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Appalachian Regional Model for Organizing and Sustaining County-Level Diabetes Coalitions

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Abstract: This paper describes a model for developing diabetes coalitions in rural Appalachian counties and presents evidence of their sustainability. The rural Appalachian coalition model was developed through a partnership between two federal agencies and a regional university. Coalitions go through a competitive application process to apply for one-time \$10,000 grants. The project has funded seven to nine coalitions annually since 2001, reaching 66 total coalitions in 2008. Sustainability of the coalitions is defined by the number of coalitions that voluntarily report on their programs and services. In 2008, 58 out of 66 (87%) coalitions in the Appalachian region continue to function and voluntarily submit reports even after their grant funds have been depleted. The factors that may contribute to sustainability are discussed in the paper. This model for organizing coalitions has demonstrated that it is possible for coalitions to be maintained over time in rural underserved areas in Appalachia.

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Appalachian Regional Model for Organizing and Sustaining County-Level Diabetes Coalitions

Coalitions are one way to implement the public health model. The driving force of coalitions is that they involve the community, mobilize local resources and develop local leadership (Roussos & Fawcett, 2002). In this article we describe a model for organizing coalitions in poor, rural, Appalachian counties, and present evidence of the sustainability of these coalitions. These coalitions were organized to address diabetes and its related chronic diseases in rural Appalachia through such efforts as organizing cooking classes, support groups, and walking clubs and by advocating for health policy changes in schools and other public institutions.

Coalitions are strategic alliances of community organizations that join to address common problems. One major advantage is the synergy from pooling talents and resources from multiple organizations (Butterfoss & Francisco, 2004). These coalitions are characterized by membership of multiple institutions and universities, have formal organizational structures and function with relatively large amounts of funding (Butterfoss & Francisco, 2004; Butterfoss et al., 2006; Airhihenbuwa, 2006). A key assumption of coalitions is that community organizations are more effective when health programs are designed and implemented jointly than individually (Butterfoss & Francisco, 2004). Major public health funding agencies have made substantial investments in mobilizing coalitions intended to address stubborn public health problems. Some examples include W. K. Kellogg Foundation's Community-Based Initiative, Robert Wood Johnson Foundation's Allies Against Asthma and the Centers for Disease Prevention and Control's (CDC's) Racial and Ethnic Approaches to Community Health (REACH) initiative (Butterfoss & Francisco, 2004; Airhihenbuwa, 2006; Butterfoss et al., 2006). The REACH coalitions are an example of a national network of coalitions designed to reduce racial and ethnic

disparities in health care. Initiated by the Centers for Disease Control and Prevention in 1999, the coalitions address six priority health care areas (Collins, 2006). For example, the Alabama REACH coalition targeted breast and cervical cancer (Wynn et al, 2006). Academic, non-profit, faith-based, and community based organizations joined forces to identify barriers to care for minority populations. Based on their findings, the coalition trained lay health advisors and designed an education program to train community leaders about risk factors and interventions for preventing and treating these cancers.

A number of papers have described models for organizing coalitions (Butterfoss, 2004; Cramer, Atwood & Stoner, 2006; Kegler, Steckler, Malek & McLeroy, 1998; Veazie et al., 2001; Butterfoss, Lachance and Orians, 2006; Butterfoss et al., 2006). While nomenclature varies, the common elements are a defined mission, explicit goals, well defined organizational infrastructure, leadership development, and maintenance or sustainability. The ability of coalitions to get multiple systems to work together on specific health problems is a critical factor in their success (Rosenthal et al., 2006). To accomplish this, coalitions must have a relatively high level of organizational complexity. In this regard, Butterfoss et al. (2006) postulate that coalitions go through four developmental stages: formation, implementation, maintenance, and institutionalization. Ultimately the criterion for success in all the models is sustainability (Butterfoss et al., 2006; Cramer et al., 2006; Rosenthal et al., 2006). These authors point out that funding is one of the keys for achieving sustainability. The period immediately following the end of their grant funding is critical for coalitions, since they are likely to dissolve without ongoing sources of financial support (Butterfoss et al., 2006).

Numerous models exist for evaluating coalitions (Glasgow, Vogt & Boles, 1999; Cramer et al., 2006; Butterfoss & Francisco, 2004). These models vary in how they emphasize process or outcome measures. Glasgow et al. (1999) argue that the complexity of the organization and environment in which coalitions function requires a comprehensive evaluation framework.

