Alleviate Asthma!

Cultivating a Successful Pediatric Asthma Initiative:
Strategies from the Inner-city Asthma Intervention

Tool Kit
for
Health Care Organizations

INSIDE

Making the business case for programming
Assessing organizational readiness
Practical tips from the ICAI for program planning, implementation and sustainability
Recommendations for overcoming potential barriers
Program tools, sample documents, timelines and other helpful hints

The Alliance of Community Health Plans is a leadership organization that brings together innovative health plans and provider organizations that are among America's best at delivering affordable, high-quality coverage and care to their communities. ACHP's mission is to improve the health of the communities we serve and actively lead the transformation of health care so that it is safe, effective, patient-centered, timely, efficient, and equitable. The purpose of this important CDC-funded project is consistent with these ideals, and we are extremely grateful to have coordinated an effort that has made a major contribution to the health and well being of inner-city children with asthma and their families.

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ACKNOWLEDGEMENTS

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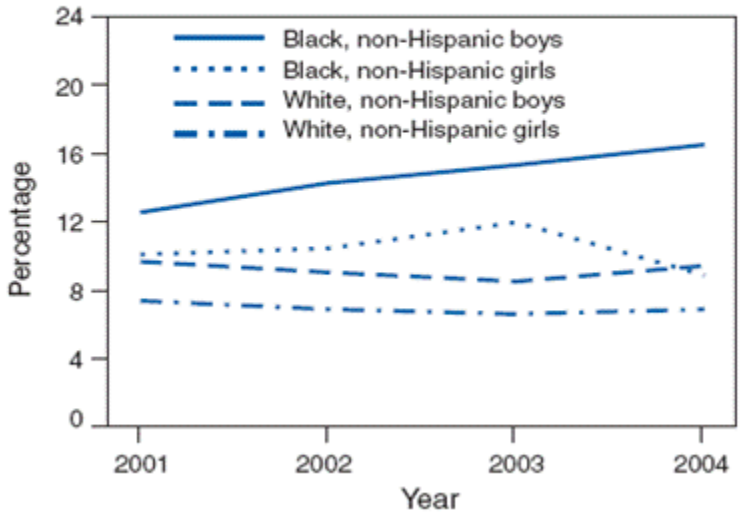
FOREWORD

Asthma is a highly prevalent disease that affects the quality of life of many people in the United States. About 9 million US children under the age of 18 (12%) are diagnosed with asthma; about 20.7 million adults have a lifetime asthma diagnosis. Children in poor families (14%) are more likely to have ever been diagnosed with asthma than children in families that are not poor (12%). Non-Latino African American children are more likely than Latino children to have had an asthma attack in the past 12 months (8% and 4%). Almost 4 million children (6%) had an asthma attack in the past 12 months. Asthma is a major cause of emergency room visits, hospitalizations, and missed school and workdays, many of which are preventable. The burden of asthma is especially great in urban areas with high levels of poverty and large minority populations. From 2001-2004, the Centers for Disease Control and Prevention reports a steady increase in the percentage of African American boys with asthma. The table below shows the comparison to other groups.

Percentage* of Children Aged <18 Years with Current Asthma, by Race/Ethnicity and Sex — United States, 2001–2004



SOURCE: National Health Interview Survey annual data files, 2001--2004. Available at this link.

The National Institute of Allergy and Infectious Diseases (NIAID) at the National Institutes of Health (NIH) can point to a rich history in developing protocols and approaches to treating asthma in the inner city. The National Cooperative Inner city Asthma Study (NCICAS) sponsored by NIAID proved that using a masters-level social worker as an asthma counselor for inner city children and their families can be successful in a number of ways, including successfully empowering families to manage childhood asthma better, and reducing symptoms and unnecessary service use.

The National Center for Environmental Health at the Centers for Disease Control and Prevention adopted the NCICAS protocol results and funded a four year project, the Inner-city Asthma Intervention (ICAI), to implement the NCICAS model in 20 plus communities across the Nation. The CDC commitment to this multi site, multi component project aimed at addressing one of our Nation's major health problems was a worthy intervention strategy.

The ICAI project, which we at the Alliance of Community Health Plans managed for over four years, is an excellent example of how working together, a highly-motivated team of public health professionals and their partners can effectively translate the latest research information into community practice. This project is the basis for the information contained in this tool kit.

The information contained in this tool kit has been developed so that the health care organizations—including health plans—that are interested in addressing childhood asthma as a public health issue will have a useful body of information to study as they develop options for different kinds of programs. ACHP's hope is that health care organizations will find the experiences described and the information shared in the tool kit a valuable contribution in their organization's quest to develop a meaningful and effective pediatric asthma intervention. We think this is important information worth sharing.

SECTION I: TOOL KIT ORIGINS, AUDIENCE, CONTENT AND USES

What is the Inner-city Asthma Intervention?

In 1991, the National Institute of Allergy and Infectious Disease (NIAID) at the National Institutes of Health (NIH) funded the National Cooperative Inner-city Asthma Study (NCICAS). The NCICAS demonstrated that an individually tailored intervention carried out by masters-level social workers trained in asthma management could reduce symptom days. The Inner-city Asthma Intervention (ICAI)—the national project, funded by the Centers for Disease Control and Prevention (CDC), and the project on which the information contained in this tool kit is drawn, was modeled after the successful NCICAS protocol. The ICAI concentrated on practical ways to implement the NCICAS findings in real world communities. Both interventions—NCICAS and ICAI--demonstrated that committed health care organizations, using trained and experienced individuals, could empower children and families to manage childhood asthma.

For Whom is This Tool Kit Intended?

This tool kit is a product of the experiences of the ICAI participant sites, and has been designed to assist health care organizations that treat a large number of children with moderate to severe asthma to establish or advance asthma management and treatment for families based on a proven research model. Organizations serving an indigent, urban population that could benefit from implementing an initiative similar to the ICAI include: health plans and other types of managed care organizations, hospitals, outpatient clinics, community health centers, and other health care organizations.

Many organizations reviewing these materials are likely to have some experience with an asthma population and will probably already have some information indicating that an intervention of some sort is needed for the population about which they are concerned. These organizations are the primary focus of this tool kit. They will benefit most from the information presented. Other organizations not as far along in their experience or thinking about implementation of a pediatric asthma management project, may find the tool kit useful as well.

What Does the Tool Kit Contain?

The ICAI demonstrated that the NCICAS protocol could work successfully in a variety of ‘real world’ settings, though modifications were necessary to accommodate local circumstances. All of the ICAI sites tailored the implementation to deal with their own organizational issues and circumstances. In most cases these modifications led to improvements at the site. Some of the changes led to national program-wide modifications to the intervention protocol. This tool kit presents lessons learned and highlights strategies that worked—both those required by contract and those implemented based on local circumstances.

It addresses topics ranging from whether an asthma management project is a viable project in an organization, to best practices and recommendations for implementation. It provides suggestions and guidance on how to approach the design and implementation of asthma management programs similar to the ICAI. It documents issues that may affect an organization's ability to develop and implement a childhood asthma management program.

The tool kit addresses the value of buy-in at the organizational and community level, marketing the intervention within the organization and to possible partners, staffing and other resource needs, space requirements and which types of data to collect in order to capture information to be of use in the future.

The tool kit contains an Organizational Readiness Questionnaire as a guide in planning a project. Basic information about asthma, sample documents, suggested resources, useful links, a glossary, and a list of ICAI sites are also included. Sample documents can be found at this link.

How to Use This Tool Kit

Information presented within this tool kit is a starting point for organizations that wish to consider, develop, or enhance current intervention efforts to educate and empower families to better manage their child's asthma. It is not intended as an unalterable recipe for project design and implementation. The intent is to share lessons and provide information that may be useful to organizations considering an asthma management project similar to the ICAI. In that context, organizations should draw on the experiences presented, seek additional information from the resources and links provided, and plan carefully during the design of the project under consideration.

SECTION II: CONSIDERATION OF ASTHMA PROGRAMMING

Why Consider an Asthma Intervention: The Costs of Asthma and Benefits of Intervention Programming

Asthma is on the rise. Asthma, a serious chronic condition, has increased in prevalence over the past two decades. Close to 20 million Americans were diagnosed with asthma in 2003. Of that number, more than 6.2 million American children under the age of eighteen were diagnosed with asthma. The rate of asthma diagnoses in children under the age of five also increased in the past two decades. Asthma prevalence is 39 percent higher in minority children, and is generally most widespread in lower socio-economic groups, regardless of race.[1]

Costs and burden increase. In the United States in 2004, the American Lung Association reported that direct health care costs for asthma were in excess of $11 billion a year. Direct costs include charges for medication, outpatient (clinic and office visits) and inpatient hospital services, emergency room services, physician and staff services.[1] The cost of medication alone increased from $1.4 billion in 1985 to about $2.5 billion in 1994.[2]

In the inner city, office and emergency room visits for asthma have increased steadily for the last 25 years.[3] About 1-in-6 pediatric emergency room visits is caused by an asthma attack episode. In 2003, there were 12.7 million office visits and 1.2 million outpatient department visits due to asthma-related issues.[1] These continuing increases have a huge impact on community health organizations and resources, providers, consumers, the quality of care, and costs.

Costs to society multiply the true expense of this chronic condition: $4.6 billion in lost productivity; 12.8 million missed school days, and 24.5 million missed work days for adults.[4] In addition to the financial implications of asthma, there are countless other components that add to the burden that families of children with asthma will encounter, particularly those with low incomes.

Asthma can have tragic outcomes. Asthma is one of the most treatable chronic diseases, yet the CDC reported 4,261 deaths from asthma in 2002, over 200 of them in children, a twofold increase from 1982. African Americans are three to five times more likely to die from asthma than White Americans.[5]

Urban communities and asthma. Urban communities have a greater percentage of children diagnosed with asthma. A study of pediatric asthma-related hospital discharge data in Chicago, Illinois found:

- 85% of asthma related hospitalizations occurred in zip codes where the population was predominantly African-American.
- In the zip codes where the population was predominantly African American and that had the lowest rate of asthma related hospitalizations, the rate of hospitalizations was more than double the rate of hospitalizations in zip codes where the population was predominantly White with the highest rate of asthma-related hospitalizations.
- From 1999-2001, taking into account all 64 zip codes that comprise the city of Chicago, the primarily African American populated zip codes represented 47% of all city-wide asthma-related hospitalizations versus 8% in the primarily White populated zip codes.[6]

Many urban families feel they are appropriately handling an asthma episode with urgent or emergency care. Great advances have been made in the area of pharmacology to help keep asthma under control. Still many families do not understand the function of the various drugs and how their use can help manage childhood asthma.

Appropriate asthma care. Proper diagnosis of asthma combined with medical care and continuing treatment, and appropriate prescribed drugs can help patients, especially children, control asthma and lead an active life. A person with an asthma diagnosis should have a personalized asthma action plan written by a physician for home reference. Once the family understands that the action plan documents the diagnosis, the severity of the asthma, the drugs prescribed and emergency steps to be taken in case of an asthma attack, it enables the physician and patient/family to use the action plan as a basis to work together on asthma care and treatment.[7]

Asthma Treatment Guidelines. Physicians have been concerned about asthma in the United States for many years. However, standardized treatment varies among medical specialties and facilities. In 1997, the National Asthma Education and Prevention Program (NAEPP), Second Expert Panel on the Management of Asthma released a report entitled, *Guidelines for the Diagnosis and Treatment of Asthma*. The report can be found at this link. It contains state-of-the-art clinical practice guidelines for diagnosing and managing asthma that incorporate the most recent scientific information available on the care of patients with asthma and provides information on treating asthma at all severity levels, stressing both clinical and self-management strategies. Despite establishment of these guidelines for the treatment of asthma, a substantial gap remains between the recommendations and the actual practices of many clinicians in treating people with asthma and their families.[8]

As an indication of the importance placed on asthma treatment nationally, the NIH-National Heart, Lung, and Blood Institute adopted the Second Expert Panel Guidelines as national asthma treatment criteria and goals for all asthma patients. NHLBI expects that with regular assessment, proper care and management, families should expect to meet these criteria.

- Freedom from severe symptoms day and night, including sleeping through the night
- Have the best possible lung function
- The ability to participate fully in any activity the patient chooses
- No missed work or school because of asthma symptoms
- Lessen or eliminate the need for urgent care visits or hospitalization for asthma
- Utilize medications properly, with as few side effects as possible
- Patient satisfaction with asthma care

Asthma Education is not enough. The medical community has a great deal of information to share that can make a significant difference in the lives of children with asthma. Studies have documented that families of children with asthma frequently have a high level of asthma knowledge, yet they are frequently non-compliant with physician care plans. Asthma education, alone, is not the solution.[8]

Proper Counseling matters. An organized program of education and empowerment sessions similar to the ICAI approach is more systematic and structured than what is found in many institutions or organizations. For example, at many institutions, counseling is delivered at times of urgent or emergency care. However, counseling only in a time of crisis does not appear to net lasting behavioral changes. Asthma education classes help to impart coping strategies, but a systematic, structured approach to family empowerment is also needed.

