysis is confined to CAI patients. For QOL measure, two parameters, the number of missed school days for children and the number of missed workdays for parents/caregivers, are used.

Cost Analyses

In determining efficiency, a number of studies use a conventional cost-benefit analysis based on return on investment (ROI).

In this case, the cost is to the hospital and funders, and savings are to insurers and society. However, the calculation of ROI does not adequately capture QOL improvements for individuals or for members of society. CAI calculates ROI and Social Return on Investment (SROI). Social Return on Investment (SROI) is an analytic tool that not only aids in measuring and accounting for a much broader concept of value, but also takes into account all benefits accrued to all members of society from an investment. Thus, SROI provides a more relevant analysis of any health and social sector investment, as it examines the overall impact the program has at different tiers; for individuals, families, payers, hospitals, or the overall community.

The cost savings from the intervention are computed using the difference in costs for ED visits and hospitalizations comparing one year before with one

year and two years after intervention. Similar cost changes for ED visits and hospitalizations between the year prior to the index date and one and two years after the index date are computed for the comparison group. Since both intervention and comparison groups are studied over the same time period, we do not adjust for inflation. The QOL improvement is measured by the reduction in the number of missed school days for children and the number of missed workdays for parents/caregivers. The cost of missing school days is calculated using the daily instructional cost incurred by the school district per student each day.

The imputed value of savings resulting from missed workdays is computed as a reduction in loss of earnings for patients/caregivers. Two efficiency parameters, Net Present Value (NPV) and SROI, are used to quantify the economic benefits resulting from the CAI intervention. For the computation of these parameters, all costs and benefits are converted into present value at the beginning of the year, on January 1, using an annual discount rate of 10% due to the high inflation rate for health care. The present value of both costs and benefits are computed over a two year period. The present value results are then used to determine both the SROI and the NPV, using the formula to the left.

Statistical Analyses

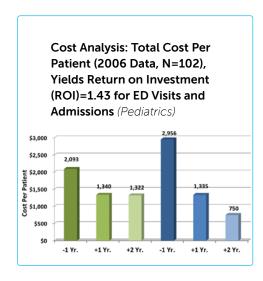
Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. Pediatrics Feb. 2012;129:465-472.

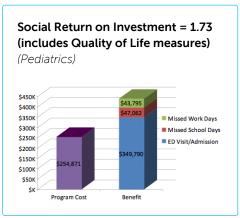
The case management outcomes database is run and analyzed at least two times per year. Data is entered with SPSS version 19 and analyzed using STATA version 10.1. Outcomes obtained by parental report include whether patients in 6 month time intervals had ED visits or hospitalizations (events), or days of limitation of physical activity, missed school or parent/guardian missed work due to asthma, and if the patient had an up-to-date AAP. The events/days are analyzed both as dichotomous variables of the percentage of patients with any (>1) events/days vs. none, and continuous variables of the number of events/ days. Demographic characteristics such as age, gender, race/ethnicity (Black/ African American vs. others, Hispanic vs. others), insurance status (private vs. public), household income (<\$25,000 vs. higher income), and asthma severity scores are collected. For the trichotomous variable for asthma severity (severe, moderate, others), two indicator variables were developed for moderate vs. others and severe vs. others for the multivariate analyses. The number of home visits and any (>1) nurse home visits are tracked. Analyses evaluate changes from baseline to 6 or 12 months, or the combined follow-up variable (using the latest follow-up visit available).

For the intervention group, attrition analysis for demographic and asthma characteristics is performed using $\chi 2$ tests for categorical variables and unpaired t-tests for continuous variables, comparing baseline values for initial and follow-up time points. Paired analyses use McNemar's test to assess differences in dichotomous outcomes between the baseline and follow-up measurements. Paired t-tests are applied for comparisons of continuous variables at two time points. Dichotomous outcomes across three time points are compared using unadjusted and adjusted repeated measures random intercept logistic regression models (displayed with odds-ratios with their 95% CIs).

