

**Report on the  
Findings and Recommendations of the Pediatric Asthma Intervention  
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**Mount Sinai Hospital  
La Rabida Children's Hospital and Research Center**

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# Table of Contents

Background and Significance .....	3
Methods .....	8
Site Selection .....	8
Subject Recruitment .....	9
Training of Personnel .....	9
Study Design and Randomization .....	10
Case Management .....	11
Data Collection and Analysis .....	12
Statistical Analysis .....	15
Population Characteristics and Findings. ....	16
Enrollment and Attrition - Mt. Sinai .....	16
Enrollment and Attrition - La Rabida .....	17
Baseline Characteristics - Mt. Sinai .....	17
Baseline Characteristics - La Rabida .....	19
Collection of Baseline Data - Mt. Sinai .....	21
Health Education Session - Mt. Sinai .....	21
Monthly Follow-Ups - Mt. Sinai .....	21
Case Management - Mt. Sinai .....	22
Collection of Baseline Data - La Rabida .....	27
Health Education Session - La Rabida .....	27
Monthly Follow-Up -La Rabida .....	28
Case Management -La Rabida .....	28
Outcome Analysis .....	29
Cost Benefit Analysis .....	38
Cost benefit analysis – Mt Sinai .....	38
Impact of Study on Patients and Participating Institutions .....	40
Patients .....	40
Participating institutions .....	40
Recommendations .....	42
For other health care providers .....	42
For further research .....	43
For public policy .....	44
Conclusion .....	47
Study summary .....	47
Cost implications .....	49
Evaluation of study method .....	51
Dissemination of Program Results .....	53

School Program ..... 54  
References ..... 56

## **Background, Literature, and Need Statement**

Over 12 million people in the United States suffer from asthma, the majority of whom are young patients, most under the age of eighteen. In fact, asthma affects nearly 7% of children in the United States (Najada, Abu-Hasan, & Weinberger, 2001). Asthma morbidity and mortality are increasing at alarming rates for children living in inner city environments (Greineder, Loane, & Parks, 1999). Despite improved understanding of the pathophysiology of asthma, improved medications, and the implementation of the National Heart, Lung, and Blood Institute (NHLBI) Guidelines for Asthma Management the rate of children with asthma continues to rise (National Asthma Education Prevention Program Expert Panel Report 2 Guidelines, 1997).

Nowhere is the increase in childhood asthma more acutely felt than in the inner-city neighborhoods of Chicago. Chicago's rate of hospitalizations for asthma is 2.3 times higher than the national average (42.8 per 10,000 as compared to 19.5 per 10,000) (Thomas and Whitman, 1999). Mortality from asthma is among the highest in the nation for persons 5-34 years of age (Chicago Department of Public Health, 1998). Additionally, asthma is believed to have a significant impact on quality of life, lost wages, and medical costs (Evans, 1992).

In 1998, 6,418 patients with asthma were seen in the Sinai Health System (2,839 younger than 18 years of age); 1,487 visits were made to the emergency department (681 by children); 1,379 were hospitalized (396 were children), and 12,806 ambulatory visits occurred (4,808 by children). Asthma encounters at Sinai Health System have grown by 78% in the last five years (Sinai Health Systems, 2000). At La Rabida Children's Hospital and Research Center, there were 370 hospitalizations for asthma and approximately 2,500 outpatient asthma encounters in 1999 (La Rabida Children's Hospital and Research Center, 2000). It is not surprising in light of these statistics that the West and South sides of Chicago are at the epicenter of this exponential rise in childhood asthma.

Moreover, the costs associated with asthma are staggering. In 1990, the indirect and direct expenditures for asthma exceeded 6 billion dollars in the United States (Weiss, Gergen, & Hodgson, 1992). The Illinois Health Care Cost Containment Council estimates 1.4 billion dollars were spent in Illinois on the direct medical care expenditures for asthma (IHCCCC, 2002). Moreover, one study reported that \$2.28 is saved for every \$1 spent on asthma intervention programs (Creer, Backin, Burns, Cleary & Martin, 1988).

As part of this study we reviewed the relevant literature on asthma education. To date, there has been a plethora of literature surrounding asthma education but few studies have included case management as a component. Moreover, none of the literature compares the impact of case management with that of health education alone. Many studies have concluded that asthma education works. As such, it is not surprising that significant evidence exists suggesting that health education programs are effective in improving asthma management in children.

Six publications described the evaluation of intervention programs containing a group health education component (Lewis, et al, 1984; Hindi-Alexander, Cropp, 1984; Whitman, et al, 1985; Clark, et al, 1986; Shields, et al, 1990; Wilson, et al, 1996). While all but one of these studies reported results in support of the effectiveness of the intervention, there was significant variation between intervention groups with regard to the type of health education program utilized, its intensity and the targeted population. Further, all but two were conducted using white, middle class children.

The next set of articles that were reviewed included one-on-one, case specific health education as a part of their intervention (Fireman, et al, 1981; McNabb, et al, 1985; Mitchell, Ferguson & Norwood, 1986; Stout, et al, 1998; Kelly, et al, 2000; Kropfelter & Winkelstein, 1996; Greineder, Loane & Parks, 1999; Greineder, Loane & Parks, 1995; Hughes, et al, 1991; Wissow, et al, 1988). In all but one case (McNabb, et al, 1985), this health education was reinforced, meaning the components were periodically reviewed with the patient and/or caregiver. Six of these studies were conducted using urban, low income, primarily minority children, and all but one study (Mitchell, Ferguson & Norwood, 1986) reported results suggesting the intervention provided was effective in improving the management of asthma in the study group. The results of this review suggest that individualized, one-on-one asthma education is more effective than group education primarily in the most vulnerable of populations.

Seven studies published between 1988 and 2000 were located which used a model that loosely fit the definition of case management in children with asthma (Stout, et al, 1998; Kelly, et al, 2000; Kropfelter & Winkelstein, 1996; Greineder, Loane & Parks, 1999; Greineder, Loane & Parks, 1995; Hughes, et al, 1991; Wissow, et al, 1988). These seven studies were all included in the above discussion of reinforced, one-on-one asthma education as well, but in addition to patient education each made some additional attempt at helping patients/caregivers in the management of other aspects of their complex lives which might interfere with the optimal control of asthma. Examples of components of case management incorporated into some of these studies included arranging transportation to and from clinic visits, communicating with schools about a child's asthma control needs, assisting with housing issues and enrollment of caregivers in smoking cessation programs.

*Unfortunately, no study included a control group that received everything but the case management component, making it impossible to definitively ascertain whether an improvement in outcomes was attributable to case management or to some other aspect of the intervention design. Regardless, case management intuitively makes sense as a means of helping vulnerable populations plagued with a multitude of extenuating circumstances that may impede the proper control and management of children with asthma.*

Starting in the late 1970's asthma was managed on an acute basis with aerosolized respiratory treatments coupled with oral and or intravenous medications such as theophylline. These medications worked by bronchodilation but did nothing to reduce

inflammation. In the 1980's, as the pathophysiology of asthma was better understood and new drugs began to reach the market, the importance of controlling symptoms and improving lung function by inhibiting inflammation became the focus of treatment. Providing asthmatic patients alternatives to unpredictable and often detrimental exacerbations became the goal of treatment. While bronchodilators, referred to as rescue medications (e.g. albuterol) remained critical to reducing the acute effects of an asthma attack, the clear focus of asthma care became achieving and maintaining control of asthma symptoms by reducing inflammation. This approach prevents, rather than just treats, asthma attacks and thereby enhances the patient's quality of life, maintains optimal lung function and reduces the long-term complications due to chronic inflammation. With the advent of inhaled corticosteroids and leukotriene receptor antagonists, preventing asthma symptoms and exacerbations became a reality.

In an effort to improve asthma management, the National Asthma Education Program (NAEP) Expert Panel, sponsored by the NHLBI, published guidelines for the diagnosis and management of asthma in 1991. These guidelines emphasized the importance of the appropriate use of preventative (controller medications) and treatment (rescue medications) medication. These guidelines are considered the standard of care for asthma patients in the United States. Despite the availability of the NAEP practice guidelines, asthma treatment remains woefully inadequate due to the failure of healthcare providers and/or patients to follow them.

In 1997, the National Asthma Education Prevention Program Expert Panel Report II Guidelines described the four components necessary for an effective asthma management program. The fourth component emphasizes education and an active partnership with patients. This remains the cornerstone of asthma management. The plan for optimum care of pediatric asthma patients should incorporate frequent communication between the patient, their caregivers and their health care provider. Reduction of the disruptive effects of asthma on the patient and their family requires adherence to an asthma medical regimen. It also requires the ability of the patient and family to make appropriate judgements about a variety of daily activities believed to be important in the management of the disease and to self-adjust the patient's medications. This plan to self-adjust medications and activities on an as needed basis is referred to as an asthma action plan. This can only be achieved through careful education of the patient.

Despite the introduction of the NHLBI Guidelines in 1997, there are still wide discrepancies in the care pediatric asthma patients receive. Finkelstein et al (2002) reported that of 1,648 Medicaid insured pediatric patients, 73% reported underuse of controller medications. While the authors cited several reasons, lack of parental education, inadequate access to health care resources, and lack of an asthma action plan were all indicators of this widespread underuse of controller medications.

*Asthma continues to be a serious and growing problem not because clinical remedies to address asthma have not been found, but because the clinical solutions are not sufficient. What was and currently is still needed is patient and family education about asthma and its management, activities currently not supported by the financial reimbursement system.*

*Although several studies have examined the effect of education on the management of asthma, few have focused on health education and case management in underserved, urban areas. Health education is one way to increase the ability of patients to more effectively manage asthma. The failure to find literature combining case management and health education in pediatric asthma led us to this study.*

In 1999, Linda Miller, Vice-President of Care Management at Mount Sinai Hospital proposed a plan for education and outreach regarding asthma in the community. Her proposal was the foundation for what we know as the Pediatric Asthma Intervention.

The Department of Pediatrics at Mount Sinai Hospital in collaboration with La Rabida Children's Hospital and Research Center initiated this research study intended to assess the utility of case management in addition to one-on-one education, reinforced education, and case specific education in improving the health of inner-city children with asthma.

To this end, we sought to implement a plan that involved: evaluation by a subspecialist to determine appropriateness of asthma medical care and treatment, basic asthma education for all, enhanced and reinforced asthma education for one group, and enhanced and reinforced asthma education plus case management for another group.

This study utilized an integrative, collaborative model of asthma care including: identification, classification, assessment, treatment according to clinical practice guidelines, coordination of care, patient education, case management, tracking, and follow-up. Educating and training health educators from the community to further partner with the community in asthma identification, recognition, and intervention techniques was also a key component of this program.

The overall goals of the Pediatric Asthma Intervention were:

- Improvement of the health status of identified asthma patients.
- Improvement in the coordination of care for pediatric asthma patients on the West side and South side of Chicago.
- Reduction in subsequent emergency department visits among project participants.
- Reduction in hospitalizations among project participants.
- Cost savings resulting from reduction in hospital and emergency department visits.
- Participation of primary care physicians in appropriate asthma treatment, consultations, and education.
- Reduction in school/work days missed as a result of asthma.
- To demonstrate the value and cost-benefit of a model of care which integrates patient education and case management into the medical processes.
- To promote this model as a new standard in effective care and treatment of pediatric asthma patients.

*The hypothesis for the Pediatric Asthma Intervention study was: The most economical path to maximizing the health status of inner city children with asthma is through a process of reinforced health education combined with case management services. The*

*purpose of this project was to gather evidence that would support or contradict this hypothesis.*



## Intervention and Research Design

### Site Selection

Two sites were selected for this study. Originally founded in 1919 as a 60 bed hospital to serve needy Eastern European immigrants, Mount Sinai Hospital is now a 432 bed facility, and currently fulfills its mission in a community primarily comprised of African Americans and Latinos who are either unsponsored or publicly insured. The hospital and main campus is situated at the intersection of four Chicago area communities: the Near West Side, the Lower West Side, North Lawndale, and South Lawndale. In 1990, these four communities comprised less than 8% of the population of the city, yet accounted for more than 13% of city residents living below the federal poverty level. The median household income is \$4,000-14,000 dollars per year. Most of the pediatric population in this community receive Medicaid, are underinsured or lack insurance. Despite its deeply impoverished base, Sinai Health System remains committed to providing services for all in need of health care regardless of their ability to pay, ethnicity, gender, language, education or physical condition.

La Rabida Children's Hospital and Research Center was established in 1896 as "a place for the children of the poor living in crowded, unwholesome districts of the city". La Rabida has dedicated itself to excellence in caring for children with disabilities, chronic illnesses, or who have been abused. The 66 bed facility is located on the South East Side of Chicago. The majority of the population La Rabida serves is African American. This population is a combination of Medicaid and private insurance recipients.

Chicago has amongst the highest asthma related hospitalization rates, and mortality rates, in the country. Evidence has shown a clear association between poverty, race/ethnicity, and the inner city for asthma related prevalence and severity. We can conclude that the rate of asthma is high in the areas surrounding our two institutions and significantly affects the patients we serve.

*While both sites experience a high demand for asthma care and management, the sites chosen had basic inherent differences in care. While La Rabida and Mount Sinai have the same mission regarding care for all, La Rabida has resources more fully developed for pediatric asthma patients than Mount Sinai, especially in the area of case management. Furthermore, all of the study participants at La Rabida were established patients within their system, had been receiving asthma care and treatment by a pediatric pulmonologist, often for many years, and were receiving ongoing and long-term case management services from the team at La Rabida. Because of this, as well as insurmountable demographic differences between the two study populations, the data from Mount Sinai and La Rabida had to be analyzed separately and a comparison of the two data sets is not statistically possible.*

## **Subject Recruitment**

Patients with probable asthma diagnosis can be identified by utilization of services, self-report, or claims data analysis. There are no universal criteria consistently utilized to identify a patient with asthma. Although definitions have been published and guidelines written, primary care physicians and some specialty providers have been reluctant to label patients as having asthma due to concerns about their insurability. The result of this is an under-reporting of the disease (Clark, Feldman, Evans, Levinson, Wasilewski & Mellins, 1995).

