

Citizen Health Care: A Model for Engaging Patients, Families, and Communities as Coproducers of Health

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Citizen health care is a way to engage patients, families, and communities as coproducers of health and health care. It goes beyond the activated patient to the activated community, with professionals acquiring community organizing skills for working with individuals and families who see themselves as citizens of health care—builders of health in the clinic and community—rather than merely as consumers of medical services. Over the past 7 years, the authors and their colleagues have developed and field-tested a structured process for implementing this model into everyday practice settings. In this article, we describe the origins of the model, its core tenets and practices, and examples of its implementation in community settings. We discuss how citizen health care differs from other models of collaborative and community-based work, and we outline research and training directions.

Keywords: community-based participatory research, action research, citizen health care

Many observers believe that the U.S. health care system needs a fundamental redesign if we are to have a healthier population and avoid exhausting our economic resources (Future of Family Medicine Project, 2004; Institute of Medicine, 2001). Leaders in collaborative family health care and related fields have made important strides in articulating a redesigned model for clinical care focusing on teams of biomedical and psychosocial professionals working collaboratively with one another and with patients and their families (Blount, 1998; McDaniel, Hepworth, & Doherty, 1992; Peek, Heinrich, Bischoff, Scherger, & Patterson, 2002; Seaburn, 1997). This article addresses an additional step: moving beyond clinical collaboration to community collaboration.

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nity—rather than merely as consumers of medical services. Over the past 7 years, the authors and their colleagues have developed and field-tested a structured process for implementing this model into everyday practice settings. In this article we describe the origins of the model, its core tenets and practices, and examples of how this model has been applied in community settings. We discuss how the citizen health care model differs from other models of collaborative and community-based work and outline future directions for research and training.

ORIGINS OF THE CITIZEN HEALTH CARE MODEL

Citizen health care emerged from work across a variety of disciplines. We only briefly mention disciplines that are familiar to readers of this journal, while elaborating on work that is less familiar. First is family therapy with its systems orientation to viewing individuals within the contexts of their larger relationships, families, and social systems (Minuchin, 1974; Imber-Black, 1988). Second are medical family therapy and collaborative family health care, which add biopsychosocial dimensions to family systems theory and view the therapist as part of a larger, integrated treatment team (McDaniel et al., 1992; Rolland, 1994). The third key influence came from outside of health care in the realm of political theory. The *public work* model of the Center for Democracy and Citizenship at the University of Minnesota was developed by Harry Boyte, Nancy Kari, Nancy Skelton, and their colleagues (Boyte, 2004; Boyte & Kari, 1996; Boyte, Kari, Lewis, Skelton, & O'Donoghue, 2000); the following is a description of this model adapted from Doherty and Carroll (2002):

Harry Boyte, a political theorist who was schooled in the civil rights struggles of the 1960s and the Saul Alinsky tradition of community organizing, moved from a radical-left political philosophy in the 1970s to what he calls a *new populism* in the 1980s

and 1990s. The public work model brings together strands of American pragmatism (e.g., Dewey, 1997), public realm theorists such as Hannah Arendt (1958) and Jurgen Habermas (1979), and related philosophical and theological traditions dealing with humans as “*homo faber*” (constructing the world). The model maintains three principal orientating ideas:

1. Human beings as producers or cocreators of the world. Public work is defined as sustained, visible, and serious effort by a diverse mix of ordinary people that creates things of lasting civic or public significance. In contrast, the provider/consumer dynamic of American culture renders people passive recipients of services (from professionals, the state, and the market) rather than cocreators of important work.
2. The importance of public life. Without denying the importance of the intimate sphere of family and friends, the model emphasizes the role of a public life to a full human life. Private life cannot be cut off from the public life in the “commons,” and the privatization of contemporary life leads to the unhealthy dominance of the market and the state over human affairs.
3. Democratic, relational power. Ordinary people working together can influence, through “civic muscle,” the world of institutions, professions, and the marketplace. Democracy in this sense is not just about voting and volunteering as a private citizen; it is about joining with other citizens to build a robust public world. Although not timid about conflict, the model stresses the development of relationships of mutual interest and collaborative energy to work on public solutions, in contrast to the traditional politics of protest.