Families Benefit from Intervention. Numerous studies have documented the value of an intervention program in addition to education. The primary purpose of the ICAI was to translate asthma knowledge into skills and behavioral changes that would reduce asthma morbidity. Overall the goal of an asthma intervention is to decrease the severity and frequency of asthma symptoms in children by encouraging them, together with their family (or other caregivers) to assume direct responsibility for controlling asthma symptoms.[8]

Interventions Can Be Cost-Effective. One of the peer reviewed papers describing the NCICAS, "The cost-effectiveness of an inner-city asthma intervention for children," published in the *Journal of Allergy and Clinical Immunology* in 2002, shows clearly that a "multifaceted program with trained social workers deployed as asthma counselors reduced symptom days, was cost-effective overall, and was cost saving in children with more severe disease.[9]

A more recent study, "Cost-effectiveness of a home-based environmental intervention for inner-city children with asthma," published in the November 2005 issue of the *Journal of Allergy and Clinical Immunology* found that a "targeted home-based environmental intervention improved health and reduced service use in inner-city children with moderate-to-severe-asthma," and that the intervention demonstrated cost-effectiveness "when the aim is to reduce asthma symptom days and associated costs."[10]

Potential Benefits of Asthma Programming. Given the above documented costs and related burdens of asthma, including the provision of unnecessary health care visits and related care, health care organizations may wish to consider programs similar to ICAI. Potential asthma program benefits include:

- Improves quality of life for inner-city children by reducing symptom days
- Reduces unnecessary health care visits and related care, including unnecessary hospitalizations
- Empowers families to seek and provide the best care for their families, which may help them with other health care interactions
- Improves member satisfaction with health care organizations
- Demonstrates the health care organization's concern for children with asthma
- Creates an organizational atmosphere that prizes the recommended standards of asthma care

Summary. The prevalence of asthma in the inner city is increasing, despite the fact that it is one of the most treatable and manageable chronic diseases. That burden is borne disproportionately by low-income children. The financial costs are in the billions; the human costs cannot be quantified. The needs of families in the local asthma community are varied and complex. Asthma guidelines are available, and urban communities are in need of understanding and appropriate treatment, with state-of-the-art-care. Families need help to bridge the gap between their understanding of asthma and operating at a level of compliance that will improve their child's quality of life. An organization with a trained professional in the asthma counselor position and an investment in the infrastructure and space to carry out the intervention has the potential to empower children and their families to control asthma and improve their quality of life, and reap valuable savings by reducing unnecessary urgent and emergency care.

SECTION III: INTERVENTION BACKGROUND AND IMPLEMENTATION

The National Cooperative Inner-city Asthma Study (NCICAS) developers abstracted and utilized the best elements of previously tested interventions, while adding and expanding other features proven to be successful in assisting families of children with asthma. The ICAI project was designed to implement the NCICAS protocol in the community setting.

The National Cooperative Inner-city Asthma Study (NCICAS)

The NCICAS was a multi-faceted, multi-modal intervention designed to address the wide range of problems families encounter dealing with life's stress and a child with asthma. It demonstrated that an individually tailored intervention carried out by masters-level social workers (MSW) trained in asthma management could reduce asthma symptoms among children in the inner city.

Successful Asthma Intervention. The NCICAS was designed to empower families of children with asthma to manage moderate to severe persistent childhood asthma. It was initially funded through the National Institutes of Health's National Institute of Allergy and Infectious Disease (NIAID) in 1991. Implemented over the course of a 14-month period, the NCICAS was successful in reducing the number of symptom days among the participant group.[7]

Specially trained masters-level social workers, asthma counselors, were supervised by a program manager, generally a physician or nurse with extensive asthma experience, whose role was to provide guidance, answer questions, provide training and make patient referrals. Intervention designers chose masters-level social workers for the asthma counselor position because their training qualified them to understand and navigate the complex lives of inner-city families.

Asthma counselors used a problem-solving, empowerment approach to help families cultivate the skills necessary to partner successfully with physicians, school personnel, family members, caregivers and others who might impact the lives of the children. They helped develop appropriate intervention options and promote compliance with a treatment regimen.

The criteria for a family's participation were that their child:

- have a diagnosis of moderate to severe-persistent asthma, and not currently be under the care of an allergist or asthma specialist
- be age 5-to-11
- require assistance in managing their asthma or if the family demonstrated difficulty with compliance
- be willing to participate in the intervention

NCICAS Intervention Approach. The goals that shaped the content and approach of the program included asthma treatment (regular doctor visits, effective drug treatment without adverse effects and normal peak flow rates), asthma management (identify and avoid asthma 'triggers', use medicines correctly, recognize an impending attack, treat it early with a physician-designed medicine plan), and improved communication skills (empower people to make appropriate and medically sound decisions and choices, discuss problems, feelings and ask questions, talk with family members and others in the child's life about asthma).

The primary aim of the NCICAS was to provide families with knowledge and skills leading to behavioral changes that would reduce asthma morbidity and decrease the severity and frequency of asthma symptoms. It proved successful in reducing asthma symptoms, and proved cost-effective in some situations affecting those children with more severe asthma. It also demonstrated the utility of a social work trained asthma counselor as a valuable tool in working with children with asthma and their families.

About the Inner-city Asthma Intervention

In 2000, the National Center for Environmental Health, Air Pollution and Respiratory Diseases Branch of the Centers for Disease Control and Prevention (CDC) awarded the Alliance of Community Health Plans a four-year contract to implement the NCICAS protocol in the community setting. The ICAI utilized the approach and findings from NCICAS as the foundation for the intervention. It was designed as a one-year intervention for families. A major goal of the ICAI was to implement the NCICAS protocol outside of the research setting.

A Variety of Organizations Participated. Organizations chosen to implement the ICAI protocol in were primarily in urban areas and served mainly indigent populations. They included health plans, managed care organizations, hospitals, outpatient clinics, and other health care organizations. A list of ICAI sites is found in the Appendices at this link.

The intervention sites were funded and implemented in "intervention units," consisting of one full time asthma counselor and up to one full time support person serving 80 eligible children with a diagnosis of asthma and their families per year. Sites were to have a physician, nurse or other health professional as a program manager. The cost of this physician/nurse/health professional position was to be borne by each site, not by the project funds. Each of the sites received a fixed price contract paid in equal monthly amounts. This amount covered the salary of the asthma counselor, the full amount or fraction of applicable time of the support person's salary and fringe benefits associated with the asthma counselor and support person positions, asthma counselor training, office supplies and materials, asthma educational materials and supplies. Office space and furnishings, computers, and project management were to be furnished in-kind by the site.

Implementation. Sites were required to have a planned approach to program marketing, recruitment and retention. Medical coverage was necessary to assure that participating children would have an opportunity to access asthma care at the level stipulated by the NHLBI (regular doctor visits, allergy testing, obtaining and utilizing appropriate

preventive, maintenance and emergency prescription drugs, spirometry and regular peak flow readings).

Enrollment began with the risk assessment. The Child Asthma Risk Assessment Tool (CARAT) helped identify risk factors for asthma morbidity identified as problem areas in the NCICAS: exposure to allergens and irritants in the home environment, asthma care, psychological well-being of the child and caretaker, asthma attitudes and adherence to treatment plans. The assessment results were used to identify each child's asthma risks and to individualize the intervention for each child and family. A copy of the CARAT can be found at this link.

Intervention activities consisted of core and follow up activities. The core activities included: two adult group sessions, two child group sessions and a family session to clarify and individualize the intervention approach. Families were taught about the various prescribed medications and how and when to use them. Medical devices, such as peak flow meters and spacers, were provided and children and parents were instructed on their proper use. Strategies for dealing with identified environmental triggers were developed. The core activities were to be completed in the first two months after enrollment.

Follow up sessions occurred for the remaining 10 months of the one year intervention period via face to face meetings and telephone contacts with the asthma counselors and the families. During this time, the asthma counselor worked with the family to develop solutions to a wide range of family needs and issues: additional resources for the family, training, or special intervention sessions to deal with school, environmental or adherence issues.

SECTION IV: ADMINISTERING AN ASTHMA INTERVENTION: CONSIDERING ORGANIZATIONAL NEEDS

In addition to considering the needs of the asthma community an organization serves, it is also important to consider the organization's dynamics, culture, processes, and collective purpose. A replication of the NCICAS or ICAI models will not work for all organizations. Organizations will need to tailor their efforts to accommodate organizational culture and circumstances. This section of the tool kit presents some of the organizational issues to consider in determining whether it is appropriate to implement an ICAI-like asthma intervention. The topics covered within this section of the tool kit include:

- Characteristics of a site location
- Patient medical coverage and appropriate asthma care
- Office space and equipment
- Program personnel
- Internal and external buy-in
- Potential Enrollment
- Data needs

Population and Site Characteristics. Several different kinds of organizations implemented the ICAI project; there is no one set of characteristics for a "model" intervention site. Hospitals were the predominant implementing entity, but other kinds of organizations were a successful part of the project as well. Each project site had its own issues and characteristics; however, all served a similar population primarily in the inner city, and thus were located near the population they were serving.

Patient Medical Coverage and Appropriate Asthma Care. The ICAI was never meant to replace appropriate medical care. It is a tool, when combined with a tailored asthma action plan, medical support, and pharmacology, to improve the health of the asthma community. An ICAI-like intervention will work most effectively with families and children already receiving care for asthma through the physicians at a site or another network of physicians connected to the organization.

An organization would face substantial additional work associated with arranging for or seeking out medical care for children and families who do not have coverage or who are not already under the care of a physician for the child's asthma. If assisting families or children to secure health insurance is a function your organization regularly performs, then this type of help would not create additional processing challenges.

Office Space and Equipment. Implementing an ICAI-like project requires adequate space for convening group and individual counseling sessions. Adequate waiting areas for family members will be important as well. The workspace for the asthma counselor and the support person should be carefully planned. Space is one of the factors that will

give participating families an indication of the level of importance placed on the project, and it will have an impact on the success of the program.

Personnel. The ICAI positions and tasks were adopted based on the NCICAS study. The ICAI required three pertinent staff positions:

- A part-time physician/nurse/health care professional Program Manager (PM),
- A full time Asthma Counselor (AC)
- Up to a full time support person.

Depending on the local organizational needs and project design, additional staff may be utilized, or added, or some aspects of the positions combined to be most effective. Additional staff may include administrative, reception, community health workers, respiratory therapists, medical assistants, asthma educators, nurse practitioners, nurses, physicians, and other social work personnel. Positions without direct patient contact, such as public relations or marketing may also play an important part in the success of the program. It is important to determine what additional staffing would be needed to implement an intervention at the optimal level.

Community and Organizational Buy-in. Organizations do not exist alone in their community. Other health care and social service organizations may have an interest in or potential contribution to make to an asthma management project. Referring patients and coordinating care are among the most important benefits that can result from a thoughtful and thorough approach to informing other community organizations about your organizations "new project." At many sites, organizational relationships developed only after the ICAI had been implemented. This made it more time-consuming for the asthma counselor to make community linkages and referrals to other organizations because he/she often had to introduce and explain the project to the broader asthma community.

Communication. Another administrative consideration is the extent to which your organization has necessary communication structures in place. A good system of internal and external support and referral is an important factor to consider. ICAI families came to the project by referral from a physician or other medical professional, from emergency and urgent care waiting rooms, systematic file review by ICAI staff, or patient inquiry and self-referral.

> An organization must have a communications method in-place or invest time developing communication strategies to inform all stakeholders and potential partners in the community about the project.

Outreach. Most of the outreach occurred through relationships established with other asthma, health, school, or child-centered organizations. Site personnel established contact with school nurses, local clinics, and state, local or national asthma organizations as a way of expanding knowledge of the program and increase referrals when possible.

Enrollment. Enrollment goals were specified by the CDC in scope of work for the implementation and operation of the ICAI. In the case of a new intervention, local organizational needs would determine the size of the population to be served. The volume of enrollees in a new project will be based on a number of factors, including but not limited to:

- trained staff and support persons
- informed, experienced and engaged medical supervision
- availability of medical care
- volume of children with the defined severity of asthma
- ability to recruit
- space to conduct an intervention
- availability of equipment
- the length of the intervention term
- the cost to the organization

Data. Organizations planning to implement a major asthma management project must consider development of evaluation strategies before project implementation begins. Pre-implementation planning for evaluation is essential.

Organizational Readiness

There is an Organizational Readiness Questionnaire included in Section VII of the tool kit. The purpose of this questionnaire is to:

- provide a framework for your organization to think through the issues of initiating a pediatric asthma program,
- determine whether your organization has the necessary characteristics in place, and
- make an informed decision on whether or not to pursue programming efforts the information gleaned through the implementation of the ICAI.

The types of issues highlighted in the questionnaire are derived largely from information and lessons learned from the ICAI. It is divided into sections on organization/setting, client base, intervention structure, asthma care, staffing, data and costs, with questions for consideration under each section heading. It is not an exhaustive list of the issues that an organization will face in the design and implementation of an asthma program, but the questionnaire is a start.

SECTION V: ICAI LESSONS LEARNED: ORGANIZATIONAL AND ADMINISTRATIVE COMPONENTS

Many administrative components contributed to a successful intervention. This section describes the lessons learned at numerous sites. Buy-in is a necessity at every level. Taking steps to assure that personnel and other entities are made aware of plans to conduct an intervention allows for valuable input in the intervention structure, rollout and protocol.

Physician, Organizational and Community Buy-in

ICAI Requirements: Physician, Organizational, and Community Buy-in
The original Request for Application (RFA) required proposals from potential ICAI sites to address the following areas:

- organizational commitment to the implementation (via support letter)
- strength of the project site management plan and the availability of the program manager for day-to-day oversight
- approach to program marketing, enrollment and retention of clients
- adequate office and group meeting space
- physician and administrative support

Implementation Issues: Physician Buy-in. It was not uncommon to find that medical staff was not fully aware of the intervention protocol and the enrollment criteria. Depending on ICAI site set-up, some physicians may not have realized that they were treating children who met the ICAI enrollment criteria.

Physicians may not have been aware of the program's existence. Challenges sometimes occurred when a child with acute asthma symptoms encountered the ICAI project through urgent care at a clinic or hospital. Their primary care physician often became aware of the project after receiving a request for referral form a patient or the asthma counselor. Some of these physicians, not involved in the intervention, were not aware of the NHLBI guidelines and did not always provide that level of care to their patients. This placed the asthma counselor in the position of trying to change the behavior of physicians, who occasionally felt the intervention infringed on their treatment plans.

A solution to this problem was to have the physician/nurse/health professional program manager deal with these situations as a colleague. Another approach was to have the department head speak with the physician. Unfortunately, in situations where there was no champion, or concerns arose about the value of the intervention, the patient usually failed to participate or left the intervention early.