Each of the participating hospitals served as a locus for patient identification and service delivery. Institutional review board approval was obtained for La Rabida, and Mount Sinai. Participant criteria included: ages 0-16, diagnosis of asthma, a willingness to participate, and informed written consent of the primary caregiver.

Participants for the study were recruited in several ways. Patients presenting in the clinic, in the emergency department, or in the inpatient units were asked to participate. Patients were then evaluated by a pediatric pulmonologist to determine asthma diagnosis and severity according to the National Heart, Lung, and Blood Institute Guidelines (NHLBI), appropriateness and effectiveness of the patient's current medical treatment, as well as appropriate eligibility for inclusion in the study. Patient's treatment plan was altered as needed by the pediatric pulmonologist upon entry into the study.

As per the NHLBI Guidelines, participants were classified as:

- Step 1, Mild Intermittent, with symptoms < 2 times per week, nighttime symptoms <2 times per month, patient is asymptomatic between exacerbations and exacerbations are brief, from a few hours to a few days with variable intensity.
- Step 2, Mild Persistent, with symptoms >2 times per week but <1 per day, exacerbations may affect activity, and the patient has nighttime symptoms >2 times per month.
- Step 3, Moderate Persistent, where the patient has daily symptoms, uses an inhaled short acting beta 2 agonist daily, exacerbations affect activity, exacerbations are >2 times per week and may last for days, the patient has nighttime symptoms >1 time per week.
- Step 4, Severe Persistent, the patient has continual symptoms, limited physical activity, frequent exacerbations and frequent nighttime symptoms (NHLBI, 1997).

## **Training of Personnel**

Two full time asthma health educators were trained to provide asthma education and collect data for the Pediatric Asthma Intervention. Both asthma health educators were African American and from the community in which they worked. The importance of utilizing members of the community for health education cannot be stressed enough. Participants felt a connection and sense of acceptance when able to interact with people they felt comfortable with and trusted. Both the actual training of the health educators

and their compassion were equally important aspects to consider when implementing this portion of the study.

The asthma health educators were trained in several ways. Both attended an Asthma Basics Training course sponsored by the American Lung Association. This course focused on the pathophysiology of asthma as well as proper medication usage, trigger identification and control, symptom recognition and management, implementation of an individual personal action plan, patient monitoring, emergency action, and health care follow-up. Additionally, a pediatric pulmonologist, the asthma educator at Mount Sinai, and the Pediatric Nurse Practitioner trained the health educator. This afforded the asthma health educators a hands-on experience and provided a reliable mechanism of training to ensure a consistent and comprehensive delivery of asthma education to participants in the study. Patients and their families received printed teaching material in their preferred language for reinforcement.

### **Study Design and Randomization**

In this randomized clinical trial, data was collected retrospectively for one year prior to the study and prospectively for nine months following enrollment. Trial randomization was sequential.

After the study was explained to the participant and written consent was obtained, patients were randomized into three groups: *Group One* was given basic asthma education by a trained asthma educator. This education consisted of one 20-30 minute session and included information on basic pathophysiology of asthma and recognition of asthma triggers. Medication and equipment use was tailored to participants' individual needs to ensure proper technique and usage. A personal action plan was developed and each patient was instructed on its use. This group was instructed to follow-up with their primary care physician or pulmonologist as instructed by their health care provider. They were contacted by telephone for nine months for data collection. If the participants in this group needed guidance or information regarding their care, treatment, or education, they were referred to their primary care provider.

*Group Two* was also given asthma education by the trained asthma educator following consent. This initial education was identical to that described above. Participants in this group were encouraged to call the asthma educator if they had questions. Education was reinforced as needed and during monthly data collection phone calls.

Participants of *Group Three* were given reinforced asthma education as in Group Two with the addition of case management. An initial case management evaluation was completed on all participants in Group Three by the nurse practitioner. Problems and needs were discussed and agreed upon by the participants' caregiver and the nurse practitioner and a plan of action was jointly developed. Finally, the participants were contacted monthly for data collection and to reinforce education. Participants were also contacted on an as needed basis to resolve issues and problems regarding asthma case management.

Since patients experiencing breathing difficulty often utilize the emergency department as a first course of action, we felt it imperative that every participant in the study be provided with an *action plan* of care for asthma exacerbations. The plan outlined a step by step approach to handling breathing difficulty including the proper use of rescue medications and recommended criteria for seeking medical attention including the use of an emergency room.

In Groups 2 and 3 opportunities to reinforce asthma education were identified by the health educator during follow-up phone calls, by the provider during visits, by encounters with the case manager, and if there was an unanticipated ED visit or hospitalization. We identified several areas where additional teaching was implemented. For example, if a parent or caregiver had difficulty articulating aspects of care, medication usage or delivery methods, lack of compliance, or unexplained requirement of additional medications, teaching reinforcement was implemented.

### **Case Management**

Although there has been some evidence in the literature that case management can be an effective component of an intervention, a generally accepted definition of case management has not yet been identified (Greinder, Loane & Parks, 1995; Kropfelder & Winkelstein, 1996; Wissow, Warshow, Box & Baker, 1988). Each study defines case management and the process of case management in a different manner. The resulting confusion in the literature led us to more clearly identify the process that we utilized for the Pediatric Asthma Intervention.

According to the Case Management Society, case management is: “a coordinated care practice that originated in the mental health arena and more recently utilized to promote effective management in a variety of chronic medical conditions including asthma”. A broader definition of case management which we will offer here for the purpose of our research is: “the provision for some greater continuity of care through periodic contact between the case manager and the client that provides greater coordination and brokerage of services than the client would be expected to obtain without case management.”

Unfortunately, since case management has no universally accepted specific definition or model, there is not a consistent manner in which to evaluate its effectiveness. Given the absence of a specific universally accepted definition or model, it is not surprising that the evidence regarding the effectiveness of case management in improving the control of asthma in urban, minority low income children is not as conclusive as that on health education.

The PAI case management team performed the assessment of a patient’s needs in collaboration with the patient and their family. After the initial assessment was completed, the case manager and the family identified issues that were important to the child and would enhance the child’s well-being. Once these areas of concern were identified, the case manager and the family would formulate a plan of action. The case

manager would assist the family in obtaining the necessary resources to aid in resolving the issues at hand. Telephone interviews with the parents were used to follow-up on problem resolution as well as to assess compliance or areas of further need. Although not all families required weekly follow-up, most of Group 3 were followed at least weekly the first month and at least monthly thereafter through the study period.

Empowering the participant and their family through this process was one of the goals identified early in the case management process. One of the lasting messages we wished to communicate to the families enrolled in Group 3 was the importance of seeking the necessary tools to ensure their continued success in fighting their child's asthma and as well as maintaining and enhancing their quality of life.

While the importance of case management should not be minimized in a chronic disease such as asthma it is important that case management resources are utilized cost-effectively. Not every participant's parent or caregiver was willing to accept case management or follow through with the collaborative plan agreed upon by the case manager and the family. Need and active, willing participation on the family's part is integral to the long-term success of case management. Additionally, a supportive, trusting relationship between the case manager and the family are key to the success of any program. Many of the relationships developed between the case managers and the families in Group 3 are ongoing and have contributed to an enhanced quality of life for the participants.

### **Data Collection and Analysis**

The main outcome variables of interest include: hospitalizations, hospital days, emergency department (ED) visits and clinic visits. These variables were also the main components utilized in the cost-benefit analysis. Other outcome variables assessed included school days missed, asthma knowledge and symptoms. A copy of each data collection instrument is attached in Appendix A.

#### *Health Resource Utilization and School Days Missed:*

Baseline data on health resource utilization and missed school days in the year prior to enrollment were collected via recall from the primary caregiver of the child. Follow-up data were also collected from the primary caregiver of the child during monthly phone interviews over a period of nine months. The data were uniformly collected from participants in all three-study groups. However, when participants asked questions of the interviewer regarding their asthma, those in Group 1 were referred back to their primary care physician for further assistance.

The total number of hospitalizations, hospital days, ED visits, clinic visits and school days missed for the 9 month follow-up period were calculated by summing the individual monthly follow-up values. Missing data points were filled in with the average value over the remaining follow-ups. To make our follow-up data comparable to our baseline data, it was extrapolated out to represent one year's time.

Both nationally and in Chicago, a trend has been shown to exist in which more asthma-related hospitalizations and ED visits occur in the Fall months, and less occur in the summer months than in other seasons (Weiss, 1990; Thomas & Whitman, 1999). If this trend existed within our sample, then it would not be valid to arbitrarily extrapolate out the missing 3 months of data for these outcome measures. To assess the presence of a seasonal effect, the follow-up data were pooled (months 1-9) and categorized by the season in which the follow-up occurred. There were no significant differences in the proportion of participants who reported at least one hospitalization or ED visit nor in the average number of hospitalizations, hospital days or ED visits by season of follow-up. We therefore extrapolated follow-up data to one year's time to make it comparable to baseline data.

#### *Asthma Knowledge:*

Prior to the basic asthma education session, the health educator would assess the initial knowledge base of the participant/caregiver regarding pathophysiology, symptoms, triggers, medications, and monitoring. The educator would rate the knowledge in each of these areas as poor, fair or good. By averaging scores in the 5 areas, an overall asthma knowledge summary score was created. During the 9-month follow-up interview, this assessment was repeated. As such, we had information available regarding changes in knowledge from baseline to study completion for all three-study groups.

#### *Symptoms:*

Information on the frequency of asthma symptoms ( $\leq$  once a week, 2-6 times a week, daily) was collected at the time of enrollment into the study. It was also collected during each follow-up interview, at which time information was also requested regarding specific symptoms experienced during the preceding month. This information allowed for the assessment of changes in symptom frequency from baseline to follow-up. It has been hypothesized that seasonal trends exist with regards to asthma symptom frequency, with an expected decrease in the frequency of symptoms during the summer months. An analysis of symptom frequency by season of follow-up using our data supported this hypothesis. We therefore stratified our analysis of symptom frequency by the season of follow-up (summer vs. other).

#### *Case Management:*

Our literature review had revealed that while a few studies had provided case management services to a pediatric asthma population, in no case was the intensity of the case management documented. As such, one of our main objectives was to document the types of issues encountered (i.e. problems attaining medications and equipment, landlord/tenant issues, smoking cessation, school issues, etc.), the amount of time spent working on different issues and the proportion of issues that were successfully resolved. This information would be both interesting and useful in estimating the cost of

conducting the intervention. The “Case Management Summary” form (see Appendix A) was used to document the case management process for participants in Group 3.

*Cost Benefit Analysis:*

The cost-benefit analysis sought to estimate expected savings to the Illinois Department of Public Aid (IDPA) resulting from the intervention. Approximately 90% of study participants were Medicaid insured, making this approach appropriate. Mt. Sinai data for health resource utilization was used in conducting the cost-benefit analysis. The average reimbursement by Medicaid for asthma-related hospitalizations (\$5,865), ED visits (\$132) and clinic visits (\$19) during FY 1998 for Mt. Sinai’s Primary Service Area (PSA) was obtained from Dr. Ted Naurekas (Assistant Professor of Clinical Medicine, University of Chicago). The average cost-savings to IDPA for health resource utilization could then be estimated by multiplying the average number of hospitalizations, ED visits and clinic visits at follow-up by the average level of reimbursement, and subtracting the same estimate derived using the baseline data. The cost-savings was calculated separately for each of the three study groups.

The majority of study participants in our sample were not properly medicated prior to enrollment. As such, it would be expected that the intervention would increase medication costs. It was therefore deemed important to include the added cost of medications in the cost-benefit analysis. According to IDPA FY 1998 data, for children residing in Mt. Sinai’s PSA, an average of \$164/child/year was spent on asthma medications. This amount was taken to be representative of the costs incurred for asthma medications by our study participants in the year prior to enrollment, and was added to the baseline year health care costs. At most, a properly medicated child would be on an inhaled steroid and a beta agonist, and would also have access to a rescuer. On the average, IDPA paid between \$461-\$723/child/year on children who were on both an inhaled steroid and a beta agonist. The high end of this range was added to the health care costs for the follow-up year. Our choice to use the high end of the range assures that our cost-savings estimates err on the side of being overly conservative.

As participants in all 3 study groups were seen by a pulmonologist upon enrollment into the study, the cost for this initial visit (~\$50) was also included in the health care costs for the follow-up year.

The cost of conducting the intervention was estimated and subtracted from the cost-savings. Estimates of the amount of time spent on various activities by the health educator/case manager were available and made it possible to more confidently estimate the cost of conducting the intervention due to salary in each of the three study groups. While our particular intervention utilized a Nurse Practitioner (NP) as the Case Manger, a well-trained health educator could also undertake this role. The program costs dependent on salary were therefore calculated two ways: once using the salary of the health educator for both the health education and case management components, and once using the NP’s salary for the case management component. Besides the salary of the health educator/case manager, start-up and operating costs (\$5,000) were also incorporated into

the program costs. The average cost of conducting the program with those who were eventually lost to follow-up was also integrated into each group's program costs. Appendix B contains more detailed information regarding time spent on different activities, and specific program start-up costs.

### **Statistical Analysis**

Population demographics and baseline data were compared across study groups by using  $\chi^2$  or Fisher's Exact test for categorical variables, and using Analysis of Variance (ANOVA) for continuous variables. The change (difference) between the average number of hospitalizations, hospital days, ED visits, clinic visits and school days missed from the baseline to follow-up year served as the unit of analysis for the main outcome variables. Using the change from baseline as the outcome variable in statistical tests allowed for control of the history of the same outcome in the baseline year. Paired t-tests were used to assess the statistical significance of within group changes from the baseline to follow-up year. The between group differences were assessed for statistical significance by ANOVA.

Improvements in other outcome variables (knowledge and symptoms) were evaluated as both categorical ( $\chi^2$ ) and as continuous variables (ANOVA for between group differences, paired t-test for within group differences). When considering changes in symptom frequency, the analysis was stratified by season of enrollment or follow-up (summer vs. other). This was necessary because, within our sample, it was determined that participants reported significantly less symptoms in the summer months than in other months.