Through the influence of the public work model, we expanded our perspective of health care beyond the traditional clinical setting to the civic and citizenship arenas. We became sensitized to the inherent limitations of interdisciplinary, collaborative clinical care in a culture of health care that emphasizes provider/consumer relationships and to the problems inherent in advocacy approaches to health care change in which the expert professional attempts to obtain resources on behalf of passive communities. We knew that beginning a cultural change by engaging citizens as co-creators of health care would mean developing new methods beyond those of contemporary medical family therapy and collaborative family health care.

The fourth influence on the development of citizen health care is the community organizing tradition going back to Saul Alinsky (1946) and those who followed him in the Industrial Areas Foundation (IAF) and similar groups. The goals of contemporary community organizing go beyond the politics of protest and instead emphasize the renewal of local democracy, the reorganization of relationships between power and politics, and the restructuring of the physical and civic infrastructures of communities (Warren, 2001). From the IAF we learned the importance of listening to patients and families to determine what is most important to them, to work closely with them to understand a problem before generating action solutions, and to continually identify and develop new leaders in health care communities. Unlike most community organizing approaches, however, ours has a role for professionals as partners and, at the outset, catalytic leaders.

In 2001, we adopted *community-based participatory research* (CBPR), also known as *action research*, as a paradigm for evaluating our projects (Mendenhall & Doherty, 2005). CBPR emphasizes close collaboration among clinical researchers and community participants who are directly affected by an issue to generate knowledge and solve local

problems. Within this partnership, hierarchical differences are flattened, and all participants work together to create knowledge and effect change. The democratic and participatory nature of this approach is manifest throughout every stage of the research process, from defining and gathering information regarding a problem, to developing and implementing an intervention to address the problem, to evaluating the effectiveness of the intervention, and then to altering the intervention in accord with the investigation's evaluative results (Bruce & McKane, 2000; Minkler & Wallerstein, 2003). CBPR has become the principal research tool for citizen health care projects.

To recap the historical influences on citizen health care: the original influences came from our professional backgrounds in family therapy, medical family therapy in family medicine settings, and collaborative family health care. To these we added democratic political theory in the form of the public work model, contemporary community organizing strategies, and CBPR. From these influences came the Families and Democracy Project, which consists of community organizing initiatives on issues as diverse as overscheduled children in middle-class communities to the challenges of urban unmarried new parents (Doherty & Carroll, 2002). Citizen health care is a leading edge of the Families and Democracy Project applied to health care.

PRINCIPLES OF CITIZEN HEALTH CARE

Tables 1 and 2 outline the main principles and strategies of the model. Citizen health care aims to engage a resource that is largely untapped in our strained health care system: the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives. This is different from the traditional way of thinking about an activated patient who becomes a responsible agent for his or her own health. The idea of *citizen* refers to people becoming activated along with their neighbors

Table 1
Citizen Healthcare Model: Core Principles

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1. The greatest untapped resource for improving healthcare is the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives.
 2. People must be engaged as coproducers of healthcare for themselves and their communities, not merely as patients or consumers of services.
 3. Professionals can play a catalytic role in fostering citizen initiatives when they develop their public skills as citizen professionals in groups with flattened hierarchies.
 4. If you begin with an established program, you will not end up with an initiative that is “owned and operated” by citizens, but a citizen initiative might create or adopt a program as one of its activities.
 5. Local communities must retrieve their own historical, cultural, and religious traditions of health and healing and bring these into dialogue with contemporary medical systems.
 6. Citizen health initiatives should have a bold vision (a BHAG—a big, hairy, audacious goal) while working pragmatically on focused, specific projects.
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and others facing similar health challenges in order to make a difference for a community. Ordinary citizens become assets in healthcare, coproducers of health for themselves and their communities. They are no longer simply consumers of services who look out for their own health and that of their immediate loved ones.

