ANNALS OF FAMILY MEDICINE

Appendix. Presentations of Community Advisory Board Members

Wendy Thunderchief

My mother's clan is the Mountain Cove People, and I was born "for my father's clan," the Red House People. We are descendants of Chief Mañuelito. We are the descendants of one of the original 7 Navajo clans. My husband is called Clinton Thunderchief, and he is one of the chiefs of his tribe. We are gifted with 3 children, and I am the one called Wendy Grey Eyes Thunderchief.

I would like to share reflections based on my experience in the field of mental health with American Indians in urban settings. I also will comment briefly about the task before the mentees in this program, as I have had my own experience with research and being under the microscope.

American Indian people have long been subjects of well-intentioned research. A long time ago, as children roaming the hills on the reservation, we had our close encounters with those desiring to know more about us. We would glance at each other, and the proper glance would indicate whether or not we would take on the poor soul. For a couple of cans of Vienna sausages and a box of those old salt crackers, we'd sit around the fire and tell the poor soul whatever he wanted to hear, mostly all completely made up. So I'm sure that my sisters and brothers and I are partially responsible for some of the misconceptions out there. But it was fun and, more importantly, we were hungry. I hope by now the ante is up a bit, and the research methods improved.

As a people we have a history of being research subjects, an uncomfortable position that produced results for someone, somewhere, but not necessarily for us. I hope your research produces realistic, usable, workable, relevant, culturally appropriate, attainable, sustainable results for the people you are researching. We must remember our history as research subjects, as well as the volumes already out there about us.

I believe the task becomes more challenging for you as the realistic picture of American Indians comes into focus. With resources dwindling even as we speak, and with the anticipated closure of numerous programs for American Indians, including the threatened closure of the local Indian Health Service hospital, and with the minimal and insufficient availability of mental health services for American Indians, I hope there is a place for you as well as the results of your research.

As a contract counselor in an elementary school, I have found that American Indian children respond to culturally appropriate therapeutic approaches. This conclusion is evidenced by my work with a third grader who at first was unmanageable, defiant, and uncontrollable in the classroom. His outbursts landed him in my office. During our third session together, he came in as usual, sat down on a chair, then all of a sudden he saw my necklace, a beaded sunburst. He wanted to hold it. He knew what it was. It was a Sundance medallion. He knew the significance of the colors, the directions, and pattern. For the next 30 minutes this defiant child, who reportedly had a short attention span, could not carry on a conversation, and would not sit still, became the expert and took me on a little journey about his grandmother who is a Sundancer. She makes the medallions. He told me that she also participated in the Vision Quest, and he helped watch over her. This story became the focal point of our work together, as ceremony, in this and other cases, holds many lessons.

My parents and I grew up in tumultuous times in the historical evolution of my people. We were and still are a people in search of ourselves, experiencing the residues of physical and psychological colonization, and the continual assault of manifest destiny. During that time, our mental health problems as well as the solutions were defined for us, completely disregarding traditional methods of healing that worked for hundreds of years. Indigenous people the world over understood adaptation to and sustainability

of the environment, which naturally evolved into reflections of healing. We believe we are connected to the land, earth, and the cosmos, the great circles of life.

My early formative years were abundant with ceremonies. Those years later became the glue that held my precarious life together. As I began my journey through the educational system, I learned there were people who thought they knew who I was, who I was not, or what I should be. Most of these pedagogical assumptions rose out of Western research. Like the pendulum swinging back and forth between the co-present images of the ascendant and descendant noble savages, I had my own pendulum. My entire educational experience, even through my master's degree, has been one of reshaping the experience to fit my view of the world, an additional layer that my nonnative colleagues did not have to contend with. There are numerous rituals and ceremonies that blend in beautifully with healing. Almost every tribe has a form of the sweat lodge, the purification rites that precede all ceremonies and that involve our direct interplay with the 4 sacred elements. During the Vision Quest, we become directly involved with the elements of the universe; this experience shapes and focuses our work throughout the year. Most tribes have the pipe, the bowl representing female, the stem representing male, and together they represent life. Our world view is naturally circular. All of life occurs in circles, and all ceremonies unfold in circular fashion from the sweat lodge, the ways we dance, pray, pass the pipe, and so on. It is within that circle that we find and maintain our place. When we are not within that circle, such gives rise to conflict.

Early on I remember the care with which sand paintings were created. I remember the silence, the feelings of the preparation, the sound of the sand. Many years later, now I watch children involved with sand trays. Sand, after all, is the skin of Mother Earth.

So, if ceremony works, and some of us know that it does, then why have traditional ways been excluded as a viable modality in the healing process? I realize there are scattered efforts that include traditional healing in various communities, including the Navajo Reservation, but we need them here, and we need them now. They need to be a viable part of our health care system and not a retrofit.

