

Many Ingredients, One Sublime Dish

The Recipe for the Passage of Illinois HB5412 Into Law

Venoncia M. Baté-Ambrus, ABD; Amparo Castillo, MD; Erica Martinez, MPH, MBA; Jamie Campbell, MPH; Leticia Boughton-Price, BA; Melissa Gutierrez Kapheim, MS; José O. Arrom, MA; Wandy Hernandez, AS; Jeffery Waddy, MCHES, DrPHc; Sheila Castillo, MUPP; Margie Schaps, MPH; Yolonda Williams, PhD

Abstract: This article contextualizes the need for Illinois House Bill 5412 (HB5412), which calls for the establishment of a state board to create recommendations for the community health worker (CHW) field in Illinois, including a scope of practice, core competencies, training and certification standards, and sustainable funding and reimbursement mechanisms. Multisectorial partnerships and their outputs, coupled with frontline CHW interventions, created a synergistic climate conducive to the passing of this historic CHW legislation. This article provides a timeline and recipe for legislative success as described through processes and activities collaboratively undertaken, concentrating on a 5-year period (2009-2014). **Key words:** *coalitions, community-campus partnership, community health workers, policy*

INTRODUCTION

Community health workers (CHWs) are nonclinical professionals or volunteers who empower residents of their communities by increasing health literacy, promoting better access to health care and social services, thus serving as cultural liaisons between community and institutional stakeholders. Health promotion, disease prevention, and wellness are areas in which CHWs are adept change

Author Affiliations: *Research and Training UIC-Midwest Latino Health Research, Training and Policy Center, Chicago, Illinois (Dr Castillo); Health & Medicine Policy Research Group, Chicago, Illinois (Ms Martinez); Sinai Urban Health Institute, Chicago, Illinois (Ms Campbell); HealthConnect One, Chicago CHW Local Network, Chicago, Illinois (Ms Boughton-Price); Sinai Urban Health Institute, Chicago, Illinois (Ms Gutierrez Kapheim); HealthConnect One, Chicago, Illinois (Ms Hernandez); Health Profession & Sciences, South Suburban College, South Holland, Illinois (Mr Waddy); UIC Midwest Latino Research, Training and Policy Center, Chicago, Illinois (Ms Castillo); Health & Medicine Policy Research Group, Chicago, Illinois (Ms Schaps); and De Paul University, Center for Community Research, Chicago, Illinois (Dr Williams). Ms Baté-Ambrus is Independent CHW and Community Health Psychologist, Chicago, Illinois, and Mr Arrom is Independent Practicing Anthropologist, Chicago, Illinois.; and The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.*

The authors thank the Illinois CHWs and supporters, many of whom were mentioned in the article and others too numerous to name, including but not limited to, Laura Babena, Alfredo Lopez, Janna Simon, Charles Williams, Steve Whitman, IL HB5412 sponsors, especially Representative Robyn Gabel, and Gov Pat Quinn Dr Tiffeny Jimenez for advisement.

Correspondence: *Venoncia M. Bate-Ambrus, Independent Consultant Chicago, IL (criollav@botmail.com)*

DOI: 10.1097/JAC.0000000000000095

agents. Community health workers have been educating community members and service providers in the United States since the 1950s—and even longer internationally (Baté, 2013). Community health workers operate under various titles, including lay health advisors, peer tutors, outreach workers, promotores de salud, and many others (Baté, 2013; Sanabria, 2004).

This article contextualizes the need for passing a CHW bill, summarizes Illinois House Bill 5412 (HB5412), and provides a timeline and recipe for its passage, which includes some of the processes, initiatives, and activities collaboratively undertaken from 2009 to 2014. This was a CHW-led effort that combined the strengths and work of many partnering organizations, advocating alongside CHWs. These collaborations were synergistic and led to the landmark passage of HB5412, which is the first official recognition of the CHW profession in Illinois. When preparing any dish, or passing any law, in this case HB5412, it is crucial to have the right ingredients. The ingredients for HB5412 passage included the following:

- The will of CHWs and their champions (legislators, organizational partners, and community allies)
- The capacity to build upon an existing CHW employment and education infrastructure
- The ability to utilize research and the CHW policies of other states to inform Illinois efforts
- The political climate conducive to strengthening the CHW infrastructure

Key questions must be asked when preparing a dish or passing a bill:

1) If we create it, will others join us at the table and share the dish? 2) Do we have the right ingredients necessary to prepare this dish? And if not, where can we find them? 3) What's for dessert i.e. what outcomes are expected post-bill passage? These questions and more will be answered subsequently. The intention of sharing this case study, along with its successes and lessons learned, is to provide an example for other states seeking to legislatively advance the CHW profession. Described are the collaborations of CHWs and mul-

tisectorial partners and how they advanced legislation intended to strengthen the Illinois CHW infrastructure.

