

# COLLABORATION IN ACTION

## Partners in Diabetes: A Collaborative, Democratic Initiative in Primary Care

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Contemporary healthcare is in a state of rapid and constant change. With these developments has come an increased appreciation for the complex landscape of competing constituencies and multifaceted elements that define it. As efforts in medicine extend beyond visit-based services into the comparatively less familiar territory of preventive and patient-oriented care, a call has emerged for increased partnerships between providers and patients (Hayes, 1996; Standridge, 2000). These partnerships are in contrast to traditional hierarchal modes of care that position providers as experts who deliver services to passive patients, and can overcome commonplace barriers of limited resources and time constraints that frequently impede new initiatives. Active patient involvement can thereby tap important and already existing resources that have not been tapped previously for the benefit of individuals and communities.

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Partners in Diabetes (PID) is a new initiative with a high level of patient involvement and provider/patient partnership in a primary care setting. Every aspect of the program has been approached in a collaborative and democratic manner, with the underlying principle that all participants are stakeholders who bring important knowledge and resources to the work. In this account, we summarize our experiences with PID, placing particular emphasis on how the program evolved as an initiative that required major shifts from traditional models of how providers, patients, and families work together. A research report on PID as an Action Research project is being prepared as a separate article.

### **PARTNERS IN DIABETES: A BRIEF INTRODUCTION**

Partners in Diabetes involves two Minnesota-based clinics in which patients and families that have lived-experience with diabetes are connected with others who are struggling with the illness for the purposes of support. Fourteen PID "support partners" were nominated by their physicians to receive training and then reach out to other patients and families (PID "members") across a variety of contexts, including home-visits,

restaurants, over the telephone, and on clinic grounds. Support partners represent a range of ethnic and socioeconomic diversity, as do the patient communities in which PID is positioned. Professionals involved in this initiative are similarly diverse by discipline, including physicians, dietitians, diabetes nurse educators, clinic administrators, and family therapists. Support partners commit at least two hours per week toward the project. The whole group (providers and support partners) meets monthly to consult collaboratively and discuss challenges that support partners have experienced while working with members, and to develop solutions to issues identified as warranting attention.

Partners in Diabetes is guided by the Families and Democracy Model (Doherty & Carroll, 2002), which was designed purposely for professionals who work with families in community settings. Providers are viewed as citizens with knowledge and skills who work actively with other citizens who also possess important knowledge and skills. Participants in Families and Democracy initiatives self-consciously and explicitly avoid conventional provider/consumer dynamics by recognizing and valuing all members' contributions to a common mission. Families are active producers and co-creators of action and change, and thus do not function in a conventional consumer/patient role. A key difference between PID and traditional volunteer programs is that every aspect has been planned and implemented in a democratic fashion with patients, families, and providers.

### **PLANNING THE INITIATIVE**

Partners in Diabetes was first initiated when the second author (WJD) approached key persons of leadership in HealthPartners (HP), a large Minnesota-based HMO, and offered to assist them in starting a community engagement project. He introduced the Families and Democracy

Model as a guiding framework, and discussed how patients and providers could work together in new ways to improve health in an identified community. Diabetes was identified as an area of particular interest by HP leaders, and we were granted access to clinic providers. Most of these staff were open to the idea in a general sense, particularly because they saw merit in tapping patients' lived experiences as a resource that cannot be offered by a provider who does not live with diabetes on a daily basis.

Throughout Partners in Diabetes' evolution, endorsements and support by clinic leaders (e.g., medical directors, attending and chief physicians) were key to making it work. Early process notes (i.e., detailed conference minutes) evidenced a consistent pattern of HP leaders expressing their support and endorsement for PID, and this enthusiasm was quickly echoed by other involved staff. This support was essential as PID struggled initially in terms of its slow pace and the limited membership of patients involved in early planning phases.

Early discussions with clinic staff devoted considerable attention to identifying providers' frustrations with how the current medical system is "maxed out," and how traditionally the idea of doing something "new" entails doing something "more" and thereby requires increased staff time and energy. For example, providers discussed at a number of meetings how previous attempts with focus groups left everyone frustrated because patients asked for more services (e.g., weekend clinics) that staff could not offer. We framed these experiences as connected to traditional models of care that position providers only as a source of services that patients passively consume. The Families and Democracy Model was then described as a solution to this frustrating pattern insofar as it facilitates a productive role for patients. Providers began to see PID as a way past the limitations of traditional provider/consumer dynamics, and with this

they became increasingly enthusiastic about the program. One provider remarked:

What we've done with chronic care, diabetes being a good example, is that we've tried to convert that 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, not only outside of the clinic, but 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 healthcare has to be done out in the real world on a day-to-day basis.