Transforming the privatized culture of health care—the notion that patients should take care of themselves while health care professionals and government officials worry about the health of the public—is daunting, to say the least. We believe it cannot be done either by community members working alone or by professionals working alone—nor will it be accomplished by macrostructural changes alone, as needed as these are. Health care is too complex and expert driven for citizen groups to organize on their own while maintaining credibility outside of partnerships with health care professionals. A citizen group might organize to demand a new facility or more culturally sensitive care, but win-or-lose, professionally driven, third-party-paying health care would likely go on as usual, perhaps with a new building or more language translators. Citizen health care emphasizes an important role for professionals as leaders and partners with other citizens in communities. This is in contrast to community organizing traditions that are highly skeptical regarding professionals’

ability to play a constructive role in community renewal (e.g., McKnight, 1996). In our experience, professionals with a track record of collaborative care with individuals and families often have sufficient trust in the community to call people together to address a community health need. What these professionals require is the development of their public skills as citizen professionals working in groups with flattened hierarchies, that is, where community members and professionals work with a disciplined, democratic process to pool their distinctive knowledge areas and skills and where professional expertise is “on tap,” not “on top.”

This combination of leadership and flattened hierarchy is a distinctive and difficult to learn feature of citizen health care. Although the goal is to develop citizen leaders, at the outset the health professional must bring a vision and set of democratic public skills to the process of identifying key issues of concern to the community and to mobilizing citizen groups to work on these concerns. The professional brings a disciplined process to the citizen initiative so that it is genuinely democratic and is not hijacked by a dominant group member or lapses into conventional provider/consumer dynamics that both patients and professionals are so accustomed to. However, the professional does not control the outcome of the group process by bringing in

a plan for others. A principle of citizen health care is that if you begin with an established plan or program, you will not end up with an initiative that is owned and operated by its citizens. However, after considerable investigation, a citizen group might adopt a program as one of its activities.

A key decision point in implementing citizen health care is the delineation of the community to be involved in a project. Here the model reflects the influence of the community organizing tradition and its emphasis on mobilizing relatively small communities where people can have face-to-face relationships. We have found that a clinic population serves as a good community boundary for citizen health care initiatives—and within that clinic community, a subcommunity of people dealing with the same health issues, such as diabetes or depression. In a new project, we are starting with a clinic and then engaging a larger local community, but even here we work with a subcommunity of people facing a common health challenge. No matter what community, each citizen health care initiative should have its unique flavor instead of simply adopting what another project did. Local communities must retrieve their own historical, cultural, and religious traditions of health and healing and bring these into dialogue with contemporary medical systems. For example, in our new work in a Hmong community in St. Paul, it has taken a number of months, and the gradual development of trust, to get to the root of how community members experience and perceive what professionals label as clinical depression. A key to all of these community conversations in citizen health care is the blending of the “I” and the “we”—how the health issue challenges not just each individual in the group but also the whole community, and how ordinary people can organize to address problems facing the larger community.

Reflecting the public work and community organizing elements in citizen health care, this model calls for expansive lan-

guage and not just the rational–technical language common in health care professions. It calls for a bold vision about making a big difference in the community and the world and not merely delivering volunteer services. The language of citizenship and “we the people” pervades citizen health care initiatives, as does the vision of each small project working locally but contributing to a broader movement toward reclaiming health care as work by, for, and with citizens.

We have done 12 projects in citizen health care and the larger Families and Democracy Project since 1999. Core elements of these projects apply across a diversity of socioeconomic and ethnic groups, and their implementation differs across different communities and problem areas. The three projects described below represent mature applications of the citizen health care model and illustrate the guiding principles and strategies outlined above.