HB5412 is the preliminary step in strengthening the Illinois CHW infrastructure by giving official recognition to the profession and mandating a yearlong discovery process on the integration of CHWs into the health and social service workforce. Specifically, it calls for the creation of a state board to advise the Governor, the Illinois Department of Public Health, and the legislature on matters impacting the Illinois CHW profession. The Advisory Board is charged with establishing a CHW scope of practice, core competencies, and best practices. In 2016, it will provide recommendations for CHW training and certification standards and sustainable funding/reimbursement mechanisms.

This Illinois CHW legislative policy development case study discusses “how” and “why” HB512 was developed and passed (Yin, 2003). The authors used archival data (public records, meeting notes, published reports), qualitative analyses of CHW/stakeholder focus groups, an online survey, and direct observations, and were participants in 1 or more of the activities described. This case study provides an example for states endeavoring to develop CHW policies.

Kingdon's agenda setting theory and Patton's action research are 2 methodological lenses for this case study. In the agenda setting theory, 3 vital streams meet at a particular point in time, creating a window of opportunity for policy generation (Kingdon, 2011), wherein the actors/policy entrepreneurs harness the political climate to facilitate change. This article describes how social and community conditions, the leadership and will of the Chicago CHW Local Network (The Network), the employers' need to validate CHW competence, and the federal Triple Aim mandate for improved patient care, improved population health, and reduced health care costs (Findley et al., 2014), merged to open a policy window allowing for significant change to occur.

Action research intends to solve problems in a program, organization, or community by

being “part of the change process,” creating less-defined boundaries between research and action in a way that is “less systematic, more informal and quite specific to the people, problem and organization . . .” (Patton, 2002, pp. 221-224). This approach is well-suited to research with CHWs, who, by the nature of their work, may operate within, between, or outside traditional service systems, in formal and informal settings and in specific or broad contexts based on the needs of their communities.

Putting HB5412 into historical context

As previously stated, the CHW profession has existed in the United States since the 1950s. For decades, Illinois CHWs have used their skills to empower communities, increase health literacy, facilitate access to needed resources, and advocate for social justice (Castillo et al., 2010; Forst et al., 2004; Margellos-Anast et al., 2012; Sanabria, 2004). Hospitals, federally qualified health centers, health departments, and community and faith-based organizations in Illinois have utilized paid and/or volunteer CHWs to reach at-risk populations. Researchers have studied the beneficial impact of Illinois CHWs on asthma (Margellos-Anast et al., 2012), diabetes (Castillo et al., 2010), HIV prevention (Sanabria, 2004), and eye health and safety (Forst et al., 2004). Despite these valuable societal contributions and the associated research, CHWs continued to function for decades without official definition, recognition, or sustainability. Reiff and Riessman (1965) describe other challenges experienced by “indigenous workers”:

- unclear roles/undefined scope of practice,
- interprofessional tensions between clinical and indigenous workers
- training and certification concerns
- lack of opportunities for professional advancement

These historic and contemporary challenges necessitated remediation through legislation, making the HB5412 passage a sublime dish for many Illinois CHWs who were hungry for

change! The new law is the culmination of years of CHW and stakeholder advocacy.