Some asthma counselors accompanied medical staff as they made their in-patient hospital rounds as a way to support real time decisions about whether children who were being seen met the criteria of the ICAI.

Implementation Issues: Organizational Buy-in. Among the most important predictors of a successful ICAI intervention was internal support and community buy-in for program goals and objectives. However, in many cases it was difficult for sites to implement the ICAI as described in their proposals.

- In most cases, a fairly small group of individuals at the ICAI participating institution made the decision to conduct the intervention.
- In a number of cases, a lack of understanding about the intervention caused tension and resentment because the referral process might have required additional work or assistance.
- In some cases where the asthma counselor had to rely on external physicians or personnel, turf questions arose and thwarted intervention involvement.

In these cases, an initial investment in internal communication with all organizational components that would potentially interface with clients and/or staff of the program might have allowed the site to avoid these kinds of communication and turf problems. Organizations considering the development and implementation of an asthma intervention will need to create ways to deal with internal communication issues.

Implementation Issues: Community Buy-in. External community buy-in is essential to the continuing success of a program like the ICAI. It is important to explain and assure awareness about all aspects of the proposed intervention.

As program recruitment needs expanded, asthma counselors moved out into the greater community to seek additional referrals and clients. Many community organizations were initially not aware that the ICAI had been implemented in their area. It would have been helpful for the asthma counselor if their implementing organization had discussed the project with potential community partners before it became necessary to seek their cooperation and participation.

In conducting education within the implementing organization and outreach to other organizations in the community, it is important to explain the participation criteria for the intervention to those who may be referring patients to the project. This will help promote more referrals and will also reduce the number of referrals of children who are ineligible.

> Buy-in can mean the difference between robust intervention and ineffectiveness: a course of action that is embraced and valued by the staff or a program that is an unpleasant additional duty.

One of the important lessons learned was that although there were many complementary and supplementary programs available through other community resources, it was difficult to establish meaningful links without first assuring community awareness about the ICAI and its objectives.

Asthma counselors need a comprehensive system of medical and social support to assist families effectively. The ICAI was more effective and valuable when community relationships were established. The ICAI became more valuable to the institution once

the asthma counselor and/or program manager became involved in community and state coalitions and agencies.

Recommendations: Physician, Organizational, and Community Buy-in

1. An organization considering intervention should examine and explore all potential internal and external relationships that will be needed to bring families in contact with intervention services. Early investment in building these links will contribute to a stronger project during implementation.
2. Reaching out to all physicians from within the organization who might come in contact with the asthma management project will lead to fewer misunderstandings and problems in project operation.
3. Physicians, nurses, and respiratory assistants who deal directly with asthma patients must be aware of and committed to the program.
4. Developing brochures or pamphlets that provide information about the program will be useful when meeting with community organizations to explain the program.
5. Organizations considering this type of asthma programming should include key external partners in the early planning stages of programming. For example, community organizations could be asked to sit on a planning committee.

Staffing and Space

ICAI Requirements: Staffing and Space
ICAI sites were required to have the physician/nurse/health professional program manager, asthma counselor, and administrative staff positions. Contract funds covered the cost of the asthma counselor and the administrative support person. The program manager was an "in kind" function. Asthma counselors were required to have a master's degree in social work. Each asthma counselor received additional training to prepare for his or her counseling and educational job requirements.

Asthma Counselor training. Social workers attended a brief initial group training session. This training allowed the social workers to establish a network and support system for feedback and ideas. Asthma specialists trained social workers about the epidemiology and biology of asthma, disease management, crisis stabilization and pharmacological treatment. The intense training prompted two social workers (asthma counselors) to obtain the additional training at their sites necessary to acquire the Asthma Educator certification (AE-C) from the National Asthma Education Certification Board (NAECB).

Each individual site was responsible for providing supplemental training with asthma specialists throughout the intervention. The supplemental training included materials research and practical on-the-job learning. Specific asthma training includes but is not limited to:

- Biology of asthma and lung functioning
- History of asthma health care

- Disease management and standards of care
- Pharmacological treatment and biological effects
- Environmental and household triggers
- Asthma and allergy symptoms and reactions
- Guide to helping children with asthma, which is a manual compiling information gathered during the NCICAS
- Self-guided reading and research

Implementation Issues: Staffing and Space

Asthma counselor and program manager relationship. Among all ICAI sites a successful relationship between the physician/nurse/health professional program manager and asthma counselor led to a more successful project. The depth of the program manager involvement differed among sites.

- At most sites, the physician/nurse/health professional program manager was an asthma specialist and was likely to have an existing relationship with the family or some familiarity with the child's case. In these situations, the family received support and encouragement to participate in the intervention from their doctor and the asthma counselor.
- In many cases, the physician program manager was also a department head who was able to inform and guide the department and the implementation and also contribute to case identification and referral. Some department heads were not closely tied to the day-to-day tasks of the asthma counselor, so they were not able to relate to some of the challenges that the asthma counselor faced. In a smaller number of cases, the physician/nurse/health professional program manager was so far removed from the intervention that they questioned some aspects of the asthma counselor's duties, or the program requirements. In these cases, the asthma counselor usually dealt with another physician or staff person on project management and patient issues. Over time, many sites were able to find a balance between autonomy for the asthma counselor to make decisions necessary to manage the intervention and the support and guidance from the program manager. This type of balance promoted an efficient and effective working relationship.

Asthma counselor and administrative support person relationship. The asthma counselor and administrative support person were the key personnel of the team who dealt with families and children at the ICAI sites. They worked the most closely with families and with one another.

- An effective support staff person enabled the asthma counselor to spend more time on working with families in counseling and education without having to deal with management and administrative issues.
- Some sites assigned only a part-time administrative support person. In many cases this resulted in the asthma counselor having to do considerable, additional administrative work.
- Many sites benefited from having administrative support persons with superior software skills. This enabled the asthma counselor to leave many of the duties

associated with data to the support person.

- A support person with superior administrative and interpersonal skills became an invaluable component of the intervention by maintaining accurate records for prospective participants and for participant's follow-up needs.
- Support staff assisted the AC during recruitment by introducing the intervention to the patient while the AC was occupied with other patients or tasks.
- A few sites were able to combine the support position with a nurse, respiratory therapist or medical assistant giving the asthma counselor and the families additional access to medical information in case of emergency or urgent need.
- An effective support staff person was another set of eyes for the asthma counselor and helped to maintain strong relationships with the families and ties to the intervention.
- At times, the support person was also providing childcare for siblings of children in group sessions. It was very difficult to find staff with the needed administrative skills and that were equally interested in childcare duties.

Asthma project team. A few sites developed a team concept where the asthma counselor was the specialist for dealing with participating families, and an additional social worker or team of nurses and social workers assisted the asthma counselor with follow-up when families missed appointments or for intervention follow-up sessions. In one case, a BSW could be assigned to work with the family to conduct home visits or to make referrals for other services as needed.

Cultural competency. Many sites had a majority Latino population. Most of these sites hired bilingual asthma counselors to address their clients' language and cultural concerns. At sites where the asthma counselor was monolingual English speaking, and there was a substantial population of Spanish speaking persons, the administrative support person was generally bilingual.

Families working on the changes necessary to improve their child's asthma need to feel accepted, culturally and otherwise encouraged and empowered. Families are more likely to participate in the intervention if family-friendly sites, for example, with space for extended family members waiting for other family members, are available.

Staffing changes. Few things disrupted the intervention like a change in asthma counselor. The nature of the position is such that the asthma counselor, because of the relationship developed over time with the family, is privy to information regarding family issues and dynamics. A new asthma counselor did not have that same relationship or information on day one of assuming his or her role in the project.

Recordkeeping systems varied among ICAI sites. Some asthma counselors kept case notes in the family's file, some kept them separately, and some did not keep case notes as such. In replacing an asthma counselor, sites had difficulty in dealing with these different approaches to information collection, retention and retrieval.

Space concerns. Over the course of the project, ICAI sites learned about the number of families that the asthma counselor could deal with at one time. Generally, a comfortable number of patients for an experienced counselor was between eight and ten for a group therapeutic meeting. Knowing the families is key, and the rapport built in the beginning at recruitment is essential in determining whom you will have to accommodate during each session. For example, depending on culture and demographics the family may be one parent and one child or grandparents, parents and children.

The sites also learned how many people the support person could deal with at one time. Adults were typically comfortable waiting for the completion of a child session, but children were less content with waiting. Therefore, while the adults were in their education session the support person needed to be able to maintain control and decorum. Having too many children to deal with was often overwhelming and chaotic. The asthma counselor might have invited ten families to attend a particular session, but more than ten children might show up and expect be included in the group. In fact it was common for parents to bring all of their children even if only one child suffered from asthma.

There were often challenges when the asthma counselor did not have available space set aside. Some counselors had to seek out an empty office to use for privacy. Occasionally this resulted in mid-session shifts to accommodate the person whose office was occupied.

Having the intervention office near the treatment space appears to improve the effectiveness of the program. At sites where space, equipment and access to information were under the control and responsibility of the organization, the intervention program and treatment were generally co-located.

Sites that utilized affiliations with other entities to connect with intervention participants often had to make arrangements with a third party for use of space and equipment, privacy and any other requirements. Special consideration should be given to supplying the space necessary to conduct group sessions. Space must be sufficient to secure files, hold equipment and hold private conversations. In sites where the asthma counselor was located in a cubicle that was adjacent to others, interviews had to be conducted elsewhere. The asthma counselor space should have access to the standard office equipment and allow for computer, phone and internet access. Providing space became a major issue at sites where space was a problem organization-wide.

One site utilized an asthma physician's office on Saturdays. It was located at a hospital with a parking garage and close to public transportation with a waiting area and conference room located in the same suite as used during the week. There was a private conference room for the group sessions. This hospital was located within walking distance from the clinic the patients already visited and was very accessible.

Recommendations: Staffing and Space

Invest in developing a good relationship between the program manager and the asthma counselor. This relationship will affect nearly all aspects of the project. Clarity and delineation of functions are important on a personal level, as well as within and among different organizations.

1. The asthma counselor should be dedicated to the work that only they are qualified to do.
2. Provide adequate administrative support for the project. An effective support person is essential.
3. Separate the childcare and other responsibilities of the administrative support person.
4. Hire people who reflect cultural compatibility and competence with the target population of the project. Language compatibility is most important, but other cultural competency issues are important as well. Bilingual asthma counselors and support staff can enhance likelihood of the project's success when language is a variable.
5. Think about succession planning for the asthma counselor. The demands of the position may make it a time-limited activity. It will not be possible to have a new asthma counselor enter the project with the same relationships as the departing asthma counselor. Succession planning is essential.
6. Data and information about families must be updated and readily available for any successor asthma counselor. An organized data collection system gives a new asthma counselor insight into the family's progress, challenges, referrals, special needs and other valuable information collected to help tailor the intervention.
7. Keep the families aware of changes in the project. They should be formally notified when the out-going counselor leaves and when the incoming counselor begins. A "meet and greet," or a brief introductory letter is important. Families participating in the intervention often have challenges with stability and may feel resentful if changes are not handled in a way that respects their time and interest.
8. Space needs are important. Families participating in an intervention will be sharing medical and personal information. They should be afforded privacy to share the information necessary to tailor the intervention.
9. Group meeting space is also important. At a minimum, the number of families invited should be able to fit comfortably in the meeting space with room for extra family members, not too many to overwhelm the AC and support person, yet enough to make the session productive.

Why Social Workers?

The NCICAS showed that social workers with a master's degree were successful in empowering families and reducing asthma symptoms. Masters-level social workers have psychosocial expertise with groups, individuals, families and children. When the basic social work skills are coupled with additional asthma-specific medical training, the asthma counselor was uniquely qualified to promote education and behavior changes from clinic to home, school and social environment. Social workers are adept in altering each family's specific medical plan to meet the patient where they are. The asthma counselor social workers received classroom and practical training to become fluent in working with diverse families and children.

Social workers are trained in therapeutic and social service coordination to provide the public with all opportunities. Social workers address medical obstacles with general asthma knowledge gathered by specialists and researchers and presented the data via educational sessions to arm the families with important up-to-date information. Social workers not only addressed the medical problems that plagued families with asthmatic members, but also the social and environmental factors that impacted their medical treatment adherence.

Social workers established relationships with families that fostered the trust and openness needed to talk about private family issues and alleviate underlying issues the families may or may not realize. The social worker becomes a person the family depends on in times of asthma stress and for hospital/clinic navigation, service coordination and as a family advocate.

Equipment, Supplies and Incentives

ICAI Requirements: Equipment and Supplies

The ICAI project provided each child with a peak flow meter, and at some sites, two peak flow meters. In addition, the project provided one child and one adult educational reader to ensure the educational information would be available for reference at home. The ICAI protocol provided mattress and pillow covers for children who tested positive for allergies related to dust mites. Sites also provided transportation or parking incentives to eliminate or minimize that potential barrier. The AC provided handouts and information about medicines and medical research to update and constantly inform the families.

A spirometer was mobile or permanent within the ICAI clinic and utilized by all asthma physicians or solely by the ICAI. As with any clinic, emergencies did occur. Albuterol, prednisone and epinephron were available for adverse reactions to the allergy testing and for patients who had problems upon arriving at the clinic. Other emergency options include oxygen and nebulizer machines.

Some other types of equipment utilized by the AC's included, but were not limited to:

- data collecting materials
  - forms
  - electronic filing/tracking system
- presentation equipment
  - overhead projectors and sheets
  - computers with presentation programs
  - projectors
  - television and VCR
- Props and utensils (to promote participation during groups)
  - games (activities for waiting family members)
  - incentive items

ICAI Requirements: Incentives

ICAI sites were not permitted to use contract funds to pay families to participate in the project. Under the ICAI contract, a modest amount was budgeted for incentives, mainly in the form of small gifts and prizes for the children who participated in sessions. Monies were also set aside for transportation assistance. Sites were permitted to use funds from other sources to cover the costs of incentives not allowed in the ICAI contract.