EXAMPLES OF CITIZEN HEALTH CARE PROJECTS

Partners in Diabetes (PID)

The PID initiative arose out of a long history of frustration in a large Midwestern health maintenance organization (HMO) regarding their urban, adult patients with diabetes. Despite repeated efforts in hosting focus groups and classes, conducting group visits, and imparting the elements of good diabetes management, patients’ health remained poor. Providers complained about noncompliant patients and their poor health indicators (e.g., HbA1c, weight). Patients complained about providers who appeared insensitive to their psychosocial and cultural/ethnic struggles.

Program Initiation

William Doherty approached this challenge with a community-based participatory research project, using the citizen health care model as a guiding framework. Early meetings between Doherty, Tai Men-

Table 2

Action Strategies for Citizen Healthcare

1. *Get buy-in from key professional leaders and administrators.* These are the gatekeepers who must support the initiation of a project based on its potential to meet one of the goals of the healthcare setting. However, we have found it best to request little or no budget, aside from a small amount of staff time, to allow the project enough incubation time before being expected to justify its outcomes.
2. *Identify a health issue that is of great concern to both professionals and members of a specific community (clinic, neighborhood, cultural group in a geographic location).* Stated differently, the issue must be one that a community of citizens actually cares about—not just something that we think they should care about. The professionals initiating the project must have enough passion for the issue to sustain their efforts over time.
3. *Identify potential community leaders who have personal experience with the health issue and who have relationships with the professional team.* These leaders should generally be ordinary members of the community who in some way have mastered the health issue in their own lives and who have a desire to give back to their community. Positional leaders who head community agencies are generally not the best group to engage at this stage, because they bring institutional priorities and constraints.
4. *Invite a small group of community leaders (three to four people) to meet several times with the professional team to explore the issue and see if there is a consensus to proceed with a larger community project.* These are preliminary discussions to see if a citizen healthcare project is feasible and to begin creating a professional/citizen leadership group.
5. *This group decides how to invite a larger group of community leaders (10–15) to begin the process of generating the project.* A major task of the small initial planning group is to decide on the criteria for expanding its membership, for example: only within the clinic community or beyond its walls; or people known to group members who are connected to a cultural community or soliciting nominations from health professionals. One necessary criterion is that those invited should have leadership potential.
6. *The full planning group implements the community organizing process.* Over the next 6 months of biweekly meetings, the group works through the following steps:
 - exploring the community and citizen dimensions of the issue in depth,
 - creating a name and mission,
 - doing one-to-one interviews with a range of stakeholders,
 - generating potential action initiatives and processing them in terms of the citizen healthcare model and their feasibility with existing community resources, and
 - deciding on a specific action initiative and implementing it.
7. *Employ the following key citizen healthcare processes:*
 - *Democratic planning and decision making at every step.* As mentioned before, this requires training of the professionals who bring a disciplined process model and a vision of collective action that does not lapse back into the conventional provider/consumer model, but who do not control the outcome or action steps the group decides to take.
 - *Mutual teaching and learning among community members.* Action initiatives consistent with the model first call upon the lived experience of community members, with the support of professionals, rather than recruiting community members to support a professionally created initiative.
 - *Creating ways to fold new learnings back into the community.* All learnings can become community property if there is a way for them to be passed on. Currently we have vehicles for professionals to become learning communities, but few vehicles outside of Internet chat rooms for patients and families to become learning communities.
 - *Identifying and developing leaders.* The heart of community organizing is finding and nurturing people who have leadership ability but who are not necessarily heads of organizations with turfs to protect.