How we shape some of these agonizing reflections into high-quality research questions and research projects are tasks before us now. Toward this effort I would also like to reiterate that we remember our history as research subjects.

Roberto Chené

Our community is locked into an unhealthy, dysfunctional relationship, and it is called assimilation. Once a society sets up a system where some populations must assimilate to other populations, you begin a fundamentally unhealthy relationship, which always will be riddled with conflict. There is no way to make such a one-way relationship healthy without doing some restructuring, a re-creation of that fundamental relationship. Assimilation is a coercive structure. When minority cultures experience historical trauma, that trauma is a consequence of a coercive relationship. The challenge is how to heal the problem, how to re-create this relationship which is not working, and how to get past the stalemate of conflict.

Good research should start with an accurate description of these problems. Academic institutions need to collaborate with the community, but these institutions also can exist in a relationship of dominance toward the community. What kind of mediation skills do we need to facilitate communication between the community and the institution?

For example, we want collaboration; we want community input into policy. If you really ask for that input, however, along with the input you get conflict, or at least venting of frustration. This conflict discourages us from getting the input needed for policy. The result is that we talk about how nice it would be to collaborate with the community in the creation of policy, but the implementation falls short.

Those who ask for community input can start to feel as if they, not the community, are the victims. When we ask someone who has been left out to tell us the truth, their truth and attitude can cause our discomfort level to increase. At that point we have a new problem—managing our discomfort levels. If we hold power, we tend to exclude the voices that generate discomfort and make policy without them.

Can we devise pilot projects outside our usual comfort zones that will help us redefine the relationship with the people we want to serve? In other words, which people make me the most uncomfortable, and how can I include them, and what kind of strategic research project would I need to develop? We need to figure out how to educate and manage the discomfort levels of those on the inside and mediate the hostility of those on the outside. If we are talking about intercultural collaboration, we have to understand from research the discomfort of those included and the discomfort of those excluded.

A final thought about historical trauma: The legacy of assimilation generates internalized oppression. When we talk about black-on-black violence, black-on-brown violence, or people of color violence within our community, we are not talking about dysfunctional persons who somehow like to play out violence on each other. There is no cultural group in the world that does not have violence within it. Those subcultures, however, usually people of color, internalize generations of exclusion in a painful manner, which often manifests in escalated self-destructive behavior. There is an extra edge of violence that is correlated with pressure from the dominant culture. People of color are blamed for their dysfunction by people from the mainstream who are naive or in denial about the dynamics of dominance.

This history takes common dysfunctions and pushes them to the level of severe dysfunction. The intense experience of dysfunction and a deep lack of self-esteem run so deeply that you almost systematically work against each other. That, in my opinion, is a mental health issue throughout the country.

We have to develop research methodology to identify internalized historical violence as a mental health disorder. Second, we need to get funding and to develop leadership who can intervene to heal this hurt in communities of color. We have to stop pretending that these communities somehow decided to do violence to themselves. This is not to say that communities of color are not responsible for themselves. But once you have set up a system of cultural dominance, you have begun a legacy of mental dysfunction. The paradigms of research methodology should address this issue in a very concrete way.

Lorenzo García

My sister-in-law died a few years back. She suffered from mental illness for 14 or 15 years prior to her body being discovered in the river. When I was about 23 or 24, my wife and I and a few other people started the second foster group home in Albuquerque. One of our residents, a young man, was looking through the coats in the bedroom while at a party. An undercover police officer had left a gun inside his jacket. Marvin took out the gun and some of the bullets to play Russian roulette and proceeded to blow his brains out.

Living now in the South Valley, not far from where I grew up, I continue to hear stories of people I grew up with who are dead, or strung out on drugs, or having some kind of mental illness, making them part of the statistics we often look at without putting faces to them.

There is a line in the movie *Casablanca* when the police captain, the head of the security force, says, "Okay, round up all the usual suspects." That line is appropriate for people here who are interested in research on mental health and primary care. I say that in appreciation, believe it or not. I appreciate you for daring to think in the midst of confusion, for deciding not to be discouraged when discouragement is something that is promoted and reinforced over and over again. Thank you for your work as researchers. Hearing about you and looking through your booklet, it is obvious that you are the brightest and the best we have.

As faculty, as far as I can tell, you are the odd balls. You are the ones who stick out like sore thumbs when the deans decide what positions they are going to cut and say, "Well, so-and-so, they are the rabble rousers, they're the ones who always say the wrong things and never go along just to go along." I appreciate you for not going along.

To many of you who are young adults and who are minority students and PhDs (I do not think I have been in a room with so many PhDs), I would like to say: You are your community's pride and joy! I acknowledge your struggle, your efforts, and your willingness to give a good fight.

