COMMUNITIES in control 2004
Revolution in Community: Why? How? – Now! Dates: 7 & 8 June 2004

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The New Agenda:

Health and Wellbeing Achievements When Communities Decide

Introduction

We are on the verge of a revolution—one without guns, bombs or harm to others. Ours is a revolution of social change. Ours is a revolution that follows a path to make people's lives better. Ours is a path that is built by community, is led by community and is sustained by community. We are communities in revolution and the time is now. And you in Australia have the courage and the will to acknowledge, honor and support the health and well-being achievements when communities decide.

The stories and successes that I will be sharing with you today are examples of greatness, inspiration, action and change. These are stories that have special significance to me personally and are part of the human condition we all share. The successes of people and communities united for the common good never cease to inspire us and give us hope that if someone, some community can do something extraordinary, we can do it too. And you in Australia today are bringing all these extraordinary people together to share and grow a vision where we are connected through our humanity, connected through our communities and are healthier as a result. The world is watching and learning through you!

Faulty Logic

If we can discard the faulty logic that we as experts know what's best for people then the revolution will be able to move ahead at great speed instead being driven by a driver with one foot on the brake and one on the gas. Without really taking the time to ask people what they think, what they want, what they know and what they are already doing, we are throwing away our most valuable asset and creating a wall of distrust that will be hard or impossible to break through. The unfortunate shared history of many people all over the world is a long one of outsiders, in good faith and bad faith, making decisions for us, about us, -without us. -

Len/Richmond

My esteemed colleague, Dr. Leonard Syme, who spoke here last year at your Communities in Control conference, told his own humbling story about devising a "brilliant" 5-year smoking cessation intervention in a low-income community in Richmond, California. As Len would say— it was a complete failure. There were no significant differences in smoking rates between people who had 5 years worth of this intervention and those who did not. Why? Because this "brilliant" intervention was imposed on this community. The people were never asked what they thought was important. Len discovered the hard and expensive way, that this community had vastly more important priorities in their lives — whether their children would be shot on their way to school, whether they were being poisoned by simply breathing air filtered through the emissions of the oil refineries. Obviously with these pressing issues dominating people's daily lives, all the education in the world and all the strategies for quitting smoking don't mean a thing.

Nigeria

Len's experience reminds me of a story I recently heard on the radio. It seems that a few cases of polio are beginning to resurface in Nigeria. And obviously, the World Health Organisation is very anxious to do something about this. So they sent a group of health workers and polio experts to the remote villages where the cases were appearing or expected to appear and decided that the community needed to be immunised. But when they got there, the local residents told them that they had been warned by their religious leaders not to take any of these shots from the strangers since they believed the vaccines contained viruses causing AIDS and chemicals causing sterility. I imagine Nigerians in these communities saying— after all, since you never helped us before, and since our people are dying all the time from dysentery and other diseases, why should we trust or want this intervention? And my response would be Exactly So—there is no reason to trust. But just imagine if these health workers had gone in and worked to keep babies and others from dying needlessly, don't you think the community would have trusted these workers to immunise them?

The people of Richmond, California and the people of Nigeria have much in common—great need and a distrust of people who know what's best for them. I think that today, we can unite to say communities know best, communities can lead the way and we as government officials and health professionals can and must follow their lead.

Stories from the Community—Successes and Achievements

Billy Club

The Community Manifesto that grew or rather blossomed out of last year's conference and was written so eloquently by Rhonda Galbally and her team states "Community groups are the practical means of generating social connectedness and community networks. These social relations have a huge impact on economic and social innovation, as well as on people's health and wellbeing." (p.6 Manifesto) Well my first story is all about generating this connectedness and is something I happened upon from dumb luck early in my public health career.

Back in the mid-1980's, in the early stages of a peaking AIDS epidemic, I was hired to be the AIDS Education and Prevention Coordinator for Mendocino County—a rural county in California that covers a large geographic area and has a small population—similar to Australia in many ways. I was told by the county health department that I had to bring gay men into the health department to sit through classes on safe sex and that I had to get them to come in for "anonymous" testing that was set up for gay men only on one day a week at a specific time.

