Childhood Asthma Disparities in Chicago

Developing Approaches to Health Inequities

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We conducted a needs assessment to develop an evidence-based, locally tailored asthma care implementation plan for high-risk children with asthma in Chicago. Our team of health policy experts, clinicians, researchers, and designers included extensive stakeholder engagement (N = 162) in a mixed-methods community needs assessment. Results showed the lines of communication and collaboration across sectors were weak; caregivers were the only consistent force and could not always manage this burden. A series of recommendations for interventions and how to implement and measure them were generated. Cooperative, multidisciplinary efforts grounded in the community can target wicked problems such as asthma.

Key words: asthma, child, health care disparities, research design

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DESPITE many advances in asthma interventions for children, inequities in outcomes persist.[1,2] The President's Task Force on Environmental Health Risks and Safety Risks to Children convened an Asthma Disparities Working Group to align information and federal programs regarding asthma disparities.[3] In December of 2014, the National Institutes of Health announced 2 companion funding opportunities to support implementation research that addressed these disparities. The first was a 1-year U34 mechanism to conduct a community needs assessment, design a comprehensive Asthma Care Implementation Program (ACIP), and propose a clinical trial to evaluate the ACIP. The second was a 6-year mechanism to implement and evaluate the ACIPs. ACIPs needed to address asthma in 4 sectors: medical care, family, home, and community.

This national focus on pediatric asthma inequities aligned with local efforts in Chicago, Illinois.[4–8] Strong partnerships existed between asthma advocacy groups, health systems, clinicians, community leaders, schools, local and state public health departments, engineers, and experts in design. Multiple initiatives evolved from these partnerships, including the Coordinated Healthcare Interventions for Childhood Asthma Gaps in Outcomes

(CHICAGO) Plan, a multicenter comparative effectiveness trial funded by the Patient-Centered Outcomes Research Institute (PCORI).[9] This trial tested an emergency department (ED) discharge tool called the CHICAGO *A*ction *P*lan after *E*D discharge (CAPE)[10] and community health worker (CHW) home intervention. The PCORI-funded study focused on the ED to home transition, but the investigators and partners had a broader vision about opportunities to improve asthma care, which was realized with the receipt of 1 of the 9 U34 awards in September 2015 (CHICAGO Plan II).

The CHICAGO Plan II was conducted to inform the design of future implementation research for pediatric asthma in Chicago. We sought to actively engage a diverse group of stakeholders who would support a community-based needs assessment (CNA) to determine the essential ACIP components. Stakeholders would review the CNA results and generate a final ACIP as well as determine the design of a research study to evaluate it. In this article, we describe the CHICAGO Plan II process and results, as well as implications that this type of stakeholder engagement and planning can have on implementation research design and program development in areas experiencing health inequities.

METHODS

Collaborative research team

The CHICAGO Plan II was led by a team of 5 principal investigators (PIs) who represented 2 community advocacy organizations, a community-based research institute and a university-based health care system. Collaborators included design and qualitative research experts, and experts in asthma technology interventions, implementation science, school asthma interventions, systems engineering, and economic analyses.

Provisional Asthma Care Implementation Program

The provisional ACIP was a proposed set of interventions that were supported by a strong evidence base. Our ACIP included a decision support and education tool called the CAPE.[10-12] We also incorporated a digital health tool called Propeller Health. Propeller Health is a Food and Drug Administration-cleared, Health Insurance Portability and Accountability Act-compliant digital therapeutic platform that combines inhaler sensors, mobile apps, predictive analytics, and personalized feedback to help patients and their physicians better control asthma.[13-16] The Propeller sensors passively monitor the use of inhaled medications, capturing the date, time, number of actuations, and geographic location (when paired with a smartphone). These signals provide an objective assessment of adherence to preventive therapy and rescue medication use. Patients and care teams have access to these visualized data through web dashboards and smartphone applications. CHWs (frontline public health workers who are trusted members of the community served)[17] were proposed for incorporation into EDs, hospitals, ambulatory clinics, and homes, as they have been shown to be associated with a range of improved asthma outcomes.[18-20] In schools, the ACIP included education for students with asthma and their adult caregivers, school staff and parents, as well as direct observed therapy of medications in schools, and use of school-based health centers.[21-24]

