Merck Childhood Asthma Network
Care Coordination Initiative Program Sites

The Children's Hospital of Philadelphia's Asthma Care Navigator Program

Principal Investigator: Tyra Bryant-Stephens, MD, Director and Founder, Community Asthma Prevention Program, Children's Hospital of Philadelphia (CHOP)

Lead Organization: The Children's Hospital of Philadelphia (CHOP)

Key partners: All internal to CHOP:

- CHOP CARE Network Administration, led by the Director of Ambulatory Care and the Medical Director of Ambulatory Care. Dr. Bryant-Stephens engaged them from the beginning of the program in order to attain sustainability after MCAN phase two was completed. Although CAPP has had home visits for many years, because it was not directly tied to the CARE Network, it was difficult to obtain institutional support. This program was strategically designed in order to place the Asthma Navigators in a medical home which would serve to close the gap between the community and the clinical office and garner institutional support. Annual reports were shared as well as the preliminary findings. Further support from the Medical Directors of the individual practices was gained through regular updates of progress given by Dr. Bryant-Stephens. Through the support of the administration, we are now able to sustain these positions.
- Asthma Care Committee, a multidisciplinary group which includes generalists, specialists, outpatient and inpatient professionals; led by Dr. Bryant-Stephens, it includes physicians and nurses who work at the three inner city offices and are responsible for carrying out asthma QI initiatives in that office. The ACC was essential to success of the implementation of this program.
- Asthma Clinical Science Research group, of which Dr. Bryant-Stephens is a member, which is also multidisciplinary hospital-wide group responsible for determining asthma care practice throughout the network. This group reviews scientific literature and makes recommendation to all general pediatricians as well as specialists managing asthma in the CHOP network.
- Other essential partners include the Social Worker at each practice, inpatient physicians and nurses, residents, and school nurses. The AN attended monthly ACC meetings and discussed any concerns, problems or barriers to implementation of YCACC. These meetings proved to be effective for identifying barriers and troubleshooting. Since the three practices were represented, often solutions were shared among the practices which facilitated implementation of the program.

Geographic Area of Focus: West, Southwest and South sections of Philadelphia

Eligibility Criteria:

1. 10-17 years of age at the time of enrollment;
2. have a diagnosis of moderate to severe persistent asthma;
3. either one asthma related inpatient admission or two asthma related emergency department visits 12 months prior to enrollment;
4. prescribed an inhaled corticosteroid;
5. medical assistance (Medicaid) as primary health insurance
6. have a primary care physician at one of the three urban primary care practices within the CHOP Care Network.
7. English as primary language of caregiver

How families were recruited/enrolled:

- retrieved a daily asthma inpatient census report that provided information on patients who were admitted to the hospital for acute asthma exacerbations.
- Emergency department (ED) physicians and nursing staff were asked to refer patients who presented in the ED for asthma flares to the program.
- CAPP also received referrals from primary care providers and clinical staff from each of the 3 urban primary care centers within the CHOP Care Network either by email, EPIC messages, and/or phone calls to the asthma navigators or program manager.
- After the first year of study related activities, CAPP opened the referral base to include community referrals, particularly receiving referrals from school nurses and daycare providers.

Participants

- **Targeted to enroll:** 270
- **Enrolled:** 255
- **Completed follow-up:** 255
- **Race:** 93.4% African American
- **Age:** 4.97 years (±3.5)
- **Sex:** 64.8% male
- **Income level:** (all eligible for Medicaid)

Description of Asthma Care Coordinators and number on project:

- 2 Asthma Navigators: Charmane Braxton and Carmen Perez
- Community Health Workers with 7-10 years' experience in in-home asthma education
- Asthma Health Care Navigators (AHCNs) observe the home, communicate the social context of the family to the providers and provide support and resources for families of high risk children with asthma.

Brief history of program: This program was built upon seventeen years of experience that the CAPP program has with utilizing community health workers and training primary care providers. The YCCAC program was implemented in three Children of Philadelphia inner city practices located in three of the highest areas of asthma prevalence in the city (Bryant-Stephens et al. J Asthma 2012).

