Community Participation Can Improve America's Public Health Systems

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Prepared by The Lewin Group, Inc.
for the W.K. Kellogg Foundation

TurningPoint

Communities must respond collaboratively

if they are to effectively address

and resolve

public health problems.

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Dear Fellow Stakeholder in Public Health:

The W.K. Kellogg Foundation is pleased to share with you the enclosed report, *Community Participation Can Improve America's Public Health Systems.*

The Kellogg Foundation has a heritage of commitment to public health. This commitment began 70 years ago with the new Foundation's first programming — The Michigan Community Health Project (1931–1951) — and continues today. The commitment is anchored in two convictions: communities have strengths and everyone has a stake in public health. In 1996, the Foundation applied these convictions to the challenges facing contemporary public health through its initiative, Turning Point: Collaborating for a New Century in Public Health.

Evaluation and learning is key to the work of the Kellogg Foundation. The Foundation uses evaluation to inform policy and practice in the field, as well as to improve our own programming. The lessons that emerged from the three-year evaluation of Turning Point by The Lewin Group are especially important as the Foundation seeks to assure a continuing policy and program focus on public health. This report highlights the level of diverse community participation within the 41 local Turning Point partnerships, the impact of community participation, and strategies for sustaining meaningful involvement of community stakeholders promoting the public's health.

While I am just beginning my work as vice president at the Kellogg Foundation, my professional background is in public health. I have followed the Turning Point initiative with great interest, and believe strongly in its underlying principle that *everyone has a stake in public health.* This report is timely as more community members are asking, *What can I do? How can I help?* The following pages include ideas and insights about how these questions can be addressed.

The Turning Point initiative has been under the outstanding leadership of Barbara Sabol and Roslyn Brock (who now holds a position outside the Foundation). To learn more about Turning Point, you may get in touch with Ms. Sabol at (616) 969-2026. We look forward to hearing from you.

Sincerely,

Marguerite M. Johnson
Vice President for Programs – Health

Introduction

Public health agencies and core public health functions[1] have long been stereotyped and taken for granted in the United States.

While public health activities touch aspects of all our daily lives, these health activities are seldom noticed by the typical citizen when the system is perceived to be working smoothly. Public health officials have unwittingly been architects of these perceptions by developing plans, promulgating policy, and monitoring related health services with limited community interaction. Community members are typically brought into public health processes when community support is needed for priorities already identified and programs that are already targeted for neighborhoods selected by officials, not by the affected community. As a result, the public health field has frequently missed opportunities to mobilize significant non-governmental resources and to address public health concerns in more community-relevant ways.

Often, both policymakers and most Americans see public health primarily as a provider of clinic services for poor people, and public health's critical population-based responsibilities are not understood.

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1 The Core Functions of Public Healthcare Policy, Assessment, and Assurance. In: Institute of Medicine. *The Future of Public Health.* Washington, DC: National Academy Press; 1988: pp 41–47.

Governmental authority and the science knowledgebase that characterize public health is most successful when the community is informed and engaged in priority-setting and the execution of public health plans. Fully engaged community constituencies have supported many of public health's greatest successes, such as HIV/AIDS prevention.

The anthrax scare in the wake of the September 2001 terrorist attacks dramatized the void between official public health authority and science, and the local community, including workers, businesses, media, and families. These events bring new urgency to effectively inform and engage communities in public health activities.

From its outset, the national Turning Point Initiative (TP) saw the importance of engaging the community in public health work. It sought to strengthen the voice of traditionally underserved constituencies in public health planning and policy setting.

A basic premise of the Initiative was to increase community awareness of public health priorities and responsibilities, and to mobilize community groups to assume shared ownership for some public health activities.

This report describes lessons learned from Turning Point communities that may be useful to local, state, and national policymakers and communities striving to build public health partnerships.

It examines the level of community participation in local Turning Point partnerships and describes efforts to engage diverse constituencies that have traditionally participated peripherally or episodically in setting community health priorities and public health policy. This report also considers strategies to sustain and institutionalize "community voice" as part of the public health infrastructure of local jurisdictions.