Engaging stakeholders

We used a tiered approach to actively engage diverse stakeholders in the CHICAGO Plan II ACIP. Level 1 stakeholders were organizational leaders who served as advisors to the project with decision-making responsibility. They participated via quarterly phone calls or in-person meetings. Level 2 stakeholders included caregivers of children with asthma and staff/providers in the community who care for these families. They were engaged through the CNA activities and an asthma-specific community advisory board. Level 3 stakeholders included scientific collaborators and consultants who agreed to serve on working groups. Work groups were organized around specific activities. Stakeholders were identified through the wide networks of the PIs and collaborators, via direct outreach, e-mail, web postings, and community meetings.

Community needs assessment

Because of the health disparities, we directed our CNA at 2 regions in Chicago with the highest asthma ED rates for children (247-349 per 10 000 children, the citywide average is 147 per 10 000) and comparable demographics.[8] A range of methods was used (Figure 1).[25] To be included, participants either had to work in a health care or school setting in 1 of the 2 regions, or be a caregiver of a child aged 5 to 14 years who lived in 1 of the 2 regions and had been in the ED for asthma at least once in the past 12 months. Non-English speakers were excluded due to limited resources. Participants were recruited by stakeholder outreach.

In-person key informant interviews were conducted with organizational leaders in the medical care and schools sectors and clinicians and school staff, to identify resources and barriers to implementing the ACIP. These occurred in the place of

