

# The Road to Advocacy—Searching for the Rainbow

The essence of public health advocacy is spreading the word—spreading the word to members of one's community about ways to protect and promote health, and spreading the word to decisionmakers about health policies that need to be enacted.

The authors profile 2 women who spread the word—one who focuses on breast cancer in the Asian American community and one who works in cooperation with churches in the fight against HIV/AIDS in African and African American communities—and discuss the importance of “creating shoulders for others to stand on” in the fight for social change. (*Am J Public Health*. 2003;93:1207–1210)

Byllye Avery and Samiya Bashir

*Stop sitting there  
With your hands folded  
Looking on, doing nothing,  
Get into action  
And live this full and glorious life.  
Now.  
You have to do it!*

Eileen Caddy<sup>1</sup>

## IMAGINE THE FIRST TIME

someone walked through a patch of poison ivy, emerging with their legs and feet covered with painful, itchy, inflamed hives. How many times did this happen before someone began to spread the word, telling their neighbors to beware? These people, those who sat with mothers and children, hunters and gatherers, to share the warnings about the waxy plant's painful effects, were among our first public health advocates. This is the essence of the work—spreading the word, arming yourself and your neighbors with the information they need to avoid disease and discomfort, pain and premature death.

This is the work I undertook in founding the National Black Women's Health Project over 20 years ago, and it is the work I continue now, with The Avery Institute for Social Change, as it celebrates its first anniversary. Our mission is to provide a platform for grassroots activists, scholars, caregivers, and policymakers to strategically examine health and social justice issues. Through our efforts, we hope to promote linkages between community activism and research that will shape local, national, and international public health

policies. We are also examining the details of how to organize, how to survive and take care of ourselves and each other, and how academics and grassroots workers can come together to support each other's often mutually dependent work.

The journey toward advocacy is often triggered by tragic experience. Health problems force us to quickly understand that our health is both personal *and* political. When we face our mortality, we often gain an instant perspective on what's important in our lives and learn to carefully pick the battles we want to fight. Most health advocates begin with little training or preparation and have only their own sense of urgency to guide them into stepping out and speaking up.

## THE ROAD TO ADVOCACY: 2 STORIES

### Susan Shinagawa

Susan Shinagawa is a third-generation Japanese American who, at 34 years of age, found a lump in her breast and sought help. Doctors assured her it was nothing. There was no need for a biopsy, she was told—she had no risk factors and nothing to fear. “The doctor said I was too young to get breast cancer,” said Shinagawa. “He said that Asian women don't get breast cancer.”

But she had taken a breast self-examination class and continued to be concerned when, 2 months later, the pain in her breast had not gone away. Searching again, she found a

doctor who reluctantly performed a biopsy and informed her that the tumor she had found was malignant.

“Asian communities, and other communities of color, have become my area of focus because there's a lot of untruth out there,” said Shinagawa, “not only in the communities themselves, but in medical and research communities as well.” Shinagawa's experience led her to begin speaking out to Asian women, many of whom were unaccustomed to talking about these issues, much less in public forums. Within months, Shinagawa became a public speaker, a role model, and an advocate, traveling to conferences around the country, giving self-breast examination workshops, and joining committees whose mission was to address the impact of cancer on Asian and Pacific Islander populations.

“When I first started my advocacy there were no other Asian-identified men or women out there as survivor advocates,” said Shinagawa. “A lot of that has to do with the culture of the community. In Japanese cultures, you don't talk about your disease. You don't burden other people with your problems. In some communities there's still a lot of misinformation—such as that cancer is contagious. A lot of Eastern philosophies believe in Karma. So if you get cancer there's nothing you can do about it, or it's because you're being punished for something you've done or something one of your ancestors has done. It's

considered shameful so you don't want anyone to know about it."

For 12 years, Shinagawa has been speaking out, and she often does her work while struggling with chronic pain. "When I was diagnosed with my recurrence, one of the symptoms was severe lumbar pain. When I finished my treatment, all of the other symptoms went away but that one," she said. "I'm still trying to find the right cocktail."

"What keeps me going is that I talk to women all the time that have been diagnosed with breast cancer. They still have a hard time getting a biopsy or getting anyone to take them seriously. They are told they are too young. Asian women, especially younger Asian women, are still told [by physicians, nurses, receptionists] that they can't get breast cancer. There's obviously a lot of work that still needs to get done."

### **Pernessa Seele**

Much advocacy has sprung from a simple question. When we fail to ask the question, refuse to search for answers, or simply accept the status quo, we miss an opportunity to create new ways to solve problems. In 1989, Pernessa Seele was working at Harlem Hospital, where she repeatedly saw people die of AIDS with no family, no support, no community of friends or faith. She kept wondering: "Where is the church?" She resolved to go and find it.

