

# ENGAGING AFFECTED POPULATIONS IN HEALTH EQUITY



## AN EMERGING FRAMEWORK IN COLORADO

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Cover photo: *Parent leaders and members hold a protest for healthier schools outside of the Denver Public Schools offices. Photo provided by Padres & Jóvenes Unidos.*

## » INTRODUCTION

Recognizing the importance of supporting advocacy for policy change, in December 2013 The Colorado Trust Board of Trustees approved \$7.2 million to advance health-equity policy solutions through a field-building approach to advocacy. Using a field-building approach is intended to help build an effective and inclusive cohort of grassroots and grassroots advocates working together toward health equity. By providing resources to build skills and adaptive capacity within organizations, grantees will be better able to inform, shape and respond to changes in the policy environment. Field-building as a grant strategy requires a long-term commitment to fully evolve and succeed. Called the Health Equity Advocacy Strategy (HEAS), this multi-year effort is intended to begin the work to build a strong field of advocates for health equity in Colorado.

As well as the unique focus on field-building as a grantmaking strategy, the *process* of how the strategy unfolds is a first for The Colorado Trust. HEAS brings together four entities in a collaborative endeavor—a cohort of 18 grantees (see list on p. 15); the research and evaluation firm Social Policy Research Associates (SPR); strategic consultant, facilitator and thought partner Jamie Morgan; and Colorado Trust staff—to collectively approach how to build the stability and long-term capacity of the health equity advocacy field. Together, these four entities, called the “HEAS partners,” plan, strategize, make budget-allocating decisions and implement strategies to advance this effort. This is the first time in the 31-year history of The Colorado Trust that grantees, evaluators, facilitators and staff have had equal voice in how the work progresses.

Within this collaborative endeavor, a core focus of the HEAS partners has centered on discussions around effective, appropriate and authentic community-engagement strategies. Prioritized by the 18 grantees, identifying and implementing effective solutions to make progress on health equity demands engaging a wide range of partners representing diverse constituencies and points of view, including direct involvement of affected communities.

This report is the first in a series of learning papers from the evaluators that focus on specific facets of the HEAS. This paper describes the work of the grantees and how they have engaged affected populations. We hope this will be valuable to others who believe policy should not be made when the voices of those most affected remain silent.



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### » BACKGROUND

Colorado is known for its varying topographical landscape that encompasses the commanding Rockies, the expanse of the Eastern Plains, the Western Slope and the desert-like southern San Luis Valley sitting at the headwaters of the Rio Grande. Colorado is also home to a diverse population throughout the state—an indigenous Native American population, a growing Latino population, Asian immigrants and refugees, a largely urban African American population and a white population with varying socioeconomic backgrounds.

It is across this diverse population that we see persistent differences in health outcomes by race, ethnicity, geographic location and income. According to the Colorado Department of Public Health and Environment, dire health inequities are experienced by communities of color, people with limited English proficiency, LGBTQ communities and others who may have experienced systematic discrimination or exclusion.<sup>1</sup> By and large,



Youth leaders share "Know Your Rights" pamphlets (school discipline information) with their peers at North High School in Denver, Colo.

~ Photo provided by *Padres & Jóvenes Unidos*

these minority groups experience the lowest median household income, the highest infant mortality rates and the highest rates of diabetes in the state.

While addressing health inequities has long been a priority of many Colorado nonprofit organizations, there was no concerted effort to strategically coordinate and amplify efforts on critical health-equity policy opportunities. Further, the voices of affected communities (populations that experience the brunt of poor health outcomes and inequities) have largely been excluded from advocacy efforts focused on health equity in the state.

### THE HEALTH EQUITY ADVOCACY STRATEGY

Against this backdrop, The Colorado Trust launched the HEAS, a multi-phased, multi-year effort aimed at building a strong and effective field of health equity advocates. Over the last two years, the HEAS brought together and supported a cohort of 18 grantees, made up of a range of grassroots and grassroots advocacy, service and organizing groups to collectively approach how to build the stability and long-term adaptive capacity of a field of organizations that can influence and shape a constantly changing health policy landscape.

This paper presents a framework developed by SPR in collaboration with the HEAS cohort of grantees to assure authentic engagement of affected communities at multiple points in their health equity advocacy—including at the front end of surfacing issues, developing change agendas, bringing community stories to the fore in advocacy campaigns and assuring that on-the-ground implementation of successfully passed policy is faithful to its intentions. To gather information for this





## FAITHFUL LISTENING: TOGETHER COLORADO

Together Colorado works to build the capacity of diverse faith communities to resolve community issues on their own behalf. They begin by listening, conducting congregational listening campaigns and clergy caucuses to understand the stories of the congregations they serve and the issues they feel are most pressing to address. Currently, these issues focus on education, health care, public safety, immigration and economic justice. After identifying the issues, Together Colorado supports its faith-based communities with trainings designed to build their capacity to mobilize and advocate for justice in those arenas.