The goal of the You Can Control Asthma Navigator Program was to study the effectiveness of an integrated Asthma Health Care Navigator (AN) model into inner city primary care practices which already incorporates best practices into their management of low-income and minority children with asthma. We hypothesize that the combination of two evidence-based models, *Yes We Can* and Patient Navigators into the "You Can Control Asthma" care coordination program, will result in a program which will improve care, reduce barriers to asthma care and improve caregiver satisfaction with asthma care.

Rationale: Due to the high prevalence of asthma in the CHOP PCC's and the lack of follow-up after hospital and emergency room visits, the primary outcome for this program was to increase follow-up visits. Our rationale is that if asthma navigators are able to connect with the caregivers to understand and address barriers to optimized care, their children would have less asthma exacerbations, better quality of life and improved satisfaction with the health care system.

GOALS AND OBJECTIVES

- Identify high-risk children with asthma and enroll in care coordination program
- Implement the Asthma Care Navigator Program care coordination model within four medical practices
- Improve asthma control and reduce asthma services utilization in target population
- Improve caregiver and patient's self-management skills
- Connect caregivers with resources needed

Los Angeles Unified School District Asthma Program

Principal Investigator: Kimberly Uyeda, MD, MPH, Director, Student Medical Services, Community Partnerships and Medi-Cal Programs, Los Angeles Unified School District

Lead Organization: Los Angeles Unified School District: Student Medical Services and District Nursing Services

Key partners:

- The Los Angeles County + University of Southern California Breathmobile
- Clinic (LACUSC) Breathmobile
- The Los Angeles Unified School District, School Nurses

Geographic Area of Focus: The Los Angeles Unified School District (LAUSD) is the second largest public school district in the nation serving more than 650,000 K-12th grade students, in over 850 schools. LAUSD covers an area of 710 square miles that includes the entire City of Los Angeles and 26 other cities and unincorporated areas.

Eligibility Criteria: The criteria to refer a student to the Asthma Program for intervention include one or more of the following:

- Ten or more days of school absences related to asthma
- Student recently in the emergency room related to asthma symptoms
- Recently discharged from the hospital due to asthma
- Recently diagnosed with asthma
- Parent request for asthma information
- Student makes frequent Health Office visits to take asthma inhaler without relief of asthma symptoms

Those targeted for the care coordination program include all of the following:

- Pre-school and school-age children and youth (generally 4-18 years old) and their parents/family
- Reside in LAUSD school boundaries
- Diagnosed or experiencing symptoms of asthma
- ACT score of 19 or below

How families were recruited/enrolled:

Students for the program were identified through existing school district health information and referrals from school nurses (78.5%), attendance counselors (9.6%), Parents (4.7%), School District Doctors (1.8%), the Breathmobile (mobile asthma clinic; 1.8%), School Principal (1.2%), PE teachers (0.2%), and other school staff (2.3%) when a child presented with symptoms suggesting asthma. Students for identification and referral met one or more of the following inclusion criteria; 1) 10 or more absences due to asthma, 2) recent use of emergency room or hospitalization due to asthma, 3) inability to participate in school curriculum due to asthma, 4) referral for assistance in asthma medication management, 5) other indication of a need for asthma-specific health education and assessment, and 6) an ACT score of 19 or less.

Approximately 1,200 referrals were made to the LAUSD Asthma Program from January 5, 2011 through June 20, 2013 and were attempted for enrollment by an asthma nurse. On average, 4 attempts were made to reach the students' caregivers for an initial home visit and baseline measure before a determination was made that they could not be located or interviewed. Approximately 160 of those referred had an ACT score of >19, and therefore were not counted as part of the sample discussed in this evaluation. 512 baselines were collected from January 5, 2011 through June 20, 2013.

Participants

- **Targeted to enroll:** 300 annually (not all stratified into Cross-site Evaluation group)
- **Enrolled:** 512
- **Completed follow-up:** 231
- **Race:** 68% Latino; 19% African American
- **Age distribution:** 13% aged 5 or less; 40% 6-8; 24% 9-11; 16% 12-14; 8% 15 or more
- **Sex:** 63% male
- **Income level:** majority are low income

Description of Asthma Care Coordinators and number on project:

- 3-4
- School nurses

Rationale:

LAUSD's vision is that every student will receive an education in a safe, caring environment, and every student will be college-prepared and career-ready.