That year, she launched the first annual Harlem Week of Prayer for the Healing of AIDS. Seele, along with activists and leaders from over 50 community churches, marched through Harlem streets to raise awareness about the devastating effects of

AIDS in the Black community. In the 14 years since its inception, the event has expanded from its first 50 churches in New York City to over 10,000 around the country that have committed to educating their congregations about HIV/AIDS.

What started with the desire to seek help in her neighborhood, and the will to approach every well-known area pastor who would listen, has grown into the world's largest HIV/AIDS awareness program targeting the African American community. Seele started by simply asking church leaders to pray, a request many in the faith community would have a hard time refusing. The program, now called The Black Church Week of Prayer for the Healing of AIDS, along with the organization that it spawned, The Balm in Gilead, has grown to reach over 2.5 million people. Since the early 1990s, these churches have become the backbone of HIV/AIDS grassroots organizing and education in the African American community.

"First you look at the situation and you see that the church is affected by HIV," said Seele of the methods she now models worldwide. "Then you find what it is about this epidemic, about the Black church, that you can design a vehicle around so that the Black church can hear the conversation. Look at what the church responds to: prayer and healing. So let's create an AIDS awareness program the church can hear and make the church itself a responsible advocate."

The Balm in Gilead provides training, organizational, and technical assistance to churches, church groups, HIV/AIDS service organizations, and health departments working with the

church to develop and disseminate culturally appropriate educational materials. Seele has expanded her work, with the help of Christian churches and organizations, into 6 African countries: South Africa, Tanzania, Côte d'Ivoire, Nigeria, Kenya, and Zimbabwe.

The program challenges churches to address the real-life issues of sexually transmitted disease, homosexuality, drug use, and adultery in their congregations. "We don't come to the church and put the issues in their face," she said. "We talk about people, get them to understand that HIV is in their church, it's in the mosque, these are the people they love. There are mothers in the church whose sons have died. AIDS awareness training and education provides them with an opportunity to say something that makes sense. People want to share their burdens with their pastor, or their imam, so it's about educating the leadership so they can engage their congregations in appropriate ways."

### **SPEAKING TRUTH TO POWER**

We need unchained voices to challenge the powers that rule our world. Advocates tend to work outside of the system. Because most advocates are not wealthy, and are generally funded by independent means, we often have the ability to speak out creatively where others cannot because of political or economic conflicts. Advocates have the freedom to agitate for the advancement of agendas outside of the interests of a powerful few. Start something up, we say. Think outside the box, or the globe even! Ask the question: Why not?

"Some people have used the word 'pioneer' for what I did," said Shinagawa. "It really just meant that there was nobody else out there. As a result I got appointed to a lot of advisory councils and committees." For a long time, she was the only one in the room to argue her point. "In the beginning I thought it was because they didn't have their token Asian," she continued, "but it took a long time before I met other Asian women who would say publicly that they had breast cancer."

It is one thing to know the politics of a situation, but for an advocate to be truly representative, she must be in touch with what people are saying and feeling. For Seele, it was important to move beyond prejudice and stereotype to get to the heart of what was keeping Black churches out of the discussion about HIV/AIDS. "I think it's a myth that [the churches] don't want to talk about AIDS," said Seele. "Those of us in the West often don't understand that people are just not educated. As long as people are not educated they are driven by their myths, by their stigmas. When we educate the leadership of the church, things begin to happen."

A public health advocate needs to be a good listener and messenger. She delivers the message from the people to the institutions of power in a way they can hear. If we have to go to Capitol Hill and speak a hundred times on the same issue, we have to be able to articulate what the people are saying and perhaps target that message a bit differently each time to be effective. Fighting is often what it's all about. We have the right to go and speak truth to power wherever it is. The advocate

takes this right and makes it her duty.

Advocates struggle to manage the idealism that fuels our passion. We learn that ideas and perspectives that make perfect sense are often the hardest to implement. You need resources. You need other people to help you accomplish your goals. “I founded this organization with just one person to help me,” agreed Seele. “I now have a staff of 24 people and it’s still not enough.” Successful activists rarely work alone. If they do, they are rarely successful for long.

“I’ve got a lot of awards and honors and that’s nice,” said Shinagawa, “but I think that has happened because there haven’t been other Asians to give them to. I have felt very strongly that there needed to be more people who feel safe and comfortable speaking out, and now there are people who are talking about it within the community where it really makes a difference.”

## CALCULATING RESULTS

If we work hard as activists, we are going to get results. Unfortunately, those results are not always what we anticipate. We’ve got to remain flexible and not get distracted. The key to good advocacy is not expecting perfection, but rather a commitment to learning from our mistakes.