Together Colorado works with communities at multiple levels, depending on the issue and

the desires of the communities served. Some actions are congregation-specific, but larger actions might involve multiple congregations. Staff emphasize, however, that the actual strategy deployed for addressing an issue is less important than how you engage communities around those issues. Listening and encouraging communities to define their issues are critical to shaping meaningful and effective solutions that will result in the changes they seek. As one staff member noted:

*“Everything we work on comes directly from the folks we are working with. Ultimately, the approach you take in engaging affected populations is much more important than the strategy or format [for addressing an issue].”*

paper, SPR interviewed all HEAS cohort members and thoroughly reviewed their grant documents, including proposals and grant reports. SPR then created a draft framework based on the data collected and presented it to the cohort at one of its quarterly meetings. Cohort members and SPR engaged in deep discussion about the framework, and the cohort provided SPR with feedback. SPR then incorporated the feedback and presented an updated draft to the cohort for a final round of discussion.

The paper begins with a section that highlights some of the cohort’s strategies for

engaging affected populations and the shared values inherent in those strategies, followed by a presentation of the framework itself, which is designed to highlight the various strategies used by the cohort members to engage affected populations, and to serve as a basis for further discussion about shared strategies for the field.

### HARNESSING SHARED VALUES AND PROMISING PRACTICES

The HEAS cohort is made up of a diverse group of organizations from across the state that focus on health equity in different ways—from state- and local-level policy advocacy



Family Leadership Training Institute's first graduation class (October 2015), a 20-week class in Leadville, Colo. facilitated in Spanish to increase civic engagement of immigrant leaders. ~ Photo provided by Full Circle of Lake County, Inc.

organizations, to community organizing groups, to direct-service providers. Given the diversity of organizational foci, not all cohort members work directly with affected populations. However, they all have in place strategies for assuring varying levels of touchpoints with affected communities; while direct engagement may not always be the best or most strategic approach for every organization, all HEAS cohort members share the same values around the importance of engaging affected communities. Specifically, they believe that those most affected by inequitable policies and systems must have a voice in shaping policies and strategies aimed at rectifying those inequities.

Interviews revealed three distinct models for community engagement employed by cohort members: (1) direct engagement with community members; (2) engagement of community leaders/representatives; (3) strategic partnerships with those who directly engage community members. Within those

models are an array of strategies used by the HEAS grantees:

**Listening.** In their interviews, cohort members emphasized the importance of investing time, space and resources to “really listen” to community members—to let them articulate their issues and the obstacles that hamper their ability to thrive, rather than relying on statistics to make the case for change. They added that, too often, policy advocates define the issues for a community and only pull community members into the conversation when they need a testimony—a practice some likened to a “dog and pony show.” Talking directly to community members and engaging in authentic listening provides policy advocates an opportunity to talk to the “people behind the numbers,” in order to more accurately illuminate what the data means. It is important, cohort members emphasized, not to assume that the data, on their own, are self-evident, nor that advocates share a lens with affected populations that

## BUILDING CIVICALLY MINDED FAMILY LEADERS: LAKE COUNTY AND THE FAMILY LEADERSHIP TRAINING INSTITUTE

Full Circle of Lake County, Inc. (Full Circle) and Lake County Build a Generation (LCBAG) fundamentally believe that families are a horizontal thread in vertical systems, and that it is critical to bring their cultural diversity and experiential knowledge to policy advocacy. Building civically minded family leaders enables community members to advocate for equitable state and local policies that impact the health of people who live in Lake County. Full Circle, a direct-services agency focusing on at-risk youth and families, has partnered with LCBAG, a local community organizing entity, to offer an advocacy leadership training designed specifically for families, the Family Leadership Training Institute (FLTI).

FLTI, a 20-week civics program, provides leadership development for family members in self-advocacy, public policy, public speaking, and political and community processes. FLTI acts as a bridge to transition family members who participate in Full Circle's direct-service programming (such as parenting classes and English classes) to LCBAG's family advocacy and organizing programming. FLTI is now in the process of enrolling their second cohort of FLTI participants in Leadville. Project directors are proud of this effort, stating that FLTI graduates from the first cohort in 2015 are already taking on visible leadership roles that carry a significant level of responsibility, and that participation

in FLTI has empowered family leaders to use their voices to advocate for their needs. They shared stories of family leaders speaking eloquently with high-powered officials to seek resources for their community. They also spoke of other participants who, as a result of their participation, learned about the systems that impact their children and families and how to navigate and advocate within those systems.