As only participants who were at least one year old at the time of enrollment would have information available regarding the baseline year, the health resource utilization outcomes analysis had to be limited to those participants. In the interest of consistency, and given substantial evidence that asthma manifests itself differently in very young children, all outcomes analyses here presented are also limited to children at least one year of age at enrollment.

For all statistical tests, a p-value of .05 or less was considered statistically significant. Two-sided tests of hypothesis were used. All statistical analyses were performed using SAS statistical software, version 8.2 (SAS Institute, Inc., Cary, NC).



## Population Characteristics and Findings

### Enrollment and Attrition - Mt. Sinai

At Mt. Sinai, the first participant was enrolled into the study on 7/12/2000 and the last participant was enrolled on 5/9/2001. Data collection was completed for the final participant on 2/14/2002. A total of 264 participants were enrolled into the study, of whom 89 (33.7%) were randomized to Group 1 (G1), 90 (34.1%) to Group 2 (G2) and 85 (32.3%) to Group 3 (G3).

Sixty-five (24.6%) participants were lost to the study, 9 of whom actively withdrew and 56 of which were lost to follow-up (Figure 1). A participant was considered lost to follow-up if he/she could not be contacted for 3 consecutive months. If a participant had completed up through month 7 of follow-up, then he/she was classified as having completed the study. The distribution of loss was even across study groups. While the attrition rate of 24.6% is somewhat higher than desirable, it is not surprising given an inner-city, low-income study population. The most common reasons for withdrawing from the study included: belief by caregivers that their child “is not sick” or “doesn’t have asthma” (n=4), change in caregiver (n=3) and moving (n=2). The most common reasons that people were lost to follow-up included: disconnected phone (57.1%), wrong phone number provided (17.9%), moving (12.5%) and losing contact for 3 or more months (10.7%). More specifics on enrollment and attrition are displayed in Figure 1.

**Figure 1: Subject enrollment, randomization and attrition at Mt. Sinai.**

<b>Enrolled n=264</b>											
<b>Group 1 n=89</b>				<b>Group 2 n=90</b>				<b>Group 3 n=85</b>			
<b>Completed n=66</b>		<b>Lost to Study n=23</b>		<b>Completed n=68</b>		<b>Lost to Study n=22</b>		<b>Completed n=65</b>		<b>Lost to Study n=20</b>	
<1 y/o n=11	≥ 1 y/o n=55	WD n=4	LFU n=19	<1 y/o n=14	≥ 1 y/o n=54	WD n=3	LFU n=19	<1 y/o n=10	≥ 1 y/o n=56	WD n=2	LFU n=18

**WD =Withdrew, LFU = lost to follow-up, y/o = year old**

Participants lost to the study were examined against those completing the study for a number of characteristics and baseline values. The two groups were found to differ significantly with regards to the season of enrollment, with those who were eventually lost to the study being more likely to have been recruited in the summer months (65% vs. 36%, Fisher’s Exact Test, p<.05). The first study participants were enrolled in the summer, and as such, it’s possible that this finding may be an artifact of developing skills

in the tracking down of participants for follow-up as the study progressed. It may also have to do with the extraordinarily high gas prices during the unusually cold winter of 2000-2001. We found that many of our families had their phones disconnected in order to pay their gas bills, thus making follow-up difficult. Other significant differences between the two groups which included baseline symptom frequency (46% of those reporting symptoms < once a week were lost vs. 18.7% of others, Fisher Exact Test,  $p < .001$ ) were likely explained by the differences in the season of enrollment, since the frequency of symptoms reported was lower in the summer months than in other months (data not presented). Participants with milder symptoms may not have felt as committed to the study. Other significant differences between the two groups which included baseline symptom frequency (46% of those reporting symptoms < once a week were lost vs. 18.7% of others, Fisher Exact Test,  $p < .001$ ) were likely explained by the differences in the season of enrollment, since the frequency of symptoms reported was lower in the summer months than in other months (data not presented).

### **Enrollment and Attrition - La Rabida**

At La Rabida, the first participant was enrolled into the study on 12/5/2000, and the last participant was enrolled on 5/5/2001. The last participant completed follow-up on 2/6/2002. A total of 48 participants were enrolled into the study. As previously mentioned, the two study sites had inherent differences in the standard of asthma care due to the prestudy availability of case management services for all La Rabida patients. Case management services were only available to Mount Sinai patients enrolled in Sinai's G3, and only after study enrollment. As such, the study team, at the insistence of the staff at La Rabida, decided participants at La Rabida could not be randomized into the three study groups since to do so would be to deny case management services to patients that would normally have access to case managers. All La Rabida patients were therefore provided with the G3 intervention.

Seven (14.6%) study participants were subsequently lost to the study. All were lost to follow-up. The most prevalent reasons that participants were lost to follow-up included: disconnected phone ( $n=4$ ), moved ( $n=2$ ), and could not be reached for follow-up for 3 months ( $n=1$ ).

### **Baseline Characteristics - Mt. Sinai**

The baseline characteristics of the study population are shown in Table 1. There were no significant differences across groups with regards to gender, race/ethnicity, age, insurance status, caregiver's level of education, symptom frequency, regularity of albuterol (rescue medicine) use, mean overall knowledge score or average number of school days missed (limited to school-aged children). When assessing differences in baseline health resource utilization, the analysis was limited to participants  $\geq 1$  year of age at the time of enrollment ( $n=212$ ; 74 G1, 68 G2, 70 G3). This was necessary, as only children who were at least 1 year old would have a year's worth of baseline data. There were no significant differences with regards to baseline health resource utilization, with the exception of unscheduled clinic visits. In the baseline year, participants in G3

reported significantly more unscheduled clinic visits than participants in G1 or G2. The relative uniformity across groups with regards to baseline characteristics suggests that the randomization process was successful.

**Table 1. Baseline characteristics upon enrollment into the study-Sinai**

	<b>Group 1 (n=89)</b>	<b>Group 2 (n=90)</b>	<b>Group 3 (n=85)</b>	<b>p-value<sup>‡</sup></b>
<b>Gender</b>				
Male	52%	61%	59%	NS
Female	48%	39%	41%	
<b>Race/Ethnicity</b>				
non-Hispanic Black	72%	62%	66%	NS
Hispanic	28%	38%	33%	
Other	0%	0%	1%	
<b>Age</b>				
<1	16%	23%	17%	NS
1-4	45%	44%	37%	
5-12	32%	27%	38%	
> 12	7%	6%	8%	
<b>Age (mean)</b>	4.66	3.97	4.76	NS
<b>Insurance<sup>§</sup></b>				
None	2%	0%	0%	NS
Medicaid	89%	91%	93%	
HMO/Private	9%	9%	7%	
<b>Parent's Education (mean)<sup>§</sup></b>	12.15	11.92	12.13	NS
<b>Symptoms<sup>§</sup></b>				
Daily	0%	0%	2%	NS
2-6 times a week	80%	84%	76%	
once a week or less	20%	16%	21%	
<b>Albuterol Use (rescue med)<sup>§</sup></b>				
Daily	14%	9%	18%	NS
2-6 times/week	42%	48%	44%	
once a week	32%	21%	17%	
< once a week/rarely	14%	21%	21%	
<b>Health Care Utilization (one year pre-intervention)<sup>∇</sup></b>				
ED Visits (mean)	1.87	1.62	2.10	NS
Hospitalizations (mean)	1.01	1.03	1.07	NS
Hospital Days (mean)	2.11	2.04	2.53	NS
Unsch. Clinic Visits (mean)	2.53	2.53	3.46	<.05
<b>School Days Missed (mean)<sup>*</sup></b>	6.65	5.38	6.62	NS
<b>Overall Knowledge Score</b> (scale of 1-3, 3 is best)	2.02	1.99	1.99	NS

Statistically significant difference between groups

‡ Chi-Square/Fisher as appropriate was used to assess significance of categorical variables; ANOVA for continuous variables. NS = “not significant” (p > .05).

\* Only applicable to children ≥ 5. n=34, 29 & 39 respectively for Groups 1,2 and 3.

∇ Includes only children ≥ 1 year of age at enrollment who have an “Initial Patient Medical History” (n=212: 74 G1, 68 G2, 70 G3).

§ Collected on “Initial Patient Medical History” 3 subjects were missing the form. (n=261: 88 G1, 89 G2, 84 G3).

The Sinai study population was primarily male (57%), non-Hispanic Black (67%) and Medicaid insured (92%). The average age was 4.5 years, with only 39% of participants being school-aged ( $\geq 5$  years old). The average caregiver had a high school level education.

At the time of enrollment, caregivers were asked a variety of questions intended to assess the degree of exposure to asthma triggers within the home environment. The most commonly cited environmental triggers included dust/dust mites (87.7%), carpeting (73.2%), pets (27.6%) and cigarette smoke (23.8%). Also, nearly all participants (95%) lacked air conditioning in their home. The types of triggers most commonly encountered did not differ significantly across study groups.

### **Baseline Characteristics - La Rabida**

The baseline characteristics of the La Rabida study population in comparison to Sinai G3 are presented in Table 2. Baseline symptom data were not available for La Rabida. The two populations differed significantly from one another with regards to their demographics. Specifically, the La Rabida sample was almost entirely non-Hispanic Black (94%) and school-aged (mean age=8.7 years), whereas the Sinai sample was approximately two-thirds non-Hispanic Black and one-third Hispanic and younger (mean age=4.8 years). The La Rabida sample also had a significantly higher baseline knowledge score than the Sinai sample (2.57 vs. 1.99), which was not surprising given differences in standard of care between the two sites.

There were 3 La Rabida study participants with extreme baseline values for health resource utilization. These three participants were excluded from further analysis as their inclusion biased the findings. The baseline data presented in Table 2 with regards to health resource utilization and school days missed therefore also excludes these 3 participants. They are however included in the baseline demographics presented.

The most commonly cited environmental triggers reported by the La Rabida population included dust/dust mites (62.8%), cigarette smoke (58.1%), carpeting (48.8%), mold (41.9%) and pets (25.6%). Also, nearly all participants (90.7%) lacked air conditioning in their home.

The significant differences in the demographics of the two study populations (La Rabida and Sinai) make it impossible to pool them, or to directly compare them. The majority of the data will therefore be presented separately for Sinai and La Rabida.

**Table 2. Baseline characteristics upon enrollment into the study: La Rabida vs. Sinai G3.**

	<b>LR Group 3 (n=48)<sup>**</sup></b>	<b>Sinai Group 3 (n=85)</b>	<b>p-value<sup>†</sup></b>
<b>Gender</b>			
Male	69%	59%	NS
Female	31%	41%	
<b>Race/Ethnicity</b>			
non-Hispanic White	4%	0%	<.0001
non-Hispanic Black	94%	66%	
Hispanic	2%	33%	
Other	0%	1%	
<b>Age</b>			
<1	0%	17%	<.001
1-4	19%	37%	
5-12	67%	38%	
> 12	15%	8%	
<b>Age (mean)</b>	8.73	4.76	<.0001
<b>Insurance<sup>§</sup></b>			
None	0%	0%	NS
Medicaid	81%	93%	
HMO/Private	19%	7%	
<b>Parent's Education (mean)<sup>§</sup></b>	14.09	12.13	<.0001
<b>albuterol Use (rescue med)<sup>§</sup></b>			
Daily	9%	18%	<.05
2-6 times/week	35%	44%	
once a week	9%	17%	
< once a week/rarely	47%	21%	
<b>Health Care Utilization (one year pre-intervention)<sup>∇</sup></b>			
ED Visits (mean)	2.58	2.10	NS
Hospitalizations (mean)	0.51	1.07	<.01
Hospital Days (mean)	2.21	2.53	NS
Unsch. Clinic Visits (mean)	1.54	3.46	<.001
<b>School Days Missed (mean)<sup>*</sup></b>	8.90	6.62	NS
<b>Overall Knowledge Score<sup>**</sup></b> (scale of 1-3, 3 is best)	2.57	1.99	<.0001

Statistically significant difference between groups

† Chi-Square/Fisher as appropriate was used to assess significance of categorical variables; t-test for continuous variables. NS="not significant" (p > .05).

\* Only applicable to children ≥ 5 and excludes LR outliers. n=32 & 39 respectively for LR and Sinai Group 3

§ 5 LR and 3 Sinai children missing "Initial Patient Medical History" (MH). Information off MH has N of 43 and 84 respectively.

∇ Includes only children ≥ 1 year of age at enrollment and excludes outliers (n=40 and 70 for LR and Sinai respectively).

### **Collection of Baseline Data - Mt. Sinai**

Baseline data was collected using 3 instruments: the “Screening Form”, the “Initial Patient Medical History” and the “Health Educator Asthma Teaching Checklist” (Appendix A). Of the 264 enrolled participants, all had a “Screening Form” completed, 261 (99%) had an “Initial Patient Medical History” and all had the “Health Educator Asthma Teaching Checklist”. The information for the “Initial Patient Medical History” was generally collected from the caregiver (78%), but it was sometimes abstracted from the medical record (22%). Patient medical record numbers were incorrect for the 3 participants who were missing the “Initial Patient Medical History” making it impossible to abstract the information from the medical record. All 3 of these participants were eventually lost to follow-up. Variables collected on the “Initial Patient Medical History” are noted on Tables 1 and 2, and the correct sample sizes are provided.

### **Health Education Session - Mt. Sinai**

In most instances (97%), it was a parent who was being educated as the primary caregiver of the child. When it was not a parent, it was either a grandparent (n=7) or a foster parent (n=2). The health education session was about 30 minutes in length. All but one participant completed the entire session. A translator was used during the health education session by 8% of participants. The proportion using a translator did not differ by study group or age, but did differ by race/ethnicity (24% of Hispanic participants used a translator vs. 1% of non-Hispanic Black participants, Fisher Exact Test,  $p < .0001$ ).

