Cultural Capital and the Tribal Diabetes Prevention Programs

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Special Diabetes Program

In 1997 the United States Congress established the Special Diabetes Program for American Indian and Alaska Natives (SDPI).[1] Funds for the SDPI are administered by Indian Health Service (IHS) and are available to all federally recognized tribes for the design and implementation of locally directed diabetes prevention and control programs. Since 1998, these funds have been awarded annually. Over the past thirteen years, the tribal diabetes prevention and control programs have grown and evolved to offer valuable examples of ways in which cultural capital can build and enrich the design and operation of locally relevant health programs. Abel defines cultural capital as "the operational skills, linguistics styles, values and norms that one accrues through education and lifelong socialization."[2] Benefiting the tribal diabetes programs, staff members, including program managers, are predominantly Native and are members of the communities being served. By virtue of being community members, these lay and mid-level public health practitioners are acutely attuned to local social practices as well as to acceptable and even locally "trendy" communication styles and behavioral patterns. They have integrated this collective cultural capital and extraordinary creativity to develop locally relevant prevention and treatment programs.

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Oversight and Guidance of Tribal Diabetes Programs

To receive the SDPI funds, each tribal diabetes program must develop a progress report of the previous year's objectives, activities and outcomes, a work plan for the next year of funding, an estimate of diabetes mellitus (DM) prevalence within its service population, and a budget and budget justification. Over the years, other information has been requested. Tribes have been asked to provide estimates of the number of community members with DM in specific age brackets; to group objectives as primary, secondary, or tertiary prevention; to list state, regional, and local collaborating agencies; and to link those collaborations to program objectives. The extent and structure of the guidance and mentoring provided to each tribe by IHS in program development, budget design and management, and program evaluation has varied over the years. A thorough set of guidelines has been provided every year, but reporting requirements, format, and technical assistance have changed. In the early years, face-to-face regional workshops were offered, but more recently assistance has been in the form of online videos and contact information for IHS employees and consultants who can assist with site-specific inquiries.

In some communities, recruiting, retaining, and training program staff were formidable tasks in the early years. Recognizing limited health intervention capacity in some communities, the IHS provided diabetes prevention and management workshops, coordinated intervention strategy-sharing conferences, and linked tribal employees to educational programs offered by consultant groups, colleges, and universities. The intent was to infuse tribal programs with the knowledge and skills needed to develop programs that would transform tribal communities into health-promoting environments. Through all these efforts, IHS emphasized local and cultural relevance, visibility, and involvement of all age groups.

Cultural Capital and Program Design and Implementation

Despite procedural changes and the continuous threat of funding cuts, tribes have persevered. They have combined their familiarity and skills in following federal guidelines and reporting requirements with their creative talents to convene, educate, and inspire their communities. For example, tribal programs are told that federal funds cannot be expended on food. Program staff knows that offering food is a critical and normative component of the social behaviors of inviting, hosting, and convening community members. To adapt, program staff coordinate potluck gatherings, establish "pack a healthy lunch and trade" events, and partner with church groups and other community programs that can provide food.

Similarly, tribal programs cannot expend funds on construction projects. Yet when programs conducted forums and surveys to collect community members' ideas for preventing and controlling diabetes, staff found that the need for safe, well-equipped recreational and exercise facilities consistently ranked among the top five recommendations. Again relying on local cultural capital and their knowledge and ability to leverage local resources, tribal program staff used a number of strategies: (1) some purchased modular buildings, allowable under the federal guidelines, and transformed them into fitness centers equipped with resistance weights, free weights, and group exercise rooms with rubberized floors; (2) some submitted building construction proposals to federal commissions, such as the Office of Surface Mining Reclamation and Enforcement, that were obligated to improve resources in tribal communities; and (3) some submitted proposals to their own tribal councils or tribal enterprises to support the construction of fitness centers or recreational facilities such as outside basketball courts, tennis courts, walking/bike paths, and baseball fields.