Well, what's a girl to do? I thought to myself that if I were a gay man, I would be the last person I would listen to. So I called my friend Henry and asked him what I should do. Henry had already lost many friends to AIDS and he thought it was important to mobilise the gay community. Henry told me that he had been wanting to have a party and asked if my program could help pay for it, help pay for bodyguards in case any "homophobic rednecks were interested in making trouble," pay for food, condoms and risque safe sex videos. Well, that is exactly what happened—my program funded the first safe sex party for gay men—definitely in the county and maybe in the state.

Billy

Well of course I wasn't invited to the party but I heard it was fabulous—and this group of about 30 men decided to have another party a few months later. They started referring to themselves as the "Billies" and anyone attending the party was automatically part of the "Billy Club"—that is if they helped set up, cook, and clean. The next party took place a few months later and this time, more people were invited—friends invited friends— and more people heard about it and more people came. During this time, the organisers of the party .were encouraging their friends to get tested for HIV, but their friends told them they were not about to come to the health department for "anonymous testing for gays only." So when the nurses and staff found out that this was keeping people away, they changed the way they did business. They integrated HIV testing into regular clinic time and all people, young and old, gay and straight shared the waiting room—no one was singled out for coming in for any particular reason.

As a result of listening to community leaders, the number of people getting tested for HIV jumped dramatically—just about at the time when AZT was showing promise. The Health Department was no longer perceived as the hostile foe and actually became the advocate for many of its patients who were then able to get free drug treatment.

And the Billy Club grew and grew. It grew out of Mendocino County into neighboring Humboldt, Sonoma, Marin and San Francisco counties. And the reputation of being a Billy grew with it. They threw great parties, supported and nurtured one another, took care of the people who were sick and kept many more from getting infected in the first place.

And as I mentioned, I never did get to go any parties. But you know how dignitaries are often given honorary degrees?

I was made an honorary Billy .And to this day, I can say that this was definitely a highlight of my career.

Looking back on my dumb luck, the lessons I learned from this experience I always carry with me and I will share them with you — it's not rocket science: make sure you have the right message; make sure you have the right messenger and make sure you have the right venue. In this case the message was safe sex is fun and it can save your life. The messengers were gay men reaching out to their friends and lovers, and the venue was a party. What could be better?

I was able to provide the support for this incredible community and then I got out of the way. The rest is history — the number of AIDS cases in the county declined, the dumber of people with HIV seeking treatment increased and the Billies grew from about 30 people to a network of over 5,000 strong. And today, almost 19 years later, the Billies are still gathering and reaching out to the community — they are the community.

The AIDS Memorial Quilt — Names Project

Again, I would like to return to your Manifesto to introduce my next story.

I was contemplating the phrase in the Manifesto that refers to finding ways to convert understanding into effective action. (P.9) As I was thinking about the power of collective action, the story of the AIDS quilt came to mind. In the 1980's, when I was still muddling my way through my job to prevent AIDS, I decided that I needed to be better informed. I wanted facts, numbers, percentages, pie charts, and projections.

I decided to attend the International AIDS Conference that was being held in San Francisco. I wanted to be able to spin off these statistics with the ease of an epidemiologist — so when I told people about ADDS they would really listen to me.

But something very different happened as a result of attending that conference. I got to experience the power of what it takes to move from understanding to action. And it wasn't through graphs, percentages and statistics. It was through something as simple as a quilt and as complex as the lives it honored. I wasn't prepared for the emotional impact of those beautifully crafted panels commemorating, mourning and celebrating the lives of someone's son, daughter, father, mother, or lover. Surrounded by these panels, I was deeply moved and forever changed. And why the AIDS Quilt comes to mind when thinking about "understanding to action" is because the quilt provided the link between these two. I think of this link as a bridge that we need to build or cross. Cleve Jones, founder of the Names Project AIDS Memorial Quilt, built his bridge on love and healing. And because of him, many of us were able to cross that bridge to compassion and understanding and action.