Overt affirmations of buy-in to this type of initiative and thinking are evidenced in a number of intentional efforts made by providers to embrace patients' experiences and resources in action. One of the two involved clinics, for example, has incorporated Partners in Diabetes into its standard diabetes care plan. Any person who is initially diagnosed with diabetes is introduced to PID and offered to connect with a support partner, and any veteran patient who maintains poor metabolic control ( $A1c > 9\%$ ) across several visits is similarly introduced to PID.

An unexpected early experience in PID was that patients tended to function in the consumer role of the conventional provider/consumer sequence even when efforts by the group's first facilitator (WJD) and other staff to work democratically were explicitly put forth. Initial meetings often digressed from collaboratively creating something new to customary question-and-answer exchanges between patients and providers (e.g., about diet, exercise, and how diabetes affects eyesight). One provider recalls how continued redirections were necessary before patients began to understand this new model of partnership:

[WJD] kept reminding the whole group that this was going to be different, and if it started to turn into the old conventional model of people looking to me for advice,

he just kept on us that that wasn't the way we were going to go . . . I think this concept was foreign enough to the patients and, again, it's back to that active/passive thing . . . it took several months [before] the patients gradually got the idea . . . and we had to just keep saying, you know, we aren't going to make these decisions for you . . . but very frankly, [WJD] had coached me well enough, and I think I had enough internal passion about this that I didn't want this to be just the same-old, same-old.

As patients came to understand that Partners in Diabetes was not going to function as a conventional educational forum, several dropped out. PID's early membership waned as a consequence, and HP's administrative support declined in synchrony. A great deal of attention was paid to facilitating an understanding by all involved regarding how PID was going to be different than standard provider-led initiatives, and this led to a more discriminating self-selection of patients into the group and restoration of administrative endorsement.

As patients' participation increased in partnership with providers, they became increasingly aware of their potential to contribute through the personal lived-experience and wisdom that they possess as persons who struggle with diabetes. All of PID's support partners have spoken to this; 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 . . . You throw in the mixture and it comes out great when you get done.

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

As Partners in Diabetes has evolved into its current state of functioning, support partners recognize that they still maintain considerable influence over the program's growth. A number of decisions and activities have transpired, including the development of a pamphlet that describes PID to patients who may receive support, and the development of an information card with listings of key community resources that can be accessed by interested patients. Two PID support partners are extending themselves beyond PID's original clinic communities to actively educate and provide support to patients and families touched by diabetes in the Native American community. They have designed education and community events with community representatives that reach people in novel and culturally-sensitive formats. At a recent meeting where she was describing this work, one of these women confirmed her commitment to this manner of care and outreach: "I believe in this work, and am in it for the long-haul."

While WJD was never a HealthPartners employee with institutionally recognized power, he was the "carrier of the model" and thereby acknowledged early on as a leader through the educator and facilitator roles that he assumed. Process notes reflect this as WJD discussed and explained democratic processes to providers and patients alike, framing these processes as how PID contrasts from conventional "top-down" programs in healthcare. As mentioned before, providers evidenced a shift in functioning from hierarchical to collaborative and citizenship leadership before patients did. This is likely because providers were introduced to the PID idea before patients were, and they had already been engaged in active dialogue for some time about how to work together with

patients before any patients were even recruited.

As patients became increasingly oriented to the model, their confidence as contributors to the PID process grew. This first began as providers and patients brainstormed together to construct PID's mission statement and outlined respective participants' role-descriptions. Even the terms "support partner" and "member" were collaboratively developed, chosen over other labels that suggest hierarchy between the volunteers and those receiving support (e.g., "diabetes coach," "mentor," "client," "patient"). By the time providers and support partners began to identify areas of training for the PID curriculum, everyone involved represented a perspective with equivalent voice and influence. One support partner maintained that, "It's a joint effort . . . we've got the bottom, the middle, and the top all mixing together and getting, getting it solved."

Providers, too, no longer felt that they had to struggle to elicit patients' active contributions. Having earlier felt a strong pressure from patients to simply answer medical questions and lead the process, one provider reflected:

I think that by then, I felt like I was pretty much just another person at the table. Obviously, I had my medical training and experience, and all that, but . . . I wasn't coming up with any more ideas than the next person . . . there came a point where my doctor cap was almost off and I was just . . . another member of the group.

Throughout this development, WJD functioned as a facilitator of group processes. This role encompassed a number of activities, from helping the group maintain a democratic process that recognized all participants' unique areas of expertise, to moving group energies and focus from one topic to the next as different agenda items were addressed and negotiated. When a second clinic joined with the first clinic and PID moved into its training phase, WJD

transitioned this facilitator role to the first author (TJM). This was done because TJM was well-positioned in the second clinic as a provider, and had been involved with PID from its early beginnings.

### IMPLEMENTING PARTNERS IN DIABETES

Case-specific challenges that PID support partners encountered as they began meeting with PID members were remarkably diverse (e.g., listening empathically to frustrations about diabetes, educating members regarding basic diabetes-related information and management strategies, assisting in the procurement of new blood glucose measuring technology, sharing healthy recipes, cooking and exercising together). 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.