Currently, few states have policies to promote CHW advancement and sustainability (CDC State Law Fact Sheet, 2013). An exemplar for many states is Massachusetts, for its progressive CHW policies and practices fostering successful outcomes. Massachusetts attributes its legislative success to strong collaborative efforts by diverse stakeholders, the establishment of strong CHW leadership including formation of a statewide CHW Association, understanding and defining CHW workforce issues, navigating the political climate, and developing an effective legislative strategy (Mason et al., 2011). Similarly, Minnesota established the Minnesota CHW Alliance, a CHW and stakeholder organizing body. The Minnesota CHW Alliance defined the CHW workforce and scope of practice, created statewide standardized curriculum for community and technical colleges and through research, and built a business case for CHWs that catalyzed legislative policies for reimbursement under Medicaid (Rosenthal et al., 2010). The federal impetus for CHW policy development included official designation of the CHW occupation by the Department of Labor and the advent of the Patient Protection and Affordable Care Act (ACA) of 2010 (Mason et al., 2011).

Multiple entities have endeavored to strengthen and sustain the Illinois CHW infrastructure for decades. These entities operated both independently and interdependently. This article focuses on multisectorial partnerships whose synergy created a climate conducive to HB5412 passage, by increasing awareness and recognition of the value of CHWs and garnering support for future legislation.

The multisectorial partners described here are the Chicago’s CHW Network, the Center of Excellence in the Elimination of Disparities at Chicago (CEED@Chicago), Health & Medicine Policy Research Group (Health & Medicine), South Suburban College (SSC), and Sinai Urban Health Institute (SUHI). This list is not exhaustive, and it is acknowledged that many other individuals and organizations

helped open the policy window. Illustrated below are many of the activities that piqued the appetite for the bill.

Community-campus partnerships for training, advocacy, and research

Before receiving funding, a network of Chicago CHWs met to organize and advocate for sustainability. The Network has been funded by HealthConnect One (HC One), a nonprofit health promotion organization since 2003. The Network has driven education and policy development efforts to create a standard educational CHW curriculum and formulate HB5412. Its mission is to support and facilitate the progress of health promoters and the diverse communities they serve by providing education, information and resources, health promotion, and disease prevention, and to effect positive change, growth, and understanding in their communities, regardless of socioeconomic status. The relationships with community and academic organizations cultivated by the Network, since its inception, would later prove beneficial to its legislative and educational endeavors.

Training

Since the nineties, HC One sought to establish an Illinois core curriculum for the CHW training and education. Together with members of other organizations, HC One's executive director created the CHW Core Curriculum and secured approval from the Illinois Community College Board for its 2007 implementation at Daley City College. Once the Core Curriculum program was defunct, the Network organized forums on CHW certification and new curriculum development. Moreover, it conducted a survey and several focus groups to ascertain CHW interest and needs in these areas. The Network identified champions in favor of reintroducing the Core Curriculum and asked them to sign letter of support. The Network found a key ally in the Dean of Health Professions at SSC and shared the letters of support to strengthen the case for adopting a CHW program. The Network's curriculum workgroup collaborated with

SSC to expand the original Core Curriculum by adding new courses reflective of current CHW workforce trends, this process was informed by survey and focus group data. The new curriculum was designed with stackable credentials for basic (20 credit hours) and advanced (39 credit hours) certificates and an associate degree (69 credit hours). It was approved by SSC's Board of Trustees and subsequently by the IL Community College Board and IL State Board of Education in 2013. The first SSC CHWs matriculated in fall 2014.

Advocacy

The Network continued to converse about policy and curriculum with organizational partners, community allies, and appointed and elected officials. Champions who supported the curriculum were asked to support legislative action. One issue discussed with the director of the IL Department of Health and Family Services (HFS) was the CMS ruling that allowed clinicians to prescribe preventive services conducted by nonlicensed professionals, to ascertain the HFS position on the ruling, because of its implications for the CHW workforce (CMCS Informational Bulletin, 2013). This discussion was tabled pending HB5412 passage and Advisory Board recommendations. The Network's forums, focus groups, and survey indicated strong training, certification, and legislative interests. Consequently Network leadership discussed HB5412 with stakeholders including the Chicago Department of Public Health, Healthcare Consortium of Illinois, Illinois Workforce Investment Boards, Healthcare Taskforce, Governor's Office of Health Information Transformation, Health & Medicine, and others.

