Indian Health Diabetes Best Practices:

Community Advocacy and Diabetes

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Contents

What is community advocacy?

Community advocacy for diabetes is any action that is directed at developing a positive policy environment for diabetes, raising awareness of diabetes, and building support to address diabetes. A critical principle of advocacy is that advocacy efforts should be based on evidence (Stimson *et al*., 2003).

Why is community advocacy important?

People with diabetes are not alone. Diabetes affects families and whole communities. In addition to family support, *community* support and advocacy can make a big difference in the outcomes for people with diabetes and in promoting diabetes prevention.

Furthermore, the community is the heart of public health. Public health is the fulfillment of society's interest in assuring conditions in which people can be healthy (IOM, 1996). All community members have a role in public health. Everyone is needed to work together on diabetes prevention and treatment efforts to help make life better for people and communities affected by diabetes.

Community advocacy can help:

- Offer the community the opportunity to take action to improve health for individuals, their families, and their community.
- Encourage dialogue, negotiation, and consensus among all community members.
- Raise awareness about hopeful diabetes treatment and prevention news and to reduce the stigma associated with diabetes.
- Engage tribal leaders and other key partners in awareness and advocacy efforts.
- Mobilize and coordinate resources for community-based diabetes initiatives.

Best practices for community advocacy

The best practice for community advocacy describes the best methods for:

- Establishing community advocacy groups to mobilize the community, build local capacity, and help disseminate diabetes information.
- Developing clearly identified and measurable goals and objectives.
- Conducting community needs assessments to determine resources, interests, and requirements for diabetes efforts in the community.
- Identifying leaders who will support community-based diabetes initiatives.
- Establishing partnerships and linkages to develop, implement, and evaluate effective community-specific interventions and programs.
- Conducting community education to increase awareness of the risk factors for diabetes and to inform the community that diabetes and its complications can be prevented or delayed through sustained lifestyle changes.

Table 1 summarizes the best practices for community advocacy.

Table 1. Best practices for community advocacy.

Program Recommendations	Best Practices
1. Establish **community advocacy groups**	***Why?*** Community advocacy groups should be established to mobilize communities, build local capacity, help disseminate diabetes information, strengthen strategic partnerships, combine expertise, and leverage resources. Community advocacy groups can carry out the key functions of advocacy, which include understanding the community's perceptions and opinions; addressing misinformation; and working with community leaders, the media, and decision makers to build support for resources and policies needed to address diabetes. ***How?*** – Establish a community advisory board. – Involve a diverse group of community members and program leaders. – Develop a shared mission and vision for diabetes. – Develop written, specific, and focused objectives for diabetes (see below). – Develop an education forum to reach out to community members.
2. Develop **clearly identified and measurable goals and objectives**	***Why?*** Clearly defined and measurable goals and objectives may help facilitate program progress, accountability, and effectiveness (Maldague and Leontos, 2006). ***How?*** – Involve all partners in planning the content of diabetes-related community activities. – Use SMART objectives (i.e., **S**pecific, **M**easurable, **A**chievable, **R**ealistic, and **T**ime-bound objectives).

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Table 1. Best practices for community advocacy. (continued)

Program Recommendations	Best Practices
3. Conduct **community needs assessments**	***Why?*** A community needs assessment may help determine resources, interests, and requirements of diabetes efforts in the community (Work Group on Health Promotion and Community Development, 2006). ***How?*** – Develop a plan to identify local needs and resources. – Conduct public forums, listening sessions, focus groups, surveys, and interviews to identify community assets, resources, opportunities, and challenges. – Create a report on the community's needs to build a healthy community. – Present findings to the community in a forum-style meeting. – Use feedback from assessments and the community to develop and track the progress of effective and culturally appropriate, community-directed diabetes programs that complement and support the clinical diabetes program.
4. Identify **leaders who will support community-based diabetes initiatives**	***Why?*** Top community leadership can help community-based diabetes programs stay committed to their vision, develop initiatives and proposals that will best serve the community, organize logistics, solve problems, conduct necessary evaluation and follow-up, and ensure their sustainability (Work Group on Health Promotion and Community Development, 2006). ***How?*** – Develop and obtain partnership agreements between community leadership and diabetes programs that outline a shared understanding of diabetes and health promotion, vision for the future, and commitment to work together on diabetes-related issues. – Ask leaders for letters of agreement and support. – Assign tasks and timelines to leaders. – Provide opportunities for leaders to come together to address diabetes prevention and treatment cooperatively.