So let me give you a little history about the AIDS quilt in case you are not familiar with the story. In 1980, Cleve Jones was a young gay man living in San Francisco. He was working as a consultant to the State Health Committee when he came across an article in the federal Mortality and Morbidity Weekly Report about a mysterious disease spreading through the gay community. Stunned by the report, he tacked it to his bulletin board. Within five years, almost everyone he knew was dead or dying from AIDS.

By 1985, 1,000 San Franciscans had died of AIDS, most of them living within the 10-block radius of Jones' Castro neighborhood. During a political march to City Hall, Jones and a few friends printed the names of friends who had died of AIDS on cardboard placards and they taped these pieces of cardboard to the wall of the Federal Building. "It looks like a quilt," Jones thought to himself. And that was just the beginning.

Within the next 18 months, Jones's best friend died of AIDS. The image of the quilt remained in his consciousness until the spring of 1987 when he and his friend Joseph Durant made the first two panels of what would eventually become the NAMES Project AIDS Memorial Quilt.

Jones said:

'There was something about the process of creating the panels that was comforting. We shared memories of the two men as we worked, and tried to imagine what they would have accomplished if they had lived. For the first time since Marvin died, I was able to think and talk about him without unbearable pain."

The AIDS Memorial Quilt became as much a process of healing for communities devastated by this horrible disease as it was a call to action, a unifying movement to counter the hatred and hysteria experienced by so many within the gay community. It personalised AIDS—it gave a name and a face to all those statistics. These were real people with real lives and with many who loved them.

I'd like to show you some pictures of the quilt, to personalise what I have been talking about to you....

Today, the quilt has over 45,000 panels from every state in the U.S. and honors more than 82,000 people. The quilt is the size of about 47 football fields and it weighs more than 54 tons. Over 15 million people have visited the quilt. Talk about effective outreach... And there are quilt projects in 43 nations including Australia.

This quilt pushed major health organisations and government entities, which were slow to respond, to get moving and doing. And it was the catalyst to strengthen the rights of people with disabilities to include HIV and AIDS.

The actions of a small group of individuals, from which the AIDS Memorial Quilt emerged, has affected millions of people all over the world and has given them a way to take action and make a difference at a time when they may have felt hopeless and powerless. As Cleve Jones stated, the AIDS Quilt is "a gift offered freely to the world" and will remain "an enduring symbol of love, courage and hope."

Along with love, courage and hope, what I carry with me from this example of community achievement is that we must personalise our public health messages so they have the passion to inspire people to take action.

In Spirit

This next story I want to share with you is similar to the AIDS Quilt in that it also is about making an invisible population visible—changing awareness from what many have considered not their problem to a more universal community problem.

This is the story of Aneice Taylor and the community group she started to help quadriplegics get the attendant care they need to maintain their health and independence.

Aneice and I have been friends for over 30 years. When we were young, we lived a few blocks away from one another. Our children played together and went to the same schools. Our husbands, both artists, painted together, talked shop and often exhibited together. We were very close.

Then one day I received a phone call, which left me in shock and disbelief. A friend called to say that Aneice's house had collapsed and was completely destroyed in a mudslide. Miraculously, her husband and two young children walked away from the wreckage. But Aneice wasn't so lucky.

My husband and I rushed to hospital only to find out that Aneice's neck had been broken and it was unlikely that she would be able to use her arms or legs again. This was devastating news to all of us. And I remember seeing her on this large rotating table with a stabilising device screwed into her head and I thought to myself, if she ever regains consciousness, she wouldn't want to live this way.

I shared my grief with my mother, who is something of a psychic, and she said, "You mark my words, she will live to see her children married and to enjoy her grandchildren." But this is not the point of my story—we are talking about community, after all.

Aneice did regain consciousness, and in her own words, "decided to live." She realised how fortunate she was to have family, friends and community there to help her with the needs of dally living. But she soon realised that she needed more help with care. And she realised that there must be many others like her who also have this need. She fully intended to live at home and help others do the same.

