A Partnership for Consumer Engagement in Accountable Communities of Health:

Lessons Learned

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Introduction

NoHLA, a consumer advocacy organization founded in 1999, works toward achieving a health care system in which all individuals receive quality, person-centered, affordable health care, provided on an equitable and timely basis, and are assured of basic rights and protections. NoHLA supports the work of partner organizations and coalitions, serves as a community resource, and engages with government to seek consumer-centered policies and practices. In this presentation, we share our work in partnership with Washington Community Action Network (WACAN), a statewide grassroots advocacy organization, to ensure that consumers have a voice in guiding Accountable Communities of Health (ACHs).

Community engagement work – policy and grassroots advocates partnering to achieve solutions

In January 2014, the state proposed in its Health Care Innovation Plan to create a network of nine regional multi-sector health collaboratives called Accountable Communities of Health (ACHs). ACHs were charged with identifying and addressing the most pressing health needs in their regions with a special emphasis on improving the social determinants of health (SDoH) - societal factors other than the quality and accessibility of health care itself that have a strong impact on a population's health. This was an unprecedented opportunity to improve health across the state, combat disparities in health access and outcomes that drive many regional health problems, and invest in the SDoH. WACAN and NoHLA realized that the success of this effort depended on a firm partnership between the traditional members and institutions of our health and social service system (such as government, care providers, hospitals, and carriers) and the consumers whom ACH programs are intended to help. However, the state's plan contained few details on how consumers would be engaged in ACH decisions and operations. From this, we concluded that broad-based advocacy and organizing were needed to bring consumers into ACHs during their formative period. WACAN and NoHLA developed a project to bring a robust consumer voice to ACH tables and promote consumer-friendly policies at local and state levels.

Goals of the project

To achieve these ends, we set two major goals:
1) Create replicable policy recommendations and best practices for both grassroots communities and ACH leadership. Use these as an organizing framework to support and increase the involvement in ACHs of low-income communities, immigrants, communities of color, older adults and people with disabilities.
2) Build strong community involvement in the ACHs by directly engaging with ACHs, community groups, grassroots community members and agency staff.

We realized that a two-pronged approach offered the most effective means of reaching these goals. Our plan combined NoHLA's experience with policy analysis, advocacy and coalition building to promote policies that foster consumer engagement in ACHs, with WACAN's grassroots organizing to educate community members about ACHs and develop them to get involved in ACH decision making bodies.

We recognized that the ultimate aim of Goal 2 was to promote a high level of consumer engagement throughout the ACH system. However, the number, size and diversity of the State's regions and their corresponding ACHs, and our limited capacity, made it unlikely that we could carry out this plan statewide. Instead, we expected that our goals could be most efficiently reached by selecting areas where we could build and implement a model of engaging members of communities most impacted by the ACHs' programs; these could then serve as examples for others. We selected three regions in which to focus our organizing and advocacy – King County, Pierce County, and the Spokane area – based on the strength of: a) WACAN's membership base from which we could recruit activated consumers; and b) the existing infrastructure available to support a joint policy and organizing campaign. WACAN placed lead

organizers in these three regions to conduct power analysis trainings and to use a racial equity toolkit with community members, demonstrating how to organize in communities of color most impacted by health inequities. WACAN also developed a demographic analysis of each region to guide members in identifying the social determinants that most impact health care disparities in those regions.

NoHLA led the team's efforts in policy advocacy. NoHLA and WACAN staff, as well as staff from Puget Sound Advocates for Retirement Action (PSARA), actively participated in several committees and work groups in the King and Pierce County ACHs and their associated governing bodies and attended meetings of other ACHs. We developed ongoing relationships with state agency staff and contacts with the federal Centers for Medicare and Medicaid Services (CMS), establishing regular calls with State staff and a few calls with CMS to address specific issues. We evaluated a wide variety of policy proposals and organized allies to support and submitted materials that we drafted commenting on agency and ACH proposals and promoting our vision for an inclusive ACH system.

Here is a summary of the initiatives we pursued to reach our goals.

King County ACH: WACAN held three community meetings with a total of 53 members and developed three leaders committed to serve on ACH governing bodies and work groups. As our project staff were not initially on the ACH's governing body or its foundational committees, we moved quickly to establish relationships with board members from organizations that already worked to empower health care consumers, such as the Healthy King County Coalition, Puget Sound Sage, and Seattle Children's Hospital, as well as other interested allies, like the Lifelong AIDS Alliance and SEIU 1199NW. Together with ACH staff and allied advocates, NoHLA and WACAN helped to organize, presented at and participated in a Roundtable meeting to educate the community about the ACH and discuss priorities and next steps for engaging community members.