One of the questions I’m most often asked is how to handle conflict when it arises between individuals or organizations. We are often in the position of working with individuals and organizations whose work spans opposing sides of an issue. It is important that we manage the conflicts that arise so that everyone emerges from the experience feeling whole, without hav-

ing their position unduly compromised. This takes experience a lot of us don’t have.

Difficult challenges present us with some of our best lessons, but we can take the time to analyze what happened and study the work we’ve done. One of my favorite sayings is “when I write, I use a pencil with a big eraser.” As advocates, we have to be open to change, open to seeing when something isn’t working, and open to admitting that we don’t have all of the answers.

That flexibility is relevant to our lives both personally and professionally. We must always have a spiritual well from which to draw, a place that feeds and nourishes us where we can go to replenish ourselves. If we have access to our power centers, then even the most daunting hurdles are brought into perspective. Advocacy work can be draining emotionally, spiritually, and physically. Our passion can overtake us, pushing us to work long hours, take few breaks, and toss rest and nutrition out the window.

Shinagawa was forced by her own disability to refocus her priorities. “For the first 2 to 3 years I believed things would go back to normal,” she said. “But over the past three and a half years I’ve gone through this slow evolutionary process of realizing that maybe this is the way that it’s going to be for the rest of my life. That’s been very challenging. I’m still trying to push my limits whenever I feel up to it, and continuing with the advocacy activities is all a part of that, but I don’t want to give myself up either.”

Seele, who continues to run the organization she founded, also finds it difficult to find space to take care of herself. “If I could

just put what it takes to get the work done in the world into taking care of myself, then maybe I would be more able to accept some of the accolades that I get. People say, ‘Oh, you’re doing such wonderful work,’ and I’m very grateful and honored that they see that. But I’m also thinking: ‘But I’m falling apart!’ or ‘I haven’t had a vacation in 5 years!’”

The fact that we are doing good things in the world is no assurance that it will be easy, that resources will be available, or even that we will be successful. It takes a mixture of grit, faith, and tenacity to be able to maintain grassroots advocacy. You must be able to communicate with many types of people, articulate the perspectives of the people you represent, raise money, and learn how to work with a large, diverse group of people. “If you want to get anywhere,” said Shinagawa, “it’s not going to happen with 1 or 2 people. You really need to have the whole community involved.”

The better you are at the work you do, the more work there is to do. “Success is a very interesting thing,” said Seele. “When I was a child I just wanted to be successful, but now I’m trying to learn to manage success. Advocates are people who are constantly creating more challenges for themselves and for the work. You can delegate, but the more you delegate the more you need to delegate.”

## THE COMMUNITY AS FAMILY

The biggest reward of advocacy work is knowing that we are creating shoulders for others to stand on. Of course our long-term goals are to reduce health

disparities and address social justice issues, but it is important to stop and take stock of achievements, and to set markers for success along the way to keep up our spirits. Nothing is more contagious than excitement. It’s positive; it’s happy; it gives courage and hope. To get people excited is to say, both to them and to ourselves, “Yes! We can do this!”

“It’s a personal joy that I know I am doing the work I was called to do,” said Seele. “Congregations—and we get caught off guard when we say ‘the church,’ as if it’s a building rather than a group of people—are affected by HIV/AIDS, and when the leadership responds appropriately to the congregation then we see change. I want every Black congregation in the world today to be a voice for HIV/AIDS prevention [and] care, and for people living with HIV/AIDS, and I want governments that are responsive to that voice.”

“I hope to make it so that women don’t have to go through what I had to go through to get a biopsy,” said Shinagawa. “That means making sure that women are educated enough so that they can be strong health care consumers. The flip side of that is to make sure that the medical, research, and public policy communities understand the issues for not only breast cancer, but for cancer in general and for communities of color and communities of poverty in particular.”

Advocates leap huge hurdles every day. After a while, the race can seem endless, but to the people we serve, each hurdle represents a mountain of change. “I am an advocate who is searching for the rainbow,” said Seele. “How do you continue to create, continue to be an advocate for the voiceless,

and yet find time to smell the roses yourself while you're living? That is the rainbow. I'm still searching."

We can succeed by taking one step at a time. The rainbow, and its shimmering pot of gold, is within reach if we stay grounded by the present while remaining mindful of the lessons of the past. Then we can run

rhythmically forward without getting off track.

The essence of the work is social change. We've got to be in it for the long haul. Advocacy is not for the person who needs to see the world change drastically in 20 years. We are all part of a large continuum of change, and the work is evolutionary. It keeps changing. Our work is to

set change in motion, and if we're doing our jobs right, then we've also set up a forum, a space, and a community to help nudge that change along after we're gone. ■

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#### References

1. Caddy E. *The Dawn of Change*. Findhorn, Scotland: Findhorn Press Inc; 1997.