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Table 1. Best practices for community advocacy. (continued)

Program Recommendations	Best Practices
5. Establish new and foster existing **partnerships and linkages**	***Why?*** Successful prevention and treatment of diabetes requires the involvement of policy makers, health care organizations, people with diabetes and their families, and communities (Garfield *et al*., 2003). Community participation is particularly important to the success and effectiveness of diabetes programs; sustained positive change cannot be achieved without the support, commitment, and involvement of the community. The underlying principle of community participation is to promote change by offering the community ways to take greater control of health (Stimson *et al*., 2003). ***How?*** Identify new and foster existing partnerships with: – Decision and policy makers. – Tribal leaders. – Professional groups. – Media. – Individuals. – Community leaders and groups. – Advocacy groups. – Non-profit organizations and other federal agencies.
6. Provide **community education**	***Why?*** Community education may help increase awareness of the risk factors for diabetes and may result in positive behavior change. ***How?*** – Use evidence-based community guidelines to develop and implement community education and health promotion programs, such as programs that promote healthy eating behaviors and increased physical activity. – Use talking circles to provide an opportunity for people to talk freely about diabetes with truth and openness. Talking circles can help people understand diabetes and find support in managing diabetes and helping prevent it in their family members. This technique has been shown to be particularly effective at providing information on type 2 diabetes (Struthers, Hodge, De Cora, *et al*., 2003, Struthers, Hodge, *et al*., 2003, Struthers, Kaas *et al*., 2003, Hodge, *et al* 1999, Hodge *et al* 2002). In addition, talking circles can help health care providers understand what activities the community will accept.

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Table 1. Best practices for community advocacy. (continued)

Program Recommendations	Best Practices
6. Provide **community education** (continued)	– Provide training to health care providers on community advocacy so they can understand that working together with communities is essential for successful diabetes program planning, development, implementation, and evaluation. – Orient people with diabetes, their families, and the community to the health care system and providers. – Encourage the health care system and providers to provide patients with health-related information that is at the appropriate literacy level and culturally appropriate. – Establish programs to help community members become "expert users" of the Indian health care system. – Conduct public information campaigns. – Participate in governing boards and task forces. – Refer to the Indian Health Diabetes Best Practices on physical activity and nutrition, adult weight management, youth and diabetes, breastfeeding and diabetes, school health, and community diabetes screening.

Best practices for health care organizations

A health care organization that wants to improve community advocacy efforts must be motivated and prepared for change throughout the entire organization. The organization's leadership must identify community advocacy programs as important work. They must also develop clear improvement goals, policies, and effective improvement strategies. This will help encourage the entire organization to make changes that will help improve community advocacy efforts.

Table 2 describes the best practices for health care organizations.

Table 2. Best practices for health care organizations.

Organization Recommendations	Best Practices
System and programmatic changes	***Why?*** System and programmatic changes that help support people in their efforts to prevent and control diabetes have been associated with increased delivery of appropriate diabetes care. Community advocacy may help bring people together to raise awareness and initiate action on diabetes prevention and care (Stimson *et al*., 2003). ***How?*** The evidence suggests that the following activities may help improve diabetes care: – Create a supportive policy environment at the tribal, clinic, local, and national level to engage community members in planning, advocating, and implementing diabetes programs. – Support and provide needed resources, services, and policy changes. – Provide education to increase awareness of diabetes among community members. – Educate health care providers on community advocacy. – Strengthen cooperation between clinical programs and community programs.

Essential elements of best practice community advocacy programs

High quality community advocacy programs involve implementing six essential elements* in your health care organization. These elements are:

- Community resources and policies.
- Health care organization leadership.
- Patient self-management support.
- Delivery system design: Services, programs, systems, and procedures.
- Decision support: Information and training for providers.
- Clinical information systems: Collecting and tracking information.

Table 3 summarizes how these elements apply to basic, intermediate, and comprehensive community advocacy programs.

*Adapted from the Chronic Care Model, which was developed by the MacColl Institute for Healthcare Innovation at the Group Health Cooperative. For more information on the Chronic Care Model, visit their website at www.improvingchroniccare.org.

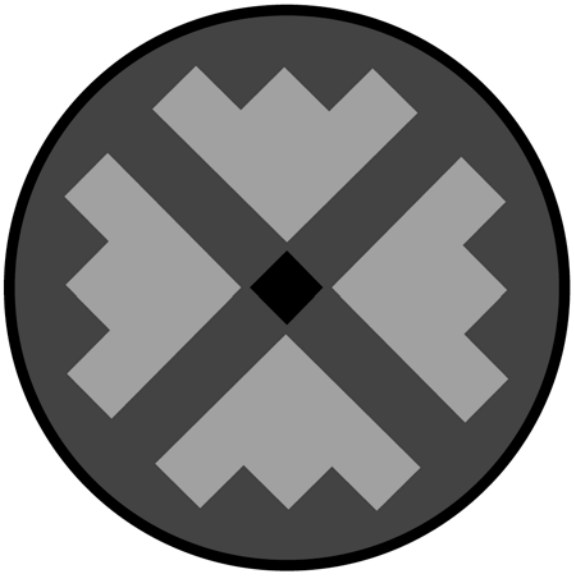

Table 3. Essential elements of basic, intermediate, and comprehensive best practice community advocacy programs.