So, after a few years of adjusting to her own situation, she decided to start a non-profit that would raise money for attendant care for quadriplegics. She named it In Spirit—which stands for In Support of Paralytics in Really Intense Times.

I'd like to show you some clips from a video that highlight Aneice's work and Aneice.

The first clip is about how Aneice started In Spirit. Then we'll see the importance of advocacy. The clip that follows advocacy is probably my favorite because it takes place at her daughter's wedding. My mother's prediction did come true. And the video ends with a glimpse into Aneice's indomitable spirit.

Aneice is an example of the leadership that is critical to the success of any community organisation. Strong leadership empowers and inspires others to have the confidence to become effective advocates. And leadership and advocacy are essential to making positive change and sustaining change.

GMOs

My next story builds on the leadership and advocacy of In Spirit and all successful community groups that are part of the revolution of social change. And as the action challenge in your Community Manifesto states,"leaders should be supported and celebrated to advocate for social change, take risks, defend unpopular positions and pioneer new approaches."

This story exemplifies how leadership and advocacy actually changed policy. It is a story about Genetically Modified Organisms, or GMOs, and how a small rural community created the first GMO-free zone in the United States. The success of this achievement is a modern-day David and Goliath tale and it highlights the power of community.

And, of course, part of the appeal of this story to me is that it happened in my own back yard— Mendocino County. The county has a population of about 80,000 people and a little over half of them are registered voters. And this is a case where indeed, politics makes strange bedfellows.

On March 2, 2004, the citizens of Mendocino County approved a countywide measure that prohibits the propagation, cultivation, raising and growing of genetically modified organisms.

The Mendocino Organic Network spearheaded the initiative. The network is made up of a group of local citizens and farmers, including co-founder Els Cooperrider, the owner of a popular all-organic brewing company and restaurant. To quote Els, "The County has never seen anything like this campaign. These multibillion-dollar corporations underestimated our savvy citizenry. Passage of Measure H is just the beginning. The revolution is just starting."

And her words are truly prophetic. But let me return to the future after going back to the past.

About a year ago, Els decided to gather signatures for a ballot initative that basically asked the question, "Why should biotech corporations control our local food supply?" Giving an example of her point of view, she said, "Farmers using genetically modified seeds are forbidden to save those seeds for the following year, even though they grew them. Instead they must buy new seed or risk arrest. It's outrageous."

Together with the Mendocino Organic Network, many local farmers joined the effort, as did vintners who were afraid that GMOs would contaminate their vines and cause irreparable harm to the growing organic wine market in the US and abroad. Add to this constituency, the local fisherman, who are almost always on the opposite side to the environmentalists, and you have strange bedfellows indeed. Local opposition grew and grew—and gained enough momentum to pass the measure.

And here's the rub—the world's largest producers of genetically modified products pumped over $700,000 into this campaign—an amount unheard-of inMendocino politics. And they failed to receive a single contribution from anyone within the county.

By contrast, more than 300 county residents donated about $11,000 to the campaign. Hundreds of these dollars were being shoved into coffee cans at local businesses. Yet these multinational companies that sell virtually all of the genetically engineered crops and seeds in the world thought this would be a slam-dunk.

After all, it had been in Oregon, where the same corporations donated $4.9 million to defeat an initiative to label GMOs, compared to $200,000 raised by Oregonians.

But it didn't happen that way in Mendocino. And to quote Measure H's Campaign Coordinator, "It's an example of local government at its best, acting to protect its citizens and the local economy and future generations. This amazing local campaign demonstrates ….no amount of money can replace the love and commitment of people who care passionately about the place where they live."

Let's look at just how down-home this campaign was...

Now to the present and the future—I have read about similar campaigns in the US and in the major agricultural states in Australia and other countries worldwide. And as I was writing this segment of my talk, I read that Monsanto dropped plans to commercialise genetically engineered wheat, at least for the near future.

The lesson learned from this is that a small group of leaders and activists can move mountains. And, no matter what your point of view about GMOs, and perhaps I should have been more politic in hiding mine, another lesson to be gleaned from this example is that perceived outsiders are rarely trusted or welcomed by communities, whether they have good intentions or not, or lots of money and resources or not.