Program design has benefited from the collective, cultural capital of local program staff. Tribes launched team weight loss competitions a decade before the method was popularized by the television show *The Biggest Loser*. They engaged fathers and grandparents in the support of breastfeeding before the western medical community advocated the active involvement of family supporters, and they also passed work-site policies allowing time during the workday for exercise before most US employers thought of implementing similar programs.[3,4] Other creative strategies have involved weeklong or multiple-day healthy youth and family camps, cooking classes using commodity foods, stress-reduction workshops, fitness series engaging participants in competitive activities every week for several months, family fun nights, drumming and dance workshops, aerobics using traditional music and dance moves, field trips to collect and prepare wild foods, traditional storytelling to reinforce cultural values related to a balanced lifestyle, community-wide game days (often including traditional running games and even snowshoeing), local health-promotion radio programs and public service announcements, often in the indigenous language, youth and community gardens, use of ropes challenge courses and climbing walls, and in California, even surfing clubs.[5]

How Cultural Capital Has Enhanced Program Outcomes

As advocates of behavioral change, program staff realized that their messages about healthy food choice, habitual physical activity, and glucose control would only be heard if community members sufficiently enjoyed themselves

to regularly attend the activities offered by the "new" diabetes program. In 1993 Jennie R. Joe reported that a diabetes diagnosis was not discussed even with family members, and the condition was considered a personal matter, not a community problem.[6] Undeniably, these programs were faced with an insurmountable challenge: to get communities to talk about diabetes and to integrate their health promotion messages into the heart of the community.

Indeed, these programs have changed attitudes, expectations, and resources in tribal communities. Prior to the SDPI programs, many tribal councils were not aware of the silent DM epidemic in their own communities, community members with DM did not openly discuss their condition, DM was not mentioned in schools, and institutional cooks working in tribal schools, jails, rehabilitation centers, detention centers, and senior centers did not think about how their meals could contribute to the fight against diabetes. One poignant example of change in community norms is the attitude toward adult exercise. In the 1980s, running along the roadside, particularly for adult women, was not acceptable in many Native communities. That behavior was associated with youth who were training for the track team and certainly was not an appropriate activity for women who were expected to be home taking care of their families.[7] Now, communities have adult running clubs and community-wide foot races enjoyed by males and females of all ages.[8] Prior to the SDPI programs, few tribes had fitness centers open to the public, and diabetes risk factors and control conversations were reserved for provider-patient consultation.[9]

The tribal SDPI programs have changed norms in their communities and paved the way for more intensive intervention programs, the SDPI demonstration programs. These programs, which were initially funded in 2004, implemented regular case management for individuals at high risk for diabetes or those with diabetes at high risk for heart disease.[10] The previous eight years of the SDPI community-directed programs changed public discourse in tribal nations and among urban American Indians. Some people even publicly announced their diabetes diagnosis and willingly served as role models illustrating the impact of behavior change.[11] In hindsight, longitudinal evaluation of these normative shifts could have contributed to the request for sustained financial support.

The Need for Program Evaluation

Program evaluation has not benefited as clearly from the influence of local cultural capital as has program design and implementation. Technical assistance provided by the IHS has emphasized increasing the program staff's

knowledge and skills in diabetes prevention and management, not program evaluation. Although the IHS has provided some technical support in evaluation procedures to tribes, and the tribes themselves have hired staff with evaluation experience, success in building local capacity for program evaluation, particularly impact assessment, has been limited. In the initial years of funding with little guidance in evaluation, tribes tended to measure program effectiveness and success in terms of outreach. The trend was to "brand" their programs with a positive, "you or we can do it" mission.[12] They established visibility by infiltrating schools, senior centers, and work sites.[13] Program success was counted by the numbers of people attending events and participating in education or exercise classes. Similarly, written feedback or testimonies that participants "enjoyed" an activity or "learned a lot" were collected and submitted to the IHS as evidence of program accomplishments.

Over the last five years and in the current economic climate, the IHS has become increasingly concerned about the security of the congressional funding that supports SDPI. Subsequently, the IHS has stressed to tribal programs the importance of demonstrating to the US Congress that these programs have been a good investment and are worthy of continued funding.[14] The IHS has worked to design ways for the more than 330 tribal programs to report impact within their annual progress reports.[15] In turn, the IHS has compiled this information to produce an annual SDPI progress report for the US Congress.[16] The collaborative efforts and essentially the collective cultural capital of the IHS and the tribal diabetes programs annually yields an extraordinary composite of epidemiological trends and personal testimonies collected from community members who have made substantial lifestyle changes and have reduced their risk of diabetes or of secondary complications. This effort to collect and "showcase" personal stories of success is notable and reflects the IHS' understanding of the weight that qualitative data can have on congressional decisions.[17]