With funding from the W.K. Kellogg and Robert Wood Johnson Foundations, 41 local communities in 14 states[2] accepted the challenge to transform their public health systems by creating public health partnerships. Some partnerships successfully engaged a wide array of community sectors in public health work, and a few moved toward institutionalizing that engagement through formal policies and programs.

Lessons Learned

ONE: Community engagement evolved over the course of the Turning Point Initiative.

The new partnerships invited agency representatives and community groups to be formal members of the TP organizational structure. Beyond those members, grassroots groups and the

2 Robert Wood Johnson Foundation funded a cohort of 14 state partnerships with two-year grants, while W.K. Kellogg Foundation funded 41 local communities within these 14 states. Subsequently, Robert Wood Johnson Foundation funded an additional seven state partnerships, *the second cohort,* for either one or two years.

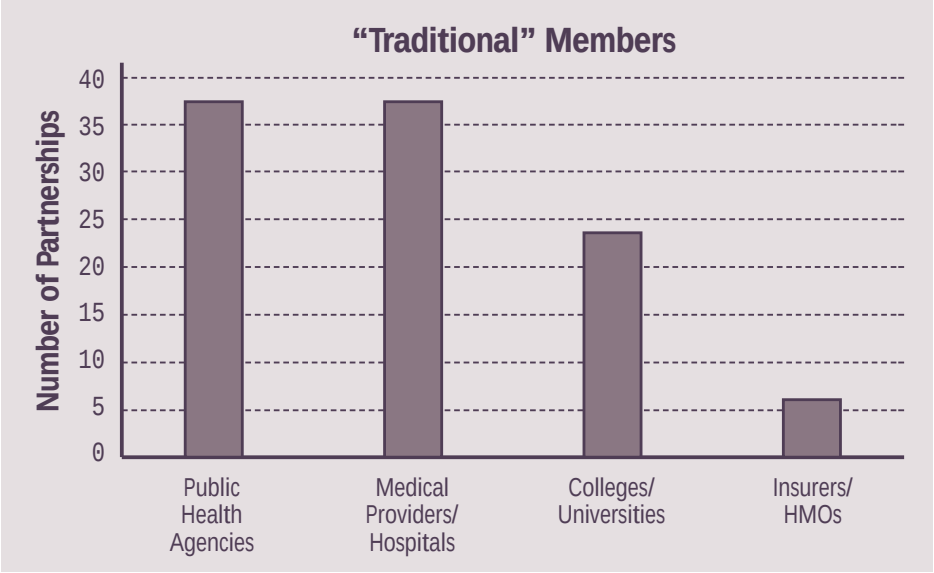
general public also helped assess public health needs, select priorities, and implement projects. Activities to bring a wide array of community representatives into the work of Turning Point evolved over the three years of the Initiative.

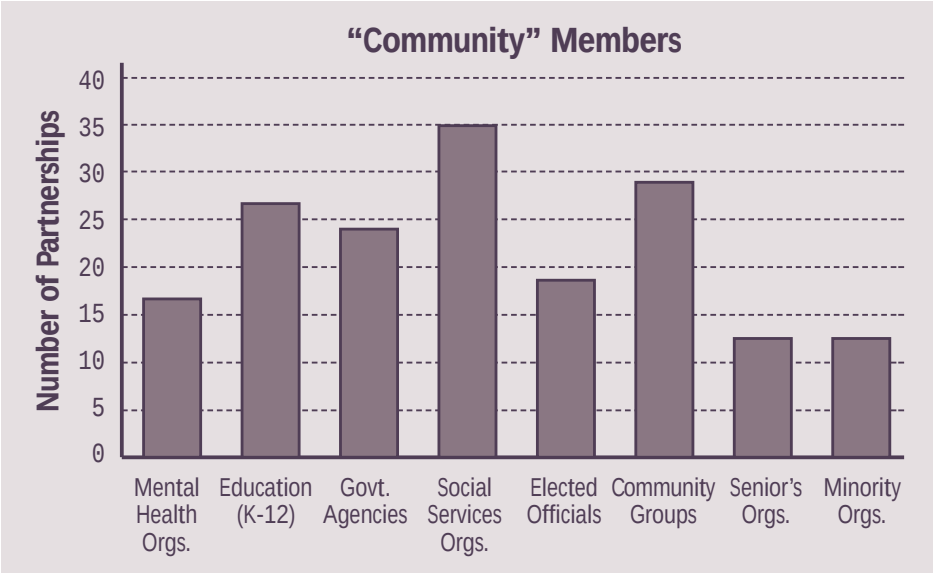
During the first year while partnerships were busy organizing, attention focused on recruiting formal members and establishing the local effort's conceptual scope. Toward the end of the second year, partnerships turned to completing "Public Health Improvement Plans" partially as a grant requirement. These plans identified priorities and helped guide partnership activities. During the plan-writing phase, community participation temporarily lessened as some partnerships drew inward, using a smaller group to draft their plans. In the third year, most partnerships moved toward stabilizing local public health improvements. Broad community participation at this point was important to mobilize and coordinate resources for newly-established public health infrastructures.