Implementation Issues: Equipment, Supplies and Incentives

The NCICAS study which offered monetary incentives for the baseline assessment, each interval of assessment and completion of sessions, enjoyed a high rate of enrollment of those eligible for participation--71% and a 33% rate of enrollment for all families approached. [11] Once families and children were enrolled, the NCICAS enjoyed a much higher level of completion, almost 82%.[12] The ICAI did not collect figures on the number of eligible families who went on to take part in the intervention, but 53% of those approached enrolled in the ICAI. The completion level for the ICAI was about 25%, significantly less than the NCICAS, although no data were collected to determine the precise cause of the variance.[13]

Perhaps the biggest barrier to maintaining participation in the ICAI was transportation. Some sites were able to use funds to provide a standard monetary amount for transportation to each family upon attending a group session. Another option is paying for parking. At one site the project would cover the cost of public transportation or parking. In addition, altering the sessions to combine child and adult meeting days reduced the number of times these costs were incurred.

Some sites were able to obtain donations to cover the costs of additional incentives. Food, which could not be purchased with ICAI contract funds, was one incentive purchased with donated monies. Some sites were able secure food donations from large food corporations. Food was a very important inducement for participation in the group sessions. Often, the families were at the sessions during mealtimes.

Bags and equipment with the site's logo and contact information were given to participants as a gift for having completed the core sessions, and also in an attempt to

promote the project. Goody bags included stickers, pens, pencils, and small toys. At some sites, gift certificates were given to children after each completed session. Most incentives were given periodically throughout the intervention after participation in a project activity, so as not to give out all the incentives to families who were not going to follow through with the intervention.

Realistically, the benefits of the intervention are asthma knowledge, potentially decreased emergency room visits, decreased emergency medicine usage, and decreased sick days. However, these benefits are not routinely realized quickly or noticeably enough to maintain patient participation. Incentives can help maintain interest until the benefits of the intervention are realized.

Recommendations: Equipment, Supplies, and Incentives

1. Providing peak flow meters, and mattress and pillow covers for children who tested positive for dust mite allergies were important. These supplies for the enrolled families will enhance your project's success.
2. Project office sites should have an available supply of informational materials and other project documents.
3. Emergency medications must be available to deal with asthmatic attacks during family visits.
4. Incentives can alleviate or eliminate some barriers to participation. Your organization should consider a program of incentives based on project goals and project financing.
5. A wide range of incentives can be made available. Transportation costs are likely to be a barrier to participation. Covering these costs removes a major barrier to effective continued participation.
6. Incentives provided should be linked to participation in project events or education sessions.
7. Often community groups are willing to donate food or other items, or even funds to cover the cost of project expenses—including incentives for families. These kinds of community relationships should be explored as early as possible in the development of the project.
8. The incentive features of the project should be described in project descriptive materials and marketing materials.

SECTION VI: LESSONS LEARNED: IMPLEMENTATION COMPONENTS

Recruitment

Intervention Requirements: Recruitment

The recruitment goal for each clinic site was to enroll at least 80 children per year, with the exception of the abbreviated first year for which the goal was 60 children. The ICAI requirements were that the children must be 5-11 years of age, with asthma severity of at least moderate persistent and should speak either English or Spanish. Sites were required to have a planned approach to program marketing, recruitment and retention.

Implementation Issues: Recruitment

Families came to the ICAI in several different ways. One principal avenue was through the assistance and cooperation of medical and support staff guiding the family to the intervention or referring to the asthma counselor for follow up with the family. Also, families sought out the intervention in response to advertising and information obtained from participating families.

Recruiting families became one of the major tasks of the asthma counselor, because at many sites it was difficult to achieve the enrollment targets. In many instances asthma counselors spent as much time recruiting as they did actually conducting counseling and education sessions. Asthma counselors and other project staff pursued a number of different methods and approaches to recruiting:

- Asthma counselors conducted education and outreach within their own organizations to remind staff and doctors about the intervention, and the criteria to take part in the program.
- Often, particularly when referrals and other case finding from within their own organization were inadequate, asthma counselors or program managers would conduct education and outreach to inform other community organizations about the program and its eligibility criteria.
- Asthma counselors, where organization and privacy rules allowed, searched medical charts and waiting areas for potential patients.
- Some sites used approaches such as storing referral forms in each examining room for staff use, or applying color-coded stickers to the medical file of a child with asthma to facilitate identification of likely participants.

Parental consent was required for a child to participate in the intervention. For any number of reasons a family's commitment to the project may have changed over time and they may have rescinded their consent. It is important to invest initially in a thorough family orientation to ensure that potential enrollees understand that participation in the ICAI would be useful only with a commitment of time. To test a family's intention, some sites utilized an "agreement" to promote the seriousness of asthma care and the commitment to the intervention.

At many sites, treating staff referred all asthma emergency or urgent cases to asthma counselors, without regard to the protocol criteria. Although the ICAI did not systematically capture data about the relative referral rates from various sources, asthma counselors and program managers generally felt that the more informed the staff, the better quality and more appropriate the referrals.

Most of the ICAI enrollees spoke English or Spanish. Although in an effort to achieve enrollment targets, some sites enrolled children who spoke other languages. Sites with a majority Spanish-speaking population usually employed a bilingual asthma counselor or administrative support person to promote access to all families and convey needed education. Sites with a minimal monolingual Spanish population generally utilized translators. Sites had to find or develop materials in Spanish; one site in particular experienced growth in other non-English speaking populations including Portuguese, Khmer, and Russian. After the ICAI project ended, sites that continued by self funding expanded the criteria to include younger and older children and children with less severe asthma.

Impact of HIPAA Regulations on Program Recruitment Methods. The Health Insurance Portability and Accountability Act (HIPAA) regulations affected implementation at each ICAI organization.

One of the main HIPAA considerations was that sites had to determine if the intervention was part of the overall care for a patient or if the intervention was a separate entity. If it was decided that the intervention was part of regular patient care, the social worker had more access to the files of potential enrollees. If not, additional paperwork was necessary to secure permission for treatment. For example, if the project was categorized as a separate entity, the asthma counselor was not able to use patient files as a means to gather history and assess eligibility until they could first recruit a patient and obtain a signed release.

Recommendations: Recruitment

1. Presenting the intervention and obtaining consent to participate in the intervention are important parts of recruitment. An asthma counselor should explain all aspects of the program requirements which include duration (determined by each site), use of the risk assessment, the type of asthma information offered, skin testing, group and individual session days and times offered, incentives for families, follow-up requirements, and potential benefits for families and children.
2. Different aspects of the program will appeal to different people. During the presentation of the intervention an attentive, experienced asthma counselor should be able to detect and expand upon aspects of the discussion that appeal to individual families. Regardless of the circumstances surrounding the patient's selection for recruitment (e.g., ER encounter, medical referral, hospitalization), each family should be fully informed of all aspects of the intervention. Every potential family should be given clear verbal and written information.
3. It is important to explain the program fully. At times families will question why they are being recruited, as opposed to the family sitting next to them. For

instance, the family may not understand how the level of asthma severity relates to their child's asthma. Asthma counselors must explain that the intervention process can help the family learn how to manage asthma.

4. The ICAI protocol was aimed at children between the ages of five and eleven. An organization may want to change the target age range for several reasons including: to access the age ranges and demographics in the target population more effectively, increase patient volume for the intervention, or simply to reach and help more families.
5. An organization considering an asthma intervention could change the criteria for the level of severity to meet the goals of the project being implemented.
6. HIPAA regulations play a part in obtaining consent at many organizations. Organizations should plan carefully to meet the HIPAA requirements in ways that are sensible and consistent with organizational goals.

Risk Assessment

ICAI Requirements: Child Asthma Risk Assessment Tool (CARAT)
The NCICAS and ICAI used the Child Asthma Risk Assessment Tool, or CARAT (available at this link) as the assessment tool to obtain and organize information about each enrolled child and family. The asthma counselor was charged with administering the CARAT before a family enrolled or participated in any ICAI activities. The purpose of the CARAT was to identify and summarize individual asthma risks, provide information for the asthma counselor to tailor and personalize asthma education, and to guide intervention activities. Each risk factor was judged by the whether it is modifiable and whether it is an existing or a potential risk. The risk factors addressed in the CARAT include:

- **Medical**--continuity of care, medication use, current care plan, follow-up appointment consistency and school cooperation
- **Environmental**--possible exposure to triggers found in the environment that may start or increase asthma symptoms including: dust mites, humidifiers or vaporizers, nitrogen dioxide sources, mold, mildew, fungus, cockroaches, rodents, pets, colds and viruses, outdoor allergens, and smoking exposure
- **Adherence**--availability of medication and the extent to which they are used as prescribed
- **Asthma Responsibility**--the role of the caretaker and their assurance that medications are actually taken
- **Psychosocial Factors**-- psychological well being of the child, caretaker and their social support and stress level
- **Attitudes towards Asthma**--specific feelings including how one feels about possible asthma improvement, problems with medication, feelings of helplessness and lack of control, and
- **Allergies**--skin testing and documentation of the results.

Implementation Issues: Risk Assessment
Many asthma counselors found it useful to complete the assessment before the group sessions. Often asthma counselors administered the CARAT at the moment families were

referred or recruited to the project, thus eliminating the need to schedule another appointment, and increasing the likelihood that families would complete the CARAT.

Recommendations: CARAT/ Risk Assessment

An assessment tool must be utilized to gather specific information about a family or individual to identify strengths and needs, and to paint a picture for the professional or group of professionals addressing the needs of the child and family. An assessment tool suited to the circumstances and needs of the implementing organization should be used.

1. The ICAI used the CARAT, but a risk assessment covering a wide range of problems and topics can also be used. However, a tailored assessment for a tailored intervention is ideal.
2. The information to be gathered and the reason for the CARAT or other assessment tool must be explained to the family before asking detailed personal questions. Establishing rapport is crucial in soliciting the most honest answers leading to the most accurate assessment. Skills attained in masters-level social work training were a valuable asset at this point in the intervention.

Skin Testing

ICAI Requirements: Skin Testing

Skin testing was a requirement of the ICAI protocol. The NHLBI guidelines for the diagnosis and treatment of asthma list allergies and other asthma triggers as factors in asthma exacerbation. Skin testing can determine exposure and sensitivity to specific aero-allergens called triggers. Parents or caretakers were required to agree to skin testing of the children.

Implementation Issues: Skin Testing

Skin testing gave the asthma counselor important information to help tailor the care needed and avoid known allergens. At sites with extensive pediatric asthma departments in place, skin testing presented a minimal challenge because it was generally part of standard asthma care. At other sites, the process of completing skin testing in the ICAI was often difficult. Some parents refused the testing. Despite asthma counselor and medical staff reassurance, some families feared blood transmitted diseases; others were concerned about the possible reaction of introducing an allergen to the child's system.

In addition to consent issues, there were significant operational difficulties in obtaining skin tests for each child in the program.

- A failure to perform skin testing limited the possibility of identifying asthma triggers, and thus reduced the asthma counselor's ability to work with families and children in managing their asthma.
- Some sites required the family to go to off-site testing facilities. At one site even though the testing facility was located next door to the clinic, there was a lower rate of testing than in sites with co-located testing capacity.
- Some physicians not connected with the intervention or not familiar with the most recent guidelines for asthma care (or for other reasons) did not feel that allergy

testing was necessary. Having a physician advocate involved with the intervention was a great asset in these cases.

Sites developed a variety of methods to complete the required skin testing.

- Sites that were able to test children in the examining room or in an area adjacent to the examining room or asthma counselor's office generally enjoyed a higher rate of skin testing.
- One site created a festive carnival-like atmosphere where the children and families were treated to snacks while the children were tested. The openness made children and parents more willing to be tested. It also and gave everyone an opportunity to meet and talk to other children and parents that were dealing with childhood asthma.
- Depending on the type of skin test utilized, superficial skin pricks or needles need to be available. Trays to organize the various types of allergy testing serums can be utilized to standardize application. Sites where skin testing supplies (serums could be refrigerated between uses) and trained personnel were located within the asthma clinic enjoyed a higher percent of skin tested children.

Lesson Learned
The most significant factor affecting testing rates in the ICAI was location of the skin testing personnel and facility. The farther away and more complicated the process of getting to the facility, the lower the number of children who were skin tested.

Recommendations: Skin Testing

1. Skin testing is an important component of an allergy intervention. Organizations should make every attempt possible to include it in the program.
2. Arrange for on site, co-located, or very near-by testing. It will improve the ability of project staff to design appropriate intervention plans.
3. Develop FAQs for the asthma counselor and other project personnel to give to families when explaining the reasons for allergy testing and the subsequent results.
4. Assure continuity and reduce barriers for families who agree to test their child.

Core Activities (group and individual sessions)

ICAI Requirements: Core Activities (Group and Individual Educational Sessions)
Following completion of the CARAT and skin testing, the families were to take part in the following Core activities:

- two group sessions for parents and caretakers of children with asthma
- two group sessions for enrolled children (and any other children that are attending the session with the child, e.g., siblings), and
- one individual family session to clarify and individualize the intervention approach, structured to occur after the completion of the group sessions.

The suggested content of these sessions is contained in "A Guide for Helping Children with Asthma", available at this link.

Group Sessions. The ICAI protocol placed significant emphasis on the value of group sessions. Adult and child group sessions were to be conducted during the first two months of the program. These sessions provided the foundation of asthma education and skills training that were built upon in subsequent individual sessions. They provided education and information, and they created an opportunity for a group dynamic that was an equally important part of the session training.

Individual Sessions. Individual family sessions were designed to allow the asthma counselor to clarify and discuss specific issues from the adult and child group sessions. They also provided an opportunity for detailed assessment of needs and risk factors and a chance for the family to express their own concerns. The ICAI protocol called for the individual family session to be at the end of the Core activities. However, many counselors found value in having the session in the beginning as a way to bond with enrolling families.