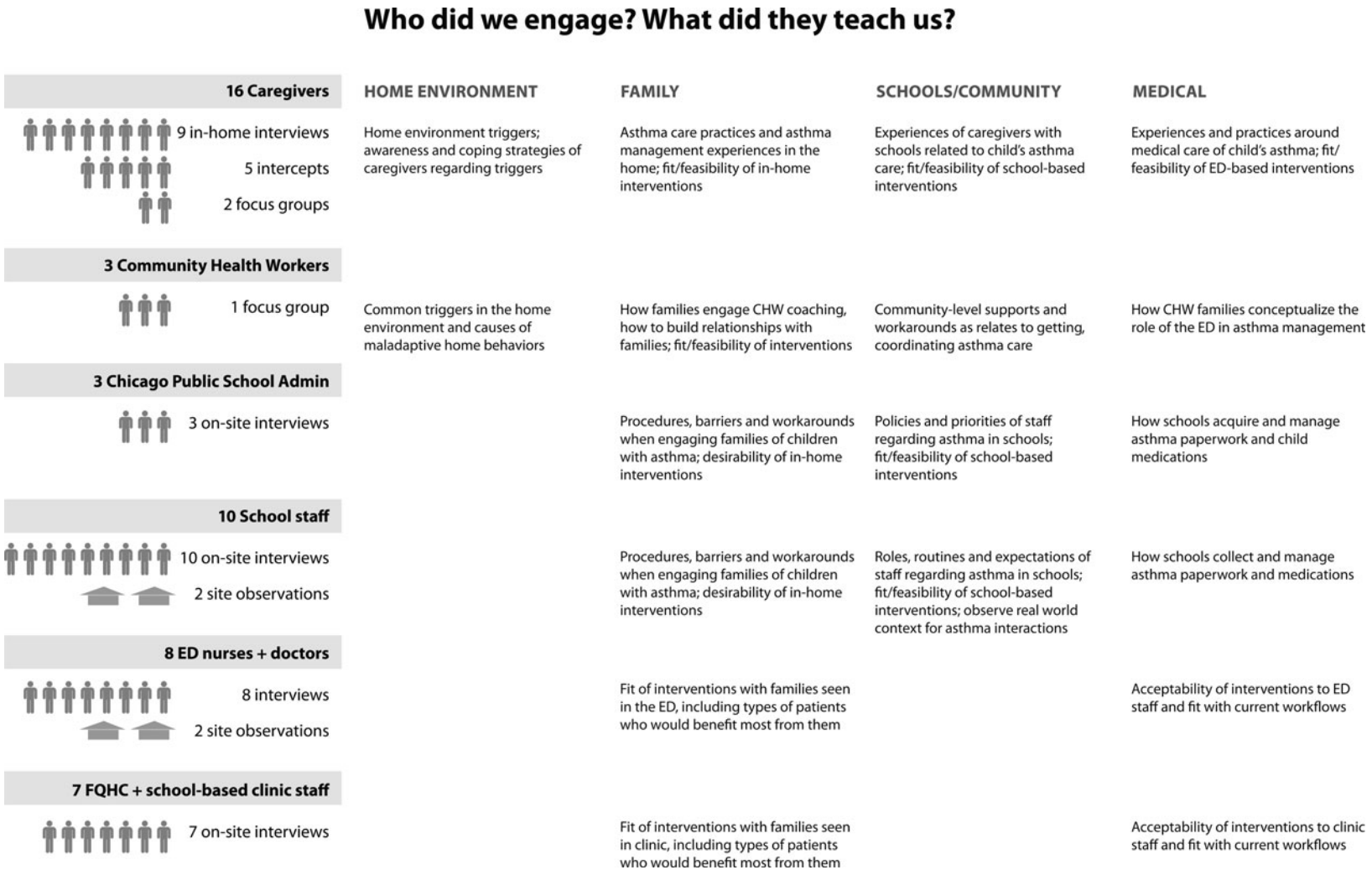

Figure 1. CHICAGO Plan II community needs assessment participants and results by sector.

employment, lasted about 60 minutes, and informants received a $25 stipend for participation.

Focus groups were conducted with caregivers of children with asthma regarding their experiences with asthma care, as well as the acceptability/feasibility of the ACIP. These lasted about 60 minutes. Caregivers received a $25 stipend for participation.

Individual interviews were conducted with caregivers of children with asthma in their homes to explore variances between what participants say they do (in focus groups) and what they actually do (in the home). These generally last about 120 minutes each. Caregivers received a $50 stipend for participation.

Technology-focused user-centered interviews/observations were conducted using Propeller Health. Providers of pediatric asthma care in both the primary care and specialty care settings were recruited from stakeholders. These providers identified children to participate. One family was recruited from other outreach efforts and participated independent of their provider. To be included, children had to have been prescribed an inhaled corticosteroid inhaler and albuterol inhaler (self-report). The Propeller sensors were attached to the participants' reliever and inhaled corticosteroid medications for 1 month to monitor the use of inhaled medications. The caregivers and providers were given access to these visualized data through web dashboards and smartphone applications. At the initial visit, caregivers were asked questions about health care usage, the home environment, trigger exposure, asthma control, and medication usage. At the end of 1 month, caregivers and providers were asked again about asthma control and about their experiences with the platform. Caregivers received a $50 stipend at the end of the observation period.

Man-on-the-street intercepts are short interviews conducted with caregivers of children with asthma. These were conducted at community events. Participants had to have a child with asthma to qualify. Caregivers were asked to reflect on ACIP components. Intercepts lasted between 1 and 20 minutes.

Community user-centered observations were conducted in several clinical and school settings. These are not interviews; they are observations of persons in their natural setting. The investigators observed for 1 to 2 hours, noting people and processes.

Data from existing sources were compiled and reviewed. This included data from the original CHICAGO Plan I study, City of Chicago data, needs assessments, and other research studies.

Analyses

Verbal interactions were audiotaped and transcribed. Comments and data were categorized into themes, following standard methodology for qualitative research.[25] We also employed the POEMS framework[26] (people, objects, environments, messages, and services) to organize observations from schools, EDs, and ambulatory health care centers, into the themes. Themes were discussed and modified in multiple research integration sessions that included investigators and community stakeholders. During these sessions, data and themes were visually presented on large storyboards that filled a room; everyone was encouraged to think about the data, ask questions, and make suggestions. These ideas were then incorporated into the data.

Finalize the ACIP using an implementation science framework

A subgroup of investigators and stakeholders reviewed the data themes and integration session feedback, and then finalized and summarized the themes through a process of group discussion. The summarized themes and their implications for the ACIP were presented to the full stakeholder group at an in-person/web-streamed meeting and distributed via e-mail for stakeholder input. The results and ACIP were updated to incorporate this feedback.