Some of the results of NoHLA and WACAN's efforts organizing advocates and community members involved in the King County ACH and its governing board are:

- A consumer/community voices (CCV) work group was created to address consumer engagement;
- Interim Leadership Council governing board seats earmarked for consumers were added, as was an acknowledgement in the charter that including consumer voices in all levels of ACH activities is a primary value.
- Inclusion of consumers in at least two of the ACH's work groups/committees. In addition to the CCV group, NoHLA served on the Regional Health Improvement Plan (RHIP) Work Group which created a draft RHIP framework that included health equity as a shared value.
- Inclusion of advocates and community members in ACH Board - NoHLA and PSARA staff were appointed to fill "consumer" seats on the ACH Board until grassroots consumers could be recruited to fill them.
- We helped develop criteria and an application process for grassroots consumers to fill governing board seats. A WACAN grassroots member of color was later selected to fill one of the consumer sector Board seats.

When the ACH's Governance subcommittee proposed that the ACH's restructured governing body should not include seats reserved for grassroots consumers, NoHLA and WACAN organized allies to sign onto a letter we drafted that successfully urged the subcommittee to reconsider. Our advocacy successes in King County resulted in part from the relationship we built with the Somali Health Board, a local organization that works to combat health disparities and improve health outcomes for the Somali community in the county and state.

Spokane/Better Health Together (BHT) ACH: WACAN organizers and members hosted monthly community meetings to educate grassroots individuals about the ACH and to build strategies addressing health inequities in the ACH's area. Each community meeting was attended by 15-20 members. Organizers trained attendees on how to use a power analysis to strategize consumer engagement with the ACH. Local allies, including the Spokane Alliance, the Peace & Justice Action League of Spokane, and Native American communities, helped us to engage community members in ACH consumer advocacy. The BHT ACH did not originally include grassroots consumers on its Board, likely because the ACH was operated directly as a project of BHT, an independent non-profit, so that any changes to the ACH's governing body would have required changes to the BHT Board of Directors. However, after WACAN joined with regional partners in asking the ACH to open its Board, BHT agreed to create additional seats for which consumers could apply.

Pierce County ACH: WACAN held two community meetings and developed two leaders, one of whom filled the consumer seat on the ACH's Interim Board of Trustees. NoHLA, WACAN, and PSARA staff participated in the Consumer Engagement Work Group, the steering committee, and the Governance Committee. NoHLA organized support from allies that resulted in the ACH amending its "Values" statement to focus more on consumers, based on language NoHLA drafted. NoHLA submitted feedback to the Pierce County ACH on a proposed scoring system for selecting members of the Pierce County ACH's Interim Board of Trustees. WACAN and allies organized support for a low-income WACAN member to fill one of the Interim Board of Trustee seats reserved for "Consumer/Community." She raised important questions to the Board based on her first-hand experience of health disparities in her native community and addressing her personal health issues. NoHLA participated in Governance Committee meetings, providing written feedback on draft articles of incorporation and bylaws.

Promising Practices Report and Recommendations: With WACAN's assistance, NoHLA drafted and released a report and recommendations on promising practices for consumer engagement in ACHs. The report is based on an analysis of characteristics of ACHs and other health collaboratives and programs in the U.S., interviews of key informants, and direct experience with the King County ACHs. The report includes three related appendices that can serve as standalone resources: a) a list of Principles for Community Participation for ACHs; b) a template Racial Equity Tool (based largely on the City of Seattle's Racial Equity Tool) for ACHs to use when making decisions with a potential impact on racial and ethnic minorities; and, c) a discussion of low-cost high-value consumer engagement practices that we recommended ACHs implement quickly.

We incorporated feedback from staff of the featured ACHs and HCA in the final report. A consumer sector member of the North Sound Accountable Community of Health (NSACH) Board and a staff member of the Seattle-King County Public Health Department told us that material in our report contributed to work in their ACHs.