The power of that knowledge and the simultaneous building of advocacy skills cannot be underestimated. As one project director recalled, this education shifted the dialogue and perceptions of power, which she described as "going from a place of, 'Can I even ask you a question?' to 'I'm going to ask a question and you better answer it because I'm a family leader.'"



The Family Leadership Training Institute class of 2016.  
~ Photo provided by Full Circle of Lake County, Inc.



## A CONSTITUENT-LED NETWORK OF COMMUNITY ADVOCATES: COLORADO CROSS-DISABILITY COALITION

Colorado Cross-Disability Coalition (CCDC) advocates for social justice for people with all types of disabilities via a network of community advocates. CCDC's mantra, "Nothing About Us Without Us," drives the organization's priority for giving people with disabilities meaningful involvement and decision-making power—not just in the organization's staffing and operations, but more broadly in advocating for rules and policies that impact their daily lives.

CCDC began training advocates in 2004 and has been growing and refining their training such that, as of 2014, training participants are able to receive continuing education credits through the University of Denver. CCDC's advocacy training approach builds community leaders at multiple levels. Advocates are trained volunteers, many of whom were clients

of CCDC at one point in time and who know firsthand the impact of struggling to access adequate health care. CCDC builds upon this personal knowledge and passion through a successful, evidence-based training program that focuses on individual and systems advocacy. Advocates learn how to represent the civil rights of individuals with all types of disabilities; navigate the local, state and federal benefit systems; and uphold the Americans with Disabilities Act. Certified advocates who have gone through the eight-week training, specialized classes and mentorship are also supported by weekly case review meetings for individual advocates, as well as bimonthly coalition meetings for systems advocates. Each year, CCDC graduates 20 or more advocates who are equipped with knowledge, skills and resources for fighting for equitable outcomes for Colorado's disability community.

enable them to make meaning of the data in ways that align with the lived realities of these populations.

In order to better understand community needs and assure their work effectively supports those needs, HEAS cohort members engage in a wide variety of listening strategies. These include community surveys; statewide listening tours to share data, gather

feedback and listen to community concerns; community meetings and town halls that bring together community members, public health officials and school officials to discuss pressing issues; population-specific focus groups to understand key concerns impacting different constituencies; and congregational listening tours and caucuses with clergy from various faith-based communities.



**Leadership development among community members.** Community leadership development is a core engagement strategy for several organizations within the HEAS cohort. This strategy enables organizations to support and nurture community leaders while also creating a more streamlined and trusted path for broader community engagement. Cohort members engage in a variety of leadership development strategies, aligned to fit the needs of their target communities and honor the capacity of their volunteer leaders. Some of these strategies take existing leadership development approaches and adapt them to fit their context. For example, a local advocacy organization employs a resident leadership model that is promoted by another local foundation, while a faith-based community organizing organization uses a leadership development model rooted in PICO-based (People Improving Communities through Organizing) approaches. Another community organizing group created its own leadership model in response to the needs and capacities of the neighborhood residents they serve. At least two cohort members run community leadership development programs focused specifically on building the capacity of community leaders to provide health education to community members and help them understand systems navigation. Two cohort member organizations utilize a *promotora* model<sup>1</sup> to support health education in the Latino community; one direct-service provider focuses specifically on building the capacity of its patient navigators to serve as strong bridges to communities and trusted recipients of the communities' health

stories. Common to all of these strategies is a focus on assisting community leaders in “stepping into their power,” and the belief that supporting communities in growing and strengthening their leadership base is key to building community power and assuring the voices of the community members themselves are heard.

**Community capacity building.** Cohort members said that a critical component of their leadership development and community engagement strategies includes a certain level of capacity-building support to assure that community members have the knowledge and skills they need to effectively voice their concerns and advocate for change. Cohort members leverage their particular areas of expertise (or those of partner organizations inside and outside the cohort) to support a wide variety of community capacity-building



Julie Reiskin, executive director of Colorado Cross-Disability Coalition, with legal scholar and citizens' rights advocate Edgar Cahn, JD, PhD.

~ Photo provided by Colorado Cross-Disability Coalition

1 Community lay leaders who are trained to provide health education to community members and support them in systems navigation and access to resources.