Basic Community Advocacy Programs	Intermediate Community Advocacy Programs Basic program *plus*:	Comprehensive Community Advocacy Programs Basic and intermediate programs *plus*:	Examples
Community resources and policies			
– Conduct an inventory of community resources. – Establish partnerships with community groups who share a common mission and related goals.	– Build coalitions and expand the number of partnerships with programs who share related goals (e.g., Woman, Infant, Child (WIC); elderly; after school; school lunch; and senior food programs, as well as diabetes care teams and hospitals). – Mobilize and coordinate resources by identifying leaders who will lend their support for community-based diabetes initiatives.	– Continue to expand partnerships that have a shared mission and vision for diabetes. – Establish a community advisory board to mobilize the community, ensure community participation and shared ownership of diabetes programs, leverage resources, and raise awareness.	– Conduct campaigns to raise awareness about diabetes prevention and treatment. – Encourage tribal leaders to be role models for healthy behaviors. – Establish talking circles to provide community members with an opportunity to talk about diabetes.

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Table 3. Essential elements of basic, intermediate, and comprehensive best practice community advocacy programs. (continued)

Basic Community Advocacy Programs	Intermediate Community Advocacy Programs Basic program *plus*:	Comprehensive Community Advocacy Programs Basic and intermediate programs *plus*:	Examples
Organization leadership			
– Identify partners with decision-making power (e.g., help tribal councils become aware of program efforts). – Work with decision makers to adopt health promotion policies. – Develop a shared vision of diabetes with specific objectives. – Develop a strategic plan for community diabetes treatment and prevention efforts. – Encourage tribal leaders to be role models for health behaviors.	– Develop and deliver persuasive presentations to tribal leadership and the community about the extent and nature of diabetes and the community's responsibility in diabetes efforts.	– Continue the relationship with the tribal council and offer data-related suggestions on policies that support healthy environments.	– Identify and work with decision makers to adopt health promotion policies. – Support a particular objective (e.g., prevent diabetes in youth). – Engage communities in planning, advocating, and implementing programs. – Identify leaders who will lend their support for community-based diabetes initiatives.

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Table 3. Essential elements of basic, intermediate, and comprehensive best practice community advocacy programs. (continued)

Basic Community Advocacy Programs	Intermediate Community Advocacy Programs Basic program *plus*:	Comprehensive Community Advocacy Programs Basic and intermediate programs *plus*:	Examples
Patient self-management support			
– Help distribute health-related information to patients.	– Provide complementary services by orienting people with diabetes, people at risk for diabetes, and the community to the health care system and to providers.	– Establish programs to enable community members to become "expert users" of the Indian health system.	– Orient patients and the community to the health care system and to providers. This will help ensure that health-related information reaches patients, and that patient concerns reach providers. – Establish programs to help community members become "expert users" of the Indian health system. – Develop community education and health promotion programs.
Delivery system design: Services, programs, systems, and procedures			
– Establish a community diabetes team that meets on a regular basis. – Establish specific goals with achievable objectives.	– Continue focus on diabetes prevention and community wellness coalitions. – Raise awareness and reduce stigma about diabetes in communities through community diabetes campaigns. – Conduct community education programs on diabetes prevention and treatment.	– Develop and implement effective ways to make sure that the programs are sustainable. – Develop long-range plans for diabetes-free future generations.	– Establish a *community* diabetes team with multi-disciplinary backgrounds.

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Table 3. Essential elements of basic, intermediate, and comprehensive best practice community advocacy programs. (continued)

Basic Community Advocacy Programs	Intermediate Community Advocacy Programs Basic program *plus*:	Comprehensive Community Advocacy Programs Basic and intermediate programs *plus*:	Examples
Decision support: Information and training for providers			
– Provide opportunities for the community, providers, clinic administrators, and tribal administrators to work together.	– Ensure that patient concerns reach providers.	– Train providers in community advocacy.	– Train providers to improve communication with communities, and to be sensitive to the needs of communities.
Clinical information systems: Collecting and tracking information			
– Use data to determine the interest in and need for diabetes efforts in the community. – Use data to persuade people that diabetes is an important public health issue. – Establish an evaluation plan to evaluate and assess the process and outcomes of community advocacy.	– Prepare regular reports to the community. – Document community advocacy efforts in periodicals (e.g., local newsletters, magazines, *Indian Country Today*, and *Health for Native Life*).	– Evaluate and report results in peer-reviewed journals.	– Use data to help programs improve diabetes outcome measures. – Use data to evaluate community-directed diabetes activities. – Use evidence-based guidelines to develop community-directed interventions. – Review IHS data and utilize findings to create specific objectives (e.g., establish education programs about the importance of diabetes prevention for youth).