However, tribal programs are not provided a standard method for collecting the personal testimonies, nor do they have the tools and skills necessary to analyze and summarize the content and themes revealed in these testimonies. National and regional themes are not described, discussed, or used to guide program design. The effort to gather poignant quotations, often accompanied by photographs of role models or "champions" to represent many of the tribal programs, is herculean and laudable, but the magnitude of the programs' impact may not be fully realized, while successes that could be used to guide future programming are underutilized. Systematically understanding the strategies that participants report as most critical to successfully reducing diabetes risk factors or controlling diabetes—such as dietary change, increased physical activity, effective health educators, or use of case managers

and/or family support—could guide program design. In the absence of collective analysis of the locally derived evidence from all the tribal programs, individual experiences are often viewed as "unique" or "noteworthy" and not the norm. Yet if the most influential strategies were identified from systematically collected and analyzed qualitative data, programs could focus their efforts. The current underlying assumption that "different strategies work for different people" can lead to a "shotgun" approach to health promotion, and this can contribute to staff becoming stretched in multiple directions, exhausted, and not being equipped to recognize if any one strategy is more effectual than another.

From 1998 to 2008, the programmatic result of not identifying specific approaches was multi-pronged interventions. In 2009, given that funds were limited and staff skill sets varied, the IHS established a new requirement in an attempt to help programs focus their efforts: namely, they instructed SDPI programs to select one or more of the nineteen IHS diabetes prevention or control best-practice programs.[18] Giving tribal programs the freedom to select the practice(s) on which they would concentrate their effort speaks to the IHS' commitment to honor and trust local-level decision making. Yet without a means to systematically analyze local observations and stories of success, tribal programs may have had little evidence on which to base their selection. Programs that elected to highlight physical activity may have been drawn to that best practice if their staff had training in that area. This practice is actually quite frequently selected because private, Native-owned fitness companies and universities have offered regular group exercise, aerobic, and weight-training courses to tribal diabetes program staff. Consequently, practice selection may have been more influenced by available skills and resources than by community need. Conversely, if trained staff and services in depression screening and treatment were not available, having programs select a practice that addressed perceived needs such as behavioral health services would have been futile. In general, training for program staff in areas other than diet and physical activity has not been readily available. Tribal diabetes program budgets generally are not adequate to relocate health professionals, and in rural areas the IHS may not provide specialty services locally.

If programs had data to support their needs, tribes could have requested the IHS or university partners to develop suitable training for a program to focus on behavioral health or other practices. Systematic collection and analysis of local stories of success could reveal if specific strategies are more likely to reduce diabetes risk or to support greater diabetes control within their service population. The IHS choice of nineteen best practices could be tailored on a national and/or local level so that the most effective strategies are implemented. To accomplish this task, tribal programs themselves need

to collect and analyze qualitative data such as narratives, and even guided observation. Through this experience, they might embrace evaluation as a useful and valued tool for refining program design, not merely a requirement of program reporting.

Value of a Mixed-Methods Approach to Evaluation

An external evaluator partnering with a tribal SDPI or any health program to assess program outcomes is confronted with the customary tasks of documenting how the program is working (process evaluation) and progress towards goals (impact evaluation). An equally important task is capturing the influence of cultural capital on program outcome and the change in social norms. Over the years, SDPI program staff members have exhibited tremendous creativity in blending their knowledge and skills in contemporary and traditional practices to promote behavioral change. In some cases, programs have promoted a revitalization of traditional healthy behaviors, such as running towards the sun in the morning, eating a predominantly plant-based diet, and engaging in physically demanding traditional subsistence activities such as farming, fishing, and hunting. In other settings, programs have used current technology to promote behavioral change by using Facebook and texting to remind participants of exercise and cooking classes, and fitness goals.

In most SDPI programs, evaluation has documented whether strategies were implemented as planned and whether expected output was actually produced (process evaluation). Examples of quantitative data collected from programs' annual or pre- and post-intervention changes include:

- Knowledge of diabetes prevention and control strategies tracked using close-ended questions (multiple choice or true/false) administered in writing or verbally;
- Daily or weekly steps counted using a pedometer;
- Prevalence of diabetes; and
- IHS Diabetes Care and Outcome Audit measures.[19]

Without supportive qualitative data, including observation, these measures and outcomes could be misinterpreted. The very wording of the close-ended questions is based on the assumption that the questionnaire designer knows most of the possible answers. A fill-in-the-blank option at the end of a multiple choice question has the weakness and additional burden of requiring respondents to write an answer. Because this task is not required of the other options, this format motivates some to pick an answer already provided.