In 2011, Network partner, the Center of Excellence in the Elimination of Disparities at Chicago (CEED@Chicago), established the CHW Stakeholder Alliance, an organizing body of Illinois decision makers in the CHW field. Housed at the Midwest Latino Health Research Training and Policy Center of the University of Illinois, CEED@Chicago convened a diverse collaboration of 40 health, social service, education, community, and faith-based

organizations that employ, train, advocate for, and conduct policy work with CHWs. The Alliance identified 7 interest areas: certification, training, workforce development, funding, research, collection and dissemination of best practices, and increasing clinician support for CHWs. The Alliance was an effective vehicle for networking and collaboration, later serving as a pool of agencies that endorsed the CHW model and supported advancements in legislation and curriculum. CEED@Chicago also created and released a presentation with videos to promote the CHW model to physicians and health care administrators by increasing recognition of the benefits of CHW health care integration for patients, providers, and communities. To better facilitate knowledge translation, the video presented relevant scientific and business information and featured CHWs and other influential health leaders including the Chicago Department of Public Health Commissioner; the President and CEO of an urban safety net hospital system; the US Department of Health and Human Services Regional Administrator and a Community Services Director, Community Health Nurse, and Promotoras de Salud from an independent suburban hospital.

Research

Research is important in documenting CHW value and legitimizes the need for legislation. As previously stated, the work of Illinois researchers has indicated the positive effects of CHWs in asthma, diabetes, HIV prevention, and eye safety. While research is available on the aforementioned, there is a dearth of research on assessing the CHW workforce. Consequently, between 2011 and 2013, SUHI researchers conducted a Chicago CHW health care workforce assessment. Evidence from this local assessment, national surveys, professional literature, and field-based case studies were used to develop the CHW Best Practice Guidelines (Gutierrez Kapheim & Campbell, 2014). The Guidelines is a toolkit for health systems seeking to implement or expand the CHW model to achieve the Triple Aim and an important infrastructure resource for Illinois and beyond. Toolkit recommen-

dations are customizable to organizational and programmatic needs and provide practical advice in addressing frequently encountered CHW program development, implementation, and evaluation issues (Gutierrez Kapheim & Campbell, 2014).

Policy partnerships

Many partners collaborated to advance the CHW agenda in Illinois. One such partnership occurred between Health & Medicine, an independent policy center, and the Network. With a 30-year history as system reformers and proponents of accessible health care, Health & Medicine provided to the Network expertise as policy researchers, developers, and advocates to advance the CHW legislative agenda. Health & Medicine's strong relationships with elected and appointed officials, state agencies, advocacy groups, and funders helped ensure that CHWs were involved in all state health workforce and reform efforts. Since 2010, Health & Medicine participated on steering committees for Illinois state health care reform efforts, advocated for CHWs to be part of the workforce expansion recommendations, and stayed engaged in the various CHW efforts, thus serving as a neutral convener and connector when policy research or policy development was necessary. In this capacity, Health & Medicine supported crucial HB5412 components: focus groups, forums (2011-2014), the Network's Policy Workgroup, strategic relationship management, funding, training, and research.

Policy development process

Besides the widespread efforts in Chicago, federal and state policies were creating a favorable climate for the official recognition of CHWs in the health care arena. The Patient Protection and ACA included grants to promote the community health workforce (Section 5313 of ACA). Illinois implemented the ACA by creating innovative health care reforms such as workforce expansion through the 1115 Medicaid Waiver application (Illinois Healthcare Reform). In metropolitan Chicago, collaborations between CHWs and stakeholders were momentous: SUHI released CHW

Best Practice Guidelines, CEED@Chicago informed physicians and administrators; SSC adopted a CHW curriculum, and most importantly the Network provided strong leadership and organization of its 500 members.

After meeting with the Network and stakeholders in 2013, Representative Gabel decided to sponsor CHW legislation. This opened a “policy window” for CHWs to be part of the political agenda and aligned the “3 streams” of the policy process (Kingdon, 2011). Merging were a legislative champion, federal and state healthcare reform climate, support from the Governor’s office and Illinois Department of Public Health, and strong policy advocates. To take advantage of the policy window, the Policy Workgroup and the Health & Medicine collaborated to draft legislative language and fact-sheets, conduct policy analysis and research, garner legislative support, leverage existing relationships, and facilitate negotiations with

opponents to guarantee passage of HB5412 (see Table 1).

