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Promoting Inclusion, Equity and Deliberation in a National Dialogue on Mental Health

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Abstract

The struggle to find adequate mental health care is complicated by underlying factors of discrimination, cultural barriers, lack of early recognition, and inadequate resources. Traditionally, it has been difficult to talk about mental health issues because of fear of bias, cultural sensitivities and the lack of a safe place to discuss public concerns. This has left many families to grapple with problems in silence. As a result of President Obama's call to action on mental health, six deliberative democracy organizations formed an initiative called Creating Community Solutions (CCS). Their goal was to develop a multi-strategy program to respond to the challenges of reducing barriers to mental health and to create greater access to mental health services, especially for youth and underrepresented populations. This article focuses on how practitioners used extensive outreach and designed the process to reduce the inequalities participants can face in deliberation, allowing them to generate action plans for creating more equitable access to services. Through six-hour town hall meetings, community conversations, and an innovative texting platform, over 57,000 persons participated in the project, including community members, people with lived experience, mental health providers and youth.

Keywords

deliberation, mental health, equity, inclusion, town halls, community meetings, texting

Introduction

It has been argued that deliberation should be an ongoing institutional process, especially if it nurtures among citizens the notion that their fates are linked and that they must cooperate to find solutions to difficult issues. Solution-oriented deliberation, also known as civic agency, is about the capacity of a diverse group of people to act together on common challenges, which include their ability to work across differences to solve problems. Unfortunately, the consistent use of deliberative democracy in communities, states, regions and the nation is still infrequent, largely because the infrastructure and political will to support routine public engagement are seldom present (Mendelberg & Oleske, 2000; Barber, 2003; Lukensmeyer, 2014; Boyte, 2014). Occasionally, however, real opportunities to engage communities across the nation in deliberation to address issues of public concern manifest themselves.

One of those opportunities took place in 2013, when President Obama, after the tragedy at Sandy Hook Elementary School, directed U.S. Department of Health and Human Services' Secretary Kathleen Sebelius to launch a national conversation on mental health to reduce the shame and secrecy associated with this illness and to encourage people struggling with mental health problems to seek help. This conversation was intended to pursue three main goals: a) get Americans talking about mental health to break down barriers and promote recovery and healthy communities; b) find innovative community-based solutions to mental health needs, with a focus on helping young people; and c) develop clear steps for communities to move forward in a way that complements existing local initiatives and activities.

The ability to make progress on the nation's mental health crisis has been limited not only by inadequate resources but also by the difficulty of addressing underlying discrimination, stigma, and cultural barriers. Indeed, some populations are especially vulnerable and underserved by mental health services. To begin, young people have high rates of mental health problems and low rates of seeking help; three-quarters of mental health problems begin before the age of 24. Second, common mental health disorders are twice as common among individuals with low incomes, and there is a strong correlation between mental illness, poverty, and crime. Third, communities of color tend to experience a greater burden of mental and substance-use disorders, most often due to limited access to care, inappropriate care, and higher social, environmental, and economic risk factors. Fourth, LGBTQ youth are sometimes rejected by their families and peers, and

experiencing bullying and bias can lead to anxiety, depression, drug use, and suicide. The stigma associated with mental illness often leads to reluctance to find help. It has been reported that up to 60 percent of individuals with mental illness do not seek treatment and services (Substance Abuse and Mental Health Services Administration, 2015).

The scarcity of safe environments in many communities to acknowledge mental health challenges and to address them systemically has limited the ability to create new solutions. Prior efforts to engage marginalized populations in mental health deliberations have not always shown positive results. For instance, in a study on the engagement of mental health service users/survivors in deliberative democracy, Barnes (2002) examined how notions of "legitimate participants" were constructed within official discourse and argued that the emphasis on rational debates could have excluded the emotional content of the experience of living with mental health problems from deliberation about mental health policy. A related study, conducted by Hughes (2016), on a deliberative system that connected federal policymakers with the disability community found that the discourse of the government agency failed to engage with social difference as a resource for inclusion and collaboration, reinforced stigma around disability, and excluded underrepresented groups. In this context, the project "Creating Community Solutions" (CCS) aimed to change social norms around mental health, reduce discrimination, and bring forward more inclusive opportunities for community engagement. Gastil (2014) contended that scholars in the field of public deliberation must produce not only rigorous research but also field reports that help reformers and public officials refine their methods of public engagement. By discussing CCS and its three engagement strategies, we hope to provide useful information and insights to public officials and practitioners interested in large-scale, solution-oriented public engagement projects.