Implementation Issues: Core Activities (Group and Individual Educational Sessions)

Many asthma counselors found it difficult to schedule and provide the group sessions as specified in the ICAI protocol. Many sites modified their approach to these group sessions so that they could reach as many families and children as possible. Often it became necessary to meet at the convenience of the parents and children rather than when it was called for in the protocol.

One lesson is that sites needed flexibility in scheduling sessions with families and children. As a result, sites loosened the intervention structure to allow asthma counselors to change the order or delivery of the sessions based on the needs and availability of the family. Having more individual sessions or additional smaller group sessions was more time consuming, but proved to be a more effective and efficient use of the asthma counselor's time.

It is typical to have a certain number of "no shows" for social service programs. In the case of the ICAI, group session attendance by all of the invited families was uncertain. Initially, some counselors would cancel planned sessions if a majority of the attendees did not show up. Other counselors adapted the group information for delivery to a small group of adults and children or an individual family. Sites also combined the group sessions in some manner that reduced the four sessions to three, two or sometimes one.

Sites had to balance the need to complete all of the protocol sessions against the benefits that accrue when the sessions are conducted in the order proven successful in the NCICAS. Because sites modified the approach to the group session order, families may have missed the opportunity to establish relationships with other families, and hear what

other families were going through including their problem solutions. The children may have missed the opportunity to socialize with other children just like them.

Conversely, offering the group sessions at different times allowed more patients to take advantage of the intervention benefits. Asthma counselor flexibility was key for most sites to include as many patients as they did. Scheduling groups to meet at night and weekends allowed working adults and school age children to attend. Asthma counselor's found that accomplishing as much as possible in the minimum number of visits often made the intervention more efficient and promoted patient participation.

Asthma counselors found that altering the sequence and timing of the individual family session lent additional efficiency to the patients and the intervention. Many of the sites found that coupling the individual family session with recruitment not only ensured that the session would be completed, but also eliminated yet another appointment or meeting the family would have to attend. Asthma counselors found that after recruitment many families were overwhelmed with the requirement to attend group and individual sessions, and as a result delayed the beginning of the follow-up phase.

Recommendations: Core Activities (Group and Individual Educational Sessions)

The NCICAS proved the utility of the group and individual sessions. Although successful, following the NCICAS protocol structure may or may not be the best way to structure an intervention to change health status and reduce symptoms for the specific target population at a given site. Organizations contemplating implementation of a childhood asthma project will need to balance the demonstrated benefits from the NCICAS against the administrative and operational realities found in the local setting.

1. Many inner city families will have difficulty adhering to a rigid schedule of group and individual sessions. Implementing organizations should allow for flexibility to meet the needs of the target families in scheduling meetings or counseling sessions, including nights and weekends.
2. A system to revise educational materials tailored to each stage of the intervention is important since meetings may not take place as planned. The materials used for a particular session will need to be revised to reflect the status of the project's implementation and meet the needs of those present.
3. There may be cost implications associated with the structure and sequence of group and individual sessions. Implementing organizations should collect information that allows assessment of the costs of alternative approaches to the counseling sessions.
4. Restructuring group sessions may require additional time in individual family sessions or during follow-up to present the information that would usually be more thoroughly examined during group sessions.

Follow-up Activities

ICAI Requirements: Follow-up Activities

Follow-up sessions were ten months of consecutive contact—alternating between phone contact and face-to-face meetings—designed to begin after the completion of the Core activities. The ICAI protocol called for the Follow-up and Core activities to take a full year to complete.

Follow-up reinforces the targeted elements presented in the group sessions and specific information discussed in the individual family session. Follow-up allows the child's medical progress to be consistently observed over time. Topics discussed are specific to each family and their problem areas. "A Guide for Helping Children with Asthma" (available at this link) gives suggestions for topics to discuss during follow-up conversations.

Implementation Issues: Follow up Activities

At some sites, it was not possible to complete the Core sessions within the two months allotted for those activities. As a result, the Follow-up activities were delayed, and it may have taken longer than twelve months to complete the intervention.

Asthma counselors found it difficult to maintain contact with all the families who had enrolled in the project. This applied to Core as well as Follow-up sessions. Despite substantial effort on the part of asthma counselors to maintain contact with families, some families dropped out of the project and did not complete the full intervention protocol.

At some sites, families absorbed and responded to the information so well that midway through the Follow-up sessions, educational topics had been exhausted and there was no additional information to present to the family. Asthma counselors reported some families making statements like "We love (seeing/talking with/meeting) you, but what else is there to talk about."

Other families did not respond as well to the education, and improvement was a struggle. Asthma counselors reported keeping these families participating well past their twelfth month in order to maintain support and offer guidance until the family became self sufficient.

A small group of families responded well, but became so accustomed to working with the asthma counselor that they continued to seek out asthma counselor support. Many asthma counselors asked these families to serve as greeters and boosters for new intervention families.

The asthma counselor worked with the family to develop solutions to a wide range of family needs and issues: additional resources, training, or special intervention sessions to deal with school, environmental or adherence issues. The ICAI protocol discouraged home visits; however, some asthma counselors found them to be useful.

Asthma counselors generally stopped Follow-up activities after four consecutive months without contact—because it was long enough to allow for family difficulties and not too long to cause a lapse in memory regarding the educational information. Despite the diligence of the asthma counselors in attempting to maintain contact with the enrolled families, every ICAI site had patients who did not complete all of the Follow-up sessions.

Recommendations: Follow-up Activities

1. The ability and stability of the patient population and their willingness to follow through with the intervention is a major consideration. For many inner-city families, committing to twelve months is daunting. The rate of losing families after partial completion rises steeply due to many conflicting obligations and families feeling they have received enough education. Therefore, having enough time to educate yet not overburden families already burdened is a fine line that will be unique to each site where an intervention is located. Organizations should establish reasonable timeline expectations.
2. A one-year long intervention may not be necessary for most families to meet the intervention goals. Sites that continued the intervention after ICAI funding ceased reduced the duration of the intervention to less than one year.
3. Using families who had completed the protocol as greeters or spokespersons for the ICAI proved successful in dealing with other families still involved in the project. This might be a useful approach to promote continued interest and participation in a project.

Sample forms for data collection and tracking follow up with families are found at this link.

Role of the Asthma Counselor in Core and Follow-up

Asthma counselors recognize that each family has unique combinations of problems and stressors that affect their daily lives of which asthma care may or may not be a priority. Therefore, reducing home and environmental stressors would increase a family's competency and attention to daily asthma care. Typically, these stressors had little or nothing to do with asthma. Most often they had to do with housing, employment, transportation, access to health care, language barriers, poverty, mental health issues or interpersonal relationships.

It is important to see the process as family-centered rather than the focus being solely on medical care. Many patients were labeled as "non-compliant" by physicians and their staff for using the emergency room for their primary asthma care, using emergency medication for daily use and for being continual no-shows for scheduled appointments. In fact, most families were not aware that asthma is a chronic disease that requires multifaceted attention. Asthma is present not just when an exacerbation is occurring.

When asthma counselors establish trust with families it allows the families and the asthma counselors to work together to develop problem-solving skills, and enables the family to work together toward a goal of asthma control.

SECTION VII: ORGANIZATIONAL READINESS QUESTIONNAIRE

The purpose of this questionnaire is to:

- provide a framework for your organization to think through the issues involved in initiating a pediatric asthma program,
- help you identify organizational characteristics required for the implementation of an asthma program, and
- help your organization make an informed decision on whether or not to pursue programming efforts similar to the implementation of the ICAI.

The questionnaire is derived largely from information and lessons learned from the ICAI. It is divided into sections on organization/setting, client base, intervention structure, asthma care, staffing, data and costs. There are questions for consideration under each section heading. It is not an exhaustive list of the issues that an organization will face in the design and implementation of an asthma program, but these questions are intended as a start.

I. Organization/Setting

The role and responsibility of health care organizations in addressing asthma will vary with the organization and its relationship to communities, families, and patients. In implementing an asthma program similar to the ICAI, it is very important to recognize and keep in mind that different components of the program will be affected by structure, purpose, and organization dynamics found in the organization implementing the program.

A. Implementing Organization Characteristics

1. What type of organization/institution is considering a pediatric asthma intervention?

2. Based on the lessons learned:

   a. What are the advantages of this setting?
   b. What are the potential barriers of this setting?
   c. How might you overcome these challenges?

B. Organizational Decision-making

1. How does your organization make decisions about initiating program efforts, e.g., a childhood asthma program similar to the ICAI?

   a. What/who are the drivers of decisions?
   b. What criteria will the decision makers use?

2. How do you plan to seek approval for the program? Key steps in the process include:

a. Proposal development
b. Project definition
c. Presentation/discussion including budget
d. Decision meeting

3. Which staff member(s) and/or departments might serve as champion of the program to administration, physicians and other decision makers?

C. Internal Coordination

1. List the internal departments that would contribute to intervention implementation

_____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

2. Of these, which ones might serve on an internal planning committee for the program?

_____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

3. Will a program of intervention conflict with other programs in your organization? How will you deal with that?

D. External Coordination

1. Would the organization need to establish partnerships to deliver services? What organizations would be good external partners/stakeholders?

Potential Partners	Services to contribute
_____	_____
_____	_____

_____ _____

_____ _____

2. How will you approach them?

E. Provider communication

1. How does your organization normally communicate with providers?

2. Are systems in place that would allow providers to communicate to an asthma counselor about the completion of performance activities, such as skin testing, or development of an asthma action plan?

3. Are additional communication mechanisms needed to support an asthma management intervention in your organization?

II. Client Base

In the ICAI, achieving and maintaining specific enrollment levels was often difficult. The number of clients to be served will affect every aspect of planning and implementing an intervention.

A. Client/Patient Volume

1. Is there an identified set of patients who need this service? How many do you seek to enroll?

   a. Already being served by your organization or its partners?
   b. In the community?

2. What data have been/would be used to identify and locate potential clients?

3. What are the outreach strategies to potential intervention participants?

   a. Within your organization?
   b. In the broader community?

B. Project Population Needs and Assistance

1. What are the health needs of the project's target population?

   a. Asthma?
   b. Other?

2. Are there other needs to address for participating families?

a. Food or childcare during meetings?
b. Transportation or parking assistance?
c. Home/environment needs?
d. School based needs?

3. Are there incentive items that the organization may secure for participants?

a. Prizes and gifts?
b. Air purifiers and other environmental supplies?
c. Gift certificates and monetary offerings?

III. Program Structure and Enrollment Criteria

The ICAI had fairly rigid structure and criteria. Children enrolled were primarily minorities age 5-11, with the required severity of asthma, for a year-long program. Many organizations would have preferred to expand the criteria in a variety of ways. Also, most team members agreed that the intervention, based on the needs of the families, could have been accomplished in less than a year's time. Enrollment, via in-reach or outreach, was generally a function of the asthma counselor, but some sites were fortunate to have outreach and referral support from the organization's marketing department.

1. What would the criteria be for this intervention?

a. Age of children?
b. Asthma severity?
c. Intervention duration/length of participation?
d. Session attendance (via phone, face-to-face contact or both)?

2. What are the avenues of patient access for the intervention?

a. Internal to your organization, e.g., asthma clinics, emergency room, or health plan enrollment?
b. External to your organization, e.g., community referral?

3. Would the intervention program structure affect current policies and procedures? How would you address any problems?

IV. Asthma Care: Coverage, Access, and Standards

It is nearly impossible to conduct an effective intervention without access to health and pharmaceutical care. Many families, unfamiliar with asthma management, cared for their asthmatic child with rescue medication and unscheduled doctor visits. The ICAI intervention helped caretakers and patients understand the patient's asthma triggers and allergies, how individual symptoms progress, the appropriate use of medications, and the need for regular doctor's visits. Using the NHLBI guidelines as a basis for asthma care, assures care at the level required for most asthmatic patients to maintain a good quality of life.

A. Medical Coverage

1. Do the children with asthma who would be included in the proposed program have medical coverage?

2. Does the coverage include prescription drug coverage?

3. Is the proposed program open to the uninsured?

4. How would patients that do not have medical coverage obtain needed medication?

5. Is there a way for the organization to assist the uninsured?

6. What are the options for obtaining assistance for potential enrollees?

   a. Medicaid?
   b. Other state insurance?
   c. Other options?

B. Standards of Care

1. Do patients have access to asthma care at the level included in the standards recommended by the National Heart Lung Blood Institute?

2. Are there systems in place to assure that patients receive physician care based on current asthma care standards?

3. What standard for asthma care would be used, if not the NHLBI guidelines?

4. Are systems in place to share information with providers on developments in standards of care?

V. Staffing

The close nature of the relationship between the asthma counselor and the family was an important factor in continuity and a family's continued participation in the project. Many of the ICAI tasks were based on the duties to be performed by the asthma counselor. During the ICAI, questions arose as to whether some or all of the asthma counselor duties needed to be performed by a MSW asthma counselor. A few sites employed a team concept with specially trained medical and/or non-MSW social workers in conjunction with the MSW position. Though the value of a central figure in the asthma counselor position cannot be over-emphasized, appropriate medical, social work and administrative support staffing freed the asthma counselor to complete the highly specific asthma intervention duties necessary to tailor the program to the families needs. Adequate staffing could streamline budget considerations and allow for the program to fit within other established asthma treatment programs at the organization.

1. What is the estimated level of effort required for:

   a. Physician, nurse or other health professional program manager/coordinator?
   b. Asthma Counselor?
   c. Administrative support?

2. How would the intervention staff be structured?

3. Are there medical personnel with the necessary expertise in asthma in your organization? If not, are there potential external partners with this expertise?

4. Would this organization employ an MSW asthma counselor?
   a. If not, who would function as the asthma counselor?
   b. Would more than one person share the duties?

5. Who would act in the role of physician, nurse or other health professional program manager/coordinator?

   a. Would they supervise the entire intervention?
   b. Would the program manager be a physician?
   c. Would an individual physician or group of physicians supervise the intervention?