To garner support for the bill, the Network joined 2 organizations in their planned advocacy days, participated in 3 advocacy trips to leverage the relationships, and provided testimony in the House of Representatives before a full vote took place. These trips provided a unique opportunity to meet legislators and staffers to raise HB5412 awareness and secure additional cosponsors.

Obstacles had to be addressed. Community organizations expressed concerns that legislation would exclude groups of practicing CHWs who would not meet new requirements and that credentialing would change CHW practice from its “grassroots” essence to a more clinical model. Nursing and physician advocacy groups alleged that CHWs might encroach upon the work of licensed professionals, and their professions would not have adequate representation on the Advisory Board.

Table 1. House Bill 5412 Passage Critical Incidents

October 2013	Representative Gabel decided to sponsor CHW legislation after meeting with the Health & Medicine and the Network
Fall 2013	Stakeholders conducted field assessment to ascertain potential CHW bill opposition Stakeholders met with Representative Gabel to discuss the potential CHW bill
January 2014–June 2014	The Network’s Policy Workgroup and Health & Medicine drafted legislation language, factsheets, and garnered support for legislation and facilitated negotiations
February 2014	Chief sponsor Representative Gabel introduces CHW bill HB5412 ^a
March 2014	HB5412 House Committee Amendment No. 1 adopted
April 2014	HB5412 passes the House of Representatives (Y84-N29) Chief Senate Sponsor Koehler introduces HB5412 in Senate
May 2014	Senate Committee Amendment No. 1 adopted HB5412 Passes the Senate (Y50-N0)
May 2014	HB5412 arrived in House for vote on concurrence Senate Amendment No. 1, House concurred (Y98-N17), and HB5412 passed both Houses
July 31, 2014	Governor Pat Quinn signed HB5412 to become IL Public Act 098-0796

^aHB5412 gained 15 additional cosponsors in the House of Representatives and Senate.

These concerns led to 2 amendments of the bill, 1 in House and 1 in the Senate. Community health workers advocated for the adoption of the American Public Health Association's definition of CHWs and refused to accept a minority composition on the CHW Advisory Board. Clinicians' concerns were addressed through a compromise that allotted 3 clinical seats on the Board to a physician, a nurse, and a licensed mental health practitioner. This accommodation changed the board composition to reflect a stronger clinical presence. In doing so, a seat originally designated for a nonclinical degreed professional such as an anthropologist or a community psychologist was eliminated.

DISCUSSION

HB5412 passage happened because there was an open policy window allowing the meaningful change that CHWs, employers, and communities hungered for to occur. The CHW desire for workforce sustainability, the employer need to meet the ACA's Triple Aim, and the communities' need for better access to and coordination of services triangulated to earn legislators' attention. Furthermore, CHWs, their employers and trainers, and post-secondary institutions have a vested interest in training CHWs for the profession's increasing and evolving demands. These interests shaped statewide conversations about certification, an issue under the purview of the IL CHW Advisory Board. Action research undertaken in Illinois and the CHW policies of other states were other influential ingredients leading to successful passage.

The synergies created via the multisectorial partnerships between the Network, Health & Medicine, CEED@Chicago, SSC, SUHI, and other policy entrepreneurs, coupled with frontline CHW interventions engendered an opportune climate for CHW legislation. Overlapping and intersecting agendas around CHW training and certification allowed for cross-pollination between the Network's policy and curriculum workgroups, CEED@Chicago's CHW Stakeholder Alliance,

and other stakeholder initiatives to strengthen the CHW infrastructure.

Now that Illinois CHWs and stakeholders successfully advocated for bill passage, what is for dessert? By design, HB5412 is a shell bill that requires additional legislation for substantive change to occur. The bill is a preliminary step to strengthening the CHW infrastructure and is an unfunded mandate that only required creation of a CHW Advisory Board responsible for making workforce policy recommendations. Therefore, the real dessert is the potential impact of the bill that has yet to be realized. It is expected, per a similar process in Massachusetts, that certification will be recommended by the Advisory Board (Rosenthal et al., 2010). What is next on the menu? Community health workers and stakeholders will focus on collective advocacy, to ensure that Advisory Board recommendations reflect the will, interests, and needs of the CHWs who have long been working to improve Illinois health.