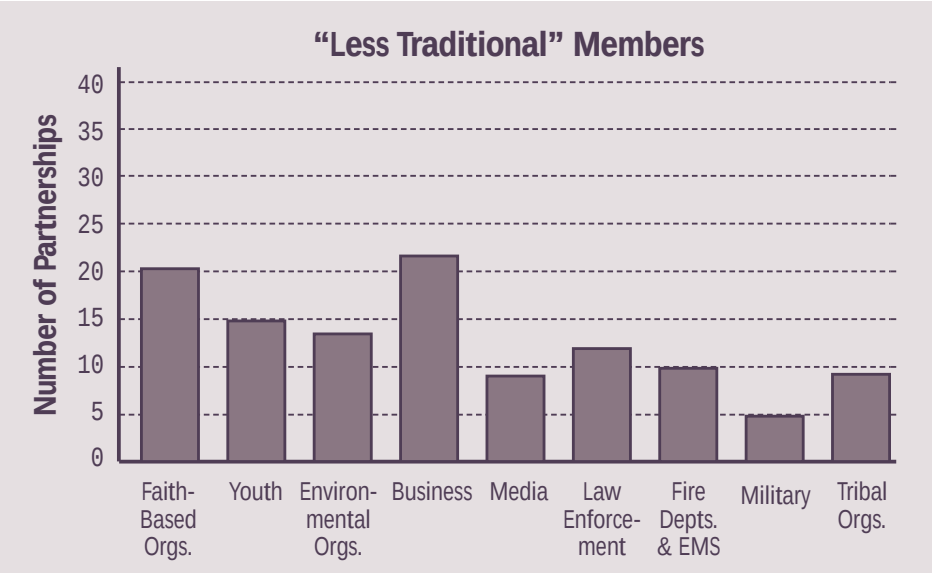
TWO: Turning Point partnerships recruited an array of formal members, thus establishing an important base for engaging other parts of the community in public health activities.

The approach local partnerships adopted to formally recruit members set the stage for subsequent efforts to engage sectors of the broader community in public health activities. Public health agencies and medical providers were members in almost 100 percent of the partnerships. Some partnerships limited recruitment to traditional public health partners such as

hospitals, provider groups, and related government agencies. Others expanded recruitment to less traditional partners such as schools, environmental groups, fire and police departments, faith-based groups, businesses, youth groups, and minority advocacy groups.







Most partnerships found it difficult to recruit and maintain partnership members representing business, minorities, and youth.

To recruit minority members and also to engage minority communities more broadly in public health activities, partnerships had to reach into minority communities and build trust. In one community, the Spanish language radio station became a communication conduit to recruit members from the Hispanic community. In Arizona, the Machan Health Communities Partnership organized "house meetings" in the homes of volunteer Hispanic families to overcome the reluctance of these community residents to attend official meetings that did not have translation services.

Several partnerships, including Chautauqua, New York; Tri-County, New Mexico; Reno County, Kansas; and Machan, Arizona, created youth councils, giving youth leadership roles and encouraging them to organize youth-directed public health

projects. The partnerships provided community leadership training for the youth and helped them learn to write grants to support their chosen projects.