Coalitions' complexity however, presents challenges in assessing their success (Merzel & D'Afflitti, 2003; Roussos & Fawcett, 2000). Some barriers to evaluation are: study design and evaluation methodology; delayed outcomes; lack of local level data; and the influence of secular trends on the coalition's outcome measures (Merzel & D'Afflitti, 2003; Roussos & Fawcett, 2000). Despite these challenges, Roussos and Fawcett (2000) found that all studies reported provided evidence that coalitions achieved varying combinations of new services, practices and policies.

The Appalachian Regional Model

Since 2000 we have supported the development of diabetes coalitions in the Appalachian region. The region follows the contours of the Appalachian Mountains and comprises 420 counties in thirteen states. It includes all of West Virginia and parts of Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee and Virginia. In the mid 1960's, Congress authorized the formation of the Appalachian Regional Commission (ARC) to address poverty in the Appalachian Region. The ARC's mandate is to: increase job opportunities and per capita income; strengthen the capacity of people in Appalachia to compete in a global economy; develop and improve the infrastructure;

and build the Appalachian Development Highway System to reduce Appalachia's isolation (Wood & Bischak, 2000). To direct funding to the region's neediest counties, the ARC developed a method for classifying counties by socio-economic status. The poorest counties are referred to as distressed counties. All the coalitions in this project are located in distressed counties.

Description of the Rural Appalachian Model

The rural Appalachian coalition model was developed through a partnership between the ARC, the Division of Diabetes Translation of the CDC, and the Marshall University School of Medicine (Marshall). State Diabetes Prevention and Control Program directors, CDC project managers, and ARC representatives participate in an advisory council. A team from Marshall manages the project.

This model for rural counties has some characteristics that differ from the models in the literature. We use Butterfoss' (2006) stages (formation, implementation, maintenance, and institutionalization) for coalition development as a descriptive framework for the Appalachian model.

At the *formation stage*, these coalitions were typically formed in a matter of days or weeks. In this rural environment, pre-existing relationship networks facilitate bringing people together. Leadership comes from local people with a history of taking initiative in health and community affairs. The counties considered here rarely have secondary or tertiary health care, specialty medical services, or a large pool of post-graduate level professionals to draw from for leadership.

Therefore leadership by non-professionals is essential. The coalition members are rooted in their communities and want to make a difference. They are not people coming in from the outside trying to fix the community, they *are* the community. The majority of coalitions have at least one person from the community who has diabetes and/or is a family member or friend of a diabetic. They typically represent informal community groups, non-profit organizations, faith-based organizations, health departments, extension services, and primary care centers. Other non-traditional members consist of retirees, county sheriffs, mayors, county commissioners and school personnel.

In the *implementation stage*, the rural Appalachian model differs from what Butterfoss (2006) described in that the coalitions have simple organizational structures and rely on volunteer staff. Coalition coordinators are chosen based their history of community activism, not professional qualifications. In this structure, formal committees or task forces typically do not exist. The action plans are often seasonal; there are often lulls in activity, such as during the winter months.

The *maintenance stage* in Butterfoss' framework involves sustaining activities until goals are met. For the Appalachian coalitions, the goals are usually short term and have relatively small task lists. Goals tend to focus on: 1) teaching people to change their behavior, such as baking food instead of frying; 2) policy change, such as getting soft drink machines out of schools; and 3) environmental change, such as creating walking tracks. Most of the coalitions also have on-going activities such as support groups and group exercise sessions. For example one coalition worked with the school board to build a walking track around the high school's athletic fields and open spaces. It is the only high school in the county and is centrally located in one of

county's few flat places. Grant funds were used for organizing, planning and promotion. Local companies donated construction machinery and materials. The local sheriff, a coalition member, arranged for work release prisoners to do some of the heavy labor. Because of its central location, the track is being used by the whole community.

The *institutionalization stage* for the Appalachian coalitions is reached when their goals become ingrained in the routine of participating organizations and individuals. For example, a number of coalitions worked with the county schools to implement a 'Walk Across America' competition for children and their families. Once schools implemented it, it became part of normal activities and institutionalized by the schools in subsequent years. Another example is the Diabetes Education Calendar that was developed by coalition members to create diabetes awareness while highlighting scenic pictures of their county and recounting personal stories of people successfully controlling their diabetes. The calendar won a state award and has become an annual project of the community.