6. How would the intervention be supported administratively?

7. Would the administrative support staff be dedicated solely to the intervention?

8. Are other staff persons available to assist with other social work, social service needs or referrals?

9. How would the staff be trained?

10. How would ongoing training occur to update staff?

11. How would information be communicated among staff members?

VI. Funding Your Intervention Project

The ICAI intervention was a fixed price contract. There was no performance-related payment component. The goal was wholly implementation. Neither CDC nor ACHP collected the cost and other data necessary to address cost effectiveness of the ICAI. However, in designing any program similar in structure to the ICAI it is important to identify costs and effectiveness measures. The kinds of questions listed below should be part of the planning and evaluation of the project.

1. What are the costs associated with the planning, implementation and operational activities?

2. Does your organization plan to cover all of these costs or will funds be needed/sought from other sources?

a. How might some of these costs be deferred?
b. Are there private or public funding sources to consider for support of the program?
c. Is it possible to receive state assistance or funding through grants or other sources?

VII. Data/Evaluation

Data and evaluation are important components of any project. There is a range of options in evaluation design, and implementing organizations should consider a strategy that is consistent with data collection capacities and commitment. Ability to collect, process and evaluate program data should not deter an organization from considering a program of intervention. It is critical to specify at the outset how the project's success will be measured. The extent to which the project is a demonstrable success will affect its continued support within the implementing organization and within the larger community as well.

A. Evaluation

1. What is your evaluation plan/goal for the project? Can you specify the evaluative variables and data requirements?

2. With process and outcome measures to consider, how do you plan to measure project success?

3. What is your plan for assessing the cost effectiveness of the project?

4. What interim measures could be used to evaluate the program?

B. Data Sources and Collection Processes

1. What data elements will you need?

2. What means will be used to capture data?

3. What are the potential sources of data (i.e., claims, reimbursement, encounter, roster, other administrative databases, and survey data)? Will your organization be able to provide these data?

4. Would you need to change existing data systems to enable collection of these data?

5. Would you need to develop new forms/processes? Are there costs associated with these changes?

6. Is there a database or spreadsheet program available for collection, tracking and calculation of needed outcome and process data?

7. Is there a qualified person to be responsible for the information technology issues included in current staff? If not what is the plan to address any IT issues?

C. Personal Health Protections and Data Concerns

1. How do you plan to assure HIPAA compliance?

2. Are the existing IRB approvals adequate?

3. Will your data collection and other project activities require new IRB approval?

SECTION VIII: SAMPLE DOCUMENTS AND MATERIALS

Sites developed a number of different approaches to the ICAI intervention. Descriptive materials, data forms, outreach and buy-in efforts, and other aspects of implementation were generally site specific. Some of the documents and materials used at the sites may be helpful to organizations contemplating development of an asthma management project. The sample documents and materials described below are available at this link.

1. Physician, Organization, and Community Buy-in

A. Community Buy-in Brochure: This is an excellent example of how an organization participated in coordinated regional care in their Massachusetts community. Families were better able to access care and providers were able to coordinate care for chronically ill children through a statewide program.

B. Physician Buy-in Letter: This site developed a series of letters to engage the patient's primary care physician (PCP) in the intervention and to promote teamwork. The three sampled below demonstrate the site's commitment to buy-in:

- Notification Letter- The initial letter thanks the physician for referring the patient, reiterates the purpose of the program and reinforces the need to work together.
- Progress Report- Periodically, a progress report is placed in the patient's chart to keep the physician abreast of the areas that were reviewed, note possible issues or areas of concern, and patient improvements.
- Completion Letter- The final letter is sent to the PCP upon the family's completion of the intervention. It discusses strengths and makes recommendation(s) to help promote compliance.

2. Outreach/ Marketing/Recruitment/Referral

A. Outreach Chart: This chart was designed by an asthma counselor to chronicle the outreach efforts made in the local community.

B. Outreach/Marketing Brochure: This brochure is colorful, informative and was placed in the offices of pediatric PCPs to inform their patients about the asthma program.

C. Marketing Brochure: This site had a significant Spanish-speaking client base, so they designed their brochure to accordion fold into a two-page English/Spanish pamphlet.

D. Referral Form: This general referral form was used to capture in-house recruitment/referrals and track where they originated. The form the gathers basic information needed to determine patient eligibility and contact the patient/family.

3. Risk Assessment

Child Asthma Risk Assessment Tool (CARAT): The CARAT format was developed by NCICAS designers to be used as the standardized tool to identify four problem areas that might require intervention: access to primary care for asthma, adherence, behavior, and environment.

4. Enrollment

A. Enrollment Letter: This notice was sent to newly recruited families. Its purpose was to share contact information, reinforce topics discussed at enrollment and to inform the families of when and where they were scheduled to attend sessions. Included with this letter was a map of the site and room location where group sessions were held.

B. Recruitment letter: This letter was used to contact families newly recruited into the intervention. English and Spanish versions were made available to provide a reminder to the family of their commitment to participate in the intervention, send a message of encouragement and provide contact information.

C. Enrollment Agreement: This form letter gives families all the basic information about the program, their responsibilities, the time commitment required, and calls for them to sign an agreement to show that they are willing to participate.

5. Asthma Action Plans

A. Asthma Plans, Statewide Coordination: The Commonwealth of Massachusetts makes statewide templates available for asthma management plans in English*, Spanish*, Portuguese, Haitian, Creole, Russian*, Chinese, Khmer and Vietnamese* based on NIH guidelines (*= sample included).

B. Asthma Plans, Bilingual English/Spanish: This is an example of another asthma plan template available in English and Spanish. It differs slightly from the previous format, but conveys all of the important asthma management information.

C. Student Asthma Form: This form was developed by the Asthma and Allergy Foundation of America. It was shared with the families to help support the child with asthma by organizing pertinent information about the child's asthma needs and how to manage the condition for the school setting.

6. Intervention Follow-up/Data Collection

A. Follow-up & Data Form: This site created forms that were the basis for uniform follow-up and data collection.

- Health Survey- Collected a variety of medical information from the family on a monthly basis. The form allows for explanation of reasons for progress or lack of progress, and valuable information about a family.
- Participant Satisfaction form- Post enrollment questions that helped determine areas for improvement in the program and quantify improvement the child and family's management of asthma from their perspective.

B. Data Collection Forms: These forms were all geared to data collection and are examples of forms that work on multiple-levels. They helped the asthma counselor track the family's progress, updated file information and collected useful data for future needs.

- Intake form- Used to collect needed information at enrollment.
- Monthly Session form- Addressed uniform follow-up for each child and family, tracked progress in managing the child's asthma and is set-up for convenient data retrieval and entry.
- Project Completion form- Used to track patient progress and to assemble follow-up information.

C. Participation Inquiry Letter: This form letter was used to inquire about a family's interest in continuing their participation in the intervention.

7. Program Management

ICAI Policy and Procedure Manual: This asthma team created a formal policy and procedure manual for the asthma program. Excerpts from the manual include the Table of Contents, a list of folders and descriptions, the marketing and outreach approach and guidelines for dealing with referrals.

The Alliance of Community Health Plans would like to thank the asthma counselors, program managers and administrative support persons who created these useful examples.

- American Lung Association of MN, St. Paul, MN
- Baystate Medical Center Children's Hospital, Springfield, MA
- CareOregon, Portland, OR
- Children's Asthma Consortium, Long Beach, CA
- Children's Hospital of NJ at Newark Beth Israel Medical Center, Newark, NJ
- Children's Mercy Hospital, Kansas City, MO
- John J. Stroger, Jr Hospital of Cook County, Chicago, IL
- Montefiore Medical Center, Bronx, NY
- Mt. Sinai Hospital, New York, NY
- University of TX Health Science Center, San Antonio, TX

APPENDICES

- About Asthma
- References & Links
- Glossary
- Site List

ABOUT ASTHMA

Asthma is an obstructive inflammatory disorder of the airways in which episodes of wheezing, shortness of breath or difficulty breathing, chest tightness and coughing occur.

During an asthma episode. Asthma is characterized by persistent inflammation, and made worse by various stimuli. It results in airway narrowing, extreme bronchial sensitivity and reaction (bronchial hyper-responsiveness) and a decrease in the lung's ability to function properly (a decrease in lung functioning). Bronchial hyper-responsiveness is when the bronchial tubes, two main branches of the trachea, leading directly to the lungs, are extremely sensitive and reactive to any stimulus.

Airway obstruction is variable and reversible, spontaneously and with treatment. It is related to the inflammatory reaction via swelling of the smooth muscle (bronchial wall), acute bronchoconstriction (quick spasmodic narrowing of the airway or quick spasms that narrow the airway), chronic mucus plug formation (the forming and thickening of mucus, and airway remodeling. Airway remodeling, a change and limitation of airflow to the lungs, may cause damage resulting from chronic severe asthmatic episodes.

During an asthma attack, the airway narrows making the flow of air difficult, leading to one or more of the episodic symptoms. With the addition of obstructive and inflammatory elements, airflow is further reduced and labored.

Stimuli associated with asthmatic episodes are labeled 'triggers' because they trigger an asthmatic response and/or cause an asthmatic response to become more severe. The stimuli that can trigger asthma episodes are just as varied.

How do triggers function? Substances that cause an allergic reaction are known as allergens. Inhaled allergens affect 60-90 percent of children with asthma. These are things like animal dander or mold. Irritants are environmental problems that can trigger an asthmatic response. Tobacco smoke, fumes from cleaning supplies and even viral infections are some examples.

Inhalant triggers are potentially controllable because the home is the place of highest contact for the asthmatic patient. Environmental and other triggers are significantly more difficult to control; they surround us and are in the air we breathe daily.

Understanding asthma episodes. Asthmatic episodes are variable in occurrence, intensity, seasons in which they take place, level of physical exertion and evening or sleep patterns. The most severe asthmatics have a higher number of asthma episodes and more unexpected symptoms, chronically, throughout the year--not just during specific seasons. They may be triggered while at rest, during physical activity, and have symptoms that interfere with sleep. Severity depends upon accurately assessing the asthmatic episodes and pertains to the characteristics of episodes over time, not a single episode. Categories of severity are mild intermittent, mild persistent, moderate persistent and severe.

Types of medication. There are three basic categories of medication to treat asthma: emergency, long term maintenance and allergy reduction. Pharmacotherapy utilizes quick relief medication to relieve episodic symptoms when they occur. Short-acting beta-agonists are used for immediate relief of episodic asthmatic symptoms, but only for a short time. All asthmatics regardless of severity utilize this type of medication, because episodes can happen at anytime. Long-term control maintenance medications reduce inflammation and bronchial constriction of the airway daily. Long term or daily control medications help to manage the underlying causes, like treating the inflammation. They contribute to more lasting stability in asthma treatment. Allergen reducing medication lessens the affects triggers have on the respiratory system. The type of medication used depends upon the severity of the episodes and symptoms displayed.

The allergy connection. It is not uncommon for children to have allergies and the source of the allergic reaction not be known. Skin testing, for children with persistent or more severe asthma, aids in the diagnosis of triggers that contribute to asthma severity. Skin testing allows appropriate recommendations to be made to the patient and/or family regarding trigger control. Acceptable forms of allergen testing are prick (precutaneous), puncture (subcutaneous) and blood (radioallergosorbent-RAST) testing.

Pulmonary function testing. Pulmonary function testing (PFT) measures lung function and assesses airflow limitation by measuring different aspects of how the asthma patient is breathing. Two devices used to test pulmonary function are the spirometer and peak flow meter.

Physicians use a spirometer to measure pulmonary function. A patient expels all the air from her or his lungs in one breath. After the initial breath is assessed, a short-acting inhaled beta-agonist is administered and then a second breath is measured to determine if the beta agonist reverses airway obstruction.

A peak flow meter is an asthma-monitoring device is intended for the patient's daily use and monitoring. A peak flow meter is small, hand held, often plastic and non-electronic. The asthma patient blows into the apparatus and the meter measures the force of the breath. A higher measure means better lung function at the time the patient is being monitored.

Appropriate asthma care. Proper diagnosis of asthma combined with medical care, and continuing treatment, and appropriate prescribed drugs can help patients, especially children, control their asthma and lead an active life. A person with an asthma diagnosis should have a personalized asthma action plan written by a physician for home reference.

An action plan documents the diagnosis, the severity of the asthma, the drugs prescribed and emergency steps to be taken in case of an asthma attack. It ensures that the physician and patient/family are on the same page with regard to asthma care and treatment. Typically, an action plan takes into account the patient's best peak flow number and noticeable symptoms and uses them to determine if the patient is in a 'good, caution, or danger zone'.

Zone readings. A ‘good zone’ means peak flow numbers are normal--take medications as directed. A ‘caution zone’ indicates symptoms are on the rise and peak flow numbers are lower than normal--extra medication might be warranted to raise lung functioning back to normal. In the ‘danger zone’ peak flow numbers are extremely low, symptoms are acute--emergency medication is needed and physician intervention might be warranted.