Blending Deliberative Methods and Designing for Inclusion

Led by the National Institute for Civil Discourse, six deliberative democracy organizations partnered to launch Creating Community Solutions (CCS). A unique aspect of this project was the willingness and ability of the six organizations to collaboratively design the initiative using the strengths of each one to reach communities and to take the program to a national scale. The design included three main strategies. The first was *Lead Cities*, with mayor-initiated, in-depth deliberative conversations using town hall meetings and neighborhood outreach in six cities. The second, *Community Conversations*, varied in length and

were held in every state in the country. The third, *Text Talk Act***,** used text messaging as a method to get young people talking about mental health. Common to all strategies was a consistent set of topics and questions, a website with supporting resources, outreach into neighborhoods and affected populations to include individuals not traditionally part of the mental health system, and a prioritization process for developing recommendations to respond to mental health challenges.

The three strategies relied on small group discussions facilitated by discussion guides and other materials. These materials included factual information on mental health problems, challenges to key cultural populations, the importance of early identification and treatment, and key questions related to the mental health field. While the larger town hall meetings brought a more representative sample of the local population and generated longer conversations, the addition of community conversations and texting platforms enabled CCS to create more inclusive participation of various segments of the population and to achieve a national reach. Indeed, CCS wanted to build a nationwide conversation but also sought to approach it in a way that would allow voices not normally heard in the discussion of mental health to be considered and acted upon. This effort was guided by three main goals. The first was to reach deeply into selected lead cities with an outreach process that included a representative sample of the population and an oversample of youth and affected communities. The second was to reach broadly across the country by supporting community initiatives to ensure that conversations were held in every state. The third was to reach young people directly by utilizing their preferred communication practices through a readily accessible texting platform.

These strategies were relevant because conversations on mental health often attract the "usual suspects." In many situations, stakeholder groups are among the first to sign up and take a prominent role, especially if they know that a national audience and local leaders are listening. While the design team understood that providers and experienced stakeholders would want to attend, CCS limited the number of mental health providers and registered participants to ensure a representative sampling of the demographics of the whole community. Through extensive outreach and the use of a questionnaire in the registration process, organizers were able to monitor the representative nature of the participants and achieve a truly community-wide conversation to hear how ordinary citizens wanted to see the system changed. As Michels (2011) noted, inclusion is often best achieved by engaging citizens through social networks, providing open access to forums, and striving to attract participants who are representative of the community as a whole.

Building Broad-Based Participation

As a result of its efforts, CCS has achieved a broad national reach. Since the beginning of the project in mid-2013, CCS has involved 2,728 participants in its *Lead Cities* town halls, generated 258 distributed *Community Conversations* among 11,500 participants, and engaged an additional 43,400 participants in its *Text Talk Act* discussions. In total, the project has involved more than 57,000 individuals. In addition, each of the project's three strategies used different approaches to ensure that participation was not just wide but also inclusive.

The first strategy, *Lead Cities,* used an outreach process that involved a diverse, representative sample of participants. The six participating cities convened steering committees and action-planning teams to design the process, conduct broad-based outreach, analyze results, and implement the recommendations through action plans. Some cities, like Birmingham (Alabama), Columbus (Ohio), and Albuquerque (New Mexico), used neighborhood-planning processes to deepen community engagement. Table 1 lists the range of outreach efforts that were used by organizers to increase the diversity of participants.

Table 1: *Outreach Efforts Used by* Lead City *Organizers*

Mixed Media Outreach	Organizational Outreach Efforts
• E-mails, letters, phone calls • Face-to-face conversations • Translation of promotional pieces • Youth radio program • Social media: Facebook, Twitter, Instagram • African-American teen radio show • Flyers (multiple languages) • Unique Twitter hashtag • Youth-developed vignettes • Local newspaper ads (senior outreach) • Stipends • Provision of transportation • Translations of dialogues into multiple languages • Survey	• Outreach team • High school counselors, local colleges, clubs, youth organizations • Charismatic spokespeople for youth outreach • Youth media team • Mayoral support and leadership • City agencies, community centers, non-profits • Churches with mental health programs • Parent Teacher Associations • Neighborhood associations • Canvassing communities • Communities of color organizer • Latina community organization

As shown in Table 2, *Lead Cities* was successful in attracting demographically diverse participation. Across all cities, 68 percent of participants were female and 32 percent were male. The racial/ethnic makeup of participants was also diverse. Due to the high African-American population in two of the lead cities (Washington, D.C., and Birmingham), African-Americans were overrepresented compared to their share of the national population. Because of recruitment strategies and objectives, *Lead Cities* was highly successful in achieving strong youth participation, with 24 percent of participants ages 14-24.