Youth members at North High School take a stand against the school-to-prison pipeline during the Dignity in Schools 2015 Week of Action. *Photo provided by Padres & Jóvenes Unidos*

activities. Political education and advocacy trainings, for example, are a core capacity-building strategy employed by the cohort's policy advocacy and community organizing groups. They describe political education and advocacy trainings as approaches that go hand-in-hand. Their political education efforts teach community members about political processes broadly, so they know their rights and how the political processes work, and targeted advocacy trainings then build

the skills to support community members in effectively raising their voices within these political processes.

In addition to broader political structure- and process-focused trainings, cohort members also provide issue-specific education in a variety of areas that impact community health, such as family medical leave, affordable housing, transit systems, school dropout rates, preschool expulsion practices and the

school-to-prison pipeline.<sup>2</sup> Cohort members also talked about helping community members build their equity lens as a core aspect of their capacity-building work. Building an equity lens generally involves taking a specific issue and having dialogues with community members to understand the connections between these issues and health equity—for example, how the lack of affordable housing or effective transit systems stress families and communities, or how inequities in education ultimately lead to other inequities that in turn affect the future health of our children. HEAS partners emphasized the importance of recognizing that communities are powerful and that the goal of these capacity-building efforts is to support them by strategically channeling that power.

**Participatory research.** While this was not as prevalent a theme, some cohort members talked about the importance of engaging community members in participatory research on specific issues. Too often, community members serve as subjects of research. Cohort members emphasized the importance of having a more inclusive approach to research, including providing community members with substantive and meaningful roles. These include asking community members' support in helping to shape the research, informing research design, collecting data and informing the analysis. Cohort members shared examples of how they have engaged community members in reviewing and designing tools (e.g., interview protocols or surveys) to assure that they are

asking the right questions and that wording aligns with the cultures and contexts of the intended respondents. They have enlisted community members to help with community focus groups, administering surveys and environmental scans to assess progress or obstacles in specific issue areas.

Cohort members reported that engaging community members in this way helps to assure that they are collecting data that are relevant to the community, and that the lenses they use to analyze that data incorporate the knowledge and experiences of community members. Moreover, by engaging community members in the research process, they are growing the pool of people equipped to tackle this aspect of the work in the future.

*“There are also organizations that don’t have ‘a constituency,’ like direct-service providers do, who are in touch with a number of directly affected people every day. So I think making a commitment to work through those organizations first, and to work through institutions that are trusted in communities across the state, is hugely helpful. We have roles to play in the ecosystem. And we should be playing to our strengths.”*

~ HEAS cohort member

<sup>2</sup> Criminalizing student behavior by bringing law enforcement into schools or by the routine use of out-of-school suspensions or even expulsions, pushing students into unemployment and increased contact with the justice system. This practice has been shown to disproportionately impact students of color both in Colorado and nationwide.



**Strategic relationships.** While all cohort members share the same values around engaging affected populations, not all members have the capacity or expertise to do so directly, nor does the cohort feel this is an effective approach for all organizations or for all communities. Indeed, some community organizing groups emphasized that advocates needed to be thoughtful and respectful of community capacity as well, noting that the very communities they are supporting are often stretched thin and cannot attend multiple hearings, trainings, events or meetings.

All cohort members emphasized the importance of relationship building to assure



Parent leaders and members protesting at Denver Public Schools offices for healthier schools.

~ Photo provided by *Padres & Jóvenes Unidos*

a solid, trusted through-line to community members. To that end, a core strategy employed by all cohort members in their efforts to engage affected populations—even those members who are already deeply engaged with community members—is the development of strategic partnerships with diverse and trusted organizations, or coalitions that have strong ties to different communities. These partnerships enable organizations to focus on their strengths so that they can lean on one another to more effectively and respectfully reach out to communities, expand community bases or support communities in their efforts to build their advocacy capacity.

The engagement strategies shared in this section are by no means inclusive of all of the engagement strategies used by each of the HEAS cohort members or their trusted network of colleagues. Instead, the strategies shared are those that were most common amongst the HEAS cohort members and illustrate their shared values on how and why to engage affected populations—to assure that the changes sought by advocates, organizers and communities together have meaning for the constituents they purport to serve.

### AN EMERGING FIELD-LEVEL FRAMEWORK

While there is certainly a foundation of work to build upon given the history of relationships and community engagement of the organizations described above, HEAS partners have acknowledged that engaging affected populations as a field of equity-focused advocates presents new challenges—namely,



how, as a field of advocates, can partners assure that community priorities and concerns drive policy-change agendas? How do partners promote equity and inclusion in their engagement efforts to avoid tokenism and

honor the complex diversity of Colorado’s communities? What are the field-level opportunities to leverage and align the relationships, engagement and resources that already exist?