Design of a clinical implementation trial

Another in-person/web-streamed stakeholder meeting was held where the final results and ACIP were presented. Then stakeholders were asked to rank a series of intervention options using the RE-AIM (reach, effectiveness, adoption, implementation, maintenance) implementation outcomes.[27] "Reach" was defined as the amount of eligible children who would receive the intervention and the representativeness of this sample. "Effectiveness" was the potential effect of the intervention on an important outcome. "Adoption" was the percentage of eligible sites that would use the intervention. "Implementation" was the fidelity of the intervention over time and associated costs. "Maintenance" was the ability to sustain the intervention after cessation of grant funding. A score of 5 was the highest or best score that could be given for each proposed option, while 1 was the lowest/worst. Stakeholders were encouraged to think about the practicality of these options if they were implemented in a trial using existing evidence. These scores were used to make decisions on the final trial design, such as which stakeholders should be involved, how to identify and recruit high risk families, and what outcomes to collect.

Ethics, consent, and permissions

This study was approved by institutional review boards at the University of Illinois at Chicago Institutional Review Board (protocol #2015-0828, covered the Respiratory Health Association, Chicago Asthma Consortium, and Propeller Health), Sinai Health System (MSH#15-44), Illinois Institute of Technology (#2016-004), and the University of Chicago (#16-0510). Participants in the individual interviews, observations, and focus groups provided written informed consent. Participants in the man-on-the-street intercepts provided verbal consent.

RESULTS

In total, 162 stakeholders were engaged, representing a wide range of agencies from all 4 targeted sectors (medical care, family, home, and community) as shown in Figure 2. This was accomplished through 9 CHICAGO Plan II projectwide meetings and 31 smaller stakeholder meetings. Stakeholders participated in the CNA design plan, provided input on proposed interventions, facilitated data collection efforts, participated in data analysis, and discussed and ranked study design options.

The CNA results (Table 1) identified 2 cross-sectional strategies for improving child asthma in Chicago. Because the lines of communication and collaboration across sectors were weak, the results suggested a need for more efficient exchange of information to coordinate care. Second, the CNA identified a need for better, more consistent asthma education and management support from schools, providers, and the community. In the current environment, the job of moving information and coordinating care across sectors fell to caregivers who are often overwhelmed and underprepared to navigate the numerous disconnected systems and requirements of each sector.

Three of the explored interventions target these issues directly (Figure 3)[28]; these interventions became the final ACIP. The first intervention is CHWs that can cross sectors to support caregivers, providers, and schools with information, care coordination, and social support. The second is an electronic version of the CAPE that supports communication of the asthma management plan among caregivers, providers, and schools. The third is a coordinated approach to asthma education through the schools to ensure widespread distribution of information and consistent messaging.

The last step was to use implementation science methods to apply local experiences and needs to the evidence to determine how to implement and test the final ACIP. A stakeholder meeting was held to discuss and rank RE-AIM implementation outcomes. In total, 23 stakeholders submitted data. Stakeholder rankings were grouped as strongest (4-5), neutral (3), or weak confidence (2-1). Regarding the CHW intervention, 80% or more of stakeholders had strong confidence in the effectiveness and adoption of CHWs in the clinic setting. About half had strong confidence in the implementation and maintenance of CHWs in the clinic setting. Opinions regarding CHWs in the ED and hospital were mixed. Regarding the CAPE intervention, confidence regarding all implementation outcomes for the CAPE was very strong overall but was strongest in the hospital and clinic settings. The strongest role the CAPE could play was felt to be as a communication tool and reminder of the medical plan. Regarding Propeller Health, the effectiveness in the family/child sector and clinic setting was ranked high by most stakeholders. Due to the dispersed nature of the proposed ACIP across multiple ED and hospital settings, stakeholders felt that there would not be the necessary continuity to adequately implement and maintain the Propeller Health intervention. Regarding education, about half of the stakeholders had high confidence in the parent, child, and school education programs, but confidence in the student-wide asthma education in the schools was low. Regarding reach, payers were ranked as the strongest source for recruitment, followed by clinics and hospitals. Stakeholders were also asked about outcomes that matter to them (Table 2). Asthma control was endorsed as an important outcome by all, with quality of life, costs, and medication usage also almost universally endorsed.