Those that successfully engaged businesses learned to speak in business terms, eliminating health jargon. They educated business groups such as the local Chambers of Commerce about the connection between public health problems and the economic well-being of the community.

To expand community membership, some partnerships used distributive structures to engage members in neighborhoods and rural areas. The Cochise County, Arizona partnership replicated Turning Point-like groups in five local communities, helped these communities to organize, and provided technical assistance as the local groups selected priorities. The county-wide partnership served as a hub for the local groups and brought them together periodically to learn from each other and coordinate plans. Partnerships used this mechanism to recruit and maintain members from diverse geographic areas.

Other partnerships engaged more community representatives by establishing layers of members to participate in the partnership's activities, such as having a small steering committee that met frequently and organized the work of a larger group that had broader community representation, but met less often.

The New Orleans, Louisiana partnership's steering committee divided the city into geographic zones. It then

invited members from each zone to participate in periodic meetings of the full partnership. The larger meetings were used to educate, gather input, and set priorities.

Many partnerships kept a wide array of civic participants engaged by using subcommittees and workgroups focused on specific tasks or projects. These strategies are typical of other partnership-building efforts. In this case, they helped sustain engagement and interest in creating new and more responsive community-based public health infrastructures.

THREE: Partnerships reached beyond formal members to involve diverse sectors of the community in public health planning and decisionmaking.

Many partnerships incorporated community health assessments, a traditional public health function, to identify and prioritize local public health needs. More than half of the partnerships solicited community input at one-time or periodic events, while others set up ways to draw sectors of the community into ongoing dialogue.

Partnerships differed in the level of decisionmaking sought from community groups. Some garnered community perspectives in identifying health priorities and included community groups or individuals in decisionmaking processes. For example, the New Orleans, Louisiana partnership established neighborhood groups that gathered periodically to vocalize public health concerns and prioritize community needs to be addressed. Others asked for review and critique of project priorities and plans, which gave grassroots constituencies less opportunity to influence the partnership's public health agenda.

Some partnerships worked to engage communities by raising awareness about public health issues. Partnerships attempted to use the news media to educate the public about Turning Point and public health more generally. Most partnerships' public awareness efforts reflected one-time or sporadic activity; few developed more strategic approaches to raising awareness about public health issues through the news media.

Several communities adopted innovative strategies to gather community input about health concerns and increase citizen awareness. For example, through a "photo voice" project, community groups, including youth, were given cameras to take photographs of public health problems and/or public health activities. The partnership then created photo collages for public display. The collages dramatically illustrated the community's perception of public health needs, and conveyed to policymakers powerful messages about public health priorities.

FOUR: Partnerships that successfully mobilized the community made explicit commitments to broad civic involvement in decisionmaking and actual public health improvements.

A few partnerships made community engagement and mobilization an ongoing priority. They brought the community into public health decisionmaking, implementation of new services, and monitoring of health concerns. They were examples of how diverse community constituencies can contribute to expanding shared ownership and responsibility for

public health beyond government agencies. The Decatur, Illinois, and Central Kenai, Alaska partnerships, among others, exemplify this level of active, ongoing community participation.

The Decatur, Illinois Partnership Mobilized the Community to Tackle Environmental Health Problems

Decatur noted an increase in childhood asthma and identified leaf burning as a contributing factor. The Turning Point partnership engaged the community to support a ban on leaf burning and implement an alternative. The partnership stimulated a community-wide effort of leaf bagging, mobilizing 36 groups to distribute leaf bags. 800 individuals volunteered to work with nonprofit organizations to rake leaves for elderly and disabled community members. The City of Decatur, State Board of Health, and the Decatur Memorial Foundation, among others, contributed financial support. The campaign has become an annual event supported by the community at large, moving beyond the original Turning Point partnership.

The Central Kenai, Alaska Partnership Built New Community Services

The Central Kenai, Alaska partnership energized the community to fill gaps in health services. Over 50 groups and businesses came together to create, and continue to support, medical transportation services. The community also worked with the local hospital and the state health department to establish a new primary care clinic. Local and state agencies signed agreements to assure collaborative funding in the future.