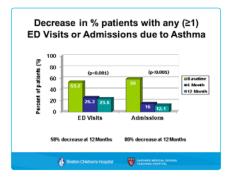
Hospital administrative data is used to compare the admissions, ED visits and hospital cost for the intervention and comparison populations for the fiscal year. Cost of the ED visits and hospitalizations for each patient is calculated with the baseline event included in the prior year and assessing events at one and two years of follow-up. A comparison group is identified for those with an ED visit or hospitalization from demographically similar neighborhoods, and using the first visit in the time period as the baseline visit. Actual costs are identified through the hospital administrative data. The ROI is calculated for the CAI patients comparing the cost savings for society (due to the reduction in ED visits and hospitalizations) over the cost of the clinical program (ROI=difference in hospital costs of baseline from Year 1 and Year 2 for CAI patients divided by the cost of the program). Clinical costs of the program, including salaries and supply costs, are documented. The clinical cost of the program in FY2006 for 102 new families included 1.0 FTE nurse, 1.0 FTE subcontracted CHW, 0.25 FTE program coordinator, 0.1 Program Director, 0.1 FTE evaluator, IPM materials, and IPM exterminator services. CHW was initially subcontracted through a community agency, but is now employed by Boston Children's for increased efficiency.

The additional cost reduction for the intervention group (CAI) over the comparison groups one year and two years after intervention are determined using a regression analysis that controls for Gender, Age, and Race. The additional cost reduction data and benefits from QOL improvements for the intervention group are used in the computation of NPV and SROI. These statistical analyses are done using STATA version 10.1 software.

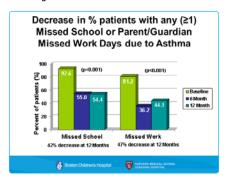


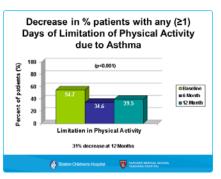


From case management data (n=), Dichotomous outcomes at baseline, six and twelve months



The frequency of the occurrence of home environmental findings from the home visiting database is enumerated below.





Evaluation Results

Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. Pediatrics Feb. 2012;129:465-472.

Community Asthma Initiative dichotomous outcomes at baseline, 6 months and 12 months:

Percentage of patients who experienced any (≥1 vs. none) Emergency Department (ED) visits, hospitalizations, missed school days, missed work days (parents/caregivers), and AAP for 283 children (all P<0.0001).

Continuous Variables using Repeated Measures (GLM) FY12, 986 patients						
	Base	6 Months	12 Months	P-Val- ue		
Number of Days with Limitation of Physical Activity	4.01	1.69	2.20	<0.001		
Number of ED Visits	0.82	0.33	0.27	<0.001		
Number of Hospital Admissions	0.67	0.17	0.16	<0.001		
Missed School Days	5.60	3.00	2.73	<0.001		
Missed Work Days	2.31	0.95	1.06	<0.001		

Home Environmental Findings					
Findings	Percent Patients				
Significant Clutter	52.3%				
Rodents	36.1%				
Pets	25.9%				
Mold	17.6%				
Cockroaches	12.2%				
Environmental Tobacco Smoke	18.3%				

Using Data to Demonstrate Your Program's Value

The powerful cost benefit data demonstrate considerable savings resulting from the intervention. These direct benefits are also accompanied with indirect QOL benefits. Indirect QOL benefits, as demonstrated by NPV and SROI measurements, show societal benefits derived from the investment in the project, and can serve as important tools for evaluation. The values of reduction in missed school days and missed work days show large economic benefits not only to their families but also to society at large. Utilizing positive direct benefit ROI numbers and indirect QOL benefit numbers, your organization can work with local hospitals, community stakeholders and child advocacy groups to

develop a business case and advocate for policy changes that can lead to reimbursement by private and public payers for nurse case management and home visits for asthma. Such a change would allow hospitals and other agencies throughout cities and states to deliver the CAI model to a wider population of children with asthma. The health outcomes can tell a compelling quality story. Asthma organizations, hospitals, and other community partners can present findings to Medicaid and state legislators, and aim for reimbursement measures that would enable providers to deliver tailored asthma interventions.

Moving Forward

Limitations

Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. Pediatrics Feb. 2012;129:465-472.

Possible underestimation of cost reduction

The cost data was obtained from Boston Children's administrative database, and did not include other costs that might have occurred outside of Boston Children's and also did not include physician costs; therefore the cost reduction was probably an underestimate of the true costs. The difference in reduction in costs between the intervention patients and the control group patients was not adjusted for asthma severity because of absence of such data for the control group. Only two of the indirect benefits were studied from the many that can arise from reduction in morbidity. So, these analyses provide a first order estimate of the benefits to society relative to program costs and the actual societal benefits may be many orders of magnitude higher.