Asthma profoundly impacts students, communities and schools in LAUSD. According to the Center for Disease Control and Prevention, 9.3% of children have asthma in the nation. In Los Angeles, the active asthma prevalence among children 5 to 17 years of age is 11.6%, higher than other age groups. While there is no uniform surveillance of asthma prevalence in LAUSD, the District does collect health records with parent-reported asthma. Approximately 5.4%, or 36,549, school-age children enrolled in LAUSD are identified as having asthma from parent report. We believe that the prevalence is higher, as previous Los Angeles school-based screening programs had found a prevalence of 12% for "probable asthma."

In addition, we know there are racial and ethnic disparities among children who suffer from asthma. African-American children are disproportionately affected with higher rates of asthma, hospitalization and emergency room use. Latino children and youth suffer from higher morbidity and mortality rates compared to White counterparts, but there are significant differences based on Latin country of origin, and as a group they are not as severe as African American counterparts.4 Children who suffer from asthma miss more school days, particularly if the asthma is not well controlled. Supporting other studies that have found this association, we have consistently collected data through the LAUSD Asthma Program that indicates school attendance improves with better control of asthma. While the link between asthma and

academic achievement is not as well documented, it has been suggested that students that suffer from poorly controlled asthma have poorer academic performance. There are limited studies that have looked at this relationship, but it is well accepted that if children have better controlled asthma, attendance improves, and the potential for better learning and achievement is established. It is with this context in 2000, LAUSD established the Asthma Program within District Nursing to address asthma in students, schools and our communities.

Brief history of program

Initially the Asthma Program was funded by a Center for Disease Control and Prevention (CDC) grant, and other funders over the years have included the Environmental Protection Agency (EPA), LA Care (a large Medicaid managed care health plan), and National Asthma Control Initiative (NACI). The Asthma Program staff included a core group of asthma nurses (school nurses) that provided an array of services, including home visitation, school visitation, case management, education, indoor air quality improvement training, environmental mitigation, and professional development. In 2005, LAUSD Nursing Services received a grant from the Merck Childhood Asthma Network (MCAN) to implement evidence –based programs that address childhood asthma and decrease health disparities. The grant facilitated the growth of the Asthma Program's home/school visitation by allowing additional staff to be hired, trained and deployed. The MCAN grant also allowed the Asthma Program staff to reach a larger geographical area in LAUSD, to reach underrepresented racial and ethnic groups, and refine and standardize the assistance to children with asthma and their families. A full description of the LAUSD Asthma Program and the outcomes is available in the "LAUSD Comprehensive Asthma Program: Final Report for Merck Childhood Asthma Network," March 31, 2010. In 2010, LAUSD was selected for Phase ll of the MCAN grant-funded programs. In Phase ll the Asthma Program researched and selected an evidence based care coordination model "Yes We Can" Children's Asthma Program and adopted and made modifications to make the model suitable for implementation within a school district. It should be noted that the Yes We Can model was used because so many of the components were aligned with the existing LAUSD Asthma Program, and certain components were adjusted or modified to begin to create "practice-based evidence" on what works effectively to improve asthma outcomes in school settings.

GOALS AND OBJECTIVES

- Improve access to and quality of asthma healthcare services for children enrolled in LAUSD schools by providing intensive care coordination services to high risk children and families
- Improve knowledge about asthma and self-management skills among affected children and their families
- Make communities and schools more asthma friendly to help children and families better manage the disease

Addressing Asthma in Englewood Project (AAEP)

Principal Investigator: Dr. Victoria Persky, Professor of Epidemiology, University of Illinois at Chicago School of Public Health

Lead Organization: University of Illinois at Chicago School of Public Health

Key partners:

- Damen Clinic
- Beloved Community Family Wellness Center (FQHC)
- St. Bernard Hospital
- Teamwork Englewood

Geographic Area of Focus: Communities of Englewood and West Englewood, located seven miles south of downtown Chicago

Eligibility Criteria: Children with a physician diagnosis of asthma aged 0-18 living in the communities of Englewood and West Englewood (this is the only site that did not require that the asthma be persistent)

How families were recruited/enrolled: Community Health Educators (CHE) recruit and provide education one day per week at local clinics: St. Bernard Hospital, Damen Clinic, Beloved and Englewood Neighborhood Clinic/UIC ; participants are also referred directly by a physician, schools, community based organizations, community events, and families already enrolled in the program