Table 2 (continued)

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- *Using professional expertise selectively—on tap, not on top.* In this way of working, all knowledge is public knowledge, democratically held and shared when it can be useful. Professionals bring a unique font of knowledge and experience—and access to current research—to citizen healthcare initiatives. However, everyone else around the table also brings unique knowledge and expertise. Because of the powerful draw of the provider/consumer way of operating, professionals must learn to share their unique expertise when it fits the moment and to be quiet when someone else can just as readily speak to the issue. A community organizing axiom applies here: Never say what someone in the community could say, and never do what someone else in the community could do.
 - *Forging a sense of larger purpose beyond helping immediate participants.* Keep the big, hairy, audacious goal (BHAG) in mind as you act in a local community. Citizen healthcare is not only about people helping people; it is about social change toward more activated citizens in the healthcare system and larger culture. This understanding inspires members of the citizen health project about the larger significance of their work. It also attracts media and other prominent community members to seek to understand, publicize, and disseminate citizen healthcare projects.
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denhall, and other providers addressed how engaging patients and their families as collaborators in the design of supplemental services could tap their experience and wisdom of living with diabetes. Fourteen adult patients and their spouses or significant others met with providers to build a citizen initiative that would improve the lives of patients and families in the clinic's St. Paul community.

Program Description

PID (Mendenhall & Doherty, 2003) connects patients and families who have lived experience with diabetes to others who are struggling with the illness for the purposes of support. Patients and their spouses or significant others (called *support partners*) worked with providers to design and receive training. The trained support partners reach out to other patients (and their families)—called *members*—who have struggled with their diabetes for some time (e.g., three consecutive HbA1c tests of > 9%) or who are in the initial phases of adjusting to the disease (i.e., after diagnosis). Meetings occur across a variety of contexts: home visits, restaurants, telephone calls, and on clinic grounds. Support partners have diverse ethnic (e.g., American Indians, African Americans, and Caucasians) and socioeconomic backgrounds, re-

flective of their local patient community. Support partners commit at least two hours per week to the project, and the whole group (providers and support partners) meets monthly to consult and address challenges that support partners have experienced.

Qualitative analyses of the PID project (Mendenhall & Doherty, 2003) reveal that it took a significant amount of energy and time for providers and patients to learn how to work and relate with each other in a collaborative and democratic manner. As providers became oriented to the CBPR process and the tenets of the citizen health care model, they began to see PID as a way past the limitations of traditional provider/consumer dynamics. One physician remarked that

What we've done with [diabetes] is that we've tried to convert [care] into a series of acute visits. . . . [In PID] the patients became more and more empowered . . . really doing a lot of the stuff themselves. . . . [We are] moving care . . . outside of the boundaries of it having to all be done by the medical professionals. . . . It does break outside of the institutional walls and starts to show people that health care has to be

done out in the real world on a day-to-day basis.

As support partners' participation increased in partnership with providers, they became ever more aware of their potential to contribute through the personal lived experience and wisdom that they possess as persons affected by diabetes. One recalls coming to the realization that "I had some influence as a person with diabetes . . . a 'life expert.' Maybe not a 'knowledge expert,' but a 'life expert.'" Another recalls being excited by the process of everyone (providers, patients, patients' spouses) contributing to PID's development: "It's like having a jigsaw puzzle, you know? You have a few pieces, but once you get all the pieces, you've got the whole picture. . . . It's like putting a recipe together. It makes something good. . . . It's an old-fashioned goulash. You throw in the mixture and it comes out great when you get done."

Instead of providers designing a program that patients then participate in (conventional model), PID evolved through the contributions of professionals and patients (and patients' spouses or significant others) alike.

Case-specific challenges encountered by support partners are considerably diverse, from listening empathically and validating members' frustrations and confusion about diabetes to assisting members in finding out how to update their blood glucose measuring technology. One support partner recollected how he worked with someone who was uncomfortable with giving herself injections:

[Member] wasn't giving herself injections. . . . She refused . . . and I tried different techniques. We would go out to lunch . . . so that she could see me take my injection before I go in and eat and [I tried] to give examples of different techniques for giving the injections, different locations, that might be more comfortable for her.

Another support partner recalls surprise when "[Member] announced almost when I got . . . into the apartment . . . 'Well, you know, I never eat breakfast.' And I thought, and my mind was just screaming, 'You never eat breakfast?! What's the matter with you?'"

