EVALUATION OF *LIFT UP YOUR VOICE!* ADVOCACY TRAINING FOR OLDER ADULTS AND THEIR CAREGIVERS

EXECUTIVE SUMMARY

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Executive Summary

Introduction

This report presents the results of an evaluation conducted for Community Catalyst of *Lift Up Your Voice!* (*LUYV*), a component of the National Campaign for Better Care (CBC). The goal of the one-year evaluation was to assess the effectiveness of the *LUYV* advocacy training program in identifying and recruiting potential advocates, educating them about the underlying issues of the state and national health care campaigns, empowering them through advocacy skills training, and engaging them in a state-based campaign infrastructure that sustains their involvement in system and policy change. At the onset of the evaluation, there were *LUYV* programs in Massachusetts, Ohio, and Pennsylvania.

Methods

The evaluation plan included site visits to each of the three states, key informant interviews with former and current staff from the three state partner organizations and Community Catalyst (n=14), and surveys of training participants (n=50). The study was approved by the UMass Boston Institutional Review Board.

Key Informant topics included participant recruitment, training logistics and curriculum, follow-up with trained advocates, and program sustainability. The primary purpose of participant surveys was to learn graduates' perceptions about the training and their engagement in post-training Campaign activities.

Participant profile

Participants ranged in age from 25 to 85; over two-thirds were 60 and older. Seventy percent were female and over 40% self-identified as Black non-Hispanic. Participants represented a wide range in education levels: 24% with high school or less and 30% with post-graduate degrees. Seventy percent had one or more chronic conditions, and a third were caregivers. Most surveyed graduates reported previous civic and/or service-related volunteer experience. Participants identified multiple types of volunteering and/or volunteering for multiple organizations. Approximately the same number of participants reported civic engagement (55%, for example—political activities or serving as board members) as service-oriented volunteering (58%, for example—church, library, children's organizations, retiree group, Meals on Wheels, or nursing home).

Results and Recommendations

Both training participants and key informants spoke positively about the *LUYV* trainings. Informants spoke of *LUYV* as one of the most successful components of the Campaign for Better Care, noting a major success of *LUYV* as the engagement of committed grassroots advocates available to work with the state Campaigns. Participants reported that the training opened their eyes to ways to get involved with local health care advocacy. For example, "[It] opened my eyes to being a voice for [the] unfortunate and how, as a group, to help." Participants also reported that the training helped them realize they were not alone in experiencing issues with the health care system and that the training empowered them.

Recruitment and training logistics. Informants overwhelmingly stated that participant recruitment was the greatest challenge for *LUYV*. There was mixed success in recruiting the target grassroots populations of older adults with chronic conditions and caregivers without their having had previous advocacy training. Interestingly, survey results showed that participants with prior volunteer experience were more likely to become involved with the Campaign post-training events than were participants without volunteer experience.

Thus, identifying grassroots people who are active civic or service-oriented volunteers appears a promising recruitment strategy.

Organizers, over time, identified effective recruitment solutions. Effective strategies included: (1) building on strong organizational partnerships and personal relationships with grassroots constituencies; (2) targeting senior-friendly organizations such as senior centers, faith communities, and senior housing (especially those with active resident organizations); (3) targeting groups with a history of working together on community issues; (4) linking recruitment to a local community Campaign initiative (such as hospitals actively forming Patient-Family Advisory Councils).

There is no one successful recruitment strategy; organizations need to develop a toolkit of strategies tailored to their organizational capacity and Campaign goals.

Training curriculum. Informants agreed that the training curriculum is comprehensive. Moreover, half of the survey respondents reported reviewing or using material from the resource binder distributed at the training that contained information on CBC, state policy and budget process, advocacy tools, and contact information for state legislators.

There was consensus that *Telling a Good Story* (27-9-3) [an activity in which participants identify a personal health care experience(story) and, with guidance, learn how to articulate it concisely] may be the most powerful and empowering training component of *LUYV*. One informant reported “They [trainees] love when they’re able to do it... It empowers them.”