Those TP partnerships that mobilized communities to create new public health capacity differed from other partnerships in several ways.

They were more likely to include community members in defining public health needs and in setting the partnership agenda, as opposed to asking them to react to assessments and plans developed by formal partnership structures.

They developed distributive mechanisms that allowed people to become involved in public health activities at a variety of levels, either through replicating Turning Point-like partnership processes at neighborhood levels, or generating projects that involved community members in new roles and responsibilities.

Partnerships that stimulated community involvement also articulated a broad definition of public health that included social determinants of health, environmental and safety issues, and a broad view of community well-being as illustrated in Exhibit 2.

Partnerships that focused on internal health department/health agency agendas, or on using data to

The partnerships that generated broad community involvement and sharing of resources across agencies tended to have a more interactive and long-term relationship with community constituencies moving well beyond gathering one-time data. Turning Point experiences suggest that mobilizing the community more broadly opens up a new world of resources to address public health objectives.

Exhibit 2[2]: Scope of Partnership Definitions of Public Health

assess community health status, were less likely to have effectively engaged the community. They used the more traditional approach to public health needs assessment, relying on disease morbidity and mortality data, and vital statistics to compile a statistical picture of community needs and priorities, and were less responsive to community input and perceptions. Some of these partnerships, however, also collected qualitative data from the community using surveys, interviews, and public meetings.

2 The *Core Public Health Functions* diagram was developed by The Lewin Group to illustrate findings from the evaluation of the National Turning Point Initiative.

FIVE: Partnerships made explicit policy and resource investments to sustain or institutionalize community participation.

Ongoing, active community engagement requires the investment of partnership resources to establish and sustain the involvement. Some partnerships began to establish more formal, potentially stable structures and processes, including governance to sustain community input into policy and priority setting.

- The Chautauqua, New York partnership set up a formal process to prepare youth to participate in planning councils and forums. These "Kidsultants" have been included in legislative meetings and are members of the local tobacco-cessation coalition.
- Tri-County, New Mexico, established county health councils in each of the three participating counties and required them to engage the public through regular town meetings.
- The New Orleans, Louisiana partnership established "Community Health Networks" to replicate the Turning Point process at the neighborhood level. The partnership provided grant funding to support neighborhood partnerships to develop leadership and facilitation skills, and identify and respond to neighborhood-level public health needs.

SIX: Partnerships found that community education and technical assistance programs enabled citizens to participate in public health activities.

A number of the TP partnerships developed education and technical assistance programs to help train members of the community to participate actively in public health review and improvement. They created new roles and functions for community members and enabled them to assist public health agencies with some public health responsibilities.

- In Onslow, North Carolina, the partnership developed a "Business Partner Certification" to educate local business owners about public health workplace standards and acknowledge efforts to implement the standards. The governor expressed interest in expanding the program to other parts of the state.
- Several partnerships launched programs preparing community members as lay health educators in such areas as prenatal care, chronic disease prevention, and water safety. The African American Faith Partnership in Arizona trained members of faith groups to visit homes and offer chronic disease education, and the Tri-County, New Mexico partnership trained community members to provide childbirth education.
- The New Orleans, Louisiana partnership is creating the Center for Empowered Decision Making to serve as an educational resource for communities and to prepare local people as leaders in community assessments and policy development.

- The Cherokee, Oklahoma partnership is establishing the Center for Rural Development to help communities connect public health and economic development activities using grassroots community members to carry out planning and assessment activities. Several rural TP partnerships are participating in this coordination effort.
- In Sitka, Alaska, the partnership launched a "train-the-trainer" program to prepare high school students to be community public health leaders and advocates for public health policy.
- The Machan, Arizona partnership set up a "Neighborhood Academy" to train community members in leadership, communication, and cultural awareness. They will serve as advocates for their communities' needs, and work in their neighborhoods to solve health problems.

SEVEN: Partnerships found that neighborhood/ community work groups could be instrumental in generating and sustaining support for public health improvements.