***Table 2. Gender, Race, and Age of Participants in* Lead Cities**

Demographic Categories	Total (%)
Sex	
Male	32.08
Female	67.92
Total	*100.00*
Race	
Asian-American/Pacific Islander	6.33
Black/African-American	40.20
Latino/Hispanic	9.80
Native American/American Indian	1.20
White/Caucasian	32.33
More than one race	7.93
Other	2.20
Total	*100.00*
Age	
14-18	14.79
19-24	8.31
25-34	13.57
35-44	13.44
45-54	18.91
55-64	20.53

Demographic Categories	Total (%)
65 and better	10.47
Total	*100.00*

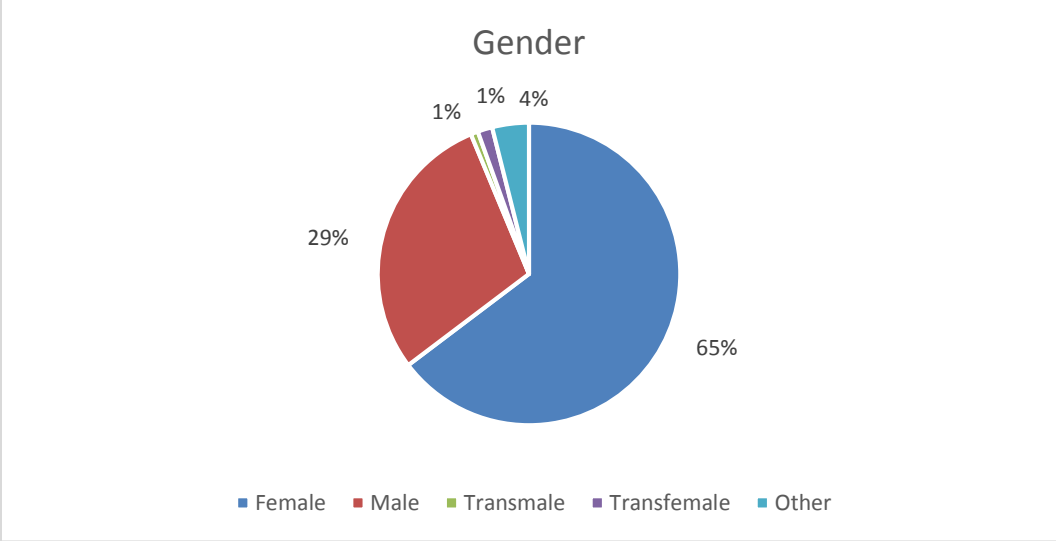
The involvement of a diverse and broad sample of the populations of each of the *Lead City* communities was essential to success and, as one organizer noted when reflecting on the diversity of participants, it provided an important source of learning that otherwise might not have occurred:

> Because it was diverse, there were genuine learnings for us. I didn't comprehend the cultural differences on mental health until I went to the dialogue process. We learned about the differences and about the additional challenges that you face if you live with mental illness in one of these communities.

The second strategy, *Community Conversations,* mirrored the effort of the *Lead Cities,* but allowed many more communities to participate in varied ways that resonated locally. Often led by grassroots activists, public officials, and local mental health agencies, the *Community Conversations* sought to increase awareness of and educate people about mental health as well as to reduce stigmatization of those who suffer from mental illness. Along the same lines of the *Lead Cities*, communities hosting conversations aimed at bringing together a diverse cross-section of participants, enabling participants to explore common mental health issues and developing recommendations that could be implemented in the community. To meet the needs of a diverse constituency of organizers, the distributed conversations were supported through three main resources. The first was a website that featured a community dialogues map. This map allowed potential organizers, funders, and facilitators to find one another, announce upcoming events, provide resources, and report on the results of their conversations. Secondly, the team produced a variety of resources and training materials, particularly a toolkit that consisted of a discussion guide, an information brief, and a planning guide. Additionally, community-generated materials were developed and shared, including a "Quick Start" abbreviated discussion guide. Besides these materials, CCS held webinars on a range of topics. Last but not least, the project included a community liaison who provided technical assistance by phone and e-mail to local, regional, and statewide organizers across the country, and acted as a bridge between CCS and the local community.