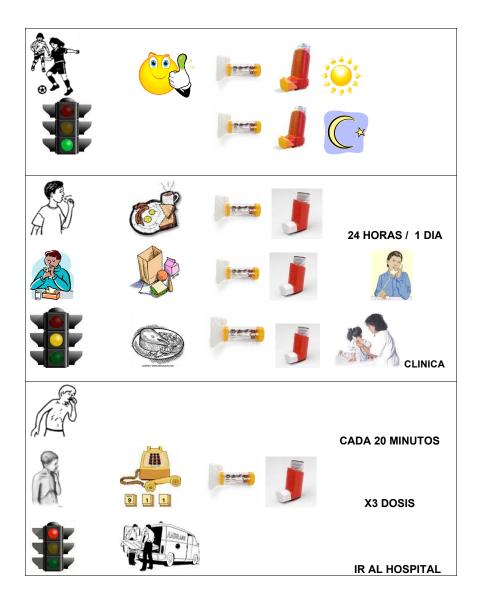
Potential Barriers

Sustainability

CAI provides an effective enhanced care model that could be included in a bundled or global payment system to reduce the cost of asthma care to society and improve the health and quality of the lives of children living with asthma. The CAI model can be used to respond to the health care reform call for "accountable care organizations" (ACOs) and expansion of care under the medical homes for patients with chronic illnesses.¹⁹ ACOs are responsible for the quality of care, as measured by standard outcome metrics,²⁰ and would receive bundled or global payments for care with potential shared savings for providers and payers.²¹,²² CAI has started working with Medicaid and other stakeholders to develop and implement a bundled payment pilot.

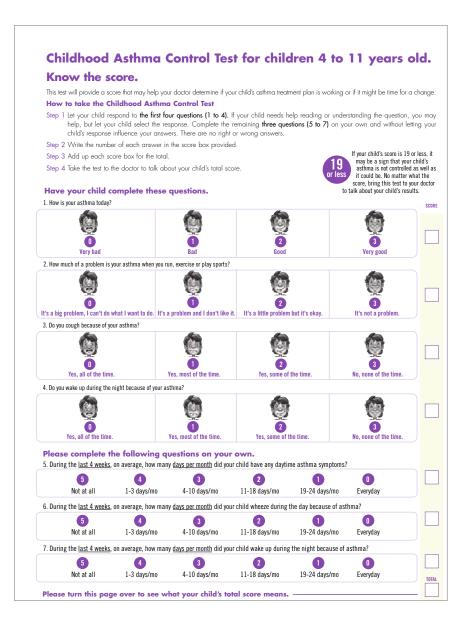
Appendices

Appendix 1



OR PATIE	NTS:						(F	Toda Patient's Nam	ny's Date: ne:	
ake the					-				yrs ar	nd older
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				ımber of ead h score box			ore box	provided.		
				to the docto	,		ır score.			
1. In the past 4		ow much of the Most of	_	our asthma keep Some of		getting as muc A little of		work, school or None of		Score
the time	(1)	the time	(2)	the time	(3)	the time	4	the time	5	
2. During the p	ast 4 wee	eks, how often	have you	had shortness o	of breath?					
More than once a day	(1)	Once a day	(2)	3 to 6 times	3	Once or twice	4	Not at all	5	
				thma symptoms ual in the morni Once a week		Once or twice	4	Not at all	5	
3 or more	ast 4 wee	1 or 2 times	have you	used your rescu 2 or 3 times	e inhaler	or nebulizer m Once a week	edication ((such as albut	terol)?	
times per day		per day	(2)	per week	•	or less		HUL AL AII	•	
	ou rate yo		trol durin	g the past 4 we	eks?					
Not controlled at all	1	Poorly controlled	2	Somewhat controlled	3	Well controlled	4	Completely controlled	5	
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of your scor	r doc		s, you	ır asthma	ı may	not be o	ontro	lled as v	vell as i	t could be
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 Supported by A self-adminis 					n help v	ou assess vo	ur patien	ts' asthma d	urina the n	ast 4 weeks
Reference: 1. Nathan							, p=o.,		5 6	