Another TP strategy for sustaining community involvement centered on projects that required diverse community groups to collaborate and coordinate resources. Community-based organizations and individuals provided financial and in-kind support to sustain the projects beyond the life of Turning Point grant funding, thus building ongoing community capacity to address health concerns.

- After organizing the leaf-raking squads mentioned earlier, the Decatur, Illinois partnership expanded its community clean-up activities by implementing "Sparkle and Shine," an event that stimulated active community participation in cleaning up the city. Both the leaf-raking and "Sparkle and Shine" events have become annual activities led by community groups and individual residents.
- The Twin Rivers, New Hampshire partnership organized a wide variety of established civic or professional groups —including architects, heavy machine operators, and business leaders, among others—to build and maintain a walking/biking trail that is being sustained as a community volunteer project.
- In Onslow, North Carolina, the partnership developed a process for organizing and coordinating community-based efforts, and helped two local communities implement the process. The communities put in place planning and problem-solving structures to focus local resources on locally-selected priorities.
- Several partnerships used a mini-grant process to engage community members in identifying and then addressing public health needs and projects.

Turning Point's Implications for Policy and Practice

The Turning Point demonstration projects supported by the W.K. Kellogg and Robert Wood Johnson Foundations over the last three years clearly illustrate that efforts to engage diverse community-level constituencies in the work of public health can be successful and can enhance public health infrastructure. Ownership and responsibility for public health can spread out into the community and expand on the ground resources to accomplish community-selected objectives. Community engagement also offers the potential of a powerful network to advocate for public health policy and funding.

Two sets of recommendations are derived from the Turning Point experience. The first set of recommendations focuses on state and community efforts to replicate Turning Point by establishing similar partnership structures. The second set of recommendations targets national agencies and policymakers, including the Turning Point national partners (i.e., the foundations and program offices).

Community participation can assist public health agencies in fulfilling traditional public health functions, expanding public health beyond traditionally defined roles, and helping to maximize the efficiency and effectiveness of local public health systems.

ONE: Recommendations for public health partnerships:

- Partnerships interested in engaging a variety of community sectors will benefit from early planning to include diverse sectors as formal partnership members, and establish mission statements and values that embrace a broad and inclusive definition of public health.
- Partnerships will commit to community involvement, sharing priority-setting and decisionmaking with community representatives, allowing their full participation in planning processes as contrasted with simply asking for review and comment on plans being developed or nearly complete.
- Partnerships that fully engage the community in the planning process need to prepare themselves to accept community-driven priorities that may generate some political and financial discomfort if they are different from established agency or government agendas.
- Partnerships must use innovative, culturally competent strategies to engage minority groups that have often been marginalized in our society.
- Partnerships should establish distributive mechanisms to keep community members informed about public health issues and involved in public health activities. Turning Point partnerships offer numerous examples of creative strategies that might be adapted to other settings.

TWO: Recommendations for national agencies and policymakers:

- Public health system and standard-setting initiatives such as those being developed by The Centers for Disease Control and Prevention (CDC) should advance community-engagement efforts. This can be achieved by including community engagement as a principle or value in public health standards and by providing guidance for implementing community engagement efforts. As an example, federal agencies might turn to the success that the Maternal and Child Health (MCH) Bureau and family constituencies have had in making "family involvement" an integral part of MCH policy and program development. The MCH Bureau and its partners, determined to insert family involvement into the standards for children with special health needs programs, held national policy forums on the topic, helped to fund family advocacy groups and resource centers, and included family involvement requirements in grant application packages.
- Governmental and private sector funding should be provided to support the organizational and educational activities necessary for effective community engagement as part of improving America's public health system(s). Direct community funding of partnership development, that is, extending Turning Point-like grant funding initiatives, is one option. Another would be to adjust current categorical grant programs to accommodate more community involvement. Support could be

provided for placement of interns or advisors in local communities, including cooperative agreements or offers of graduate-level fellowships. In lieu of direct funding, federal agencies, foundations, academic institutions, and other national agencies could offer technical assistance to local partnerships.