Participants

- **Targeted to enroll:** 200
- **Enrolled:** 203
- **Completed follow-up:** 134
- **Race:** 97% African American
- **Age distribution:** 28% aged 0-4; 45% 5-11; 27% aged 12 and up
- **Sex:** 57% male
- **Income level:**

Description of Asthma Care Coordinators and number on project:

- 1-2
- RN who was a parish nurse
- Another person provided education in the clinics towards end of project; not sure what her training was
- At start there was a CHE who ended up not following protocol, and the families she served are not included in the data set

Brief history of program

Phase I: Phase I of AAEP was a natural evolution of twenty years of Dr. Persky and Turyk's experience with community based asthma interventions based on the community health worker model. Previous projects had been lodged in health centers, schools, and community groups. The most developed of these programs was the Controlling Asthma in America Project funded by CDC. Several issues arose from that initiative that remained unresolved at its completion. The targeted area included a diverse group of 500,000, the size and diversity of which precluded comprehensive screening of the schools and provider intervention.

There were challenges inherent in lodging educators at a variety of sites across the city. Results from the home intervention program showed large and significant decreases in measures of asthma morbidity. There were approaches, however, developed by others for integration with local providers that would allow for greater integration of community health works with local health care providers. Our approach in Phase I was to modify our geographically defined multifaceted intervention to a smaller, very challenged community on the South Side of the city, incorporating approaches used in previous studies: Kreiger (2002, 2005), Evans et al (NCICAS, 1999) and Morgan et al (ICAS, 2004). In Phase I we screened almost all the schools in the targeted community, educated many of the health care providers and community groups and achieved more than 50% reduction in asthma morbidity and health care utilization. We felt, however, that more progress could be achieved in overall care coordination.

Phase II: The purpose of Phase II of AAEP was to define the extent to which a refined coordinated care model improves asthma outcomes and identifies specific strategies that are most effective utilizing a Community Health Educator (CHE) focused approach based on Yes We Can and a focused home intervention that would be enhanced with a more solidified physician-based effort. During Phase II of the project we refined the intervention model developed in Phase I of AAEP. Specifically we sought to demonstrate improved communications among families with CHEs, medical providers, schools and social service providers. The project aimed to further strengthen linkages among families of children with asthma and the institutions serving them, increase asthma knowledge in the Englewood and West Englewood communities, develop local infrastructures to address the disease, and provide home education and case management for families with more intensive follow-up where appropriate, as well as monitoring of cost and benefits of individual intervention components.

Rationale

AAEP was initially conceptualized as a community based, rather than provider based, program with strong ties with local clinics and individual practitioners. This model was founded on the lack of central health care facilities in the area, decentralization of the provider base and minimal infrastructures on which to build the program. The structure was created to reach underserved families without strong ties to large health care providers. A major goal was to work with community based organizations to help develop sustainable infrastructures.

La Red de Asma Infantil de Merck de Puerto Rico

Co-Principal Investigators:

- Marielena Lara, MD, MPH - RAND
- Gilberto Ramos Valencia, DrPh - University of Puerto Rico

Co-Lead Organizations:

- RAND Corporation
- University of Puerto Rico

Geographic Area of Focus: The G8 Communities, located in San Juan, Puerto Rico

Key partners:

- HealthproMed, Inc. (FQHC in San Juan)

Target Population: Children with moderate and severe asthma who live in the G8 communities and receive clinical care from the Federally Qualified Health Center HealthProMed.

Eligibility Criteria: Moderate and severe asthma, 0 – 17 years, receiving health care from Health Pro Med Community Clinic. Required a caregiver report of a medical professional diagnosis of asthma and any of the following:

1) daily asthma symptoms in the last two weeks
2) two or more nights of asthma symptoms in the last 2 weeks
3) 1 or more asthma hospitalizations in the last year
4) 2 or more ED asthma visits in the last year
5) use of preventive asthma medicine every day during the last week or rescue medicine at least twice a week.