Sometimes members simply needed a pep talk over the telephone, and other times members and support partners met regularly for 3 months or more in each other's homes, at restaurants, etc. While happy endings are not universal, the majority of PID connections that have been made are described by support partners as successful.

Difficulties addressed during this process were myriad. For example, the group struggled initially with HP's safety policy that volunteers not give their home telephone numbers to those receiving support. Members frequently felt put-off after a satisfying initial conversation that was followed by a support partner refusing to give out his/her telephone number, and

coordinating meetings was difficult without the benefit of being able to play "phone tag." The group dealt with this in a variety of ways (e.g., using workplace or cell-phones [which cannot be linked to a home address], using PID providers as contact liaisons). This and a number of other challenges were collaboratively addressed and resolved by PID's patient and provider members.

From early tasks that were accomplished in a spirit of egalitarian collaboration and decision-making (e.g., designing PID training), to later tasks of problem solving (e.g., decisions regarding the disclosure of telephone numbers), it has become increasingly clear that support partners maintain a personal stake in PID's ongoing presence and replication. Examples of this include: (a) an informational pamphlet about PID was designed by the group for distribution to all new PID members, and maintains that the most unique characteristic of PID is that the volunteers have lived-experience with diabetes (i.e., not training per se); (b) support partners are actively participating in informing how training can be improved in future PID initiatives; and (c) based on their positive experiences, support partners are enthusiastically advocating the utility of applying PID's principles to other medical foci (e.g., breast cancer, HIV/AIDS, hospice care).

PID experienced a number of setbacks during its evolution that illustrate potential pitfalls to avoid in further work of this kind. The first major misstep occurred when providers reversed an already-established group decision about how to conduct invitations to a large public PID-sponsored forum in the time between meetings. The turnout for the forum was disappointing and support partners' enthusiasm waned vis-à-vis the experience of providers assuming a hierarchical role that was inconsistent with PID's guiding philosophy. Other lapses followed similar patterns, wherein providers

unconsciously shifted away from the collaborative and flat hierarchy central to the program's guiding Families and Democracy Model. As PID has matured as an established democratic initiative, providers have worked hard to de-center their roles and consistently facilitate democratic processes in which citizenship functioning is both stable and enduring.

## DISCUSSION

It is important to recognize that no two communities are entirely alike, and that our experiences with PID cannot be wholly generalized to every community initiating a similar project. Initiatives like PID are frequently cited for this limitation, with the tradeoff gain of creating something with immediate relevance for the community in which efforts were positioned (Casswell, 2000; Morrison & Lilford, 2001). Lessons learned from PID will nevertheless be helpful in informing future efforts as providers and patients collaboratively develop outreach programs that include all participants' voices, and which use already existing family and community resources. PID's intentional use of existing resources (rather than relying on grants or external funding) was fundamental, insofar as external funding tends to bring with it the expectation of specific "outcomes" that are defined by funders according to a preset schedule. This can undermine the democratic process of developing a project through citizenship participation. Furthermore, projects supported by external funding are generally difficult to replicate without similar funding.

While Partners in Diabetes appears to avoid some of the pitfalls of historical one-of-a-kind initiatives, it is important to recognize the importance of demonstrating transportability through replication. Lessons learned from PID are only beginning to be tried out, with the Families and Democracy Model serving to guide democratic partnerships between multiple stakeholders

as they address distinct concerns and embrace unique resources in local communities. Early work has begun in a large hospital system in North Carolina that is applying a citizenship-initiative oriented to newly diagnosed adolescents with diabetes. This project includes providers in partnership with adolescent patients and their parents, and has traversed the journey from initial meetings with hospital administration to patient recruitment, training design, and project implementation within one year. TJM has been actively involved with these efforts, and is encouraged by the group's ready internalization of the Families and Democracy Model and its energy in collaboratively creating a program that is unique to the community's resources and needs. In Minnesota, initial conversations are now occurring regarding another diabetes-related initiative, which will involve providers in a primary care clinic in partnership with members of an underserved immigrant community.

Partners in Diabetes and the Families and Democracy Model offer something new to the field of collaborative family healthcare by emphasizing democratic planning and decision-making processes between teams of providers and groups of patients and families. In other words, there is not only collaboration between professionals and between professionals and individual patients and families, but also partnership with communities of patients and families who function as co-creators of an initiative rather than as consumers of healthcare.

In closing, the greater vision for Partners in Diabetes is to create a model of healthcare as work by and for citizens, with all stakeholders working as active contributors. Citizens in PID show a sense of doing work of profound and far-reaching significance, and they appear to be energized by this sense of broader vision. At an early meeting when a provider maintained that this work was about changing how healthcare is done in this country, a support partner interrupted

and asked, "What about the world?" As future efforts in Partners in Diabetes and other citizen initiatives proceed, this vision of transforming healthcare will serve as a sustainer of energy and commitment in the face of this difficult but inspiring task.

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