Personal follow-up with participants after the training to develop stories further and determine ways to use the stories (in a video, letter to the editor, or testimony), as is increasingly done by state Campaign staff, may make this an even more powerful advocacy tool.

Key informants and participants found the *Shining the Light* (on problems with the health care system) activity engaging and powerful; participants see that they are not alone in experiencing similar health care barriers. Some Campaigns have used this exercise in other CBC settings, apart from *LUYV*. *Putting It Into Practice* (group Campaign planning activities) was also mentioned as empowering, especially when state Campaign coordinators encourage participants to select the issue and type of activity on which they want to work, participants produce something they can actually use, and state partners follow-up with participants after the training to ensure they do use it (e.g., a letter to the editor gets published).

Continuing challenges for trainers have been balancing the presentations (power points) with participatory activities as well as finding the appropriate balance of “advocacy 101” and health care policy to address the needs of mixed participant backgrounds.

It is unlikely that there will ever be or should be a one-size-fits-all LUYV training. State organizers (or other LUYV users) should continue to modify the training for different audiences and purposes.

Training logistics. Training checklists were developed in response to problems around planning, recruiting, and facilitating the trainings. These have been used successfully and have helped reduce most of the unforeseen logistic and technical problems (such as accessibility, AV equipment, adequate meeting space, refreshments). The most successful training sites, with fewest accessibility challenges, were buildings where older people naturally congregate, especially senior housing sites.

Having local staff personally visit training sites prior to the trainings, rather than relying on communication with third parties, will help ensure sites are accessible and meet training requirements. Despite best preparations, however, there will always be the need for flexibility (a back-up plan) and designated staff person to trouble shoot.

Advocate engagement. Several advocates have become heavily engaged in state Campaigns in a variety of ways. Half of the survey participants reported participating in one or more Campaign activities within 6 to 10 weeks of their trainings. Most common activities were contacting elected officials and attending community events. All but one of those who had participated in a Campaign event had identified as having had volunteer experience. Key informants provided the following examples of how trained advocates were involved in state Campaigns:

- Campaign spokespersons for care coordination
- Local patient family advisory council member
- Written letters to the editor (two states reported letters published)
- Media interviews
- Attended legislative rallies or testified at briefings
- Legislative visits
- Participated in monthly CBC calls
- Postcard campaigns (to affect health policy)
- Creative Advocacy Quilt project (in defense of Medicaid/Medicare)
- Members of “healthy hospitals” groups
- Planned and/or attended Town Hall meetings
- Written or video-recorded personal stories
- Older women of color wrote stories to engage legislators
- Maintains a cadre of advocates who are really engaged in state Campaign
- [Plan to] have advocates host (and recruit for) CBC house parties
- Graduates organizing community events at churches

Both key informants and participants spoke of the potential value of and desire for follow-up trainee workshops, and one state has already launched a series of these events.
Follow-up (refresher) sessions are recommended as opportunities to give interested trainees, especially those without prior civic experience, a stronger grounding in advocacy and health care policy and opportunity to practice advocacy strategies, especially if targeted to a specific Campaign policy priority. Refresher courses would also provide opportunities for trainees to meet, bond, and share experiences.

Coordinators have found that while electronic communication (email, e-newsletters) requires the fewest staff resources, it is not always effective. Many graduates do not use email at all (38% of survey participants), and others use email irregularly. Key informants reported that personal contact is more effective in bringing trainees "to the next level." State organizers have found that systematically tracking trainees' interests and Campaign participation helps with targeting people for activities in which they are likely to be interested and participate. Among trainees who had not participated in a Campaign activity when surveyed (24 or 48%), over two thirds had not been contacted by state Campaign staff.

Thus, while the Campaigns have engaged many older adults and caregivers, there is an untapped segment of training graduates that may be ready and willing to get involved in the state Campaign if they were personally contacted and invited into Campaign activities.

Another challenge for state coordinators has been identifying and providing sufficient and appropriate Campaign activities to engage graduates, especially in a sustained way. Targeting activities that require greater advocacy understanding and involvement of individuals based on their identified interests has been helpful (such as testifying at legislative briefings, planning community events, media interviews) while other graduates can be invited to more general events (legislative rallies).