Medicaid Transformation Waiver: In August 2015, Washington State applied for a Sec. 1115 Medicaid Waiver ("MTW") that proposed to significantly augment the role of ACHs. Over the next year and a half, NoHLA led a work group of legal advocates serving low-income clients that focused on promoting consumer interests in the proposed "demonstration" project. The group engaged regularly with agency staff, focusing on the waiver's ACH-related initiative and on its long-term services and supports (LTSS) programs. We submitted comments to HCA on a series of project planning templates related to ACH waiver proposals, HCA evaluation, and both HCA and ACH accountability in implementing them. We also submitted comments to CMS staff responsible for the MTW and discussed with them consumer

engagement in ACHs. CMS incorporated some of our feedback in the Special Terms and Conditions for the state's waiver issued in January 2017.

Raising Awareness: Since project funding ended, we continue to deliver presentations on our ACH consumer engagement work, including to the state-created Health Innovation Leadership Network (HILN), of which NoHLA's Executive Director is a member. We are also active in the HILN's Communities and Equity Committee, which works to magnify the consumer/community voice in ACHs.

Addressing systematic inequities

Our project was based on the premise that to be fair and effective, ACHs must address longstanding inequities in their communities' health and SDoH and remedy historic structural inequities in how health care systems make decisions. Most of those with executive authority over health-related organizations that serve low-income populations (e.g., hospitals, insurance programs, Medicaid, etc.) are disproportionately comprised of members of demographic groups that are not representative of the populations they serve. It is vital to let those communities articulate their needs and advocate for how those needs would be best served. Opening up ACHs to consumer participation is imperative – both to prevent these inequities in health system decision making from being replicated, and to enable ACHs to do their job effectively. Specifically, if an ACH wants to do the best job it can identifying and addressing the most significant health care and social needs of its community, it must include the voices, experience and judgment of members of that community in setting its priorities and guiding its operations. Our advocacy was aimed at addressing systemic inequities and health/social outcomes experienced by low-income individuals, communities of color, persons with disabilities, seniors, immigrants and other disempowered groups that would be affected by the ACHs.

One example of the project's work to undo systemic inequities is our successful advocacy for the King County ACH to adopt a health equity tool to guide its project selection and other decisions. In our promising practices report, we surveyed equity tools and advocated for ACHs to use them when making significant decisions that impact the communities they serve. In our initial work on this project, we found that ACH, agency and health system partners often stated their support for using an equity lens in making decisions, but that these statements did not always translate to concrete actions to promote health equity. By contrast, the health equity tool we proposed requires an organization that uses it to: a) consider what communities will be impacted when it makes a major policy decision; b) consult with those communities about the decision; c) consider the decision's possible impact on equity and the equity impacts of possible alternatives and, when feasible, choose a course of action that increases equity; and d) document these steps. Initially, some were enthusiastic but others were concerned that using the tool could be cumbersome. It was thus particularly important that the King County ACH created such a tool and actually used it in selecting project proposals. This illustrated to other ACHs how an equity tool can be used in a practical way that does not impede ACH decision making and how using such a tool can enable ACHs to meet their commitment to making equitable and effective choices.

Another advocacy area that highlights how we worked to combat systemic inequities in the health care system was our insistence that ACH bodies and deliberations should not just be open to consumer participation, but that ACHs must take affirmative steps to facilitate consumer participation in such activities. For example, some meeting locations were more conducive to public transportation, or parking costs could prove overly burdensome for low-income consumers. CCV and ACH Board meetings were initially held during normal business hours when consumers might be working and unable to take time off to attend meetings. With our and WACAN's advocacy, the King County ACH held evening

community convenings for individuals who may be unable to participate in daytime meetings due to other commitments. The ACH also committed to covering transportation costs for consumers to participate, provide stipends for time as most other participants in ACH bodies were paid for their time through their employers, and committed to making available services including childcare, interpreters, and translation of materials if requested in advance of scheduled meetings.

Successes and Challenges

NoHLA has been successful in its work by raising issues we learn of from the community, bringing them to the attention of decisionmakers, and advocating for changes in policy and practice. This feedback loop is effective due to our organizational credibility and resources, which allow us to elevate concerns and work toward their resolution using a variety of tools strategically including, when necessary, legal advocacy. In our work with WACAN, we recognized the importance of leading through support and collaboration in order to build power within disenfranchised communities. Leadership development allows individuals to gain skills to advocate for themselves. Having trusted members of the community and established local organizations share a common goal of wanting consumers to help shape ACH policies, allowed community members to be effective communicators and advocates of their own health. Collaborating with these organizations and creating an inclusive environment grew more important as consumers participated in the ACH activities. While we worked to educate and organize consumers around the issues we favored, ultimately, getting out of the way to let them lead the conversation was both the right and most effective tactic.