### **Monthly Follow-Ups - Mt. Sinai**

At Mt. Sinai, 199 (75.4%) participants completed the study. Those completing the study were evenly distributed across study groups (Figure 1). The average participant had 8.73 follow-ups successfully completed (range 6-9). There were no significant differences in the average number of follow-ups completed by study group, race/ethnicity or age.

If a participant was not successfully reached for follow-up within a particular month, the data would be collected during the subsequent follow-up. These follow-ups will be referred to as recalled follow-ups. The average participant had 0.81 recalled follow-ups (range 0-4). There were no significant differences in the average number of recalled follow-ups completed by study group, race/ethnicity or age. The average recalled follow-up was collected 39.8 days later than expected. A recalled follow-up could not be more than 3 months (92 days) late because of the lost to follow-up criteria.

Among non-recalled follow-ups, the majority occurred within 7 days of the expected date of follow-up. The average follow-up occurred 1.11 days later than expected. There were no significant differences by study group, race/ethnicity or age.

Participants had to have completed at least through month 7 of follow-up in order to be classified as having finished the study. Therefore, 1% of participants were missing a month 8 follow-up, and 2% were missing the month 9 follow-up. The 2% missing the

month 9 follow-up were also missing the month 9 supplemental follow-up, which included the collection of information on asthma knowledge.

Participants who were eventually lost to the study had an average of 0.74 (range 0-6) follow-ups completed. 75.4% had no completed follow-ups. The number of follow-ups completed did not differ significantly by study group among those lost to follow-up.

### **Case Management - Mt. Sinai**

A total of 271 issues were encountered among 84 participants. All but one participant randomized to G3 required some case management services. On the whole, 907.5 total hours were spent providing case management services. The average participant received case management assistance for 3.2 problems during the follow-up period. On average a problem required 3.35 case management hours (CM hours) to resolve. In other words, the average participant required 10.80 CM hours. All but 5 problems were successfully resolved. Unresolved issues included 4 attempts at smoking cessation, and 1 case of domestic violence.

Of the four unresolved issues surrounding smoking cessation, all were adults who were not the primary caregiver of the participant. While these adults were given information regarding smoking cessation programs, offered nicotine patches, and other forms of behavior modification, none of the four adults were willing to stop smoking. The only compromise they were willing to reach was to smoke outside when the child was physically present in the home. Even though smoking cessation might have enhanced the outcome for four of our participants, it is not within the scope of case management to impose behavior change.

In reality, failure to resolve these 5 case management issues may not have significantly impacted the participant's asthma however, it is a testament as to how difficult case management can be. While for most of our families there was a willingness to participate in the case management process, some families in Group 3 were not as willing. Even though needs were identified in several families, families with these needs did not always accept the assistance of the case manager. This was particularly true if one of the other authority figures in the family was distrustful of the process or if the family encountered difficulty with assistance in previous situations. Additionally, there were some families that were unwilling to have someone come to their home, provide alternate contacts, or approach other family members with issues that may strain their relationships. Building trust and working with families over time, providing consistent resources for families and maintaining a non-judgmental demeanor on the part of the study team was paramount in the success of the project's case management process.

Forty-seven percent of the case management issues were related to acquiring proper medication for the participant. Many of the parents and caregivers said that the only way they had to get medication refills was to come to the medical care site to pick up a prescription. Of these parents and caregivers, almost all had to rely on borrowed or public transportation to come to the care site.

During the time of the initial case management interview, many participants' parents and caregivers expressed frustration in obtaining necessary equipment and medication for their child. This was a recurring theme and had several root causes. Some of the families were unaware of how to obtain medication or did not realize the importance of maintaining an adequate supply. Some were given misinformation on how to secure vital medication or equipment. Additionally, even though the majority of our participants were Medicaid they were not able to replace nebulizers that needed repair or were unusable, obtain spacers, peak flow monitors, or face masks. Most of the families were not familiar with the proper cleaning and maintenance of necessary equipment further complicating situations. Finally, many parents or caregivers were frustrated with the current system of obtaining medication and equipment. They verbalized their lack of trust in health care providers and medical equipment companies who did not follow-through and their sense of insecurity and anger when they had difficulty articulating the needs of their children. Still other parents or caregivers did not understand the importance of medicating their child according to the medical treatment plan, stating that they felt their child only needed medication when they were wheezing or having an actual exacerbation. These circumstances and beliefs on the part of the parents and caregivers necessitated ongoing education and reinforcement to communicate the importance of ensuring that the necessary treatment plan was adhered to by the participants.

Although most of the parents and caregivers could identify their child's triggers, most did not know how to remove those triggers from their environment. Roaches are a significant problem in the inner-city. It is well documented in the literature that the waste and remains of roaches are a common trigger in asthmatics, so roach and pest abatement is critical to reducing asthma exacerbations. Roach and pest abatement was an issue that the case managers spent 17% of their time assisting participant's families in resolving. Simple pest control measures were initially taught to the families and pest control devices were distributed to these families. Since most families in the PAI resided in apartment buildings, it often was necessary to involve the building's manager or property owner in resolving this issue. This was a sensitive and often time consuming issue. While parents and caregivers wanted the problem resolved, they did not want to have further issues with the managers of their homes. This required the case manager to intervene on the family's behalf rather than have the parent or caregiver advocate for himself or herself.

Another common problem were issues surrounding school attendance, medication, usage and access while at school and physical activity restrictions. While there is a state mandate that children may carry rescue medication on their person while in school, many of the schools we dealt with still were not compliant with this policy. The case manager and the health educator would identify the appropriate schools and meet with the leadership at the school to explain the state mandate and the particular child's problems. Educational sessions were offered to the staff at each of the schools. While the PAI team was at the school, they would assess the environment for possible problems such as harsh chemical cleaning while school was in session, mold, peeling paint, excessive dust, extreme temperatures, etc. These issues were brought to the attention of the leadership at the school and a plan of action was suggested. The health educator or case manager



would follow-up with the school and the parent or caregiver of the participant to ensure corrective action had been taken.

Educational inservices were provided to schools where PAI participants were enrolled. Many of the teachers inserviced had misconceptions regarding asthma. Basic information was given to the staff regarding their responsibility if a child has an episode, what a rescue medication is and why a child needs ready access to this type of medication, the goals of asthma therapy and treatment, and physical education.

The overwhelming interest and lack of asthma knowledge the school staff demonstrated further points to the great need and additional opportunity to enhance knowledge regarding pediatric asthma in the schools. Since children spend the majority of their day in school, it would be beneficial if not lifesaving to increase the awareness of asthma treatment in the schools. Additionally, increasing the asthma awareness of the staff in schools may lead to fewer missed school days by asthmatic children.

#### *Case management – example cases:*

Case 1: An example of a complex participant's case management issues was 18 month old K.T. K.T. an African-American female with four siblings under the age of five was living with her mother and paternal grandmother. K.T. had several medical problems including : a seizure disorder, failure to thrive, severe, persistent asthma, and developmental delays. The grandmother was an unwilling caregiver to these five children while the mother worked. Another complication was the fact that K.T.'s father was in the witness protection program and unable to assist his family in any way. The grandmother continued to smoke, in the presence of the children while caring for them, despite K.T.'s frequent asthma exacerbations. While K.T.'s mother worked, the grandmother had many unknown visitors and parties according to the older children. Often she forgot to feed and medicate the children. Since the mother had so many pressing issues, we arranged for emergency housing and childcare for her. Many hours were spent on the multitude of social and medical issues surrounding K.T.. Often families such as K.T.'s find themselves in a quandary. If they leave their only perceived support system and fail, what will become of them. This was especially true in K.T.'s case. The only contact with her father was through her paternal grandmother. Despite our intervention, the grandmother was unwilling to stop smoking or participate in any formal child care programs or care, or commit to a workable plan as identified by the mother and the case manager. While K.T.'s family did strike out on their own and did do well, the strain and burden on K.T.'s mother was at times, overwhelming. Even though many of the issues surrounding K.T.'s illness have been resolved for the moment, there are circumstances and problems that can not be solved by case management alone.

Case 2: One participant, J.S., a seven year-old African American male was enrolled in the study and randomized into Group 3. J.S. had severe, persistent asthma, which became worse at school. J.S.'s mother had spoken to the principal, noting peeling paint and excessive chemical use during school hours, The principal did not grasp the severity of the problem despite a letter outlining J.S's condition and treatment plan. The health

educator and the case manager visited the school and observed the same issues. Despite meeting with the principal, the issues went unresolved. J.S. was unable to attend a full day of school for several weeks. An extensive amount of time was spent meeting with the leadership of the Chicago Public School System, involving the Chicago Asthma Consortium and educating the principal, teachers, and staff at the school. Meanwhile, J.S. required tutoring while out of school, the family required assistance with child care when J.S. was out of school since his mother worked during the day, and J. S. required greater medical follow-up to ensure he was as symptom free as possible. In the months that ensued, the issues at the school began to slowly resolve however not without the diligent effort of the health educator and the case manager.

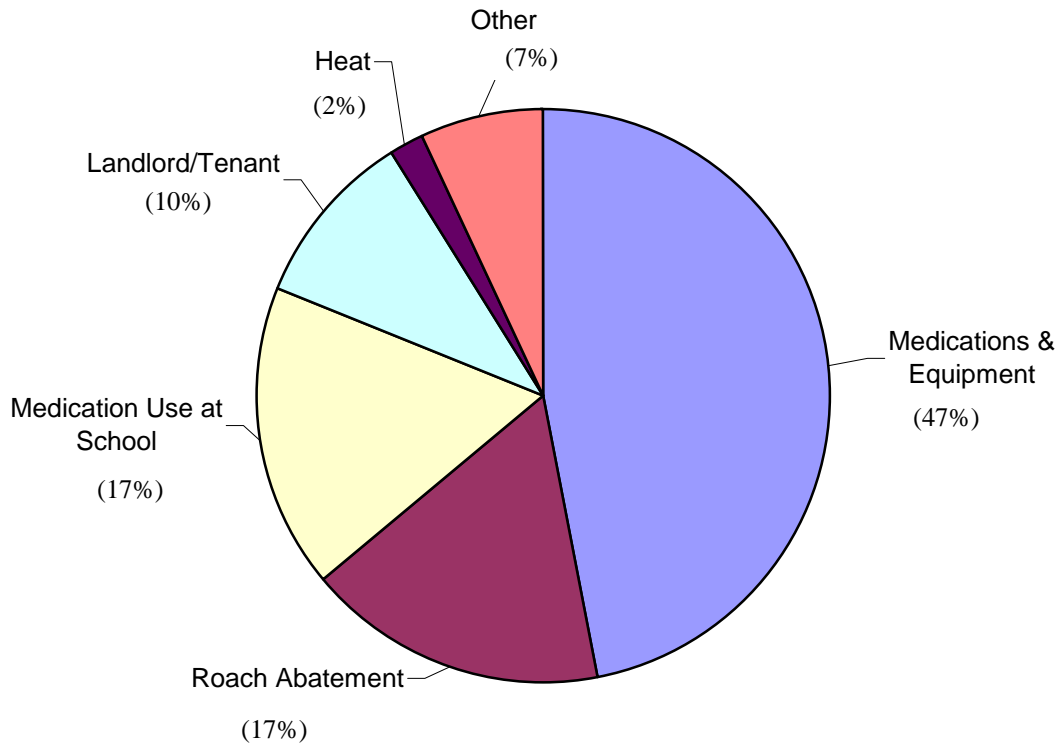
Figure 2 displays the most commonly encountered problems with which people required assistance, including acquiring proper medications and equipment (47%), roach abatement (17%), medication use at school (17%) and landlord/tenant issues (10%).

Figure 3 provides a summary of the most time consuming issues encountered. Two-thirds of the total CM time was spent working on 3 types of issues: acquiring proper medications and equipment (278 CM Hours), medication use at school (189 CM Hours) and landlord/tenant issues (178 CM Hours). In the figure, “miscellaneous issues” refer to the specific problems encountered more than once during the case management process but did not fit one of the standard categories. “Other issues” encompassed one of a kind problems encountered by families in our study.

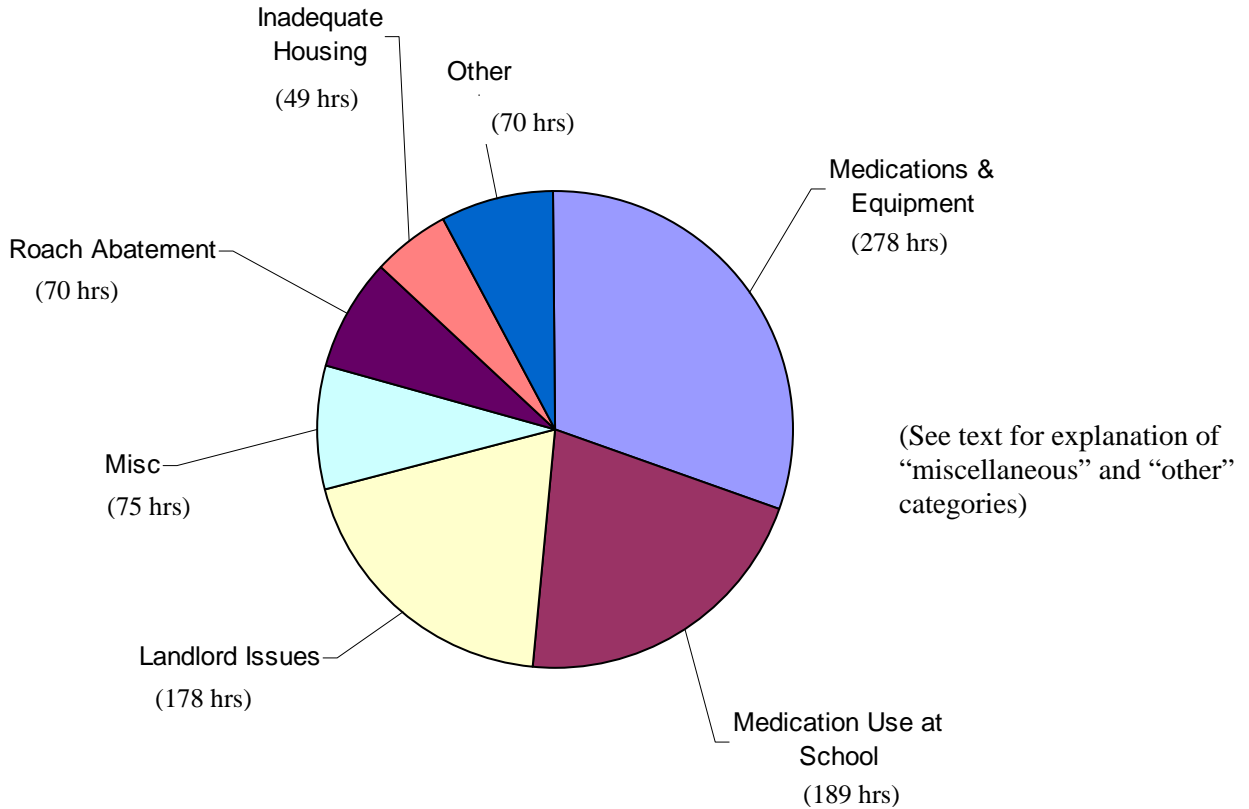
Miscellaneous issues occurred with a low frequency but were not isolated incidences. These include; lack of adequate heat or inability to pay heating or electric bills, lack of resources to pay for housing, trigger control other than roach abatement, per control and smoking cessation. Although encountered more than once, these issues were not routinely encountered and did not fit the other established categories.