Pedometer-derived data also can be misinterpreted. The validity of pedometer-counted steps is grounded in the assumption that participants are wearing

the pedometers to accrue steps and not shaking them by hand. This deceptive behavior could be a concern if incentives are offered for the accumulation of a specific number of steps. Furthermore, local observers in many tribal programs have noted that walking style, such as how much you swing your hips, can influence the accuracy of pedometers.

Even the accuracy of diabetes prevalence and audit data is influenced by context. Tribal SDPI programs often rely on the IHS diabetes registry in reporting prevalence and incidence data in their progress reports and continuation applications. Patients who have been diagnosed with diabetes are retained on the IHS registry if they visit an IHS or contract facility within the year. However, individuals who were placed on the registry but who do not regularly seek medical care or seek care with non-IHS providers are dropped after a year of "inactivity" with IHS. Complementary contextual data collected by tribal programs through interviews, personal testimonies, and support groups would reveal local patterns of appointment adherence, use of non-IHS providers, and even use of traditional healers to treat diabetes, thus explaining changes in the prevalence in audit data. Complementary qualitative data would enhance the understanding of why or why not programs are working.

The pervasiveness and acceptability of the local SDPI programs in tribal communities is a testament to the confidence and readiness of the IHS to allow local skills and approaches to blossom, as well as to the willingness of program staff members to assume new roles that potentially open them to criticism. Local criticism of programs and staff has come from those who see open discussion of diabetes and behavior change as inappropriate and who do not support social change that impacts the status quo. Staff members often are not acknowledged for their sacrifices and endure their own family members calling them "the food police" or "health nuts." Documenting and analyzing the willingness of local staffs to be the "early adopters" in Rogers' diffusion of innovation model, as well as local programs' leveraging of existing social networks and of the solidarity grounded in shared culture and life experiences, would reveal the role of cultural capital and may explain the success of some programs.[20] Using a mixed-methods approach that employs and integrates quantitative and qualitative data could reveal the subtlety of program operation and the underlying features of success.

A Locally Sustainable Evaluation Using a Mixed-Methods Approach

After several years of offering a healthy lifestyle multiday camp for youth in a northern Arizona tribe, tribal program staff were interested in understanding

the influence of the camp environment to enhance health promotion strategies, a tribe-university team decided to add a qualitative component to the evaluation of the healthy lifestyle multiday camp. The university partner brought evaluation experience, and the tribal program partners brought "the operational skills, linguistics styles, and values and norms" of the community.[21]

Data Collection: A pre/post, mixed-methods evaluation design was used. Campers' diabetes risk factors were collected on the first and last day of camp. Measures included body mass index (BMI), fasting blood glucose level, and blood pressure. Eight interview questions were codeveloped by the partners to track change in campers' knowledge of healthy foods and diabetes prevention and to probe further into the factors that made the camp enjoyable, such as "would you come back?" Based on the program staff's experience with youth, a decision was made not to use focus groups, as the youth tended to be shy on the first day of camp and would not speak up. This behavior could yield an artificially large difference between responses on the first and last day of camp when campers were notably more animated.

Campers were interviewed individually by nonprogram staff. Again, because of the youths' initial shyness and parental concerns with audio recording, the interviewer took notes. Taking notes also avoided the need for transcription.

Data analysis: The team decided to use the multi-investigator consensus method codeveloped several years earlier by the university partner and program personnel of another program in the same community.[22]

This method uses Patton's recommendations for noncomputer-assisted qualitative analysis and operationalizes the terms *content*, *patterns*, and *themes*.[23] Content is defined as recurring words, concepts, or ideas gleaned from the notes or "raw data." Patterns are grouped phrases having a similar content that reveal a descriptive trend. Theme is defined as two or three words that identify a topic or category.

A minimum of three investigators independently read and identify the content. To promote the influence of cultural capital, the team of three consists of two program staff members and one university partner. Using a predesigned data analysis table, they each record the text of recurring words and of concepts or ideas in the cells associated with specific questions or groups of questions. Figure 1 illustrates the progression of interpretation in response to questions designed to understand the motivation for physical activity (PA).

The three investigators then convene to share their content, and by consensus they identify the descriptive patterns. They then review the patterns together and by consensus identify themes. The imbalance of community and university partners (two to one) allows the nuances of the sociocultural context to prevail in the analysis.