An implementation trial design emerged that randomized participants to CHWs alone, CAPE alone, and combined CHW/CAPE. After a delay, the CHWs alone and CAPE alone arms would be offered full intervention. School intervention and CAPE integration into an electronic medical record were added in subgroups after another delay. Interventions were linked to the patients, not the health system, as requested by stakeholders to support sustainability. The investigative team included 15 individuals from clinical care, health services research, City of Chicago, Chicago Public Schools, and service and advocacy agencies. The proposal also engaged 60 advisors representing health care systems, government, and social service agencies. Recruitment would occur through Medicaid insurance payers and participating health care systems. Multiple outcomes, in the context of the RE-AIM implementation framework, were selected.

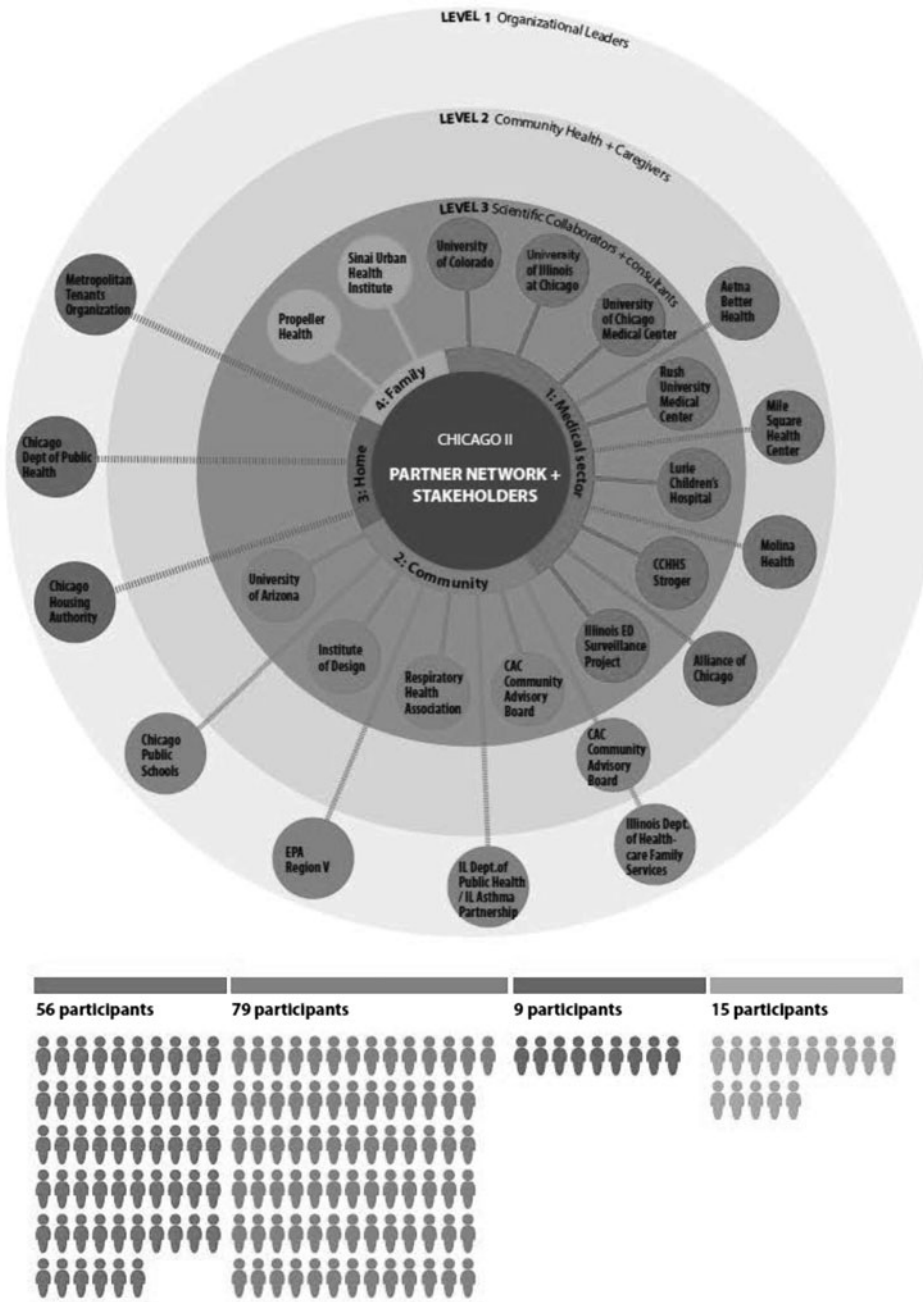

Figure 2. CHICAGO Plan II stakeholder participants.

DISCUSSION

The CHICAGO Plan II investigators and collaborators conducted a CNA of pediatric asthma in Chicago, which resulted in a final ACIP that coordinates CHWs, an electronic communication tool (CAPE), and school-based education. Then stakeholders modified these interventions for fit and feasibility in Chicago. For example, we decided that CHWs needed to be based outside of the health care setting in order to: (1) maintain adequate training, supervision, and support; and (2) follow up patients wherever they go (various EDs, hospitals, and clinics, schools, home). This model would provide well-trained and supervised CHWs that can be contracted by health care institutions and payers to provide a wide range of CHW asthma

TABLE 1. CHICAGO Plan II Community Needs Assessment Results

Medical care sector

ED important access point for high-risk children.
- Families frequently go to ED for care and services that could be obtained in other settings.
- Many families dissatisfied with ED care.
- Time, competing priorities, and technology limit ability to provide good asthma care (including education) in ED.
- Follow-up care from ED very difficult to obtain and value not clear to all families and providers.
- Recruitment for research very difficult in ED.

Community clinics in target areas.
- Quality of asthma care in clinics varies a lot.
- Some clinics have good asthma platforms in EMR but do not fully use.
- Clinic EMRs not often connected to hospitals.