Support partners clearly connect with members in ways that providers cannot. This member began eating breakfast. Other members (patients) whom providers had long since identified as noncompliant and destined to manage their diabetes poorly met with support partners and made changes. One woman who never exercised began walking with a support partner. Another who never checked her blood sugar consistently began doing so after a support partner shared easy ways to incorporate this into an otherwise busy schedule. Sometimes members simply need a pep talk and may visit with a support partner just once on the telephone. Other times members and support partners meet regularly for 3 months or more. Happy endings are not universal, but the majority of PID connections that are made are described by support partners as successful.

Program Summary and Next Steps

Every aspect of PID was approached in a collaborative and democratic manner. Patients, their spouses or significant others, and providers shared responsibility for creating and implementing the new initiative, including designing the training curriculum, establishing procedures for support partner/member connections, and co-authoring informational pamphlets. The sponsoring HMO is now considering expanding PID to more of its clinical sites, as the initiative has gained visibility with increased systemwide attention to improving patient-centered care.

ANGELS (A Neighbor Giving Encouragement, Love, and Support)

Providers in a southeastern hospital were frustrated with their adolescent pa-

tients with diabetes. Although many kids adhered to prescribed dietary regimens, their adherence to other recommended behavior—physical activity, blood sugar monitoring, and insulin administration—was poor. Despite repeated efforts in conventional interventions and education, patients continued to be brought in by their parents with poor physiological indicators (e.g., HbA1c, weight) and little overt motivation to change. Parents complained about being nags, and patients complained about adults who would not “get off their backs” or allow them the same spontaneity and freedom as their peers. Providers often felt triangulated into family conflicts—right in the exam room—without any clear idea about what to do other than go over the same old information and cautionary warnings.

Program Initiation

Mendenhall approached this challenge with a community-based participatory research project, using the citizen health care model as a guiding framework. The department’s director mobilized providers to meet, learn about the model, and discuss how engaging adolescents and parents as collaborators in the design of supplemental services would facilitate tapping patients’ and families’ lived experience and wisdom of living with diabetes on a day-to-day basis. Six families (including 6 adolescents with diabetes, 2 adolescent siblings without diabetes, and 11 parents) were invited to meet with providers and build a new citizenship initiative that would benefit adolescents and parents struggling with diabetes.

Program Description

The ANGELS connects families who are struggling with diabetes to adolescents and their parents who have lived experience with the disease for the purposes of support (Mendenhall & Doherty, in press; Mendenhall & Doherty, 2005). These efforts begin at the time of diagnosis (generally in the

context of emergency hospitalization). According to ANGELS participants, it is during this time that the desire to connect with others and the motivation to adopt healthy lifestyles is highest. Parents and adolescents meet in a variety of combinations (teens with teens, parents with parents, families with families) on hospital grounds during hospitalization, and afterward they continue to meet off hospital grounds (in support groups, telephone conversations, electronic discussion boards, and via e-mail).

Summary and Next Steps

Adolescents and parents worked democratically with providers throughout every stage of ANGELS’s development—from initial brainstorming about its mission and name to its training design, public visibility efforts, implementation, and ongoing problem solving and maintenance. By relying on existing community resources, ANGELS has maintained its democratic character and long-term viability as a community resource. Efforts are now under way to train a new generation of support partners—many of whom were members at one time seeking support during their own crisis and early struggles with diabetes. Support partners’ sense of personal ownership in the ANGELS continues to be reflected in this progression, as they are assuming responsibility for components of this training and long-term vision.

Department of Indian Work/Family Education and Diabetes Series (FEDS)

American Indian (AI) community leaders and tribal elders in the Minneapolis/St. Paul area were worried about the ever-increasing prevalence of diabetes and its impact on their people. Its pervasiveness was made even more alarming by the acquiescent sense of defeat that many AIs communicated—that diabetes is expected and not preventable. Providers working with members of the AI community shared similar concerns and were frustrated with

the failure of conventional care and educational programs.