» **FIELD-LEVEL FRAMEWORK**

Through a series of group discussions, an emerging framework of field-level community engagement in advocacy has begun to surface.

# Colorado's Health Equity Advocacy Field

**Affected Communities Driving Change**

Agenda-Setting	Empowering	Engaging
<ul style="list-style-type: none"> <li>Town halls</li> <li>Clergy caucuses</li> <li>Listening tours</li> <li>Case-file analysis</li> <li>Story banks</li> <li>Policy implementation feedback</li> </ul>	<ul style="list-style-type: none"> <li>Community leadership development (<i>promotoras</i>, block captains, resident leaders)</li> <li>Advocacy/systems change trainings</li> <li>Policy/research translation</li> <li>Equity lens building</li> </ul>	<ul style="list-style-type: none"> <li>Testimony</li> <li>Letter-writing campaigns</li> <li>Seats on advisory boards</li> <li>Legislator visits</li> <li>“Get out the vote” campaigns</li> <li>Participatory research</li> <li>Canvassing</li> </ul>

**Communication – Coordination – Alignment**

**Field-Level Strategies**

- Coordinated needs assessments, listening campaigns and story-banking
- Shared-issue tracking and agenda-setting
- Tool, resource and information sharing
- Cross-community base-building
- Partner education and mentoring

Core to this framework is an assumption that, particularly among a field of health equity advocates, engaging affected communities in health equity advocacy requires a range of engagement strategies at multiple points in the advocacy process. Instead of last-minute scrambles to insert community voices in testifying for policies intended to help them, authentic engagement of affected communities requires intentional, upfront investments to assure community perspectives and voices in the agenda-setting process. It also requires ongoing relationships with a diverse set of community representatives who represent a range of perspectives.

To accomplish this, the framework is also predicated on a value of meaningful investments in the communities themselves. Power inequities are embedded within a long history of policymaking that has not always set a place for communities at the decision-making table. Part of what is required to address this reality is recognizing the role of the health equity advocacy field in building the capacity of community leaders to navigate the policy landscape, find and express their own power and lead change on behalf of the communities they represent.

Finally, and most importantly, the framework emphasizes the power and potential of a field of health equity advocates, captured in the bullets of proposed field-level strategies at the bottom of the framework. These strategies deliberately leverage promising work taking place across the field by individual organizations and identify potential opportunities to amplify the power of many,

through coordinated data collection, joint training and education, shared-issue tracking, cross-community base-building, common messaging and aligned advocacy and mobilization. While still untested in practice, these strategies present a vision of field-level engagement of affected communities that HEAS partners intend to collectively implement in the years to come.

### LOOKING FORWARD

This framework is a living document; in the months and years ahead, HEAS partners will continue to engage the framework in practice. While rooted in the complex demographic, geographic and political contexts of Colorado, the hope is that the framework might prove useful to others prioritizing community-focused health equity strategies across different regions. Given the iterative and constantly changing nature of health equity advocacy work, HEAS partners expect the framework to evolve just as the field evolves, incorporating new, changed or nuanced strategies to align with shifts in communities, needs, capacities and practices.

The HEAS cohort members recognize the challenges that lie ahead of them, as they endeavor to move forward in a unified way while still honoring the nuances in the lived contexts of the diverse communities they represent and serve. Guided by a fundamental shared value for engagement of affected communities in defining and advancing health policy solutions, they are poised to break new ground together and affect meaningful change for—and with—all of Colorado's diverse communities.

## » ENDNOTES

- <sup>i</sup> Colorado Department of Public Health and Environment. Health Disparities, the 2013 Report: Exploring Health Equity in Colorado's 10 Winnable Battles. <https://www.colorado.gov/pacific/cdphe/health-disparities-report>. Published 2013. Accessed Aug. 24, 2016.

## » HEALTH EQUITY ADVOCACY STRATEGY GRANTEEES

- Asian Pacific Development Center
- Colorado Association of Local Public Health Officials
- Colorado Center on Law & Policy
- Colorado Children's Campaign
- Colorado Coalition for the Medically Underserved
- Colorado Cross-Disability Coalition
- Colorado Fiscal Institute
- FRESC: Good Jobs Strong Communities
- Full Circle of Lake County
- Grand County Rural Health Network, Inc.
- Growing Healthy Communities Coalition
- Lake County Build A Generation
- Northwest Colorado Health
- Padres & Jóvenes Unidos, Inc.
- Re:Vision
- Stapleton Foundation for Sustainable Urban Communities
- Together Colorado
- Tri-County Health Network



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