EDs, clinics, and payers interested in CAPE. Supports communication between providers, caregivers, and schools.
- In ED, CAPE would support discharge process, but current staff do not have time to deliver it.
- In clinics, only providers can deliver CAPE and would be difficult to deliver with time pressures.
- CAPE needs integration into EMR.
- CAPE needs to be tailored to each patient.
- CAPE needs to be portable to other providers and caregivers.

EDs, clinics, and payers interested in CHWs. CHWs reinforce information from providers, and act as liaisons between providers and patients.
- In clinics, CHWs need full integration into clinic.
- Payers concerned about lack of credentialing, plan variations, existing Medicaid care coordinators.

Propeller intervention has a lot of potential for providers and patients, although barriers identified for implementation. Practicewide implementation would work better.

School/community sector

Asthma is a priority for schools. Their role is to educate and engage parents, and asthma is part of that. But other crises dominate.

Asthma underreported in schools.
- Require provider/parent/school communication to be officially counted and there is no easy process for this; all falls on parent to coordinate.
- Majority of 911 calls in schools for children without documented asthma.

Severe staffing shortages in schools limit asthma care.
- Not all teachers and staff understand asthma properly.
- Not always qualified people available to manage asthma.

Medicines not where they need to be.
- Illinois has a law allowing children to self-carry.
- Some schools do not allow self-carry.
- Some concerns for child safety with self-carry.
- Concerns for who is managing medicines in office.

Asthma education of all important.
- For children, works best if part of curriculum.
- Stakeholders have diverse education programs.

Poor communication between parents and schools, and within school staff regarding asthma management.
- Parents and schools could use an intermediary to help connect and manage asthma.
- CHWs would help.
- CHWs could give medications in schools.

Most families do not want daily meds given at school with some exceptions.

School-based health centers work well, but there are not enough of them.

The City of Chicago health goals include asthma monitoring and intervention in the same south and west neighborhoods.

Home environment sector

South and west sides of the city are high-need areas with high smoking rates, low child opportunity, high asthma ED rates, and high lead rates (implying poor housing).