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Evidence-Based Community Pediatrics: Building a Bridge from Bedside to Neighborhood L Sanders, T Robinson, L Forster, K Plax, J Brosco and A Brito, Pediatrics 2005;115;1142-1147, DOI: 10.1542/peds.2004-2825H

Allergy & Asthma Network Mothers of Asthmatics
Website: www.aanma.org

Allergy and Asthma Foundation of America (AAFA)
Website: www.aafa.org/

American Academy of Allergy, Asthma and Immunology (AAAAI)
Website: www.aaaai.org/

American College of Allergy, Asthma & Immunology
Website: www.acaai.org

American Lung Association (ALA)
Website: www.lungusa.org

American Thoracic Society (ATS)
Website: www.thoracic.org

Annals of Allergy, Asthma and Immunology
Website: www.annallergy.org

Centers for Disease Control and Prevention (CDC)
Website: www.cdc.gov

Centers for Disease Control and Prevention/National Center for Environmental Health
Website: www.cdc.gov/nceh/

Community Health Works
Website: www.communityhealthworks.org

Consortium on Children's Asthma Camps
Website: www.asthmacamps.org

Environmental Protection Agency (EPA)
Website: www.epa.gov/iaq/asthma

Massachusetts Health Promotion Clearinghouse
Website: www.maclearinghouse.com

National Assembly on School-Based Health Care
Website: www.nasbhc.org

National Asthma Educator Certification Board
Website: www.naecb.org

National Institutes of Health (NIH)
Website: www.nih.gov

National Heart, Lung, and Blood Institute (NHLBI)
Website: http://www.nhlbi.nih.gov/

National Institute of Allergy and Infectious Diseases
Website: www.niaid.nih.gov

Pediatrics- Official Journal of the American Academy of Pediatrics
Website: http://pediatrics.aappublications.org/

Starlight, Starbright Children's Foundation
Website: www.starbright.org

Zap Asthma Simulation
Website: www.peachtreelearning.com

GLOSSARY

Many terms are used to describe asthma and related information. This glossary defines those terms that are likely used most often within the context of the ICAI and asthma programming efforts in general.

acute
The abrupt onset of illness or symptoms in reference to disease. Acute often also connotes an illness that is of short duration, rapidly progressive, and in need of urgent care. Acute, as it relates to asthma, generally refers to the sudden onset of symptoms (see asthma attack).

airway
The path air follows to get into and out of the lungs. Air enters and exits through the nose and mouth, then passes through the back of the throat, and finally out of the branching tubes known as bronchi.

airway remodeling
Changes in the structure of the airways of the lungs may occur with chronic inflammation. These changes may be permanent, and may not improve even with treatment. Changes may occur even in patients with mild asthma.

airway responsiveness
The process by which the airways respond to various triggers (see asthma triggers), at times resulting in narrowing of the airway. Increased airway responsiveness is a main component of asthma.

allergen
A substance that is foreign to the body which causes the person's own antibodies to attack the foreign substance.

allergic reaction
The production of antibodies by the body in response to "foreign" substances (i.e., substances not normally present in a specific body organ).

allergist
A physician who specializes in the diagnosis and treatment of allergies. While all doctors may treat allergies, an allergist is typically the most up-to-date on allergy treatments.

allergy
An abnormal reaction of the body to contact, via various means, with a foreign substance. Asthma is most often associated with allergies to things inhaled.

Alliance of Community Health Plans (ACHP)

The contracting organization selected by the Centers for Disease Control and Prevention to oversee the Inner-city Asthma Intervention. ACHP is a leadership organization that brings together innovative health plans and provider organizations that are among America's best at delivering affordable, high-quality coverage and care to their communities. More information is available at www.achp.org.

alveoli

Tiny air sacs in the lungs where oxygen and carbon dioxide are exchanged.

animal dander

Small scales from the skin, hair, fur or feathers of an animal, often causing an allergic reaction in sensitive individuals. Animal products such as dander, hair, scales, fur, saliva, and body wastes contain powerful allergens that can cause respiratory and other disorders.

antibody

A specialized immune protein produced because of the introduction of an antigen (a substance that is capable of causing the production of an antibody) into the body, which possesses the ability to combine with the antigen that triggered its initial production. The production of antibodies is a major function of the immune system. Antibodies can be triggered by and directed at foreign proteins, microorganisms, or toxins. The presence of certain antibodies, in infants and children, is significantly predictive of asthma.

asthma

Asthma is a chronic condition with two main components: airway obstruction (constriction)—the tightening of the muscles around the airways, and inflammation—the swelling of the airways and airway responsiveness to stimuli. Both the constriction and the inflammation cause narrowing of the airways, which may result in asthma symptoms such as wheezing, coughing, excess mucus production, chest tightness, or shortness of breath. Inflammation of the airways is the common finding in all asthma patients. Each individual suffers a different level of severity. Most common in childhood, asthma affects all age groups. The causes of asthma have been linked to heredity, obesity and many environmental factors. Asthma may or may not be related to allergies, though the resulting symptoms are the same. Asthma cannot be cured, but the positive outcome is that almost all asthma can be controlled.

asthma attack

The occurrence of asthma symptoms such as wheezing, coughing, chest tightness, or shortness of breath suddenly become more severe, more frequent, or both. They are also called asthma flare-ups or asthma episodes.

asthma counselor (AC)

In the ICAI, an asthma counselor was a full-time, masters-level social worker responsible for conducting the implementation protocol, working directly with children with asthma,

their family and physician, and to tailor the intervention based on the needs of the client. They were responsible for enrollment and retention efforts, directing all group and individual sessions and assuring the quality and completeness of required data.

asthma management

A means of assisting asthma patients and their families to control asthma by increasing their knowledge and comfort level in making decision about asthma triggers, symptoms, care and treatment.

asthma medications

There are three basic types of medication for asthma, long-term preventive medication-taken every day to control asthma, not intended for quick relief; steroidal compounds used to stabilize lung function, and rescue or quick-relief medications that provide immediate relief in cases of sudden asthma attack.

asthma severity

Asthma is categorized according to severity of day and nighttime symptoms, lung function, and the need for the use of rescue medication. The classifications are: mild intermittent, mild persistent, moderate persistent, and severe persistent. Regardless of the classification, any single asthma episode can range from mild to severe.

asthma trigger (trigger)

A substance or situation that causes an asthmatic reaction is known as a trigger. Allergies, viral/bacterial infections and sensitivity to irritants can make asthma worse and often incite an asthma attack. There are many asthma triggers and these triggers vary among patients. Some common asthma triggers are: dust, pollen, animal dander, breathing cold air, exertion, reactions to foods or medications, chemicals fumes and cigarette smoke.

asthmatic response

This refers to the entire process the person with asthma experiences from symptoms, through asthma attacks and recovery. It is designated by either early asthmatic response (EAR) or late asthmatic response depending on the severity of symptoms.

bronchial hyper-responsiveness

An exaggerated airway narrowing in response to a wide range of stimuli such as allergens viruses, smoke and other pollutants, otherwise known as "twitchy airways." It is one factor used in diagnosing asthma.

bronchial tubes (bronchi)

The airways into the lungs that branch out from the windpipe, then divide into many smaller branches.

bronchial wall/smooth muscle
The wall of the bronchial tubes is made up of different layers: The outer layer is muscle and cartilage. The muscular tone of this layer determines how wide or narrow the bronchial tube passageway is. The inner layer of the bronchial tubes is lined with mucous membranes that secrete mucus, which coats the inside of these breathing tubes to protect and clean the bronchial passageways.

bronchioles
The smallest airways in the lungs.

bronchoconstriction
This occurs when the muscles that wrap the airways constrict, pinching the airways closed, also referred to as bronchospasm. This tightening of the muscles occurs in asthma.

bronchospasm
An abnormal contraction of the smooth muscle of the bronchi, resulting in an acute narrowing and obstruction of the respiratory airway. Bronchospasm is a chief characteristic of asthma and bronchitis.

Centers for Disease Control and Prevention
The Centers for Disease Control and Prevention (CDC) is one of the 13 major operating components of the Department of Health and Human Services (HHS), which is the principal agency in the United States government for protecting the health and safety of all Americans.

chronic obstructive airway disorders
A general term that encompasses chronic obstructive pulmonary disease, chronic bronchitis, emphysema and asthma.

chronic illness
A condition that is long lasting and requires management on a long-term basis.

compliance
Following the treatment plan a health care professional has outlined. A treatment plan may include medicine, diet, and exercise.

diagnosis
The act or process of identifying or determining the nature and cause of a disease or injury through evaluation of patient history, physical examination, and review of laboratory data or the opinion derived from such an evaluation.

disease management
System of coordinated health care interventions and communications for populations with conditions where patient self care efforts are significant.

dust mites
Microscopic insects invisible to the naked eye that feed on human skin flakes. Dust mites are found in mattresses, pillows, carpets, upholstered furniture, bedcovers, clothes, stuffed toys and fabric and fabric-covered items. Body parts and feces from dust mites can trigger asthma in individuals with allergic reactions to dust mites.

environmental triggers
Indoor or outdoor substances in the immediate environment of the person with asthma that incites an asthma attack or worsens symptoms.

fast-acting inhaler
Asthma medication that provides immediate relief of sudden asthma symptoms. It is also called rescue or quick-relief medication.

Health Insurance Portability and Accountability Act (HIPAA)
Health Insurance Portability and Accountability Act of 1996 (HIPAA, Title II) required the Department of Health and Human Services (HHS) to establish national standards for electronic health care transactions and national identifiers for providers, health plans, and employers. It also addresses the security and privacy of health data.

hyperventilation
An excessive rate and depth of respiration leading to abnormal loss of carbon dioxide from the blood.

inflammation
The body's response to injury. In asthma, inflammation is present even when the person with asthma is asymptomatic. Inflammation of the airways makes breathing difficult.

inhaler
A handheld device that delivers medication directly to the lungs.

Inner City Asthma Intervention (ICAI)
A multi-year, multi-site project to implement the NCICAS (see below) research study in 'real world' settings. In the Fall of 2000, the National Center for Environmental Health, Air Pollution and Respiratory Diseases Branch of the Centers for Disease Control and Prevention (CDC) awarded the Alliance of Community Health Plans a contract to implement and manage the project.

intervention
The act or fact or a method of interfering with the outcome or course especially of a condition or process (as to prevent harm or improve functioning).

medical plan (asthma action plan)
A written set of directions or a chart that helps an individual or family manage asthma whether or not the person with asthma is currently experiencing any symptoms. Ideally, a customized document created jointly by the patient or caretaker and the health care provider.

metered dose inhaler
A device that helps to deliver a specific amount of medication to the lungs. Each inhaler consists of a pressurized canister of medication and a mouthpiece. It is commonly used to treat asthma.

mold
A type of fungus that makes spores that float in the air like pollen and often attach themselves to surfaces. Mold is found in damp areas, such as the basement or bathroom, as well as outdoors in grass, leaf piles, hay, and mulch. It is a common trigger for allergies.

mucus (phlegm)
The wet, sticky, substance produced by certain cells lining different parts of the body. In asthma, there is often too much mucus produced by the cells lining the airways; this is a direct result of the inflammation that is present.

National Cooperative Inner-City Asthma Study (NCICAS)
The NCICAS was a multi-faceted, multi-modal intervention designed to address the stresses encountered by inner city families dealing with a child with asthma. Developers abstracted and utilized the best elements of previously tested interventions, added and expanded features proven to be successful in assisting families of children with asthma. The NCICAS demonstrated that an individually tailored intervention using masters-level social workers (MSW) trained in asthma management could reduce asthma symptoms among children in the inner city.

National Heart, Lung, Blood Institute (NHLBI)
One of the National Institutes of Health (NIH), The National Heart, Lung, and Blood Institute (NHLBI) provides leadership for a national program in diseases of the heart, blood vessels, lung, and blood. The National Asthma Education and Prevention Program (NAEPP) is administered and coordinated by the NHLBI to address the growing problem of asthma in the United States. In 1997, a NAEPP expert panel established state-of-the-art, clinical practice guidelines for asthma diagnosis and treatment (Guidelines for the Diagnosis and Management of Asthma NIH Publication # 97-4051) used as the basis for asthma management for both the NCICAS and the ICAI. The guidelines were updated in 2002 (Update on Selected Topics 2002- NIH Publication # 20-5074).

nebulizer
A small, electrically powered machine that turns medicines into mists so that they can be breathed into the lungs.

peak flow
A measure of how hard and fast air can be blown out of the lungs. If asthma is under control and airways are open, the peak flow reading will be normal. If not, airways will be narrowed; and the peak flow reading is lower.

peak flow meter
A small, handheld device that measures the user's peak expiratory flow rate and displays the rate via various methods. Decreasing peak flow rates can indicate an impending asthma attack.

pollen
Microspores of seed plants carried by wind or insects prior to plant fertilization.

prevalence
The percentage of a population that is affected with a particular disease at a specific time.

preventive medicine/prevention
Preventive medicine is a proactive approach to health care. Medicine designed to avert and avoid disease; screening and treatment for health concerns before they cause disease.

program manager (project manager-PM)
In the ICAI, the PM was responsible for overall management of the project including training, supervising the intervention staff, assuring adherence to the defined protocol, and evaluating the project.

protocol
The detailed plan for a scientific or medical experiment, treatment, or procedure.

puff
Term used to describe the released medication resulting from each use (actuation) of a metered dose inhaler (MDI).

pulmonary function
The functional status of the lungs as it relates to: how much air volume can be moved in and out of the lungs, how fast the air in the lungs can be moved in and out, stiffness of the lungs and chest wall, and oxygen absorption. It is an important factor in asthma diagnosis.

pulmonologist
An internist specializing in treatment and diagnosis of conditions associated with the lungs and breathing. Pulmonologists may be board certified by the Board of Internal Medicine.

risk assessment
Highlights the presence of risk factors and estimates of the likelihood of challenges that may result from certain behavioral and environmental issues. Identifies problem areas that might effect compliance with an asthma treatment regimen. Also, defined as a standardized assessment tool.

risk factor
A risk factor increases the likelihood of getting a disease or condition. It is possible to develop asthma with or without risk factors. However, the more risk factors an individual possesses, the greater the likelihood of developing certain conditions.

spacer (inhaler spacer)
A holding chamber used with inhalers that increases ease of use and greatly increases the benefits and effectiveness of inhaled treatments.

spirometer (spirometry)
An instrument that measures pulmonary function. It helps assess the degree of airway obstruction and gas exchange. Spirometry determines the asthmatic response to drugs if tested before and after an inhaled bronchodilator is administered. A spirometer is often used by doctors when diagnosing asthma or at a check-up.

symptom
Subjective evidence of disease or physical disturbance observed by the patient. An indication of the presence of a physical disorder.

treatment regimen
A structured plan of care intended to promote health.

wheezing
A characteristic sound typically associated with asthma that indicates airway inflammation. A high-pitched whistling sound of air moving through narrowed airways.

zone system
A zone system is often used in asthma management to help the patient assess how well they are at a given time, based on lung function. Zone ranges are generally based on peak flow readings. There are usually three zones that extend from good to bad: green, yellow and red, respectively.