To successfully engage participants in state Campaigns, it is helpful to plan trainings with at least one short-term advocacy activity already planned and/or to work on a concrete activity during the training with participant input. This will give trainers the opportunity to invite all participants to participate in at least one Campaign activity. It will also give participants a clear vision of what their role can be with the Campaign and overall as health care advocates.

Both survey participants and informants reported that transportation and accessibility issues have also presented challenges to post-training engagement. Solutions have included arranging for senior housing residents use of the resident van, scheduling events within trainee communities or on public transportation routes, and having trainees coordinate carpools. *Coordinators need to consider and plan for transportation for trained advocates who do not drive, have disabilities, or live far from Campaign advocacy hubs.*

Sustainability. Key informants were asked to comment on the sustainability of *LUYV* after funding support ended. There was consensus that *LUYV* is a "fabulous tool" that can and should be used beyond the grant period to build grassroots movements. It is a "great way to engage people in health care reform advocacy." *LUYV* is sustainable if it can be seen as "reflecting the work organizations are already doing and the vision they have for their Campaigns. In as much as it is difficult to explain the state Campaigns to the community, the training provides a great way to do that – a way both to explain the Campaign and engage people. "

Informants from the state Campaigns spoke about ways they planned to continue using *LUYV*:

- Continue to do *LUYV* trainings as part of ongoing outreach and expand outreach beyond older adults (for example, people with disabilities, people of color, people who are both Medicare and Medicaid enrollees), as appropriate to organizational goals.

- Continue to keep their current advocate base connected, organized, and involved, even if not directly with the Campaign for Better Care because *LUYV* training skills transfer well to other consumer initiatives.
- Continue to use selected elements of *LUYV* (for example, the 27-9-3 exercise is a great way to get personal testimonies), but within shorter, more informal trainings.

LUYV, as conceived, was intended to be transferred outside of Community Catalyst, with the goal that organizations could deliver it independently. Community Catalyst expects to continue promoting the *LUYV* training to organizations interested in health care reform advocacy and will be available to organizations as a resource and for technical assistance. Toward that end, Community Catalyst has developed an on-line training manual that will support a train-the-trainer approach. The training is appropriate for all kinds of groups (for example, caregivers and specific disability groups) because the underlying issues are similar.

For LUYV trainings and advocacy involvement to continue within state Campaigns, state partner organizations need to commit adequate organizational capacity (dedicated staff, time, and infrastructure). Using a train-the-trainer model can optimize organizational capacity. Using training graduates to facilitate recruitment, assist with training, and engage trainees in advocacy activities creates the potential to both expand capacity and provide trained LUYV advocates leadership opportunities. Perhaps most important is maintaining active Campaign engagement of currently trained advocates. States may continue to modify the LUYV curriculum, structure, activities, and target population to match evolving organizational and Campaign needs.

To expand the use of LUYV tools and strategies beyond the current three state Campaign for Better Care partners, Community Catalyst might publicize and disseminate LUYV training materials and the trainers' manual, as well as provide modest technical support to organizations wishing to train grassroots advocates for health care reform and related advocacy work.

Conclusion

The need for grassroots advocacy will continue to grow as the pressures on health care reform mount and as states move towards implementing key pieces of the law. The most direct benefit of *LUYV* is to the state advocacy organizations because it has provided them with a cadre of advocates that they can continue to call upon when they need to organize around specific health policy issues. It has also given them an important tool for strengthening their constituency base. This is especially valuable because engaging state-based and local advocacy organizations and individuals representing the Campaign's core constituencies of vulnerable older adults and their caregivers will continue to infuse state Campaigns with a powerful moral grounding and provide an important lever with policymakers. By connecting older adults and caregivers to state-based organizations engaged in the Campaign, *LUYV* is helping create a lasting voice for this constituency. Overall, *Lift Up Your Voice!* has been a worthwhile experience for the national, state, and local partners who developed, coordinated, and implemented the training program; and especially for the older adults and caregivers who participated.