We know that effective decisionmakers, strong advocates, and engaged consumers are what make health care advances possible. By elevating a consumer voice in our state's ACHs, we continue to strengthen our network of health care activist leaders, improve our health care system and support consumer-driven innovation providing a needed example of what can be achieved through a multi-pronged approach using policy advocacy, coalition-building, and grassroots organizing.

A strategy of multi-level advocacy has contributed to our success. We try to approach an activity from a variety of angles that complement each other and increase the overall likelihood and extent of achieving our goals. We advocated with HCA to require consumer engagement from the ACHs and to provide guidelines and criteria around ACH health equity activities. We also advocated with the federal government for requirements about consumer engagement and health equity to be included in the contract with the state. And, we advocated with ACHs directly and organized allies to elevate the issues of consumer engagement in ACH activities, governance, and adoption of a health equity tool. While not all of these efforts were fully successful, we were able to make some headway in each, leading to a generally improved environment for consumer engagement.

But organizing and enabling consumers to engage in the ACH process is not easy. Some of the challenges in our ACH work related to creating effective opportunities that motivated consumers to engage. We learned that while the formative stages of ACHs were critical to establishing consumer-friendly processes, it was hard for consumers to engage at this stage. ACH meetings were focused on high level structure, governance, and administrative functions, and some consumers who attended reported that they were not easy to follow; they felt it was not a good use of time.

Second, it was challenging to establish criteria for public participation and transparency so that when consumers chose to get involved, the necessary foundation and background information would be available to them. HCA did not want to set criteria, instead allowing ACHs flexibility to meet the needs of

each community. The lack of clear criteria from HCA led to some confusion among ACHs and lengthy discussions about what meaningful consumer engagement means. It was particularly troubling when King County ACH suggested retrenching on its earlier commitment to include grassroots consumers on its governing Board and took the position that (professional) consumer advocates are sufficient to represent consumers. NoHLA organized allied community organizations to write a letter to the governance committee and participate in meetings. We supported grassroots consumers in making public comments to support consumer seats on the governing board.

As the prospect of waiver approval and funding became more real and imminent, some ACH partners, including provider group representatives, became more aggressive in attempting to assert control over ACH bodies and policy-making, requiring us to advocate for consumers to help shape ACH programs. Gains we made establishing opportunities for consumers to be involved in ACHs were challenged, requiring us to defend successes rather than focus on building on them. Nonetheless, this also presented us opportunities to engage more intensively with individual ACHs and work creatively with local allies and consumers to leverage power and move an equitable and inclusive agenda.

Another challenge was recruiting consumers who could sustain their participation as ACH community members. People who have experienced the health care system have valuable and insightful perspectives, but their health challenges may limit their participation. One consumer leader served on an ACH board, raising important questions at meetings based on her first-hand experience. However, she suffered from a health issue that limited her ability to remain involved.

Recognizing the challenges that can prevent consumers from participating over a long period on a regular basis, we advocated for ACHs to embrace the concept of "cascading levels of engagement." For some consumers, this means participating in meetings either in person or over the phone when the option was available. Other consumers should also be able to participate by keeping abreast of activities through email lists or accessing the ACH website, with meeting materials, minutes, and comment opportunities made available to the public. We encountered some resistance to our requests. For example, King County ACH held the belief that sustained participation by individual consumers was necessary for any meaningful consumer engagement to occur.

Hope for a More Equitable Future

While there is still much work to be done to achieve equity, all ACHs have begun efforts to address inequity. For example, the King County ACH is now working on developing an equity training for governing board members and committee participants to provide more depth about the equity tool and increase use of the tool to more areas of planning and decision making. Several ACHs operate community advisory boards or consumer workgroups as a means of hearing directly from the populations they most impact. As we recommended from the beginning, most ACHs have developed websites where they post key documents to make them more transparent and accessible to the community. NoHLA serves on the HILN Communities and Equity Committee, comprised of ACH leadership, HCA staff and organizations working toward health care access. The HILN and its C&E committee are platforms for ACHs to share information and approaches on addressing health inequities in their respective regions. HCA is working with the committee to create an equity curriculum for an upcoming convening so that all HILN members have a shared understanding of health equity.