Children have to stay inside because of violence.

City department of public health has the power to mandate home repairs. Provider involvement can help process.

Housing renovations difficult, take a long time, bring their own triggers.

Relocation often necessary but city process not always responsive to asthma needs, can bring new trigger risks.

Need resources for families renting without city assistance or who own their own homes.

CHWs have successfully served as connectors between tenants, providers, and landlords.

Family/child sector

Some parents do not feel providers give good care.

Caring for a child with asthma is very stressful.

Major social issues limit ability of families to focus on asthma.

Parents want and need asthma education.
- What they get currently does not meet their needs.

Parents think education should be for all, including young children and people without asthma.

Parents like school-based education, CHWs, CAPE.
- Not all families will accept CHW in the home.

Parents want CAPE and CHWs to integrate with schools.

Parents like idea of Propeller, although there were barriers identified for implementation target communities.
- Some families already use health phone apps.
- Many families have unreliable phone/data plans.

Abbreviations: ED, emergency department; EMR, electronic medical record; CHW, community health worker; CAPE, CHICAGO Action Plan after ED discharge.

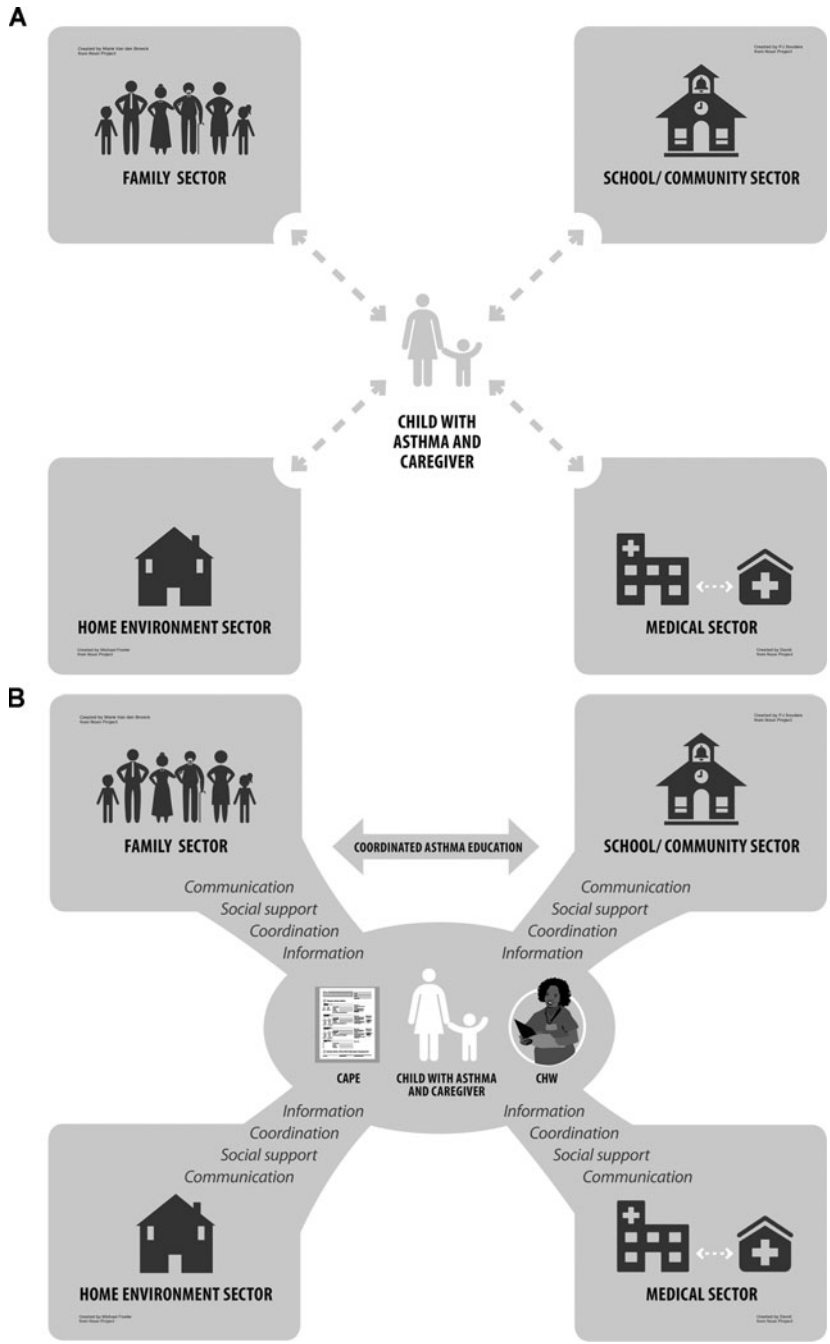

Figure 3. CHICAGO Plan II revised Asthma Care Implementation Program to address asthma inequities in Chicago children: (A) the problem and (B) the proposed solution. Adapted from Martin et al.[28]

support services to individual patients at high risk. The City of Chicago Department of Public Health played an active role in the entire research process, allowing the final ACIP to align directly with the City's official health plan.[8] The support for the ACIP and process in general was obvious when commitments of support for ACIP implementation were received from Chicago Public Schools, the Chicago Department of Public Health, the Chicago Housing Authority, 10 health care institutions from the Chicago area, 5 Medicaid-managed care organizations, the Illinois Department of Family Services

TABLE 2. Stakeholder-Endorsed Outcomes of Interest for Asthma Intervention Research

		Home Environment			Schools/ Community		Medical Care		
Sector	Family			Policy and Advocacy Organizations, EPA		Policy and Advocacy Organizations	Tertiary Care Systems	Ambulatory Care Systems	Payers
Stake Holders	Parent, child, Family	Health Department	Housing Agencies		Schools				
Asthma control	X	X	X	X	X	X	X	X	X
Quality of life	X	X	X	X	X	X		X	
Utilization (hospital/ED)		X	X	X		X	X	X	X
Individual costs	X	X	X	X		X	X	X	X
Medication usage	X	X			X	X	X	X	X