How families were recruited/enrolled: Participants were referred from Health Pro Med, a federally funded health center. Caregivers of potential participants were approached by trained La Red Spanish speaking staff in HealthproMed's Pediatric Clinics and asked to complete an 8-item interviewer delivered screening tool to determine if the child had moderate or severe persistent asthma. To maximize recruitment efforts we also worked with community leaders to recruit children with asthma who may be eligible, made community presentations, provided an inservice session for health care facility and social work personnel on the study's referral procedures, and provided staff to help with the referral process during pediatric clinic times. Promotional flyers were distributed to community leaders, and posted in the health care facilities, pediatric clinics and EDs where children are treated for asthma. Many families were recruited by "word of mouth" from enthusiastic and satisfied study participants.

Participants

- **Targeted to enroll:** 250
- **Enrolled:** 250

- **Completed follow-up:** 192
- **Ethnicity:** 98.4% Hispanic
- **Age distribution:** 64% aged 0-4; mean age 7.06 years
- **Sex:** 50.5% male
- **Educational level:** 85% of caregivers were high school graduates or less

Description of Asthma Care Coordinators and number on project:

- 2-3
- Health educator has MPH and conducts in-clinic education
- CHWs do home visits for trigger remediation; been involved in La red for many years

Brief history of program

Children living in the US Commonwealth of Puerto Rico have the highest asthma prevalence rates of all US children, with forty to fifty percent of Island children affected. Responding to this need a highly committed group of community, health care, housing, and academic partners have over the last 13 years developed and implemented multiple interventions aimed at preventing and managing childhood asthma in 4 communities in San Juan Puerto Rico. To date, these interventions have been implemented over three distinct waves, initially in the Luis Lloréns Torres Housing Project (waves 1, 2), the Manuel A. Pérez Housing Project (wave 2), the Nemesio Canales project (wave 3), and most recently the G-8 communities including Barrio Obrero both in San Juan. Each wave consists of a separate group of children with asthma, who have participated in a range of interventions evaluated by pre-post measures. Each subsequent wave has incorporated adaptation and fine-tuning from previous waves. The La Red Project is a collaboration between the University of Puerto Rico School of Public Health and the RAND Corporation to continue to implement and adapt the Yes We Can clinic-based intervention and the Inner-City Asthma Study home-based intervention for children with asthma in San Juan, Puerto Rico. The two organizations forged a partnership with the Federally Qualified Health Center HealthProMed to serve families living in the "G8" neighborhoods.

Rationale

The rationale for our care coordination program and study for MCAN Phase 2 was based on our experience during Phase 1. *La Red*'s Phase 1adaptation of the YWC and ICAS interventions was very effective in improving asthma childhood outcomes and quality of care in the Puerto Ricans communities studied during Phase 1. We believe that an important factor in the observed success was the combination of the key intervention components of YWC and ICAS. *La Red* drew upon the strengths of the YWC team-based model and supplemented it with the strength of the tightly designed, intense, and tailored environmental intervention established by ICAS. YWC did not emphasize identifying and remediating home environmental risk factors and ICAS did not provide asthma education or team-based case management. However, we believe that by integrating the two approaches, *La Red* was able to provide a more complete asthma intervention that transcended the limitations of these two evidence-based approaches.

Another important contributing factor was achieving a delicate balance between implementing the prior intervention key components with sufficient fidelity while adapting it to our local characteristics and idiosyncrasies. In our experience the successful 'translation' of the original evidenced-based interventions would not had been possible without the multidisciplinary team of academic and community staff, including the original intervention developers, that brought together the cultural and technical competencies necessary for the translation process.
In addition, from its earlier formative stages, the study was built on a community-based participatory research approach that drew on successful partnerships with key community and health care system stakeholders.

GOALS AND OBJECTIVES

- Improve access to and the quality of asthma care for children with asthma in one of the poorest communities of Puerto Rico
- Strengthen and sustain site's infrastructure for ongoing research and sustainable public health system-level change
- Serve as a local and national model for the translation of community- and evidence-based interventions in high-risk Hispanic communities, specifically Puerto Rican communities
- Refine and evaluate the Phase I adapted evidence-based interventions as part of an asthma care coordination program across home, healthcare and community settings
- Extend the reach and replicate the demonstrated effectiveness of previous programs in a third community in San Juan
- Strengthen partnerships with key stakeholders to leverage combined resources to continue research and sustain public health system-level change