The “other issues” category included the lack of child care, questionable caregivers, abuse and/or neglect, child custody, and a court appearance for one family. Since these issues occurred only once, were unique to individual families, and not readily categorized into a pre-existing category, they were grouped accordingly.

**Figure 2: Most commonly identified problems requiring assistance from the case manager – Sinai.**



**Figure 3: Most time consuming problems (total time) requiring assistance from the case manager-Sinai.**



**Collection of Baseline Data - La Rabida**

Baseline data was collected using 3 instruments: the “Screening Form”, the “Initial Patient Medical History” and the “Health Educator Asthma Teaching Checklist” (Appendix A). Of the 48 enrolled participants, all had a “Screening Form” completed, 43 (90%) had an “Initial Patient Medical History” and all had the “Health Educator Asthma Teaching Checklist”. Institutional constraints at La Rabida made a chart review to obtain the “Initial Patient Medical History” information difficult for those 5 participants who were missing the form.

**Health Education Session - La Rabida**

In most instances (85%), it was a parent who was being educated as the primary caregiver of the child. When it was not a parent, it was a grandparent (n=2), a foster parent (n=4) or “other” (n=1). The health education session was about 30 minutes in length. All

participants completed the entire session. None of the participants required a translator during the health education session.

### **Monthly Follow-Up -La Rabida**

At La Rabida, 41 (85.4%) participants completed the study. As previously mentioned, an additional three participants with extreme baseline values for health resource utilization were later excluded from the outcome analysis. However, when describing the process of follow-up, all 41 completers are considered. The average participant had 8.66 follow-ups successfully completed (range 7-9). There were no significant differences in the average number of follow-ups completed by race/ethnicity or age.

The average participant had 3.51 recalled follow-ups (range 0-7). There were no significant differences in the average number of recalled follow-ups completed by race/ethnicity or age. The average recalled follow-up was collected 45.6 days later than expected. A recalled follow-up could not be more than 3 months (92 days) late because of the lost to follow-up criteria.

While the majority of non-recalled follow-ups at Mt. Sinai occurred within 7 days of the expected date of follow-up, this was only true for about one-third of the La Rabida follow-ups. The average follow-up occurred 7.72 days later than expected. There were no significant differences by race/ethnicity or age.

Participants had to have completed at least through month 7 of follow-up in order to be classified as having finished the study. Therefore, 2% of participants were missing the month 9 follow-up. The 2% missing the month 9 follow-up were also missing the month 9 supplemental follow-up, which included the collection of information on asthma knowledge.

Participants who were eventually lost to the study had an average of 3.00 (range 0-6) follow-ups completed. Only 14.3% of participants who were eventually lost to the study had no completed follow-ups. 71.4% were lost between 0 and 3 months of follow-up.

### **Case Management -La Rabida**

Only 56% of participants required assistance from the project Case Manager. A total of 34 issues were encountered among 23 participants. On the whole, 29.8 total hours were spent providing case management services. The average participant who utilized case management services required assistance with 1.5 problems during the follow-up period. The average problem required 0.88 CM hours to resolve. In other words, the average participant who made use of case management services required 1.27 CM hours. All but 2 problems were successfully resolved.

The most commonly encountered problems with which people required assistance included acquiring proper medications and equipment (35%) and Trigger Control (12%).

Thirty-eight percent of the total CM time was spent dealing with issues of acquiring proper medications and equipment (11.2 CM Hours).

It was much more difficult to capture the nuances of the case management process at La Rabida as the project case manager was not necessarily the only case manager seen by study participants. It therefore appears that La Rabida participants required less assistance with issues than Mt. Sinai participants, but that is likely an artifact of differences in the existing infrastructure of each facility.

### **Outcomes Analysis**

As only participants who were at least one year old at the time of enrollment would have information available regarding the baseline year, the health resource utilization outcomes analysis had to be limited to those participants. In the interest of consistency, and given substantial evidence that asthma manifests itself differently in very young children, all outcomes analyses here presented are also limited to children at least one year of age at enrollment (n=165).

#### *Health Resource Utilization and School Days Missed - Mt. Sinai:*

Table 3 displays the average number of hospitalizations, hospital days, ED visits, clinic visits and school days missed during the baseline and follow-up years. While only the number of clinic visits differed significantly between the groups in the baseline year, it we still adjusted for the baseline value by utilizing the difference from the baseline to follow-up year as the unit of analysis. When compared with the baseline year, the health resource utilization outcomes in each of the three study groups all improved significantly (paired t-test,  $p < .05$ ). The same was not true with regards to school days missed (limited to children  $\geq 5$  years). While the average number of school days missed did decrease for children in G3 from 7.06 in the baseline year to 4.40 in the follow-up year, this change was not statistically significant ( $p=0.15$ ). G1 and G2 experienced a very slight decrease (-0.8) and a very slight increase (+0.8) respectively, neither of which approached significance.

When comparing differences in the degree of improvement among the three study groups, only clinic visits were statistically significant, with G3 reporting an average decrease of 2.8 visits between the baseline and follow-up year as compared to about 1.2 for G1 and G2 (ANOVA,  $p=.0001$ ). In the case of hospital days, G3 improved nearly twice as much as G1 or G2 (-2.26 vs. -1.13 and -1.20 respectively) but this difference did not achieve statistical significance ( $p=0.14$ ). While there were no significant differences between study groups for four of the five main outcome measures, in all cases there was a trend towards G3 improving to a greater degree than G1 or G2. Using the binomial formula, we calculated the probability that such a trend would occur by chance to be 0.4%. In other words, this trend is statistically significant ( $p=.004$ ).

**Table 3. Health resource utilization and school days missed: Comparisons with baseline values-Sinai**

	<b>Group 1 (n=55)</b>	<b>Group 2 (n=54)</b>	<b>Group 3 (n=56)</b>	<b>p-value ANOVA</b>
<b>Hospitalizations<sup>‡</sup></b>				
Baseline	1.02	1.00	1.09	.77
FU	0.24	0.19	0.15	
Difference	-0.78	-0.81	-0.94	
<b>% Change</b>	<b>-76%</b>	<b>-81%</b>	<b>-86%</b>	
<b>p-value*</b>	<b>&lt; .0001</b>	<b>&lt; .0001</b>	<b>&lt; .0001</b>	
<b>Hospital Days<sup>‡</sup></b>				
Baseline	2.05	1.83	2.63	.14
FU	0.92	0.63	0.37	
Difference	-1.13	-1.20	-2.26	
<b>% Change</b>	<b>-55%</b>	<b>-66%</b>	<b>-86%</b>	
<b>p-value*</b>	<b>&lt; .05</b>	<b>&lt; .005</b>	<b>&lt; .0001</b>	
<b>ED Visits<sup>‡</sup></b>				
Baseline	1.86	1.54	2.14	.25
FU	0.89	0.54	0.55	
Difference	-0.97	-0.99	-1.59	
<b>% Change</b>	<b>-52%</b>	<b>-65%</b>	<b>-74%</b>	
<b>p-value*</b>	<b>&lt; .05</b>	<b>&lt; .0005</b>	<b>&lt; .0001</b>	
<b>Clinic Visits<sup>‡</sup></b>				
Baseline	2.55	2.39	3.57	.0001
FU	1.40	1.22	.75	
Difference	-1.16	-1.17	-2.82	
<b>% Change</b>	<b>-45%</b>	<b>-49%</b>	<b>-79%</b>	
<b>p-value*</b>	<b>&lt; .0001</b>	<b>&lt; .0001</b>	<b>&lt; .0001</b>	
<b>School Days<sup>‡∇</sup></b>				
Baseline	7.28	5.24	7.06	NS
FU	6.45	6.08	4.40	
Diff	-0.83	+0.84	-2.66	
<b>% Change</b>	<b>-11%</b>	<b>+16%</b>	<b>-38%</b>	
<b>p-value**</b>	<b>0.52</b>	<b>0.63</b>	<b>0.15</b>	

‡ Average of total hospitalizations/days/visits over one year period. Baseline data represents the year prior to the intervention. The follow-up data has been extrapolated to represent 1 year's time.

\* p-value for comparison of baseline to follow-up values (within group changes). Compared using paired t-test.

∇ Limited to school-age children (≥ 5). n=25,24 and 27 respectively for G1, G2 and G3.

### *Asthma Knowledge - Mt. Sinai:*

Baseline levels of knowledge did not differ significantly across study groups (Table 4). Participants were generally most knowledgeable with regards to symptoms and triggers at baseline, and least knowledgeable with regards to monitoring and pathophysiology. Table 5 shows the level of improvement between the baseline assessment of knowledge and the 9-month follow-up assessment, both overall and in the individual areas of asthma knowledge. In all areas and for all study groups, there were considerable improvements in the level of knowledge between the baseline and follow-up assessments. Approximately 80% of participants improved with regards to their overall asthma

knowledge score. Improvements in knowledge did not differ significantly across study groups with the exception of symptoms, for which G2 and G3 improved to a greater degree than G1 (Chi-Square,  $p < .05$ ).

**Table 4. Baseline asthma knowledge - Sinai<sup>∇</sup>**

	<b>Group 1 (n=55)</b>	<b>Group 2 (n=54)</b>	<b>Group 3 (n=56)</b>
<b>Knowledge-Overall*</b>			
Good	20%	19%	25%
Fair	65%	69%	54%
Poor	15%	13%	21%
<b>Knowledge-Medication</b>			
Good	24%	20%	27%
Fair	58%	69%	50%
Poor	18%	11%	23%
<b>Knowledge-Monitoring</b>			
Good	13%	13%	20%
Fair	55%	57%	52%
Poor	33%	30%	29%
<b>Knowledge-Pathophysiology</b>			
Good	18%	22%	21%
Fair	45%	46%	50%
Poor	36%	31%	29%
<b>Knowledge-Symptoms</b>			
Good	33%	24%	30%
Fair	60%	67%	50%
Poor	7%	9%	20%
<b>Knowledge-Triggers</b>			
Good	31%	24%	32%
Fair	58%	63%	48%
Poor	11%	13%	20%

<sup>∇</sup> Chi-Square/Fisher Exact Test, as appropriate, was used to assess statistical significance across groups. There were no significant differences.

\* Overall Knowledge Score is an average of the individual scores for medications, monitoring, pathophysiology, symptoms and triggers. For individual scores 1=poor, 2=fair, 3=good. Overall Knowledge Scores is then categorized as: 0-<1.5=poor, 1.5-<2.5=fair, 2.5-3=good.



**Table 5. Changes in asthma knowledge from baseline assessment to month 9 follow-up - Sinai**

	<b>Group 1 (n=55)</b>	<b>Group 2 (n=53)<sup>∩</sup></b>	<b>Group 3 (n=55)<sup>∩</sup></b>	<b>p-value<sup>∨</sup></b>
<b>Knowledge-Overall<sup>⊥</sup></b>				
Improved	78%	83%	78%	NS
Stayed the Same	7%	11%	11%	
Worsened	15%	6%	11%	
<b>Knowledge-Medication</b>				
Improved	51%	58%	56%	NS
Stayed the Same	38%	34%	35%	
Worsened	11%	8%	9%	
<b>Knowledge-Monitoring</b>				
Improved	71%	77%	69%	NS
Stayed the Same	25%	23%	27%	
Worsened	4%	0%	4%	
<b>Knowledge-Pathophysiology</b>				
Improved	62%	62%	64%	NS
Stayed the Same	29%	32%	27%	
Worsened	9%	6%	9%	
<b>Knowledge-Symptoms</b>				
Improved	55%	58%	55%	< .05
Stayed the Same	29%	42%	38%	
Worsened	16%	0%	7%	
<b>Knowledge-Triggers</b>				
Improved	56%	60%	56%	NS
Stayed the Same	33%	40%	38%	
Worsened	11%	0%	5%	

∩ 2 subjects were missing the 9 month supplemental follow-up, on which follow-up asthma knowledge was assessed.

∨ Chi-Square/Fisher Exact Test, as appropriate, was used to assess statistical significance across groups. NS="not significant" (p > .05)

⊥ Overall Knowledge Score is an average of the individual scores for medications, monitoring, pathophysiology, symptoms and triggers. For individual scores 1=poor, 2=fair, 3=good.

*Symptoms - Mt. Sinai:*

At enrollment, the majority of participants (76% of those enrolled in the summer and 93% of those enrolled in another season) reported experiencing asthma symptoms 2-6 times per week (Table 6). There were no significant differences in baseline symptom frequency across study groups. By the first monthly follow-up, the majority of participants (100% of those with a follow-up occurring in a summer month and 79% of others) were reporting symptoms occurring ≤ once a week. In fact, 75% of participants enrolled either in the summer or in another season reported an improvement in their asthma symptoms between the baseline assessment and the first monthly follow-up. The improvement in symptom frequency persisted to the month 9 follow-up in which 81% of those followed-up in a summer month and 86% of others reported symptoms occurring ≤ once a week.