The third strategy, *Text, Talk, Act (TTA)*, included five nationwide campaigns. Because *TTA* involved small groups using cell phones to facilitate discussion, it was difficult to collect specific demographic information about all participants, so the evaluation team has only general information about individuals who have participated. *TTA* events have been targeted at young people and often carried out by schools, clubs, and student groups that were already interested in mental health issues. For this reason, the evaluation team reasonably assumed that the largest portion of participants were young people who had a personal connection to mental health and/or some knowledge about the issue. From the data collected, it is clear that participants in the *TTA* represented a diverse group. For two of the five *TTA*s (held on April 14, 2015, and May 7, 2015), the population used 355 mobile devices, representing approximately 2,192 individuals. The majority of participants (65 percent) had never participated in a previous *TTA* event. The average age was 20.5 years. The gender characteristics of *TTA* participants are shown in Figure 1.

Figure 1: Participants by Gender at* TTA *Events



Survey results indicate that people who participated in *TTA* events perceived an increase in comfort, ability, and likeliness to engage in positive mental health activities as a result of their participation. For instance, a *TTA* organizer at Pensacola State College reported that TTA is becoming part of a broader movement to engage the community in mental health awareness and advocacy.

Indeed, we are aware that new partnerships are currently being formed among stakeholders, organizations, and institutions to improve mental health in their communities.

TTA Outreach Efforts to Engage Youth

One of the key strategies for getting more traction for *TTA* was to provide youth organizers with small stipends. Most of the youth organizers had experience with mental health issues and were very motivated to bring the conversation to their college campuses, schools, or communities. As one organizer from Kansas City observed, young participants were excited about the opportunity to exercise their voice:

> It's important to get a teenager's perspective. We met for eight weeks. … They had homework assignments [and] engaged in *Text Talk Act*. When you get youth excited about mental health, you know you're helping on a larger scale than you can see. They'd call me up: "Ms. B., when are we meeting? I'm bringing my friend with me." … That gave me life. You can hear it in my voice.

This strategy also led to the launch of two national *TTA* contests, both held in 2015. The first contest awarded cash prizes for the highest participation levels in *Text, Talk, Act*. More than 95 groups participated, including 39 non-profits, 26 middle and high schools, five small colleges, 12 medium-sized colleges, and 13 large colleges. In addition, six "best action idea" prizes were awarded, based on votes by the larger CCS community.

Participants' Recommendations and Strategies

The experiences of participants in the three unique opportunities for deliberation have been remarkably consistent. Our analysis of the data shows that CCS events have had a positive impact on individuals participating in the conversations and that participants have come away with a commitment to take actions that engage new voices and partnerships to improve mental health. While *TTA* and many of the distributed conversations were designed to be singular events, the ongoing work in many communities has made it evident that CCS has tapped a broad interest in starting and sustaining significant actions to reach key populations in the mental health field. As a result of their experiences in offline meetings and online interactions, CCS participants made four main recommendations. Below is a summary of those recommendations and a few examples of actions that have been taken in light of those recommendations.

Recommendation 1: Engage the youth directly in promoting awareness of mental health

Participants called for building youth-driven campaigns using social media and other channels that highlight the importance of mental health and ways to get help, for utilizing school curricula on mental health, and for promoting positive development models. Participants have taken several follow-up actions. For example, in Kansas City, a group of high school students came together as part of CCS to consider how students could reduce stigma and bullying and increase social inclusion of students with mental health challenges. They concluded that older students have a responsibility to help younger students and that support groups should be created not just for people with a diagnosis. As one young person said, "Everyone can have these challenges, and you can't tell from looking at people what their struggles might be." Small groups of high school students went through a design and judging process to refine their ideas, mentored by college students who had lived experience with mental health challenges.

Recommendation 2: Utilize effective programs that help identify early signs and connect people with local services

In this regard, CCS participants recommended expanding mental health first aid training for adults and professionals, consolidating ways to better navigate access to services, and ensuring first responders are effectively trained. The city of Albuquerque has been especially active in taking these steps. Several city agencies helped plan the Albuquerque dialogues, including the fire department, police department, public schools, and department of family and community services. As a result, many employees across city government were introduced to the concept of "Mental Health First Aid," an important training on what to do when facing someone in mental distress. To lead off and set a powerful example, Mayor Berry and his directors all went through mental health first aid training. The city's fire chief has also pushed for some substantive changes within that department, including training all 650 staff members on the use of crisis intervention teams.

Recommendation 3: Develop specific and targeted systems of care for transition-age youth

In order to help youth who are transitioning from foster care, the mental health system, or state custody, CCS participants called for a more specific set of services for the mental health challenges facing transition-age youth and for

providing access to housing, jobs, education, and independent living programs. In early 2014, more than 20 district leaders and Washington, D.C., Mayor Vincent Gray strongly endorsed the recommendations made by CCS-DC action teams. One year later, the city cut the ribbon on Wayne Place, a new transitional housing program for 18-24-year-olds leaving the mental health or child welfare systems in D.C. who need extra support to live independently and to build the skills they will need to be self-sufficient. Wayne Place is jointly funded and operated by D.C.'s Department of Behavioral Health and the Child and Family Services Agency.