- National agencies and policymakers should evaluate experiences of federal programs that have required community involvement in their grant-funded projects. For example, the federal HIV (Ryan White) programs should be examined to determine the cost/benefit of their requirement that grantees establish community coalitions. Lessons might also be shared by the IDEA (Part C) federal/state programs, which require inter-agency collaborations to include parents and community advocacy groups. Federal agencies should further identify opportunities to bring diverse community participation into their planning and policy-setting forums.
- National foundations are uniquely positioned to build from earlier community development initiatives that may have been focused differently, but like Turning Point, established some community infrastructure that can be maintained. Foundations should consider support for efforts establishing or expanding mechanisms such as regional and national partnership meetings, Internet listservs and interactive websites, teleconferences, a national membership organization that advocates for and supports local public health partnerships, and technical assistance site visit teams. A national resource

center could be established to carry out these, and other, strategies. In this way, foundations could support the spread of Turning Point-like processes across the United States.

Timing could not be more appropriate or critical. Ultimately, science and technology are not enough to manage looming public health threats.

These suggestions for national policy could help mobilize untapped community resources to enhance and assist public health agencies. Whether confronting biological terrorism/anthrax, earthquakes, HIV, superfund waste sites, or health disparities — citizens, public health authorities, and the community must respond collaboratively if they are to effectively address and resolve public health problems.

For more information, contact Barbara Sabol, Program Director, W.K. Kellogg Foundation at 616-969-2026.

41 Local Turning Point Communities

Healthy Communities/
Healthy People
Kenai, Alaska

Fairbanks Community
Health Partnership
Fairbanks, Alaska

Sitka Turning Point
Towards Health
Sitka, Alaska

Cochise County
Turning Point
Bisbee, Arizona

African American
Faith Partnership
Mesa, Arizona

Gila River Indian
Community
Sacaton, Arizona

Machan Healthy
Community Partnership
Phoenix, Arizona

Partnership for a
Healthier Community,
Will County
Joliet, Illinois

Decatur Community
Partnership
Decatur, Illinois

Chicago Partnership
for Public Health
Chicago, Illinois

Wyandotte County
Community Health
Partners
Kansas City, Kansas

Reno County Community
Health Coalition
Hutchinson, Kansas

Northeast Louisiana
Regional Partnership for
Community Health
Shreveport, Louisiana

Southwest Louisiana
Turning Point Partnership
Lake Charles, Louisiana

Healthy New Orleans,
The City That Cares
New Orleans, Louisiana

Sheridan County Turning
Point Partnership
Plentywood, Montana

Community Coalitions
Network, Flathead County
Kalispell, Montana

Fort Peck Regional
Health Coalition
Wolf Point, Montana

Gallatin County
Community/ Public
Health Alliance
Bozeman, Montana

Buffalo County
Community Health
Partners
Kearney, Nebraska

North Central
Community
Care Partnership
Loup City, Nebraska

Healthy Manchester
Leadership Council
Manchester, New
Hampshire

Greater Nashua Healthy
Community Collaborative
Nashua, New Hampshire

Caring Community
Network of Twin Rivers
Franklin, New Hampshire

Albuquerque Service Unit
Indian Health Board
Zia Pueblo, New Mexico

Tri-County Partnership of
Chaves, Curry &
Roosevelt Counties
Roswell, New Mexico

Doña Ana County
Turning Point Partnership
Fairacres, New Mexico

Bernalillo County Turning
Point Partnership
Albuquerque, New
Mexico

Chautauqua County
Turning Point Partnership
Mayville, New York

New York City
Turning Point Partnership
New York, New York

Healthy Capital
District Initiative
Albany, New York

Lee Community
Action Network
Sanford, North Carolina

Onslow Community
Health Improvement
Process
Jacksonville, North Carolina

Tulsa Turning Point
Partnership
Tulsa, Oklahoma

Community Health
Coalition & Health
Services Council of
Cherokee County
Tahlequah, Oklahoma

Texas County Turning Point
Guymon, Oklahoma

Pathways to Care Network
Grants Pass, Oregon

Portland Tri-County
Turning Point Partnership
Portland, Oregon

Prince William
Partnerships for Health
Woodbridge, Virginia

The New Century
Turning Point Partnership
Roanoke, Virginia

Norfolk Turning Point
Partnership
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