							Nomb	e y apellid	o del paciente:	
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		Paso 2 Sume Paso 3 Lléve								
		raso a tieve	ie ia p	ичера а за с	socioi l	odra nabiar	sobre s	u puniaje	IOIGI.	
1. En las últimas	4 seman	as, ¿cuánto tiemp	o le ha in	npedido su asma l	nacer todo	lo que quería en	el trabajo,	en la escuela	o en la casa?	PUNTAJE
Siempre	(1)	La mayoria del tiempo	2	Algo del tiempo	3	Un pace	4	Nunca	6	
		act tionipa		Dempo		act delines		100.100		
2. Durante las ú	Itimas 4	semanas, ¿con q	ué frecu	encia le ha faltad	lo aire?					
Más de una vez al día	(1)	Una vez por dia	2	De 3 a 8 veces por semana	(3)	Una o dos vece	4	Nunca	5	
And all min				por semana		per semana				
3. Durante las ú	timas 4 s	semanas, ¿con qu	é frecuer	ncia sus síntomas	del asma	(respiración sil	oilante o ur	silbido en el	pecho, tos,	
	opresión e	en el pecho o dolo	r) lo/la di		e la noch		io de lo usi	ual en la mañ	ana?	
4 o más noches por semana	1	2 ó 3 veces por semana	2	Una vez por semana	3	Una o dos veces	0	Nunca	5	
	imas 4 se	emanas, ¿con qué f	frecuenci		alador de r	escate o medica	mento en ne	ebulizador (co	no albuterol)?	
3 o más veces al día	1	1 ó 2 veces al día	2	2 6 3 veces por semana	3	Una vez por semana o men	z ()	Nunca	6	
	ría el co	ntrol de su asma	durante	las últimas 4 se r	nanas?					
No controlada, en absoluto	1	Mal controlada	2	Algo controlada	3	Bien controla	ia 🚯 🛚	Completam controlada	ente (5)	
+ LÜ	MERICA ING		ta de Contro	issociation apoya il del Asma y no						TOTAL
Devectors de	autor 2002 no	CualityMetric Incorporated								
	rol Test es una	marca comercial de Qualityl	Metric Socorpo	rated.						
Aothera Con	19 ni	untos o m	enos	, es posil	ble a	ue su as	ma no	esté t	an bien cor	ntrolado
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i obtuvo omo podr ARA LOS M a Prueba Ha sido con Tiene el apo Consiste en u	ÉDICO ACT validad yo de la n breve	OS: a clínicamente a American Lu	e por e ing Ass de 5 p	espirometría y sociation (Asc reguntas al qu	ciación e el pa	Americana ciente respor	del Pulm de inde	nón)	nente y que puec	de ayudarle



irth Date:		Date:		Green means Go Zone!
	Doctor/Nurse Name:	Doctor/Nurse Phon	o #:	Use controller medicine.
atient Goal:		Parent/Guardian Name & Pho	one:	Yellow means Caution Zone! Add quick-relief medicine.
mportant! Avoid thi	ngs that make your asthma	worse:		Red means Danger Zone!
Pe	ersonal Best Peak	Flow:		Get help from a doctor.
GO – You're	Doing Well! 📥	Use the	ese daily controll	er medicines:
ou have <u>all</u> of the Breathing is good No cough or whee Sleep through the Can go to ischool and play	ze from	MEDICINE/ROUTE	HOW MUCH	HOW OFTEN/WHEN
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DANGER –	Get Help!	Take these n	nedicines and ca	Il your doctor now.
our asthma is get orse fast: Medicine is not he Breathing is hard (ast Nose opens wide Ribs show Can't talk	Iping and to GET HELP I will want to go directly	see you right away. It	's important! If you o m and bring this for	HOW OFTEN/WHEN f causing a fuss. Your doctor cannot contact your doctor, rm with you. DO NOT WAIT. an ER visit or hospitalization.
octor/NP/PA Sigr	nature:		Date:	
		ld's doctor/NP/PA or		share information about my child's asthma.
arent/Guardian S		PODV FOR STUDENT MET	Date:	ATION AUTHORIZATION**
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REGLAS DE DOS

¿Esta Controlada tu Asma?