School attendance	X	X		X	X	X			
System costs		X		X	X	X	X	X	X
HEDIS/quality measures						X	X	X	X
Asthma rates and plans in schools		X		X	X	X			

Abbreviations: ED, emergency department; EPA, Environmental Protection Agency; HEDIS, Healthcare Effectiveness Data and Information Set.

(Medicaid), and the US Department of Housing and Urban Development.

This research highlights that, for many families in Chicago and elsewhere, asthma is just 1 item on a list of important issues competing for their attention. Caregivers often know what they could do to improve their child's asthma, but a wide range of barriers prevent this. The health care setting tries to support these families but faces its own challenges. Schools, where children spend up to a third of their days, have been making significant strides to service the health needs of their students, but their budgets, staff needs, and other obligations continually challenge their attention and resources.

The issues surrounding pediatric asthma in Chicago are common to other areas where we see health inequities. These health inequities meet criteria to be defined as a wicked problem. A wicked problem involves multiple interacting systems in the social context.[29] Often there is no central authority, the persons trying to solve the problem are also causing it, and there are better and worse solutions but no "right" solution.[30] Solutions to wicked problems do not have an end and therefore have no clear testable outcome[29] The CHICAGO Plan II serves as a prototype for how cooperative, multidisciplinary efforts grounded in the community can be used to address wicked problems. Asthma in Chicago affects all sectors of a child's life and seems to require changes in and between all of these sectors. By engaging stakeholders from all sectors in the process of describing the problems and vetting solution ideas, the CHICAGO Plan II team was able to generate a proposed ACIP that addresses many of the issues surrounding pediatric asthma in Chicago. Some of the methods used in this process are nontraditional. The project was led by community asthma advocacy leaders. Standard qualitative methods were merged with methods from the field of design to inform the fit and feasibility of interventions. Stakeholders used implementation outcomes to determine application of intervention components locally. The result of these efforts was a plan to tackle asthma that was evidence based and yet tailored to the local community. These efforts also allowed stakeholders to meaningfully invest in the research process and align their programs and policies with research activities. We encourage others to consider similar approaches to wicked problems in health care.

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