As Howard Waitzkin has said in an article, sometimes it looks as though our work might be a little dangerous.[21] I want you to know that the community supports you completely. You have taken a risk by focusing on these problems, and that will continue to be the case. We appreciate that you decide over and over again to upset the apple cart.

I would like to put forward some challenges. We can begin to discuss the things that we have been conditioned not to speak of, that are pretty much socially taboo. Every oppressive society today, so far as I can tell from my reading of history, requires the appearance of conformity, if not necessarily conformity itself. An old organizer from the 1930s told me that once. For instance, we have to do what is necessary from the viewpoint of funders, to the extent that our efforts satisfy those who review our reports. Then we have to organize.

We should start by looking at our definition of normalcy. In the current order, anyone who contributes to the economic well-being of that order is viewed as normal. What does this do to us as humans? Those

who cannot demonstrate their competency in supporting the economic system are not viewed as normal. In this society we have many people who are at risk, who are marked for destruction.

When I started working with the University of New Mexico Mental Health Center a number of years ago, I was sent to work at the county jail. I got sent there because I was organizing a union among the clerical workers at the university. We were working for better pay and better working conditions.

Then we began to ask questions about the use and overuse of medication. It was starting in the 1970s, when Prolixin and other very heavy drugs were being put into people. It looked to us as though the Department of Psychiatry at the time had a number of individuals who were good, well meaning, well intentioned, but were addicted to a medical treatment model, in particular for poor people and working class people. So some people, clients, were given lots of drugs because it was convenient, and other people, practitioners, could take sabbaticals and do things that were interesting to them, all seemingly normal and manageable. But I do not think that system really worked.

What I am asking is: What do we do that is normal? Can we begin to talk about things like institutionalized mental oppression? Can we talk about sexism and classism and the systematic mistreatment of young people just because they are young? Can we begin to talk about the oppression of parents who are systematically undermined?

What can you do as researchers to help us measure whether or not our community is really empowered, whether or not we make a difference in our mental health status? We should have a group of researchers who are willing to acknowledge the relationships among social structural issues, individual mental health, and primary health care outcomes. In other words, we need research which helps us understand that it is not just ourselves, not a particular problem within Lorenzo, but that Lorenzo's particular problem is related to other people who have similar problems.

When you go about setting up a research project, do you think about taking your research back to the people that you're researching? Do you have an ongoing relationship with people that you are trying to research? We have a chance to build something new, to dare go against confusion and discouragement. There is something inherent in humans that we dare to think, dare to challenge, dare to go against the grain, and stand up for what is right.

Delfy Peña Roach

I am director of an organization called Parents for Behaviorally Different Children. I got involved in 1988, when my child was diagnosed with attention deficit hyperactivity disorder. My husband, who had bipolar disorder, committed suicide.

Our organization provides support to our families and to providers who try to care for our children. The staff of 14 includes advocates and case managers doing statewide work. There are problems of access to mental health services. One of the biggest problems is communication between providers and families. We see attitudes that families are to blame for these illnesses. Families still feel they don't have control over situations after their child is in the hospital or juvenile justice system or school. Parents help parents mainly through advocacy for better schools, housing, transportation, recreation programs, legislation, services, and training.

Other issues are economic: We do not have parity for mental health issues, so for those of us who have to pay 50% as co-payment, and have to go once or twice a month or once a week, it's very expensive. My son has been through 4 psychiatrists now. I cannot afford the full-blown, 1-hour medical evaluation; it is always more than $200.

How does clinical research relate to service delivery and practice? We need people to communicate research findings so that everyone can benefit without our having to hire an interpreter to know what they are saying. We often do not understand what researchers are saying. So put it in a way that we can understand, so that we can develop programs. The work that you do is important, and we want to be sure that we can put it into practice.

Margie Goldstrom

The National Alliance for the Mentally Ill is concerned about how society treats people who are mentally ill, about the shame and stigma of that illness, and about why people do not go for treatment. We also are concerned about the issue of cultural diversity.

Science has led to improvements in services for the mentally ill. I had a family member with a mental disorder, and that's why I'm in this organization. Although science has done well, society has not caught up with treatment of the mentally ill.

In 1979, the Alliance for the Mentally Ill was formed. Until then, there was a stigma of being mentally ill, and a notion that families caused this problem. The medical profession would say, "What is wrong with this family?" Three hundred families started the organization, and then it evolved into a national organization.