Project Implementation

The project began in 2000, and funded the first coalitions in 2001 through a competitive application process. In the first year, five coalitions were funded. Since then, the project has funded seven to nine coalitions annually, reaching 66 total coalitions in 2008. Table 1 lists the number of coalitions funded by year and by state.

Insert table 1 here.

An anomaly in Table 1 is that it lists two funding periods in 2005, and none in 2004. This is because the original funding date for 2004 was pushed back, due to its closeness to the Christmas season. The second funding date, September 2005, reinitiated the annual funding cycle.

West Virginia, Kentucky and Tennessee have the most coalitions, but also have the largest number of distressed counties. In 2008, Kentucky had 37 distressed counties, more than double the number in West Virginia, the state with the second largest number, thirteen, of distressed counties.

Applications for coalition funding are assessed based on the diversity of the coalitions' membership, their understanding of the problem of diabetes in their community, and a public health approach to diabetes prevention and control. The application guide does not ask for goals and objectives; instead, after coalitions are awarded a grant, the Marshall team trains coalition leaders in writing objectives and action plans using the CDC's 'Diabetes Today' curriculum ("Diabetes Today", 2000). Marshall modified the curriculum to fit the context of community-level planning and it is now called „Diabetes Today for Community Leaders.“ A minimum of five people from each coalition are required to attend the training, which is conducted workshop style over two days. By the workshop's end, the coalition members have an action plan with measurable objectives and implementation schedule.

The coalitions that are awarded a grant receive \$10,000. Upon submitting their action plan to Marshall, coalitions receive the grant's full amount. Coalitions use their funds for programs that engage people in healthy eating, physical activity, chronic disease self-management and

awareness building. They are not allowed to use funds for medical supplies, health care services or buildings.

There are no end-dates for using the funds. This feature gives the coalitions the flexibility to change based on lessons learned. They are not penalized if their activities stretch into a second year or longer. The absence of an end-date also gives coalitions the flexibility of proceeding at a sustainable pace over the long term and encourages them to extend their money by leveraging other grants and obtaining in-kind donations. An additional benefit is that it encourages the coalitions to continue considering themselves part of the regional project.

The Marshall team maintains an on-going relationship with the coalitions by providing technical assistance, leading training programs and conducting site visits. One of the training programs offered is the Stanford Chronic Disease Self Management Program (Lorig et al., 1999). This is a skills building course that meets once a week for six-weeks and teaches chronic disease self-management skills. The Marshall team trains coalition members to lead courses in their community. Additionally, Marshall organizes an annual conference for the coalitions during which each coalition makes a presentation on one of its programs. The conference gives the participants opportunities to learn from each other and builds relationships across coalitions in the Appalachian region.

Evaluation of Coalitions

Some of the barriers discussed earlier that apply to the Appalachian coalitions are the lack of local level data and delayed outcomes (Merzel & D'Afflitti, 2003; Roussos & Fawcett, 2000).

Specifically, some of the factors that affect evaluation of the coalitions in this model are the relatively small amount of funding that precludes items such as data management systems, and the diversity of activities coalitions implement which complicates outcome monitoring. In this case each coalition chooses its own projects; consequently, there are no consistent outcome variables that can be applied across all coalitions. The project does, however, collect process measures. The coalitions voluntarily send Marshall a quarterly report of their activities, which continues after the grant funds have been expended. The on-line report form asks for numbers of participants in leadership training, self-management training, organized healthy eating activities and organized physical activity events.

Findings

Table 2 presents the number of coalitions that reported each year. In calendar year 2008, 58 of the 66 (87%) coalitions submitted reports. All five of the coalitions that were initially funded in 2001 continued to submit reports seven years later.

Insert Table 2 here.

The type of programs and services that the coalitions sponsored in 2008 appear in Tables 3 and 4. Due to the coalitions' time and systems limitations, Tables 3 and 4 reflect participation in each event rather than unduplicated numbers of participants. The data in Table 4 represent participation in organized events such as walking clubs, cooking classes and screening at health fairs. The data correspond to the number of encounters by quarter and the cumulative number of encounters for each type of activity. An encounter in this table represents the number of times that individuals participated, which may include participating in multiple events. The data do

not reflect activities people may do on their own, such as preparing healthy meals and engaging in physical activity at home or in their neighborhood.