**Table 6. Asthma symptom frequency by group, stratified by season of enrollment or follow-up - Sinai<sup>∇</sup>**

Time Period	Season	Symptom Frequency	G1	G2	G3	Total Sample
Baseline <sup>⊥</sup>	Summer <sup>*</sup>	≤ once a week	16%	23%	27%	22%
		2-6 x a week	84%	77%	68%	76%
		daily	0%	0%	5%	2%
	Other <sup>*</sup>	≤ once a week	8%	6%	3%	6%
		2-6 x a week	92%	94%	94%	93%
		daily	0%	0%	3%	1%
Month 1 <sup>⊥</sup>	Summer <sup>**</sup>	≤ once a week	100%	100%	100%	100%
		2-6 x a week	0%	0%	0%	0%
		daily	0%	0%	0%	0%
	Other <sup>**</sup>	≤ once a week	82%	76%	80%	79%
		2-6 x a week	16%	24%	15%	18%
		daily	3%	0%	5%	3%
Month 9	Summer <sup>***</sup>	≤ once a week	75%	82%	86%	81%
		2-6 x a week	25%	18%	14%	19%
		daily	0%	0%	0%	0%
	Other <sup>***</sup>	≤ once a week	87%	90%	79%	86%
		2-6 x a week	11%	7%	21%	13%
		daily	3%	2%	0%	2%

<sup>∇</sup> There were no significant differences between groups after controlling for season (Chi-Square,  $p > 0.05$ ).

<sup>⊥</sup> Frequency for total sample differs significantly by season (Chi-Square,  $p < 0.05$ ).

<sup>\*</sup> Season of enrollment.  $n=63$  for summer and 102 for other seasons.

<sup>\*\*</sup> Season of month 1 follow-up.  $n=47$  for summer and 112 for other seasons.

<sup>\*\*\*</sup> Season of month 9 follow-up.  $n=37$  for summer and 119 for other seasons.

The types of symptoms experienced were assessed during each monthly follow-up and are summarized in Table 7. The most commonly reported symptoms included cough, wheezing, shortness of breath, and night cough. Seasonal differences in the types of symptoms reported had disappeared by the 9-month follow-up, suggesting an improved level of control over symptoms by that time.

**Table 7: Symptom type by season of follow-up – Mt Sinai<sup>∇</sup>**

Symptom	Season	% Yes Month 1 FU*	% Yes Month 9 FU**
Cough	Summer	38%	30%
	Other	45%	39%
Night Cough	Summer	2%	3%
	Other	9%	13%
Wheezing	Summer	11%	14%
	Other	37%	21%
Shortness of Breath	Summer	2%	8%
	Other	15%	12%
Activity Limitation	Summer	0%	3%
	Other	4%	8%
Other Symptom	Summer	2%	3%
	Other	5%	1%

Significant difference by season (Chi-Square/Fisher,  $p < 0.05$ ).

<sup>∇</sup> There were no significant differences between groups, so the symptom frequencies are reported collectively.

\* Season of month 1 follow-up.  $n=47$  for summer and 112 for other seasons.

\*\* Season of month 9 follow-up.  $n=37$  for summer and 119 for other seasons.

*Health Resource Utilization and School Days Missed - La Rabida:*

Table 8 displays the average number of hospitalizations, hospital days, ED visits, clinic visits and school days missed among the La Rabida population during the baseline and follow-up years. When compared with the baseline year, the La Rabida group changed significantly with regards to ED visits (-1.37, paired t-test,  $p < .0005$ ) and clinic visits (+1.54, paired t-test,  $p < .005$ ). Participants actually reported significantly more clinic visits in the follow-up year than they had in the baseline year. It is interesting to note that the changes from baseline to follow-up for ED and clinic visits essentially cancel one another out, suggesting that participants may have shifted from seeking routine asthma care in an ED setting to the clinic. Cost savings were achieved by shifting care from the ED to the outpatient clinic. Improvements from baseline to follow-up were marginally significant for both hospital days (-1.05, paired t-test,  $p = .0854$ ) and for school days missed (-2.75, paired t-test,  $p = .0567$ ). The intervention did not dramatically impact the total number of hospitalizations, however the baseline average of 0.51 hospitalizations did not allow much room for improvement.

**Table 8. Health resource utilization and school days missed: Comparisons with baseline values-La Rabida<sup>†</sup>**

	Hospitalizations	Hospital Days	ED Visits	Clinic Visits	School Days**
<b>Baseline</b>	0.51	2.27	2.37	1.60	8.52
<b>Follow-up</b>	0.33	1.22	1.00	3.13	5.76
<b>Difference</b>	-0.18	-1.05	-1.37	+1.54	-2.75
<b>% change</b>	-35%	-46%	-58%	+96%	-32%
<b>p-value*</b>	NS	NS (p=.0854)	<.0005	<.005	NS (p=.0567)

<sup>†</sup> Average number of total hospitalizations/visits over one year period. Baseline data represents the year prior to the intervention. The follow-up data has been extrapolated to represent 1 year's time. n=38.

\* p-value for the comparison of baseline to follow-up values (within group changes). Values were compared with a paired t-test.

\*\* Limited to school-age children ( $\geq 5$ ), n=31.

#### *Asthma Knowledge - La Rabida:*

The La Rabida baseline knowledge levels were relatively high for all categories (Table 9). This was not surprising given that the majority of participants had been diagnosed with asthma and followed in a La Rabida (which has a high standard of asthma care) clinic prior to enrollment into the study. Participants were generally most knowledgeable with regards to symptoms and triggers at baseline, and least knowledgeable with regards to monitoring and pathophysiology. Table 10 shows the level of improvement between the baseline assessment of knowledge and the 9-month follow-up assessment, both overall and in the individual areas of asthma knowledge. In all areas there was a considerable improvement in the level of knowledge between the baseline and follow-up assessments. Sixty-two percent of participants improved with regards to their overall asthma knowledge score.

**Table 9. Baseline asthma knowledge – La Rabida vs. Sinai G3<sup>‡</sup>**

	<b>LR (n=38)</b>	<b>Sinai Group 3 (n=56)</b>
<b>Knowledge-Overall*</b>		
Good	61%	25%
Fair	39%	54%
Poor	0%	21%
<b>Knowledge-Medication</b>		
Good	58%	27%
Fair	39%	50%
Poor	3%	23%
<b>Knowledge-Monitoring</b>		
Good	47%	20%
Fair	42%	52%
Poor	11%	29%
<b>Knowledge-Pathophysiology</b>		
Good	53%	21%
Fair	37%	50%
Poor	11%	29%
<b>Knowledge-Symptoms</b>		
Good	79%	30%
Fair	18%	50%
Poor	3%	20%
<b>Knowledge-Triggers</b>		
Good	24%	32%
Fair	76%	48%
Poor	0%	20%

<sup>‡</sup>Limited to subjects who completed the study. Excluded LR 3 subjects with extreme baseline values.

\* Overall Knowledge Score is an average of the individual scores for medications, monitoring, pathophysiology, symptoms and triggers. For individual scores 1=poor, 2=fair, 3=good. Overall Knowledge Scores is than categorized as: 0-<1.5=poor, 1.5-<2.5=fair, 2.5-3=good.

**Table 10. Changes in asthma knowledge from baseline assessment to month 9 follow-up - La Rabida**

	<b>LR (n=37)<sup>∇</sup></b>
<b>Knowledge-Overall<sup>⊥</sup></b>	
Improved	62%
Stayed the Same	35%
Worsened	3%
<b>Knowledge-Medication</b>	
Improved	43%
Stayed the Same	54%
Worsened	3%
<b>Knowledge-Monitoring</b>	
Improved	54%
Stayed the Same	43%
Worsened	3%
<b>Knowledge-Pathophysiology</b>	
Improved	49%
Stayed the Same	49%
Worsened	3%
<b>Knowledge-Symptoms</b>	
Improved	22%
Stayed the Same	78%
Worsened	0%
<b>Knowledge-Triggers</b>	
Improved	24%
Stayed the Same	76%
Worsened	0%

<sup>∇</sup> Excluded 3 subjects with extreme values. Also, one subject was missing a 9 month follow-up and therefore did not have Follow-up Knowledge Scores available.

<sup>⊥</sup>Overall Knowledge Score is an average of the individual scores for medications, monitoring, pathophysiology, symptoms and triggers. For individual scores 1=poor, 2=fair, 3=good.

## Cost Benefit Analysis

### Cost Benefit Analysis - Mt. Sinai:

Table 11 shows the average asthma-related health care reimbursement (IDPA) for study participants in each group during the years prior to and following the intervention. As all 3 study groups experienced significant decreases in health resource utilization between the baseline and follow-up year (Table 4), it is not surprising that all 3 also experienced substantial decreases in health care reimbursement, ranging from \$4,115 in G1 to \$5,166 in G3.

**Table 11. Asthma-related healthcare reimbursement in the year prior to and post-intervention.**

	Sinai Group 1 (n=55)		Sinai Group 2 (n=54)		Sinai Group 3 (n=56)	
	IDPA Reimbursement (\$)/child/year		IDPA Reimbursement (\$)/child/year		IDPA Reimbursement (\$)/child/year	
	Pre	Post	Pre	Post	Pre	Post
<b>ED Visits</b>	245.52	117.48	203.28	71.28	282.48	72.60
<b>Hospitalizations</b>	5,982.30	1,407.60	5,865.00	1,114.35	6,392.85	879.75
<b>Clinic Visits</b>	47.28	25.96	44.31	22.62	66.19	13.91
<b>Medications</b>	164.00	723.00	164.00	723.00	164.00	723.00
<b>Pulmonologist</b>	0	50.00	0	50.00	0	50.00
<b>Total Costs</b>	6,439.10	2,324.04	6,276.59	1,981.25	6,905.52	1,739.26
<b>Cost Savings*</b>	<b>\$4,115.06</b>		<b>\$4,295.34</b>		<b>\$5,166.26</b>	

\*Cost savings due to asthma-related health care costs between year prior and post-intervention.

Table 12a and 12b take into consideration the costs associated with conducting the intervention, and display the remaining cost-savings after accounting for program spending. The per person costs of conducting the program are summarized as well. The differences in the figures presented in the 2 tables are accounted for by the fact that one (Table 12a) uses a health educator’s salary for both the health education and the case management components, whereas the other (Table 12b) uses the salary of an RN for the case management component. With an RN available as the case manager, the initial medical history would also be conducted by this person, hence the differences in the per person costs of conducting the program not only in G3 but also in G2.

**Table 12a. Cost-savings attributable to the intervention when using a community health educator as the case manager.**

Sinai Study Group	Cost-Savings/person (HRU)*	Cost of Program/person	Cost-Savings/person (Program)**	Cost-Savings/\$ spent on program <sup>∇</sup>
<b>G1</b>	\$4,115.06	\$94.30	\$4,020.76	\$43.64
<b>G2</b>	\$4,295.34	\$141.02	\$4,154.32	\$30.46
<b>G3</b>	\$5,166.26	\$388.75	\$4,777.52	\$13.29

\*Cost savings due to differences in asthma-related health care costs between the year prior and post-intervention. See Table 8. HRU= “Health Resource Utilization”.

\*\* Cost-Savings (Program) = Cost-Savings (HRU) – Cost of Program

∇Cost-Savings/\$ spent = Cost-Savings (HRU)/Cost of Program

**Table 12b. Cost-savings attributable to the intervention when using a registered nurse as the case manager.**

Sinai Study Group	Cost-Savings/person (HRU)*	Cost of Program/person	Cost-Savings/person (Program)**	Cost-Savings/\$ spent on program <sup>∇</sup>
G1	\$4,115.06	\$94.30	\$4,020.76	\$43.64
G2	\$4,295.34	\$155.30	\$4,140.04	\$27.66
G3	\$5,166.26	\$662.83	\$4,503.44	\$7.79

\*Cost savings due to differences in asthma-related health care costs between the year prior and post-intervention. See Table 8. HRU= “Health Resource Utilization”.

\*\* Cost-Savings (Program) = Cost-Savings (HRU) – Cost of Program

∇Cost-Savings/\$ spent = Cost-Savings (HRU)/Cost of Program

The cost-savings are presented both as per person completing the program and as per dollar spent on the program. As it is our belief that a well-trained community health educator could effectively perform the case management activities, the results discussed here will focus on the numbers in Table 12a. Substantial cost-savings resulted from the intervention in all 3-study groups. The cost-savings were greatest for participants in G3 (\$4,778/person) as compared to G1 (\$4,021/person) or G2 (\$4,154/person). This result supports the hypothesis that case management does have an added effect on the health of the individual over health education and that this translates into further cost-savings for that individual.

Given that it is more expensive to fund reinforced health education or case management, it is not surprising that cost-savings per dollar spent were most dramatic for G1 (\$44 saved/dollar spent). However, both reinforced health education (G2, \$30 saved/dollar spent) and reinforced health education plus case management (G3, \$13 saved/dollar spent) also resulted in substantially greater savings than spending. To further illustrate the magnitude of these savings, we present the following example. To fund a community health educator in Chicago for one year would cost approximately \$35,000. Another \$5,000 would be expected in start-up and operating costs. Therefore, we would expect to invest approximately \$40,000/year for a community health educator. Based on the figures presented here, by investing that initial \$40,000 IDPA could anticipate saving approximately \$1.7 million if the G1 intervention were employed, \$1.2 million if the G2 intervention were employed and \$531K if the G3 intervention were employed. Hence, while the \$30 saved/dollar spent and \$13 saved/dollar spent do not seem dramatic when viewed next to the savings for G1 (a very low-cost alternative), they do translate into large overall savings.