Program Initiation

Mendenhall and leaders in the St. Paul Department of Indian Work (DIW) (Nan LittleWalker, Betty GreenCrow, Sheila WhiteEagle, and Steve BrownOwl) approached this challenge with a community-based participatory research approach, using the citizen health care model as a guide. Considerable effort was spent in designing a partnership with providers that was very different than conventional top-down models of care. AI community members succeeded in sensitizing clinical researchers regarding the process, pace, and importance of building trust within AI circles. As the team engaged in a series of meetings, discussions, and AI community events, this trust evolved. Researchers learned about AI culture, the diversity of cultures/tribes within this larger frame (e.g., Dakota, Ojibwe, Hockak), belief systems, and manners—all because they were allowed into the AI community itself. In turn, community members gained more insight regarding how Western medicine is oriented and thereby gained understanding into providers' *habitudes* and perspectives in care delivery.

Program Description

The DIW's Family Education and Diabetes Series (FEDS) was designed and implemented as a supplement to standard care for members of the AI community touched by diabetes. Patients, their families (spouses, parents, children), and providers (physicians, nurses, dieticians, mental health personnel) come together every other week for an evening of fellowship, education, and support. Generally 6–7 providers, 4–5 tribal elders, and 30–35 community members attend. Meetings begin with members checking and recording each other's blood sugars and weight and conducting foot checks. Participants cook meals together that are consistent with AI

culture and tradition, and a great deal of discussion is put forth regarding the meal's ingredients, portion sizes, and relevance to diabetes. Educational sequences follow (which are designed according to participants' interests and wants) and take place in talking circles and a variety of lively activities (e.g., traditional and modern music, chair dancing and aerobics, impromptu theater/role plays). Instructional topics are similarly diverse, for example, basic diabetes education, obesity, foot care, stress management, exercise, family relationships, retinopathy, dental care, and resources to facilitate access to medical services and supplies. FEDS evenings conclude with devoted time for informal sharing and support. These biweekly series are scheduled to last for 3 hours, but most participants arrive early and stay late.

Program Summary and Next Steps

It is clear that clinical and lay participants in FEDS worked collaboratively throughout every stage of the initiative's development—from early efforts in relationship building and establishing mutual respect and trust to brainstorming the program's design, educational foci and format, public visibility, implementation, and ongoing modifications. The DIW and its clinical collaborators are now considering extending their CBPR efforts to create new programs in areas of the AI community that are not readily reached by state- or reservation-sponsored care systems (i.e., inner-city, low-income AIs). This is significant because the FEDS program does not readily engage these groups; instead, it is oriented to AIs who live nearby the DIW and a suburban family practice clinic.

CITIZEN HEALTH CARE MODEL VERSUS COMMUNITY-ORIENTED PRIMARY CARE

We are often asked to distinguish citizen health care from community-oriented primary care (COPC), which is another model for identifying and addressing

health problems in a community that extend beyond the individual examination room. COPC targets community-specific needs (e.g., teen pregnancy, diabetes management) within a defined community (e.g., a particular town, membership with a particular clinic). COPC works to make efficient use of resources and generally maintains a strong preventative element within its mission (e.g., reducing cardiac arrest rates). It requires an active role on the parts of both providers and community members across a range of activities, including (a) defining and characterizing the community of focus, (b) identifying principal health care concerns, (c) developing and designing interventions to address these concerns, and (d) evaluating the impact(s) of the interventions employed (Garr & Rhyne, 1998; Harper, Baker, & Reif, 2001; Henley & Williams, 1999; Nutting, 1987; Lukomnik, 1987; Williams, Crabtree, O'Brien, Zyzanski, & Gilchrist, 1999). These aspects of COPC overlap with citizen health care.