Las reglas de dos te pueden ayudar identificar sí tu asma esta bajo control. Simplement contest las siguientes preguntas:

- ❖ ¿Usa su inhalador de alivio rápida mas de 2 veces por semana?
- ¿Se despierta en la noche por causa de su asma mas de 2 veces por mes?
- * ¿Rellena su medicina de alivio rápido mas de 2 veces por año?

Si marco alguna de las preguntas con palomita puede ser un señal que su asma puede estar fuera de control. Asegúrese de hablar con su doctor sobre su plan de tratamiento para su asma.

Cuando su asma esta controlada debe:

- Estar libre de síntomas todo el tiempo o la mayoría de tiempo
- Disfrutar de ser físicamente activo sin tener síntomas de asma
- Asistir a la escuela sin síntomas de asma
- Dormir sin tener síntomas de asma



Is your Asthma Under Control?

DO YOU OR YOUR CHILD...

Miss school or work because of asthma?

Have trouble being active or exercising because of asthma?

Sometimes need to go to an urgent care facility or to the emergency room because of asthma?

Take your "quick-relief inhaler" more than two times a week?

Awaken at night with asthma symptoms more than two times a month?

Refill your "quick-relief inhaler" more than two times a year?

If you answered "Yes" to any of these questions, your asthma is **NOT UNDER CONTROL.** Talk to your doctor about your (or your child's) asthma today!

The Rules of Two is a registered trademark of the Baylor Health Care System

NEWS FLASH!!

Toxic Chemicals are found in: Air Fresheners, Scented Laundry Products, Plug-Ins, Candles and Perfumes



Studies have shown that:
Laundry products, air
fresheners, and scented
products emit dozens of
different chemicals. Most
products tested gave off at
least one chemical regulated
as toxic or hazardous under
federal laws, but none of
those chemicals was listed on
the product labels.

These chemicals have been linked to:

**Asthma symptoms*, Headaches*, Diarrhea, Cancer, Depression, & Earaches*

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**Asthma symptoms*, Headaches*, Diarrhea, Cancer, Depression, & Earaches*

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Instead, Try Green Alternatives like:



HOW TO FIGHT PESTS WITHOUT RISKING YOUR FAMILY'S HEALTH

A Resident Guide to Integrated Pest Management (IPM)

Pests need the same things humans do. They need food, water, shelter and a way to come and go. Integrated pest management works by cutting off these basic needs.

SHUT DOWN THEIR FOOD SUPPLY

- Use covered trashcans and take out garbage daily.
- Store food and pet food in closed containers.
- Limit food to the kitchen and dining areas whenever possible.
- Empty pet bowls between meals.

CUT OFF THEIR SOURCE OF WATER

- Use caulk to seal leaks around sinks and showers.
- Wipe up spills when they happen.
- Inform housing management of leaks so they can be fixed.
- Store pet water and food in sealed containers.

SEAL THEM OUT

- Repair window screens.
- Cover vents with wire mesh.
- Repair cracks in baseboards and around pipes.
- Block holes in walls and cabinets.
- Clean up old newspapers, shopping bags, laundry and other clutter.

ERASE THEIR ROAD MAPS

 Erase their directions by washing their travel routes with soap and water

Tenants have a right to live free of pests. If problems persist, call the City of Boston's Housing Division of Inspectional Services at 617-635-5322.





	Place addressograph sticker here
Re	ferral Form
Family Agrees to referral: Yes Lives in Boston: Yes No _ Date of referral: Referrer:	No (if no, do not continue) (if no, will try to refer to other agency)
Patient Demographic Informati Child's name	<u>ion</u>
Two years of age or older: Yes If under 2, rationale for r	No referral: Language:
Parent/caregiver name: Address:	Language:
Home Telephone: Insurance:	Cell:
Single ER or repeat urgent ca Overuse of rescue medication Prescription for oral steroids	asthma a exacerbation in the last 12 months are visit for asthma in last 12 months as in last 6 months
Parent/Guardian Smo Other Secondhand Sn Mice Ani	noke ExposureRoaches
Additional Reasons for Referral Concerns about medication as Needs help with medication as	dherence
Other pertinent information Allergy testing conducted: Yes_ Positive allergy testing results):MiceRoachesDus	Pollen Animal Dander
Fax form to:	

Endnotes

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Community Asthma Initiative

PROGRAM IMPLEMENTATION MANUAL