Lessons learned

Lessons learned in the Illinois bill to law process may be generalizable to other states with similar objectives. Chief lessons learned include the following:

1. CHWs must develop, drive, and remain engaged with the legislative agenda.
2. A statewide CHW network should organize its membership, advocate for beneficial policies, and provide bidirectional, transparent, and timely communication between CHWs and stakeholders.
3. Multisectorial collaborations are key to successfully advancing legislation. Develop and nurture relationships as ally support is pivotal to successful outcomes.
4. CHW diversity and inclusion should guide policy development, and this is exemplified by designing a "grandparenting" mechanism for longstanding CHWs.
5. Relationships with elected and appointed officials are key for identifying legislative champions (and opponents).

6. The legislative process requires the art of compromise and negotiation. In this give-and-take process, figure out what you can and cannot accept.
7. Cultivate relationships with donors and funders (or those who have these relationships) as monetary and in-kind support aids CHW Networks in achieving their goals.

Based on these lessons learned, the following recommendations are offered:

1. Ensure that CHWs favor legislation (surveys, focus groups, and forums are helpful tools to make this determination) and if so are spearheading the advocacy effort;
2. Identify and engage multisectorial allies to help inform and support the policy process; and
3. Be responsive to local, regional, and national trends that open policy windows. Once these things occur, securing a legislative champion will be much easier.

REFERENCES

- Baté, V. M. (2013). *Community health workers and leadership training: A key to success*. Unpublished thesis, National Louis University, Chicago, IL.
- Castillo, A., Giachello, A., Bates, R., Concha, J., Ramirez, V., Sanchez, C., . . . Arrom, J. (2010). Community-based diabetes education for Latinos: The diabetes empowerment education program. *The Diabetes Educator*, 36(4), 586-594.
- CDC. (2013). *State law fact sheet: A summary of State Community Health Worker Laws*. Available from: http://www.cdc.gov/dhdsp/pubs/docs/CHW_State_Laws.pdf.
- Findley, S., Matos, S., Hicks, A., Chang, J., & Reich, D. (2014). Community health worker integration into the health care team accomplishes the triple aim in a patient-centered medical home: A Bronx tale. *The Journal of Ambulatory Care Management*, 3(71), 82-91.
- Forst, L., Lacey, S., Chen, H. Y., Jimenez, R., Bauer, S., Skinner, S., . . . Conroy, L. (2004). Effectiveness of community health workers for promoting use of safety eyewear by Latino farm workers. *American Journal of Industrial Medicine*, 46, 607-613. doi: 10.1002/ajim.20103
- Gutierrez Kapheim, M., & Campbell, J. (2014, January). *Best practice guidelines for implementing and evaluating community health worker programs in health care settings*. Chicago, IL. Sinai Urban Health Institute.
- Kingdon, J. W. (2011). *Agendas, alternatives and public policies* (2nd ed.). Boston, MA: Longman.
- Mann, C. (2013). CMCS Informational Bulletin: Update on Preventative Services Initiatives. Available from: <http://medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-11-27-2013-Prevention.pdf>.
- Margellos-Anast, H., Gutierrez, M. A., & Whitman, S. I. (2012). Improving asthma management among African-American children via a community health worker model: Findings from a Chicago-based pilot intervention. *Journal of Asthma*, 49(4), 380-389.
- Mason, T., Wilkinson, G. W., Nannini, A., Martin, C. M., Fox, D., & Hirsch, G. (2011). Winning policy change to promote community health workers: Lessons from Massachusetts in the health reform era. *American Journal of Public Health*, 101(12), 2211-2216.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Reiff, R., & Riessman, F. (1965). The indigenous nonprofessional: A strategy of change in community action and community mental health programs. *Community Mental Health Journal Monograph*, 1, 1-32.
- Rosenthal, L., Brownstein, J. N., Rush, C., Hirsch, G., Willaert, A. M., Scott, J. R., . . . Fox, D. (2010). Community health workers: Part of the solution. *Health Affairs*, 29(7), 1338-1342.
- Sanabria, R. (2004). VIDA/SIDA: A grassroots response to AIDS in Chicago's Puerto Rican community. *Convergence*. XXXVII(4), 37-42.
- Yin, R. K. (2003). *Case study research: Design and methods* (3rd. ed.). Applied Social Sciences Research Methods, Vol. 5. Thousand Oaks, CA: Sage Publications.