Evaluating your community advocacy program

Evaluation is important because it helps you see what is working and what is not working in your community advocacy program. It will show you if adjustments or changes need to be made in order to improve your community advocacy program. Evaluation also provides you with information that you can use to share your successes with patients, providers, tribal leaders, administrators, the community, funders, and other stakeholders.

Consider using the Centers for Disease Control and Prevention (CDC) Practical Evaluation Framework to establish an evaluation plan, document activities, and evaluate the effect of community advocacy. The goal of a practical evaluation is to look closely at the community advocacy program to determine what was done and if the program did what it set out to do.

- Step 1: Identify and engage partners and stakeholders.
- Step 2: Describe the program.
- Step 3: Focus the evaluation design.
- Step 4: Gather credible evidence.
- Step 5: Justify conclusions.
- Step 6: Ensure use and share lessons learned.
- For example:
  - Evaluate the health-related policies that have been implemented as a result of the community advocacy group's actions.
  - Evaluate the diabetes-related partnerships, task forces, and networks that were initiated by the community advocacy group.
  - Evaluate the number of partnerships established with other groups working on diabetes.
  - Evaluate whether the community increased its awareness of diabetes as a result of the community advocacy group's actions.

Sustaining your community advocacy program

Often, for diabetes goals to be reached, programs must be in place for more than a few years. Here are some helpful tips for sustaining your program:

- Share your results through communication in local and national publications and on the radio.
- Recognize the people working on community advocacy efforts.
- Obtain more support as a result of your program's good outcomes.
- Encourage other programs to use ideas from your program.
- Use community advisory boards to keep your community mobilized.
- Build local capacity to keep your diabetes programs going.
- Focus efforts on specific objectives.

Contacting others for help

Contacting other people involved in community advocacy is important because they can help you get started. Your peers at other health care organizations can share their expertise, materials, and ideas, and can also tell you what has worked for them and what has not. This can help you avoid reinventing the wheel. Here are some tips on how to connect with others:

- Ask your Area Diabetes Consultant for the names of people who may be able to help you.
- Contact the IHS Division of Diabetes Treatment and Prevention for ideas. They may be able to point you in the right direction.
- Ask the IHS Integrated Diabetes Education Recognition Program for suggested contacts. They have names and contact information for people who work with IHS-accredited diabetes education programs.
- Review resources from the National Diabetes Education Program (NDEP). NDEP offers materials that will help your program get started, including information specifically for American Indians and Alaska Natives. You can access these resources at the website: www.ndep.nih.gov.

Real-world best practice programs

Diabetes Talking Circles

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✉ Seva Foundation Native American Diabetes Project's Diabetes Talking Circles
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Diabetes Talking Circles is a research-based, culturally appropriate, and well-accepted diabetes education program for American Indians living with diabetes or at-risk for diabetes. The goal of the program is to prevent, treat, and control diabetes. The program consists of a 12-session curriculum, facilitator's manual, tool kit, as well as materials for each session. Diabetes Talking Circles uses traditional circles and food, along with group support in a spiritual setting, to create an acceptable way for participants to express their feelings about living with diabetes, receive support, absorb information, and strengthen traditional ties. The Diabetes Talking Circles program significantly:

- Reduced fatalistic attitudes toward diabetes.
- Improved diabetes knowledge.
- Improved knowledge about dietary fat and fiber (both improved among males).
- Increased exercise knowledge.
- Improved diabetes treatment compliance and adherence.
- Increased exercise frequency.
- Reduced overweight and obesity as measured by body mass index (BMI).

Helpful websites

Active Living by Design

This website provides information on the Community Action Model.

www.activelivingbydesign.org/index.php?id=293

Centers for Disease Control and Prevention

This website provides helpful information on community mobilization (please note that the information is neither diabetes-specific nor American Indian and Alaska Native-specific).

www.cdc.gov/ncidod/dvrd/spb/mnpages/vhfmanual/section8.htm

Texas Cancer Center

This website provides information on community mobilization to address childhood overweight.

http://fcs.tamu.edu/health/Health_Education_Rural_Outreach/Health_Hints/2004/april/childhood_overweight_part_4.php#section1

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