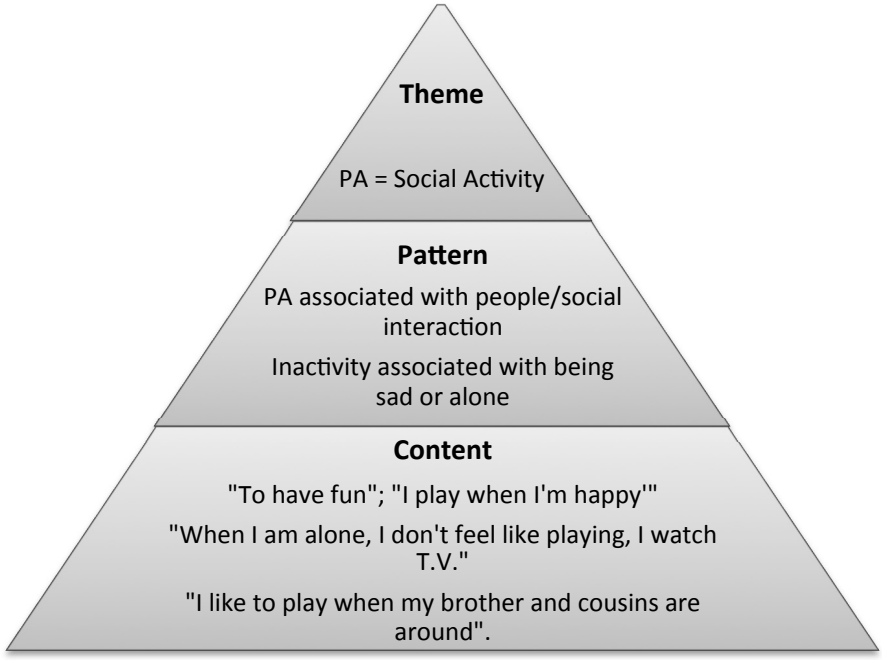

Figure 1. *Thematic analysis of responses asking "Why do kids play"? and "What are some of the reasons kids play"?*

Evaluation Results: In this application of a qualitative method, results were summarized by the team within two hours of starting the consensus process. Results were used to immediately influence family and school-based intervention strategies and, in the following year, camp activities. In the example provided, staff added daily team-building activities to reinforce social interaction and minimize the potential for clichés and isolation. At camp, staff eliminated an incentive-driven individual point-accumulation system and pedometer counts that were designed to encourage individual participation and activity, respectively, and coordinated team activities that required group problem solving, such as team scavenger hunts and relay races. Evaluation methods and results were easily explainable to the community and empowered the staff to continue program assessment for the purpose of enhancing program strategies.

Conclusions and Recommendations

The congressionally-funded, IHS-managed, and community-directed tribal diabetes programs are an exemplary model for empowering communities to

make a difference in their health. All programs have drawn on cultural capital to leverage local resources and skills and to enhance the relevance of intervention strategies. Program staff know their constituents. For example, they know how people in their communities spend their time and what factors influence decision making; which nights are open to hold gatherings to avoid conflict with other standing events such as drum groups, bible studies, and Alcoholics Anonymous groups; where people shop for food and what items are available; which member of a household generally influences food choices and meal preparation; and local perceptions of weight loss, physical activity, breastfeeding, and depression. Their knowledge and insight is invaluable in an environment in which many clinical services are provided by noncommunity members. Tribal program staff are able both to pinpoint and design motivational cues and to avoid alienating strategies. Unfortunately, this staff insight, the role of cultural capital in enhancing the acceptability and relevance of health messages and intervention strategies, and the sociocultural and normative impact of the tribal diabetes programs have not been documented systematically.

This example of a mixed-method approach to evaluation illustrates that community-driven programs can effectively review and modify evaluation options. In this case, an outside evaluator assisted in the process, and with experience the approach was locally sustainable and ultimately did not require the presence of an external resource person. The community-based participatory approach relied on local cultural capital and contributed to the design of locally acceptable and sustainable evaluation methods.

Essential to identifying and designing locally sustainable evaluation methods is that the process be a collaborative effort between the community-based staff and an evaluator with experience in assessment methods and a community-based participatory approach. These methods should use local assets—cultural capital—and yield results that the community, including the staff, and the funding agency, find meaningful and valuable. These two sets of stakeholders no doubt place different weights on qualitative and quantitative data, so an evaluation plan that uses mixed methods will meet the needs of both descriptive and numerical thinkers, and will clearly define the significance of the use of cultural capital to program success.

Notes

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