In New Mexico, there are 44,000 children and 80,000 adults, in a population of 1.8 million, who have a severe mental illness. It affects 1 in 10 people and 1 in 5 families. In our organization we target 5 illnesses: schizophrenia, depression, bipolar disorder, obsessive-compulsive disorder, and panic disorder. We provide support groups and educational meetings. Everyone can come at no charge. The community is invited, and the services are confidential. In our community the police are trained for crisis intervention to diffuse conflicts that concern the mentally ill.

The organization provides several other activities and services. We have a small but useful library. A newsletter is published every 2 months. We have a project to educate the public about mental illness. We hold an annual luncheon for fund raising and leadership development. The organization also promotes Mental Health Awareness Week. We lobby for services, treatment, and legal changes. For instance, we are promoting the Mental Health Parity Bill and are advocating an increase in funds for housing, medication, and treatment. We are all volunteers. Because we all have family members who are mentally ill, we know where to find help. We invite your participation.

Mandy Pino

I am representing Health Action New Mexico, which was organized spontaneously by a group of activists when Representative Newt Gingrich started his Contract for America. Similar groups organized across the country to stop the cuts in Medicaid and other violations of human dignity. We started as the Emergency Committee to Protect Health Care Access. In advocating against including behavioral and mental health services under Medicaid managed care, we are convinced that it should have been carved out from the rest of the Medicaid program. We have worked with the National Health Law Project to increase consumer involvement in Medicaid managed care.

How is this related to mental health? There is one common thread that runs through all of the target groups that we talk about. People of color, the minority groups, the elderly—who are also an oppressed group—the common thread is poverty.

I challenge you to network with community-based organizations, to give what you have reaped through your research so that it can help us community advocates in what we do. One project came from this program, the "Multi-method Assessment of Medicaid Managed Care" in New Mexico.[22,23] If we had been in closer collaboration, the project would have given us some better direction. There is another study that I appreciate: "Effects of Medicaid Managed Care on Mental Health in New Mexico."[24] It is a challenge to bring to community advocacy groups what has happened to the mental health infrastructure that has been destroyed with Medicaid managed care.

Policy is the heart of everything that we do or do not do. It affects our lives in every fashion that we can imagine. You cannot truly affect policy until you make folks uncomfortable. Then you have to be in a position to manage that discomfort to your advantage, and that is not an easy thing to do. But the only way that it will ever happen is through grassroots organization.

In our project we also discovered a complete lack of cultural sensitivity—especially a lack of interpreters. What are they doing for interpreter services in hospitals? They go get the janitor. In addition to the linguistic problem, cultural sensitivity is even more important, and particularly in New Mexico, where we have so many American Indian cultures. If we cannot begin to incorporate and collaborate with traditional healers in our own healing, we remain disabled. We deprive ourselves of that vast culture, oppressing people who would heal if we incorporated traditional approaches into our own work.

I challenge you to look more closely and share your knowledge with community-based organizations. We have been working for years on mental health insurance parity, so that people can obtain levels for benefits the same as for physical health problems. In New Mexico, we are in collaboration with the National Alliance for the Mentally Ill and other groups that have been working for mental health parity.

If we ask only for what we really need, they will not give it to us. Last year we went before the legislature and said, "We want mental illness defined broadly, not just the diseases of the brain. We want to define it to include abuse, alcoholism, depression, and other kinds of mental illnesses." We did not get the whole loaf of bread, but we did get a mental health parity bill passed that was a pilot project for state employees. The moral of that story is that, when you are working on policy, never ask for half a loaf because you are going to get a slice. Ask for the whole loaf, and then maybe you will get something.

Discussion

Joel Yager (University of New Mexico)

There are implications from each of the presentations. One implication is to come and speak with community groups, to make yourselves available. Another is to write newspaper articles, that is, to try to write not only for journals but also for the popular media, or to make local community television presentations. We have a social responsibility not only to hear what you say and then to go do research and publish it in esoteric journals, but also really to use the research in dialogue with the community.

Howard Waitzkin (University of New Mexico)

In planning this conference, one reason we believed it was so important to start with this type of interchange was that perspectives and agendas emerging from talks that occur nationally differ from those that are important for local communities. Community perspectives do not appear often in review procedures at the National Institute of Mental Health. We should push the envelope in this area. Review committees rarely receive applications that propose community participation in defining research questions, which is expected to be the investigator's prerogative. I encourage others to comment on how best to confront that contradiction.

Harold Pincus (RAND/University of Pittsburgh)

On the national level, expectations for community, patient, and family involvement have changed. Requirements now are institutionalized in the NIMH review committee structure requiring that consumer representatives be represented on the committees. Similar changes have occurred in institutional review boards for evaluating research on human subjects. There is now an expectation to build community partnerships. Investigators are going to be reviewed by the community as well as by mainstream scientists.

Note: references 21-24 can be found in the list of references to the online and print versions of this article.