## **Impact of Study on Patients and Participating Institutions**

### **Patients:**

The health of the study patients improved over the course of the study as evidenced by the decline in their use of health resources. They were placed on medical regimes endorsed by national guidelines, and learned about their disease process and how to adjust to changes in their lung function through the proper use of an asthma action plan. In G3, long-standing problems having to do with lifestyle, physical environment, and socioeconomics were resolved with the aid of our case managers. Although not truly examined in this study, it was the feeling of the study staff that asthma education taught by healthcare providers is often taught at a level of sophistication beyond that of many of our patients and that health related education is best delivered by someone from the community. This type of peer education was used in our study model and reinforced the usual education provided by healthcare providers, expanding study subjects' understanding of asthma and its treatment.

All participants, parents or caregivers were sent a short questionnaire and asked to complete five questions regarding their perception of the PAI: their child's present health, whether they found the program helpful, if they would participate in another program if one were offered, if they felt their child's asthma had improved, and if they would continue to seek health care services at this institution. Of the 30 respondents, 95% felt their child's asthma had improved due to the program, 91% felt the program was helpful, and 89% would participate in another program should one be offered. Additional comments written on the evaluations were statements of gratitude regarding the program itself and knowledge gained by the respondent. None of the respondents made any negative comments regarding the program. It is encouraging to know that the efforts of the PAI team were well received by the participants and their families.

### **Participating institutions:**

Our study exposed the limited use of national guidelines by primary care physicians in the communities from which our patients come. Patients either were not taught how to actualized a program of care recommended to them, or the physicians in these communities are not following standard national prescribing recommendations available since the early 1990's. We believe it is likely a combination of physician and patient ignorance that results in patients not benefiting from the major advances in knowledge and pharmaceuticals of the last 15 years. Our study addressed the patient side of this equation by providing peer education but did not deal directly with the physician side. By having a pulmonology consult as part of the project we insured patient's medications were appropriate, but did only peripheral education of their primary physician. Work is needed to educate physicians on the guidelines and how to implement them.

Mount Sinai continues to provide, through the services of our peer asthma educator, one-on-one asthma education of most pediatric asthma patients admitted to our hospital and for all patients referred to our pediatric pulmonologist. We have speculated that asthma

education of patients seen in the ED, but not admitted to the hospital, would also be beneficial. The PAI team is pursuing funds to examine, through a randomized controlled study, the impact of asthma education of the sick child with asthma and their primary caretaker while in the ED. As part of the intervention, limited case management will help ensure follow up with an asthma educated primary care provider.

There was minimal improvement in health care resource use by the La Rabida subjects suggesting their model of education and case management is effective. This has helped to reinforced the decision by that institution to continue to allocate some of its limited resources to maintaining a multidisciplinary team for asthma care.

The La Rabida asthma knowledge data demonstrated a growth in the understanding of asthma by patients and their families during the study period (see tale 10). All of the La Rabida patients were established patients and therefore had already gone through their education program conducted by physicians and nurses. Although possible the growth in knowledge by study participants may have been a function of repetition, the La Rabida study team believes the growth came from information being taught by a peer educator. They are hoping to be able to fund an asthma peer educator for their clinic.

Mount Sinai and La Rabida use the usual mechanisms, through CME activities such as grand rounds and sponsored programs, to educate primary care providers in our areas about asthma management. Both pediatric residency training programs incorporate into their curricula the NHLBI sponsored asthma guidelines with direct teaching of them by pediatric pulmonologists and allergists. Case conferences focus on asthma management. This exposure is also extended to medical students from Finch University of Health Science/The Chicago Medical School that rotate through Mount Sinai and The University of Chicago Medical School that rotate through La Rabida. In addition Mount Sinai is pursuing funding to support one-on-one asthma education of primary care office staff and providers including physicians, physician assistants and nurse practitioners. Comparison would occur for the outcome of patients seen in offices where this training occurs to those matched offices where it will not.

## **Recommendations**

### **For other health care providers**

Chicago's inner-city is at the epicenter of pediatric asthma. The problem of pediatric asthma in Chicago has far-reaching and long-lasting implications. The PAI encountered the problem of primary care provider's lack of adherence to the NHLBI Guidelines. The guidelines are either not being followed by primary care providers in our community or patients are not following the recommended treatment plan of their physicians.

Anecdotally, when participants and their families were asked about previous care and treatment for asthma they related that the only medication they were prescribed was a rescue medication. Most of our participants were not able to demonstrate proper inhaler or equipment usage and technique nor did they have a personal action plan. Many relied on the already overburdened and fragmented care of local emergency departments.

The issue of increasing primary care physicians' awareness and use of the appropriate standards of care in pediatric asthma is a challenge in the inner city. Providers must be held to standards of care. For providers affiliated with an institution, group practice, or HMO, clear asthma guidelines or protocols, based on the ones developed by the NHLBI should be created, disseminated and enforced. In those settings, chart reviews, review of prescribing habits, and case discussions with associated quality control steps are generally feasible and could help to enforce written guidelines.

In institutions with training programs, asthma guidelines must remain an integral part of the medical student and resident education. Mentors in training programs must be guided to follow the same practices and they teach and consistent practices should be followed through-out the program.

For the many storefront providers who are not affiliated with a hospital or organization disseminating asthma information and its application to patient care is more difficult. Programs to change the practices of this group of physicians will likely be successful only if it somehow linked to their reimbursement. Such programs exist within HMO contracts where reimbursement is linked to reduced use of services or type of drugs used to manage patient problems. Ideally, these kind of steps taken to influence practice patterns are used to reduce costs and improve quality of care. While it would be advantageous for every asthmatic child to be evaluated by a pediatric pulmonologist, with the current state of insurance reimbursement, lack of insurance coverage and shortage of pediatric pulmonologists, this is not a likely possibility. Education and appropriate oversight should be used to influence practice patterns.

Since many pediatric asthmatic patients utilize the ED as a mechanism for primary care, one of our recommendations is to institute an asthma program in the ED. During high volume times, an asthma educator/case manager would institute patient education and provide assistance with follow-up care. Referrals to local primary care providers would be tracked and physicians would be contacted regarding these patients. Educational assistance by the pediatric pulmonologist would be offered to the physicians caring for

these patients. The ED physicians would receive education from the pediatric pulmonologist regarding the standard care and treatment of pediatric asthma and NHLBI Guidelines. An extension of this program would include staff education in the primary care providers office by the health educator and access to information regarding health resources and obtaining medication and equipment. Primary care physicians would have access to a resource provider for questions or problem situations.

At this point it is important to emphasize that no program is without at least initial start up costs. It is imperative that some of the dollars saved at federal, state, or insurance company level be passed on to providers and their institutions for any of these new programs to be successful.

### **For further research**

As noted above, we feel the next two locations to study the impact of asthma education on quality of patient care and cost of care is in the emergency department and in primary care offices.

The ED is viewed, albeit mistakenly, as a site of primary care by many patients. ED physicians view their care of asthma patients as episodic and rarely decide to add controller medications to the rescue medications they normally prescribe to reverse an acute asthma attacks. Controller medications have little value in controlling the acute episode of bronchospasm that is the *sine qua non* of an asthma attack, yet is critical to ensuring patients remain in good health after the attack has subsided. The ED physician views controller medications as the territory of the primary care provider and their emphasis on rescue medications is confusing to the average family. Since patient use of the ED this way is likely to continue for many years to come, we feel it is incumbent upon us to examine whether asthma education in the ED can reduce ED visits and improve the care delivered to children with asthma, and can we alter the prescribing habits of ED physicians. We are proposing a study to use:

- Peer asthma educators in the ED to teach patients about asthma management,
- Train ED physicians about the proper use of controller medications in addition to their heavy use of rescue medications,
- Facilitate linkage of ED patients to asthma educated primary care providers.

We also believe it is time to examine the use of peer asthma educators in a primary care office setting without an initial pulmonology consult. We will use the same protocol used in this initiative, but add to it a one-on-one asthma education component for physicians that will lean on chart review and case studies.

Our initiative showed some value of case management but less than we expected. We believe refining the case management process by targeting users might increase the impact of their services on patient care and cost outcome.

Finally, we are currently pursuing data from IDPH on prescriptions given to the Medicaid patients enrolled in our study. We hope to use that data to address the question of

whether physicians have prescribed the use of controller medications prior to patients enrolling in our study but patients failed to use them properly. This would help answer the question of how much of the impact of our protocol was due to the asthma education and how much was a consequence of prescribing the proper drugs.

Providing asthma education to children and their families promotes healthier outcomes. Currently, there are many types of educational programs in existence. While one has not proven more beneficial than another, future research may help determine the most effective programs.

Identifying and measuring quality of life issues for pediatric patients with asthma would provide insight into issues patients and their families encounter. This would be beneficial in developing more effective case management efforts and resource utilization. Longitudinal studies in children with asthma would help identify long-term effects of medications, lung damage, physical activity and quality of life as children grow into adulthood. Issues surrounding adherence to treatment and control of asthma exacerbations over time might be beneficial in treatment choices for children.

There are many psychological issues surrounding children with asthma. In the inner city where asthma is so prevalent, there are few children who have not witnessed a child having an asthma attack or who know a person who has asthma. Asthma related mortality is in the news almost every day. Research identifying these psychological problems and how best to intervene and assist children in coping with these difficult situations would provide valuable insight for health care providers.

### **For public policy**

Effectively raising asthma awareness in the community, and for teachers and school staff and primary care providers is critical to the health and well being of our children. Placing asthma education programs where children spend most of their time, that is in school, should help with early identification of children with asthma as well as help to control triggers in their environment. Parents and caregivers must be educated on the appropriate care and treatment their asthmatic child should receive. Raising public awareness with church, school, and community programs will impact health care providers treatment choices as well.

Asthma education works. In conjunction with appropriate evaluation and treatment, significant cost savings have been demonstrated. Resources spent on developing health education programs delivered by health educators in the community are health care dollars well spent. Empowering communities with knowledge benefits everyone. Utilizing health educators within the community fosters the trust of the community in the health care system. Teaching proactive health measures to children and their parents enhances quality of life. Developing support systems for people with chronic illnesses and encouraging people to advocate for them instills confidence and promotes positive behaviors.

The fragmentation of health care in the United States is a major deterrent to the implementation of an effective pediatric asthma program. An additional deterrent is the lack of reasonable reimbursement for services of health care providers. Even though many studies have demonstrated substantial savings to the health care system when appropriate disease management is implemented, there is no mechanism to ensure appropriate medical management is undertaken nor is there any type of incentive for providers to do so. Programs that demonstrate positive outcomes for patients, cost savings for the health care system, and decreased usage of urgent and emergency care should be identified and implemented appropriately.

As a result of our study intervention the state of Illinois saved money. Reducing health resource utilization reduced cost of care for the state. The Sinai Health System saw a reduction in billable services at the level of the hospital and clinics that was partially offset by the grants for the project. For programming such as ours to be sustainable, it must include a financial incentive for health systems and/or physicians to setup and maintain this type of programming.

Illinois does not reimburse time spent by physicians and/or their offices on patient education. As a result, little time is available for healthcare providers to spend time on educating patients. Our study proves health education, and to a lesser extent case management, will reduce the cost of pediatric asthma care and improve the well being of patients. The cost of paying for this education is more than offset by the costs saving due to the reduction in the use of more expensive health resources. Physician practices are hard to change. Despite massive attempts to educate physicians about the NIH guidelines, little has changed in their office practices. We firmly believe that linking practice actions to reimbursement can influence physician practice. Linking dollars to physician practice has been used effectively by HMOs and group practices to alter physician prescribing habits and approach to care. Implementing practice guidelines is becoming more ubiquitous in the healthcare profession. We must pursue changes at the state level to create a system of reimbursement that can effectively change asthma care in medical offices.

To this end, a Medicaid program of training and payment for health education/case management, should be implemented to meet the goals of 1) ensuring that participating physicians are adhering to the 1997 NIH Guidelines for asthma care, 2) training and certifying a core of peer health educators on these same guidelines, 3) providing asthma care coupled with patient education on management of the disease, 4) quality assurance that the care provided meets the standards.

*Elements of the program:*

1. Continuing medical education (CME) of healthcare providers on the 1997 NIH Guidelines: Only those who can document this education and the follow through on the use of these guidelines in the care of their patients will be eligible to participate in a program of increased reimbursement for asthma care. We believe the most effective

model of provider education is one-on-one case based asthma education. Anticipated yearly costs for this CME component: \$250,000.

2. Training program for Bachelor level peer health educators: Participants will be community members trained and certified to be asthma educators. Anticipated yearly costs: \$500,000.
3. Grant program to fund health education/case management for eligible physicians or group practices with eligible physicians. Grants will be predicated on serving 150 patients per health educator per year, and will cover costs of salary, fringe benefits, administration and supplies. Cost per group of 150 patients would be \$60,000/year. To be eligible to participate a physician would have to be treating at least 150 pediatric asthma patients and document knowledge of the NIH guidelines as well as use of the guidelines in their offices. Anticipated yearly costs once fully operational: \$8,750,000
4. Quality assurance to demonstrate that participating physicians/health educators are accomplishing the stated goals will be conducted by IDPA or, with additional money, by a contractor. Chart review and review of prescribing practices by searching Medicaid databases will assess physician follow through on implementing asthma guidelines.