So we need to be mindful as government officials and health care experts that we cannot move forward with communities unless we are perceived as the community.

WG

My last story is about our work at the Center for Community Wellness. We are a program within the School of Public Health at the University of California, Berkeley, We have been working for over 16 years to translate research into practice—we put what we know into action. At the foundation of our work is Dr. Syme's research on empowerment which has found that when people have control over the events that impact their lives, they are healthier, happier and live longer. Dr. Syme often says that we in public health have messages to deliver but people have lives to lead and there is this disconnect or gap between the two. Our work at our Center is dedicated to bridging this gap. We look to the community to tell us what they want to know, what they need to know and how they want the information presented. Our Wellness Guide series of publications helps empower people to take positive action on diverse health and life issues because we put our messages in a life context. We show real people in real life situations making positive decisions for themselves and their families. This communicates the message to our readers that if people like themselves can take action they can too.

I have been talking throughout this afternoon about understanding to action, and the bridges that one builds or crosses to get there. There are many bridges. The ones I have spoken about today include the right message, the right messenger and the right venue. I've spoken about personalising our messages. And I've spoken about the importance of leadership and advocacy.

Even though these bridges have many names, they are all built on empowerment, making sure there are ways for people to have a voice and control over what happens to them.

I'd like to walk you over another bridge that we use at our Center, our participatory approach. And I'd like to take you through the process we used to develop our latest edition of our Wellness Guide, to exemplify this approach. First, it usually starts with financial support. We received funding from a foundation to do a guide for people with disabilities and their families. And we fully expected that we would produce a separate guide customised for this population.

So we began our process, as we always do, by going to the community. We met with people with disabilities and disability leaders throughout California. And what they told us was that they didn't want a separate guide. They said that since disability is a part of life, our guide should be inclusive of the many issues faced by people with disabilities and their families.

This way it would be sure to reach people who have a disability, including those who self-identify and those who do not. And it would let the mainstream population know that people with disabilities are not hiding or going away.

And we listened to the disability community and we changed our preconceived opinion about what would work best.

We formed an Advisory Committee that met regularly, twice a month in the beginning and once a month as the project was winding down. Everyone decided that the guide would show people with disabilities engaged in all activities of life—for example—working, commuting, going to school, in sexual relationships, parenting, and staying well and exercising, to name a few.

Along with the Advisory Committee meetings, we conducted over 50 focus groups to help determine the structure and content of the Guide. Groups included English- and Spanish-speaking seniors, people with and without disabilities, and parents of children with disabilities. Then we integrated their feedback into subsequent drafts that were tested and tested again following the same feedback loop. We are always looking for the balance between the messages that our funders and experts feel we need to communicate and what the community wants to hear.

We printed the guide in English and Spanish. Over 300,000 copies were distributed by over 800 grassroots groups throughout California. We also developed a Braille, audiotape, and CD ROM version to increase accessibility and broaden our audience.

To date, our publications have successfully reached over 10 million people. There have been several large-scale evaluations of our model with similar results: People who receive our guides demonstrate a significant increase in knowledge and confidence and a greater feeling of control over their health and wellbeing. And they are able to act on this information.

And because of our great results, our model is currently being replicated in the US and internationally in Belarus, Eritrea, Eastern Europe and here in Australia.

I'd like to show you a few clips from the video that was developed to show people how to use the guide. In many ways, these stories personalise the work we are doing at the Center and make all those stressful deadlines and rewrites worthwhile.

Concluding Remarks

To conclude, my future is brighter because I am here among all of you who have the courage to do things differently—to believe in community, to listen to community and to act in support of community.

I have shared with you the stories that have inspired me and influenced my life's work. And I know because of today and this conference, your stories are becoming my stories. And just like life, our shared story is a work in progress—built by and for community. Ours is a shared vision for a healthier and better world. And you in Australia are showing the rest of us the way. Thank you for that and thank you for giving me this opportunity.