However, a principal difference between the two models relates to the role of the professional. A noticeable theme in the COPC literature is that providers collaborate with community members so that the providers can better help the community to achieve improved health. The professional is central and in a hierarchical relationship with the community. While communities help providers in COPC, the health of the community continues to rest ultimately on the providers and whether they did an adequate job in engaging and collaborating with the community to improve that community's health. Despite its collaborative nature, COPC is often described as a type of service delivery to consumers of health care. The provider's role is to help communities through leadership in problem-identification and solution-generation processes.

Initiatives informed by the citizen health care model, in contrast, position providers and community members as stakeholders who work self-consciously

and explicitly to avoid the top-down, provider/consumer dynamics that are so commonplace in modern health care. Providers are viewed as citizens who possess knowledge and skills and who work actively with other citizens (e.g., patients, family members, hospital staff) who also possess important knowledge and skills. Individuals and families are active producers and co-creators of action and change and thereby do not function in a consumer/patient role. Work informed by this model is therefore less expert driven than traditional COPC initiatives and is overtly oriented to producing the types of sustained initiatives that are espoused by public work endeavors as described previously (Boyte & Kari, 1996; Doherty, 2002; Mendenhall & Doherty, 2005).

LESSONS LEARNED AND FUTURE DIRECTIONS

Table 3 presents a summary of key lessons we have learned while developing the citizen health care model. Two lessons relate to time. First is that doing this work does not require a large amount of professionals' time in the short run (6–8 hours per month, on average), but it does require a long-term commitment (several years or more). Second is that learning this kind of work requires considerable mentoring. There are no quick training programs to teach professionals the public skills of engaging other citizens in community organizing projects with flattened hierarchies. To disseminate this work, we have created a training program in citizen health care, in which professionals can participate in face-to-face training and long-distance mentoring as they create a new project.

In addition to training and dissemination, a major future task is in the arena of research and evaluation. CBPR is a new priority area for funding from the National Institutes of Health, based on a recognition that traditional research methods have not worked to improve public health in many areas. Thus far we have conducted a CBPR

Table 3

Citizen Healthcare Project: Key Lessons Learned

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1. This work is about identity transformation as a citizen professional, not merely about learning a new set of skills.
 2. It is about identifying and developing leaders in the community more than about a specific issue or action.
 3. It is about sustained initiatives, not one-time events.
 4. Citizen initiatives are often slow and messy, especially during the gestation period.
 5. You need a champion with influence in the institution.
 6. Until grounded in an institution's culture and practices, these initiatives are quite vulnerable to shifts in the organizational context.
 7. A professional who is putting too much time into a project is overfunctioning and not using the model. We have found that the average time commitment to be on the order of 6–8 hours per month, but over a number of years.
 8. External funding at the outset can be a trap because of timelines and deliverables, but funding can be useful for capacity building to learn the model and for expanding the scope of citizen projects once they are developed.
 9. The pull of the traditional provider/consumer model is very strong on all sides; democratic decision making requires eternal vigilance.
 10. You cannot learn this approach without mentoring, and it takes 2 years to get good at it.
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evaluation of PID, in which we documented that the citizen health care process was implemented in a way consistent with the model (Mendenhall & Doherty, 2003). We have developed additional methods of evaluating the health outcomes of citizen health care projects and are seeking funding to implement these evaluations across individual, family, and community levels. These will include traditional quantitative assessment of outcomes such as HbA1c levels in patients with diabetes as well as broader community impact. Experience with other families and democracy projects (which have attracted \$2 million in grant funding) has taught us that there is funding available for this kind of work, once professionals have learned to work as citizen professionals and maintain close alliances with communities.

Finally, this work must meet the needs of professionals for satisfying work. We have found that if this public practice fits within their values and vision, professionals can experience an expanded sense of citizenship and professional contribution, as well as a closer relationship to local communities. If health care is to be redesigned in the United States, it will take more than technological fixes; it will take new forms of

democratic partnership between citizen professionals and other citizens. The driving mission of citizen health care is to create a democratic model of health care that unleashes the capacity and energy of ordinary citizens as producers of health for themselves and their communities.

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