> **Green zone**-The range is usually between 100% and 80% of the asthma sufferer's personal best peak flow results. If peak flow measurements remain in the green zone asthma symptoms are under control.
> **Yellow zone-** The range is usually 80% to 50% of personal best peak flow result. If peak flow results fall into the yellow zone it means caution and may indicate that asthma symptoms are worsening.

Red zone- The red zone is when the peak flow rate is less than 50% of the asthma sufferer's personal best. If peak flow falls into the red zone it usually means asthma symptoms are very severe and immediate medical attention is needed.

INNER-CITY ASTHMA INTERVENTION SITE LIST

American Lung Association of Minnesota (ALAMN) has a long-standing commitment to and successful track record of providing education and support for children with asthma and their families. ALAMN offers a wide range of asthma education and support programs for people with asthma and their families and health professionals. The Inner-City Asthma Intervention program, known as The Family Asthma Program, in the Minneapolis- Saint Paul area operated between February 2001 and October 2004. The program was a partnership between the American Lung Association of Minnesota and four community clinics in two urban communities.

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Baystate Children's Hospital and its outpatient clinics, a part of Baystate Health Systems, have repeatedly been recognized as a well-managed and successful integrated network. Located in Springfield, Massachusetts, it serves as the Western New England Campus for Tuft's University Medical School. These facilities provide primary and specialty care, including inpatient asthma education, to a sizable segment of the low-income, minority population. The ICAI program is housed in the High Street Health Center Pediatrics, and serves children who reside in the Springfield Holyoke metropolitan area.

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Bronx Lebanon Hospital Center Pediatric Asthma Center builds on previous collaborative efforts between an academic institution and an inner-city not-for-profit hospital. The hospital and its outpatient clinics are located in the South Bronx and serve as pediatric teaching site for the Albert Einstein College of Medicine. This facility provides specialty asthma care to a sizable segment of the low-income, minority, often immigrant population. Full- time staff includes a pediatric-trained allergist and pulmonologist with access to pulmonary function testing and allergy skin testing, health education and social service support. The ICAI program is housed in the Pediatric

Asthma Center, which is the outpatient pediatric specialty clinic of Bronx Lebanon, and serves children who reside in the areas of the South and Central Bronx.

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CareOregon is a Medicaid managed care health plan. CareOregon, a not-for-profit organization, was built on a community partnership to care for the underserved. Initially, the health plan was a collaborative effort between a county health department, an academic center and a group of community health centers. CareOregon contracts with the State of Oregon to deliver care to over 100,000 members. Sixty percent of members reside in the Portland metro area with the remaining members residing in 13 of the state's 36 counties.

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The Children's Asthma Consortium of Southern California (SCCAC) was formed through the collaborative efforts of several Long Beach based organizations for the purpose of implementing the ICAI. SCCAC consists of the Asthma, Allergy, and Respiratory Care Medical Center (AARCMC), a medical group, AARCMC's non-profit subsidiary's two health plans, Universal Care and Molina Healthcare of California, the Foundation for Learning About Asthma and Respiratory Education (FLARE) and VONS pharmacy. Each of the participating organizations has long been committed to educating children and adults about living with asthma in the greater Long Beach Area.

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The Children's Clinic (TCC) *Serving Children and Their Families* is an independent non-profit 501 (c) (3) system of licensed community health centers dedicated to providing comprehensive health care in a culturally sensitive and linguistically appropriate manner to medically underserved, ethnically diverse, low-income populations in the greater Long Beach, California area. Founded by a group of physicians and community leaders in 1939, TCC's mission is to "partner with parents and the community to provide quality health care services and health education and promotion to needy children and families." TCC provides preventive, acute and chronic care for children, teens, and adults, as well as family planning, selected specialty care, immunizations, laboratory testing, prescribed medications, community outreach, health education and promotion, and chronic disease management for asthma, diabetes and obesity. Screening and linkage is also provided for families needing additional resources such as food, shelter, domestic violence counseling, mental health and other psychosocial services. In 2002, TCC was named a federally designated (330b) Community Health Center.

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Children's Hospital of NJ at Newark Beth Israel Medical Center is an affiliate of the St. Barnabas Health Care System, the largest integrated healthcare delivery system in the state of New Jersey. Newark Beth Israel Medical Center is a teaching hospital that provides innovative, comprehensive health care services to newborns and infants, young children, adolescents and teens in its local communities. It is the state's premier hospital caring for children. It has specialized services to treat ill and injured children, as well as preventive programs that promote wellness in the community.

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The Children's Mercy Hospital (CMH) is a leading institution in the care of underserved children in the Kansas City, Missouri area since 1895. The ICAI was housed in and supported by the Asthma, Allergy, and Immunology Section at CMH. The ICAI interacted cooperatively with The Kansas City Children's Asthma Management Program, which included asthma educators and disease case managers. Disease managers at CMH have created new models for improving asthma care to children for over a decade. With support from such organizations as the Center for Healthcare Strategies, the Robert Wood Johnson Foundation, HUD, the EPA and the CDC, these models have served in the Kansas City Community.

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El Rio Health Center, Inc. is a federally qualified health center (FQHC) that serves the medical needs of the underserved in Pima County, Arizona. The El Rio Asthma Program began with funding through the Inner City Asthma Intervention Program in 2001 and now is supported by private donations and grants. The Asthma Program provides intensive education and support services each year to 100 children with moderate or severe persistent asthma. Referrals come from 6 pediatric clinics, 2 family practice clinics, and a same-day appointment clinic within the El Rio Health Center. The Asthma Program works closely with the Arizona Respiratory Center at the University of Arizona to enroll patients in on-going clinical asthma investigations.

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Health Choice Network (HCN) is a community-based, not-for-profit organization formed and governed by a group of community health centers. Health Choice Network's member health centers operate more than 45 service sites in Miami-Dade, Broward, Less, Hendry and Pasco Counties. The centers provide high-quality, comprehensive primary and preventive care to low-income, underserved populations. The Pediatric Asthma Project was the first effort implemented under the Healthy Body, Healthy Soul initiative, a faith-based health program to increase access to health care and improve health in several predominantly minority communities. The Pediatric Asthma Project infrastructure provided the mechanism for outreach and an ideal environment for

implementation of the ICAI, based at the Helen B. Bentley Family Health Center (HBB) located in Coconut Grove, Florida, a HCN member agency.

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The Cook County Bureau of Health Services (CCBHS) is a public entity that provides health care for the low-income population residing in northeastern Illinois. The CCBHS includes John H. Stroger, Jr. Hospital of Cook County (Stroger Hospital, formerly Cook County Hospital), Provident Hospital, and the Cook County Department of Public Health, among others. The CCBHS is the recipient of numerous asthma grants and contracts from public and private sources.

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Howard University/Hospital (HU/H) located in the heart of the Nation's Capitol, Washington, District of Columbia. It is one of the eight research sites for the NCICAS intervention and has longstanding asthma expertise and experience in medical management, clinical trials, basic research, and patient and physician interventions. HU/H serves a predominately indigent population and has a history of providing pediatric asthma outreach. Howard ended participation in the ICAI prior to the end of the implementation in 2004.

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Jackson-Hinds Comprehensive Health Center (JHCHC) provides a comprehensive program of primary health care and dental services to residents of the targeted inner-city census tracts at four sites within the city of Jackson, Mississippi. JHCHC maintains linkages with hospital and physicians in the City of Jackson and Hinds County for inpatient hospitalization, emergency care and specialty referrals. JHCHC boasts nearly three decades of experience in development and implementation of effective clinical services and health education programs for low-income and indigent populations.

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Johns Hopkins Community Physicians (JHCP) is a primary care, community based, group practice in Maryland. JHCP is separate from the Johns Hopkins University and receives no university funding for its primary care activities. JHCP operates nineteen primary care practices and is a major provider of health care to Medicaid, underinsured, and uninsured patients. Within the JHCP is a group of five urban community practices whose primary mission is to provide high quality medical care to several poor, urban communities in East Baltimore. JHCP ended participation in the ICAI prior to the end of the implementation in 2004.

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Montefiore Medical Center is located in the Bronx, New York, a borough of New York City, with 1.3 million people. It serves a predominantly low-income, Black and Latino population. Asthma is the leading diagnosis for children cared for throughout the medical center and hospitalized at The Children's Hospital at Montefiore (CHAM). Montefiore's Ambulatory Care Network consists of 35 community-based sites which together care for 250,000 pediatric visits each year. The ICAI program was housed at the Comprehensive Family Care Center (CFCC), the largest pediatric ambulatory care site in the network and the main ambulatory teaching site for residents. Montefiore is the university hospital of the Albert Einstein College of Medicine.

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Mount Sinai School of Medicine/ Pediatric Pulmonary and Critical Care Division /City Hospital Center at Elmhurst; Queens Hospital Medical Center - New York, New York, the two hospitals and outpatient clinics located in Queens, are teaching affiliates of the Mount Sinai School of Medicine. Both are part of the municipal hospital system of New York City. The hospitals provide comprehensive primary and specialty care. They serve an ethnically diverse, predominantly low SES, inner city population from Queens. The ICAI programs at the two hospitals were based in the pediatric outpatient Chest Clinics and were staffed by physicians from the Pediatric Pulmonary Division at Mount Sinai and the Allergy clinic at Elmhurst.

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Mount Sinai Medical Center/ Divisions of General Pediatrics and Pediatric Pulmonary and Critical Care- New York, New York, the hospital and outpatient clinics are located in East Harlem, are the main pediatric teaching sites for Mount Sinai School of Medicine. Mount Sinai, a voluntary teaching hospital, provides comprehensive primary and specialty care and serves a predominantly low SES, minority inner-city population from East and Central Harlem, as well as the South Bronx. These neighborhoods have the highest asthma pediatric hospitalization rates in New York City. The ICAI program is located in the general pediatric outpatient facility and is staffed through a collaboration of the Divisions of General Pediatrics, Pediatric Pulmonary Medicine and Social Work.

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Parkland Health & Hospital System Community Oriented Primary Care Centers (COPC) serves as the health care provider for the county of Dallas. Parkland's COPC network consists of eleven primary care centers located in low-income areas. The COPC improve access to care and contribute to community health by providing high quality, affordable and conveniently located medical care. The neighborhood-based health clinics are multidisciplinary and provide comprehensive health care to patients of all ages. Parkland ended participation in the ICAI prior to the end of the implementation in 2004.

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Rainbow Babies and Children's Hospital is a major teaching affiliate of Case Western Reserve School of Medicine and is a non-profit institution providing primary and specialty care to the children of Cleveland and Northeast Ohio. The ICAI center is located in Rainbow Babies and Children's Hospital and is housed in the Center for Chronic Conditions of Childhood, a facility designed to conduct clinical research and to provide community and hospital based interventions to children with diabetes and asthma. Our group has previously participated in the National Cooperative Inner City Asthma Study, other federal and local funded research and asthma intervention programs, and is currently a member of the NIH funded Inner City Asthma Consortium.

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St Joseph's Hospital & Medical Center in Phoenix, Arizona has a greater than 100 year of tradition as a not-for-profit, full-service, teaching hospital. It was founded by the Sisters of Mercy, historically dedicated to the mission of providing health care to the poor and those most in need, particularly children. It is a member of Catholic Healthcare West. The ICAI was based at St. Joseph's Children's Health Center, which provides a comprehensive range of hospital-based inpatient and outpatient services. St. Joseph's also offers to the community several specialized programs providing unique evaluation and treatment services to the at-risk child.

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The University of Alabama at Birmingham (UAB), Children's Hospital of Birmingham is a comprehensive urban university, adjacent to the city's central business district. UAB is committed to excellence in research, teaching, service, and community outreach. It is one of the top thirty universities in terms of federal funding for research and development. The Children's Health System (CHS) includes the primary teaching hospital for the Department of Pediatrics at the School of Medicine. CHS treats approximately 120,000 children each year in Alabama and the southeast, providing outpatient, inpatient, and specialty care. UAB Health Systems provides the region's most comprehensive health care services.

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University at Buffalo, State University of New York, The Women and Children's Hospital of Buffalo Allergy and Immunology Clinic, located in downtown Buffalo, housed the intervention and served as the main referral site. The ICAI was a collaborative effort supported by the Asthma Coalition of Western New York, a regional coalition to improve the health and wellness of children with asthma and their families. The hospital is in a Health Professional Shortage Area (HPSA) surrounded by African American and Latino neighborhoods and is the main pediatric training site for the University. UB's Department of Family Medicine took a leadership role in the project management of the intervention.

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University of Texas Health Science Center/CHRISTUS-Santa Rosa Children's Hospital Program in San Antonio, Texas builds on previous collaborative efforts between an academic institution and an inner-city, faith-based, not-for-profit children's hospital. The hospital and its outpatient clinics are located in downtown San Antonio

and serve as the major pediatric teaching site for the University. These facilities provide primary and specialty care, including inpatient asthma education, to a sizable segment of the low-income, minority population. The ICAI program is housed in the outpatient facility of the CSRCH, and serves children who reside in the San Antonio metropolitan area.

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WakeMed is the largest health system in Wake County, North Carolina. A major teaching site for the University of North Carolina School of Medicine, it is a recognized leader in children's medical care in the Research Triangle area of North Carolina. It is the primary hospital for the disadvantaged in Wake County, providing care to all persons regardless of their ability to pay.

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Washington University School of Medicine Division of Allergy and Immunology (WUSM) has been at the forefront in the study of asthma within the inner city. The division was one of the original sites participating in the NCICAS. WUSM conducted the ICAI in conjunction with Southern Illinois Health Foundation (SIHF), a not-for-profit dedicated to the care of children and adults residing within Southern Illinois' urban areas. The ICAI was based in Centerville, IL on the Touchette Regional Medical Center grounds, in one of the communities making up the area known as East St. Louis, one of the most economically depressed communities in the nation.

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Notes

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