Recommendation 4: Ensure that services delivered are culturally specific and appropriate

CCS participants wanted service providers to work with key cultural groups to make education and awareness efforts more culturally competent and make mental health services more culturally appropriate. Sacramento (California), one of America's most diverse communities, offers a good example of how inclusive recruiting promoted an equitable action plan. To make sure the city's diversity was fully represented in the CCS discussion, community organizers were hired to work with each of the major ethnic and linguistic groups, including Latino, African-American, Asian, Russian and Slavic, Hmong, Sudanese, and Somalian, communities. As a result, a gathering of 350 people in the Sacramento Convention Center was a true mixture of ages and ethnicities. And, not surprisingly, among their eight priority recommendations was a commitment to cultural competency in mental health services. The *Sacramento Mental Health Action Plan* was very clear: "Action planning cannot go forward if groups are left out or if there is not appropriate access to services." As the work of refining and implementing recommendations has moved forward, the Sacramento CCS Network Council (the group leading this work) and Action Team members have gone through extensive professional development to increase their own cultural competence. They undertook training in the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (United States Department of Health and Human Services, 2016), developed culturally sensitive approaches to discussing mental health with different communities (particularly Muslim, LGBTQ, Russian and homeless youth/transition-age youth communities), and fostered cultural humility as a way to approach cultural competency.

The experience of Columbus, Ohio, shows how inclusive CCS dialogues addressed the needs of immigrants and refugees. The city's school district has students from 60 countries speaking 35 different languages and dialects. During the CCS dialogues, the need for culturally sensitive and language-accessible

mental health services was raised repeatedly. Participants learned that the county mental health program had no dedicated program for immigrants or refugees and that the Community Refugee and Immigration Service's mental health offerings were quite minimal. As a result of the CCS dialogues, changes have begun to happen at some local institutions. For instance, CCS organizer Fran Frazier described new approaches and practices adopted by Nationwide, the local children's hospital:

> The behavioral health department at Nationwide has really opened its doors to become a lot more culturally competent. They have revisited the materials they use, they have looked at their recruitment practices for getting more psychologists of color and they are better connected with communities of color and with both formal and informal leaders.

In addition, Everyday Democracy, one of the partner organizations, developed a mental health discussion guide specifically for immigrants and refugees, who have used it to hold some sample dialogues that lay the groundwork for future conversations.

Summary and Conclusions

CCS's efforts have led to progress in bringing community conversations and deliberative methods to underserved communities facing the difficult challenges of mental health. The use of roundtable conversations has enlightened individuals and communities about the need for safe and culturally appropriate services. Moreover, the recommendations that resulted from the CCS dialogues have influenced government funding priorities and institutional changes. At the same time, several challenges still need to be addressed to continue making progress. When considering the accomplishments and challenges of Creating Community Solutions, five main lessons can be drawn. The first is that addressing mental health is a long-term effort. Indeed, achieving improved mental health and changing social norms require broad community-based engagement over time in order to be successful. The second lesson is that attracting and retaining the right people in the process is difficult. The breadth of community participation in mental health action-planning is a core part of its strength and success, and keeping diverse communities engaged requires culturally sensitive strategies and benefits to each of the constituencies involved. The third lesson is that the persistence of bullying, discrimination, and stigma continues to undermine progress in mental health. The low levels of tolerance and acceptance of people with mental health challenges is a barrier to getting help and requires an active

public education effort. The fourth lesson is that marginalized populations continue to require a carefully constructed outreach effort to bridge the gap in treatment. Last but not least, the fifth lesson is that community engagement lends a new and legitimate voice to efforts to improve local mental health services. Indeed, the experience of CCS shows that community engagement efforts can make a difference at the individual and community-action levels. It also shows that through an enhanced civic infrastructure around public engagement, it is possible to assist communities in addressing mental health issues in more effective and inclusive ways.

Taken together, these lessons indicate that diverse representation helps to promote meaningful dialogue and strengthens the engagement of communities whose concerns have not been adequately heard. They also suggest that if we don't change our traditional approaches to mental health, we will only continue to marginalize populations that often need the most attention. CCS work on mental health has demonstrated that through targeted and creative outreach it is possible to bring previously excluded populations to the table in order to come up with useful recommendations and implement relevant actions in collaboration with government agencies. Moreover, when the voices of these communities are truly heard, actions are more likely to address underlying discrimination, language barriers and inequities in mental health services.

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