Insert Tables 3, 4 here.

The coalitions report in-kind contributions. In 2008 they reported \$139,281. In-kind contributions are unduplicated counts. Coalitions calculated these contributions based on the number of volunteer hours and on cash contributions that the coalitions raised. Volunteer hours are documented only for coalition leaders and are valued at \$10.00 per hour.

Coalitions also report an estimate of the number of people reached through social marketing. They broadcast messages and programs on local radio stations; obtain free space on billboards; and distribute flyers in grocery stores, libraries and church bulletins. The estimate of people reached in 2008 was 3,420,700.

Discussion

Ultimately the success of coalition is defined by their sustainability (Butterfoss et al., 2006). These findings provide evidence of the sustainability of the coalitions in the rural Appalachian model. One criterion we used to define sustainability is the number of coalitions that that voluntarily report on their programs after their start-up year. The annual percent of coalitions that report is consistently above 85% (Table 2). These coalitions function with simple organizational structures and no guarantee of on-going funding, but continue to sponsor programs in their communities.

The second criterion is the amount of in-kind contributions that the coalitions generated in the 2008 calendar year. Collectively they generated nearly \$140,000 (refer to page 9) which was \$60,000 more than the amount that the project invested in supporting eight new coalitions that were funded in 2008 (Table 2). The new coalitions only began their program activities in the second half of the year; the reported in-kind came from the coalitions that were funded in previous years. The significance of this finding is that it indicates coalitions used the grant funds to leverage additional funding. The amounts that they raise are relatively small, but the issue for sustainability is that they continue to sponsor programs and find local funding to do so.

A number of elements of this model may have contributed to the coalitions' sustainability. One is the non-traditional grant application process. As noted in the project description, applicants are not asked for goals, objectives, implementation plan, or a budget in their proposal. The reason for this is that in the first round of applications we discovered that applicants struggled with defining goals, objectives and activities. Consequently we changed to evaluating applications based on the diversity of the coalition membership and their understanding of a public health approach to diabetes prevention and control. The rationale for this non-traditional process is that a strong coalition can learn how to plan projects, but the best of written plans cannot save a weak coalition. For example, in the second year two applicants had well articulated plans, but they were written by one person who had experience in doing so. The rest of the coalition members went along with the plans but did not contribute substantively; consequently they had no sense of ownership. Neither of these coalitions got off the ground. Based on this experience, we engage teams of new grantees in a planning workshop, where they

bond and develop a group vision for what they want to accomplish. An important lesson learned is that the planning process is much more dynamic and representative with five or more members (as opposed to the two that were required in the original plan). This group process builds teamwork and collective ownership of the plan. Rosenthal (2006) stated that this ability to get multiple entities to work together was critical to coalitions' success.

In the Appalachian model, goals and objectives are written in the *Diabetes Today for Community Leaders* workshop, which coalition members attend upon being awarded their grant. Coalition members go through a step by step process of identifying needs, setting goals, writing measurable objectives and formulating an action plan. Most of the coalition members have little experience in writing objectives. Thus the workshop builds participants' skills by allowing them to write their actual plans, rather than putting them through a simulated exercise. It usually takes a coalition two to three hours of discussion, writing and editing to articulate their first objective. After that, coalition members are able to write their next two or three objectives in a matter of an hour or so.

A third non-traditional procedure is that the full amount of the award is transmitted to the coalition up front, upon submitting their objectives and action plans. While the funding amount is modest compared to the amounts typically given to coalitions (Butterfoss & Francisco, 2004; Butterfoss et al., 2006; Airhihenbuwa, 2006), having the funds in hand communicates that they own the funds, and that they are accountable to each other for their proper use. It eliminates the dynamic of a coalition having to ask, through invoices, for the funding agency to send their funds. The coalitions' grants are managed by a member agency that has 501.c.3 status. In the

seven years of this project, there have been no cases of funds being used inappropriately.