## Conclusion

### Study Summary

*The main goal of this study was to test the hypothesis that reinforced asthma education combined with case management is a cost effective means towards improving the health status of pediatric asthma patients in an underserved, inner-city community. The data presented here show a dramatic impact between the baseline and follow-up year on the outcomes of all participants involved in the Pediatric Asthma Intervention, regardless of study group. For example, the average size of the declines in utilization of health resources across all three groups can only be seen as enormous: about 81% for hospitalizations, about 69% for hospital days, about 64% for ED visits, and about 58% for clinic visits*

*The implications of this should not be underestimated. This study has shown that, in the face of a rising onslaught of asthma in the urban environment, there is much that can be done to effectively decrease asthma morbidity, health utilization, and associated costs. The facts that: a) the subjects of this intervention were not recruited because they were heavy users of health resources to begin with and that: b) they came from some of the most disenfranchised communities in a highly segregated urban environment further enhances the importance of our findings.*

*We are encouraged by the finding of a statistically significant trend in the main outcomes, with G3 improving to a greater degree than G1 or G2 for all five measures, and feel this lends support to the added utility of case management over health education alone. The fact that the magnitude of our results is similar to those recently reported by Kelly et al. who conducted an intervention very similar to that provided to our G2 in a similar population (inner-city, Medicaid insured, 94% Black) further validates our findings. Kelly et al. utilized a true control group, which received no intervention, and reported no significant changes from baseline to follow-up in their control group, but changes to the same magnitude as what we see in G1 and G2 for their intervention group. One of the inclusion criteria for the Kelly study was that subjects had been seen in the ED at least twice or had been hospitalized for asthma at least once in the preceding year. As such, they recruited a population that had more room for improvement than our population, and yet our participants improved to a similar or greater magnitude. Based on this comparison, we can gain confidence in our data and the fact that all 3 of our interventions are improving the health status of participants over what might be expected with no intervention.*

All study participants received a one time, individualized health education session. This suggests that even a one-time intervention can have a beneficial effect on asthma management and subsequent outcomes. Interpretation of our results is complicated by the fact that all study participants also saw a pulmonologist upon enrollment, making it difficult to separate out how much of the improvement in G1 was due to health education and how much was due to changes in medical management. Obtaining information about the prescriptions written for study patients in the years leading up to study enrollment



may tell us whether these patients were ever prescribed controller medications or just the rescue medications nearly all of them were using exclusively at the time of study entry. We are pursuing this data directly from Medicaid's database. We have obtained consent from 30 patients who were enrolled in the study to look at their Medicaid prescription history from the past few years. We hope to have the additional data sent to us by the state by the end of the calendar year.

In the current intervention, G3 participants universally received case management services. The average participant at Sinai required only 10.8 hours of case management over the course of 9 months, with a range of 2-78 hours. Obviously some participants required more assistance from the case manager than others. Future work will involve determining which participants were most likely to utilize case management services, and which derived the greatest benefit from those services. Targeting case management to those participants who would derive the greatest benefit should be a goal of future interventions. By screening and identifying those participants who require or might most benefit from the effort and cost involved in case management, the program would likely decrease overall costs as well.

We noticed during the initial medical evaluation of participants that primary health care providers on the West side and South side of Chicago are unfamiliar with the current standard of care for pediatric asthma, despite the availability of the NHLBI Guidelines. Many children were not on controller medications nor did they have personal action plans regarding their asthma care. *One of the important findings of the Pediatric Asthma Intervention was that patient and health care provider education is vital to the improvement in pediatric asthma outcomes.*

To this end, the Department of Pediatrics and the Emergency Department at Mount Sinai are submitting a grant application to initiate asthma education and appropriate follow-up with a primary health care provider while the patient is being treated in the emergency department. We are also pursuing funding for a demonstration project to educate, in their offices, primary care providers and their staff .

*The Pediatric Asthma Intervention demonstrated substantial cost-benefit. Calculated cost-savings were in the area of \$4,000-\$5,000/person/year for each of the 3 study groups.* This is substantially higher than cost-savings reported in association with other pediatric asthma health education interventions, which have ranged from \$543/person/year (Kelly, et al, 2000) to \$1,337/person/year (Greineder, Loane & Parks, 1995). As our cost-benefit analysis was conducted using IDPA average reimbursement for health resource utilization, our findings are not directly comparable to these analyses, which were undertaken from the perspective of the hospital. If we are able to obtain better estimates of asthma-related costs at Mt. Sinai, we will repeat our cost-benefit analysis from the perspective of the hospital. Also, as IDPA reimburses for hospitalizations based on Diagnostic Related Group (DRG) and therefore does not take length of stay into account, our current analysis accounts only for the effect of the intervention on total hospitalizations and not on length of stay. As G3 experienced nearly twice the reduction in hospital days of those in G1 or G2, repeating the analysis from the

perspective of the hospital and using the average cost per hospital day will show substantial differences in cost-savings per patient between groups.

### **Cost Implications**

We feel that our cost-benefit analysis was strengthened by the fact that we had very good estimates of the amount of time spent working on various issues. As such, the costs of conducting the intervention directly attributable to the salary of a community health educator could be more accurately assessed. We are also able to more accurately estimate the implications of our cost-savings to the IDPA. For example, to conduct the G1 intervention of one-time, one-on-one health education, would only require a health educator to spend about 50 minutes per subject. A full-time health educator working 2080 hours per year could therefore theoretically educate over 2000 people in a year. By saving IDPA \$4,021/person educated in asthma-related health care costs, in theory one health educator could therefore save IDPA nearly \$10 million in a year (Table 13a). It is not however realistic that one health educator working at one or two sites would encounter 2000 people in a given year, so we apply these estimates to a more plausible scenario. Sinai’s ED see an average of 600 children/year for asthma-related symptoms. If a health educator could educate 300 of those children, our cost-benefit analysis results suggest that approximately \$1.2 million in asthma-related health care costs could be prevented (Table 13a).

**Table 13a: Estimates of IDPA asthma-related health care cost-savings that could be achieved by one full-time (2,080 hours/year) community health educator in a year – Group 1 Intervention.**

Cost-saving/person completing=\$4020.76

<b>Theoretical*</b>		<b>Sinai ED**</b>	
<b>Hours/subject enrolled</b>	0.83	<b>Hours/subject enrolled</b>	0.83
<b>Patients contacted</b>	2,496	<b>Patients contacted</b>	300
<b>Patient completed<sup>‡</sup></b>	2,496	<b>Patient completed<sup>‡</sup></b>	300
<b>Cost-Savings</b>	<b>\$10,035,821</b>	<b>Cost-Savings</b>	<b>\$ 1,206,228</b>

\* Maximum number that could be enrolled based on the estimate of time spent on each enrolled subject (2,080/0.83).

\*\* It’s unrealistic that a health educator at one site could really enroll that many children. Therefore, an estimate of what could be saved if the health educator were based in Sinai’s ED is presented (~300 children encountered/year).

‡There is no follow-up associated with the Group 1 intervention.

Likewise, the slightly more time intensive G2 intervention, which includes reinforcement of the initial health education session, requires approximately 3.1 hours/child enrolled (assuming 25% are eventually lost to follow-up). Based on this time estimate, 676 children could theoretically be enrolled into the program by a single health educator in a year. Again applying the findings of the cost-benefit analysis to the model of a single full-time health educator working in Sinai’s ED and enrolling 300 children a year, savings of approximately \$930,000 in asthma-related costs would be expected (Table 13b).

**Table 13b: Estimates of IDPA asthma-related health care cost-savings that could be achieved by one full-time (2,080 hours/year) community health educator in a year – Group 2 Intervention.**

Cost-saving/person completing=\$4,154.32

Theoretical*		Sinai ED**	
Hours/subject enrolled	3.08	Hours/subject enrolled	3.08
Patients contacted	676	Patients contacted	300
Patient completed <sup>‡</sup>	507	Patient completed <sup>‡</sup>	225
Cost-Savings	\$2,104,707	Cost-Savings	\$ 934,722

\* Maximum number that could be enrolled based on the estimate of time spent on each enrolled subject (2,080/3.08).

\*\* It may be unrealistic that a health educator at one site could really encounter that many children. Therefore, an estimate of what could be saved if the health educator were based in Sinai's ED is presented (~300 children encountered/year).

‡Assumes a 25% lost to follow-up rate.

The G3 intervention is much more labor intensive, and requires 14.3 hours/child enrolled. A full-time health educator/case manager would therefore only be able to enroll about 145 subjects in a given year. Applying the findings of the cost-benefit analysis, we find that for those 145 subjects, \$521,000 in asthma-related costs could be prevented (Table 13c). If we wish to apply our results to the Sinai ED scenario, we would need to hire 3 full-time health educators/case managers to serve the needs of approximately 500 children. By doing so, we would expect to triple the cost-savings, making them similar to those expected from the G2 intervention. As previously mentioned, we could further maximize the G3 intervention savings by providing the case management component of the intervention only to those who will most benefit from it.

**Table 13c: Estimates of IDPA asthma-related health care cost-savings that could be achieved by one full-time (2,080 hours/year) community health educator/case manager in a year – Group 3 Intervention.**

Cost-saving/person completing=\$4,777.52

Theoretical*		Sinai ED**	
Hours/subject enrolled	14.32	Hours/subject enrolled	14.32
Patients contacted	145	Patients contacted	145
Patient completed <sup>‡</sup>	109	Patient completed <sup>‡</sup>	109
Cost-Savings	\$ 520,749	Cost-Savings	\$ 520,749

\* Maximum number that could be enrolled based on the estimate of time spent on each enrolled subject (2,080/14.32).

\*\*Same as theoretical.

‡Assumes a 25% lost to follow-up rate.

The current intervention utilized a Nurse Practitioner (NP) as the case manager. Cost-benefit analysis results are presented using both the NP's and the health educator's salary in accounting for the cost of the intervention (Tables 12a & 12b). The results discussed in the text however reflect program costs calculated using the health educator's salary for

case management activities. It is our belief that with effective training and preparation, health educators could easily adapt to the role of case managers allowing for the maximization of cost saving. Since ideally, the health educators are from the community, they are more keenly aware of the issues of everyday life in the communities than someone from another community. When screening participants for case management, the health educators would be instrumental in identifying potential issues. Moreover, families may be more willing to speak candidly about problems to someone from the community. Although it might still be necessary for a NP or Registered Nurse to oversee the project, the health educator could accomplish a significant amount of the case management. In this way, a more cost-effective model could be implemented.

### **Evaluation of Study Method**

No summary and conclusion section would be complete without a discussion of the limitations of our study process and the mentioning of a few “lessons learned” about the study process.

Since the study utilized recall for data collection, the ability of the caregivers to remember information may have affected our data set. Limiting the amount of time over which data could be recalled to <3 months minimized bias. To further mitigate the potential bias associated with recalled data, we are obtaining the Medicaid data on a subset of our sample for comparison purposes. Although the Medicaid data is likely not perfect, it is our hope that the comparison of these data sets will provide us with important information.

The validity of the questionnaires used to gather study related data had not been validated in other settings or by other studies. Therefore, no reliability and validity information was available for the tools utilized by the Pediatric Asthma Intervention. Theoretically, the frequency of the data collection may have influenced the behavior of the participants in the study.

The fact that there were no statistically significant differences between the Sinai study groups for four of the five main outcome measures (the exception being clinic visits) is not surprising given that G1 was not a true control group. The ability to detect significant differences between groups was hindered by the substantial improvement experienced by G1 between the baseline and follow-up years. The inclusion of 3 study groups led to a relatively small number of subjects per group, which further complicates matters. Had the sample size been larger, the degree of differences between groups reported here may have reached statistical significance. While it would have been ideal to have had the foresight to have avoided these complications in the interpretation of results, these valuable lessons in study design will prove very helpful in future work taken on by members of the team.

At the onset of the Pediatric Asthma Intervention there were several issues that were problematic. There was a lengthy process of designing the actual intervention and study protocol. The Institutional Review Board (IRB) process at the University of Chicago was

difficult and cumbersome. Additionally, there were several key personnel changes within the project, which contributed to some disorganization. Allowing for adequate start-up time is vital to the success of future projects. It is also beneficial to allow for sufficient time after the completion of data collection and analysis for production of summation reports, publications, and data presentation at local and national symposia.

## **Dissemination of Program Results**

In May 2002, Dr. Daniel Johnson presented the Pediatric Asthma Intervention Program and the preliminary statistics to the Pediatric Academic Society. The presentation was well received by the audience who offered positive comments regarding the program.

Additionally, an abstract has been accepted for presentation at the American Public Health Associations National meeting in Philadelphia on November 11, 2002. This presentation will afford us the opportunity to report our findings to the public health sector of the United States.

Several articles are planned for submission to medical, nursing, and public health journals over the next few months. The list of publications we are working on is:

- Further analysis of cost benefit
- Overview of the clinical intervention and outcomes
- Descriptive paper on case management of pediatric asthma patients
- Nurse oversight of lay educators including training and implementation
- Asthma education and its impact specifically on the use of peak flow meters and trigger alteration
- Medicaid data analysis
- Prescription practices of primary care providers

By disseminating the information we have obtained from this study, we hope to foster other conversations and interest in expanding the Pediatric Asthma Intervention.

## School Program

The final component to enhancing community education included providing education to teachers, parents, and students at various schools in the surrounding community. The asthma health educators would provide basic asthma education to small groups of individuals tailored to the group's specific needs. For example, working closely with Chicago Communities in Schools (CCIS), several schools were identified. Education was provided to groups of parents of asthmatics focusing on how to live with the disease in a manageable way. Groups of school-aged children received education regarding asthma basics. Finally, teachers were given information on asthma basics and how to respond in an emergency. Many students, teachers, and parents took part in the asthma education provided by this component of the Pediatric Asthma Intervention

From April 2001 through May 2002, asthma education was provided to seven schools on the South side and West side of Chicago. The included:

- Francis Scott Key  
517 N. Parkside Avenue  
Enrollment: 600 students  
Participants: 60 teachers
- Phobe Apperson Hearst  
4640 S. Lamon Avenue  
Enrollment: 1012 students  
Participants: 15 parents
- Lawndale Christian Health Center  
3860 N. Ogden Avenue  
Participants: 50 people from the community
- Helen M. Hefferan  
4409 W. Wilcox  
Enrollment: 566 students  
Participants: 30 teachers
- Nathan Goldblatt  
4257 W. Adams  
Enrollment: 677 students  
Participants: 75 students
- Harriet Beecher Stowe  
3444 W. Wabansia  
Enrollment: 1435 students  
Participants: 40 parents
- Douglas Taylor  
9912 S. Avenue H  
Enrollment: 799 students  
Participants: 80 teachers and parents

An important lesson learned from this phase of the Pediatric Asthma Intervention was the need for basic asthma education in the schools. There are a host of inconsistencies, myths, and beliefs regarding asthma in the community. Increasing awareness of proper

management and care of children with asthma is an essential part of future programs. The anecdotal feedback received from the participants in the schools we interacted with and CCIS supports the ongoing need for asthma education in schools.



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