A fourth difference is that the grant does not have an end-date. One of the early lessons learned is that the coalitions' initial plans were too ambitious. They would make plans in order to spend their funds in twelve months, instead of based on needs and opportunities. An open-ended funding period gives them the freedom to proceed at their own pace and take time to engage in meaningful interventions. This is significant because it communicates to the coalition that their work is on-going and not based on a funding cycle. It also helps to create the expectation that the coalition exists for the long term. It changes the coalitions' expectations in the planning process from thinking in terms of one year, to a long term mind set. Another reason is that the initial grant often generates opportunities to leverage additional funding, thus allowing the coalitions to use their funds for other activities in the future.

In addition to the non-traditional characteristics of the Appalachian model, another factor that may contribute to sustainability is the Marshall team's continual communication with all the coalitions, even after their grant funds have been expended. This contributes to coalition members feeling that they are a part of an on-going regional network. Coalition members have stated that the "personal communication and trust" with the Marshall team are motivating factors for continued participation. The technical assistance and training that Marshall conducts provide opportunities to maintain personal relationships and cross fertilize program ideas. The coalition members have stated that they are the most motivated when they are given an opportunity to share their stories, and challenges with their peers. Participants in the training programs have

reported that they benefited from the opportunity to exchange ideas, network, think outside the box, and participate in hands-on activities.

Risks Inherent in This Model

This model has a number of inherent risks. One risk is that financial accountability is not based on specific performance measures. Grantees receive their funds up front, and report on their activities after the fact. Grantees are held accountable based on comparing their work plan with their reports. However, the Marshall team approves the original work plan and budget before funds are disbursed and provides continual technical assistance throughout the project. A second risk is that with volunteer leadership the coalitions may have difficulty in following through with their plans. Additionally, leadership can change abruptly and affect program continuity. Because leaders are volunteers, positions can go vacant for long periods of time. A third risk is that coalitions can dissolve after completing their obligations with the one year grant. The lack of multi-year funding leaves the coalitions vulnerable to closing down before they have enough time to mature.

Conclusion/Summary

The Appalachian coalition model is a regional network that functions in rural, poor counties. The organizational structure is simple, leadership is made up of volunteers, and program activities consist of organizing events that teach healthy lifestyle skills and making relatively simple policy and environmental changes.

These coalitions have functioned over time with little funding. One factor that may have contributed to their success is the non-traditional application process that trains grantees in writing goals and objectives after they have been funded. Others are the open-ended funding period, and the support system that continues after funds have been expended. This model for organizing coalitions has demonstrated that it is possible for coalitions to be maintained over time in rural underserved areas in Appalachia. Thus it is a model that could be considered for other rural regions of the country.

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Table 1: Coalitions funded by year and by state

State	2001	2002	2003	2005 Jan- uary	2005 Sept- ember	2006	2007	2008	Total
Alabama	0	2	1	0	1	0	0	0	4
Kentucky	1	2	3	1	2	1	8	2	20
Mississippi	0	1	1	0	2	0	0	4	8
N. Carolina	0	1	1	1	1	0	0	0	4
Ohio	0	0	2	0	0	1	0	0	3
Pennsylvania	0	0	1	0	0	0	0	0	1
Tennessee	2	0	0	4	1	2	0	1	10
Virginia	1	0	1	0	1	1	0	0	4
West Virginia	1	3	3	2	1	2	0	1	13
TOTALS	5	9	13	8	9	7	8	8	67

Table 2: Coalitions that voluntarily submitted reports to Marshall by year

Year	Cumulative Number of Coalitions	Number and Percent of Coalitions Reporting	Number That Did Not Report
2001	5	5 (100%)	0
2002	14	14 (100%)	0
2003	27	25 (93%)	2
2005 (January)	35	30 (86%)	5
2005 (September)	44	38 (86%)	6
2006	51	45 (88%)	6
2007	59	50 (85%)	9
2008	67	58 (87%)	9

Table 3: Participation in training sponsored by the coalitions in 2008

Event Type	Number of People
Stanford Chronic Disease Self-Management Course Leaders Trained	22
Participants in Stanford Chronic Disease Self-Management Courses	310
Diabetes Care In-Service Training Sponsored by Coalitions	1,040
Total Number of Individuals Trained in 2008	1,372

Table 4: Community health encounters sponsored by the coalitions in 2008.

Event Type	Number of Encounters
Physical Activity Program	17,827
Healthy Eating Programs	5,664
Health Screening Events	6,759
Health Education Events	19,094
Number of People in Support Groups	2,489
Coalition Meeting Attendance	1,009
Total Encounters for 2008	52,842