



**Developing A Community-  
Based Response to  
Healthcare Issues**

*A Framework for  
Planning and Action*

**Prepared for The Access Project  
by Community Catalyst**

**The Access Project** is a national initiative of The Robert Wood Johnson Foundation, in partnership with Brandeis University's Heller Graduate School and the Collaborative for Community Health Development. It began its efforts in early 1998. The mission of The Access Project is to improve the health of our nation by assisting local communities in developing and sustaining efforts that improve health care and promote universal coverage, with a focus on people who are without insurance.

If you have any questions or would like to learn more about our work, please contact us.

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We want to also thank our colleagues from Building Parent Power (CT), Citizens Supporting Health Care (OR), and the Consumer Health Coalition (PA) for their willingness to share their organizational experiences.

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## INTRODUCTION

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*In time of crisis we summon up our strength. Then, if we are lucky, we are able to call every resource, every forgotten image that can leap to our quickening, and every memory that can know our power. And this luck is more than it seems to be: it depends on the long preparation . . . to be used.*

*--Muriel Rukeyser*

### Using this Workbook

For years, community groups, neighborhood organizations, and concerned residents from all walks of life have been working to make their communities healthier. They have fought against the closing of local hospitals, pushed for increased funding for clinics, and developed new programs to address the needs of the underserved. Their work, grounded in the history and experience of efforts to effect social change, offers valuable lessons we can use to improve the quality of health care in our own communities. These lessons can inform the methods we use and the choices we make to steer our own community's concerns.

This framework for planning and action provides specific steps your group can take to effectively address its healthcare issues. The ideas offered here are flexible enough to be used by any group, from an established organization with long experience to a start-up group facing its challenges for the first time. The framework can be used as a refresher on organizing for healthcare change, or as an introduction to the steps needed for larger projects. You do not have to follow the framework step-by-step. You can choose to select sections from the framework that are particularly relevant to your group and we encourage you to consult the Suggested Readings at the end for further information.

This framework will help you to:

- Identify the healthcare issues or opportunities your community faces;
- Assess the impact of those issues or opportunities on your community and recruit community support to address the issues;
- Define your goals and develop a plan of action; and
- Develop and implement a plan for evaluating your progress and learning.

One of the major keys to success in organizing is to continually build community participation at all levels. This framework will help you accomplish that goal by offering ways to outreach to new community groups and individuals and involve them in healthcare action. Together you can achieve the broader goal of improved health in your community.

A set of case studies is also presented to illustrate how three very different community groups at different stages of development, organized themselves to define and address healthcare issues their communities were facing.

## THE PLANNING AND ACTION FRAMEWORK

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The framework for planning and action is best outlined as a series of steps:

- 1. Identify healthcare issues**
- 2. Do community assessment and outreach.**
  - A. Gather further information about healthcare issues
  - B. Initiate community outreach and participation to address these issues
- 3. Develop goals and a plan of action**
  - A. Set clear goals
  - B. Define your action agenda
- 4. Develop your organization**
  - A. Define your organizational structure
  - B. Create a plan to assess progress, results and learning

Although the framework is outlined as a step-by-step procedure, effecting change rarely proceeds in an orderly fashion. The italicized highlights from the case studies accompanying the framework illustrate this point. You will notice that all three community groups had to be flexible in working with limited resources and changing environments. Developing a community-based response to healthcare issues is a dynamic process: Groups must be ready to respond to both internal and external changes. As mentioned earlier, your group may want to begin its work at some later step in the framework—for example, at steps 2, 3, or 4—rather than at what we outline as step 1.

The Key Questions that accompany each step in the framework will help to further focus your work. The Activities listed with each step are recommended tasks and objectives that might be useful in accomplishing your goals. Again, examples from the case studies, presented in italics, illustrate how other groups met and resolved their challenges.

### Challenges Ahead

In building your diverse base of support, you must help group members identify their common interests. This can be done through educational sessions and team-building exercises. The group must also learn how to deal with conflict, confrontation, and negotiation because they will eventually have to use all three in addressing the identified

**Guidelines for  
Practicing and  
Evaluating  
Success: A  
Checklist for  
Effectiveness**

health issue. To be successful, community outreach and participation is an ongoing process that requires a long-term commitment. You need to dig deep into the community to ensure that those most affected by the issue are an integral part of your group. Time and energy are a must for this part of your work.

As your group works through the steps of the framework, be sure to keep in mind the five guidelines described below. These guidelines are practices that will nurture your group's commitment to produce good results and to work well as a team. They will also help evaluate your success whether you are trying to accomplish short-term or long-term goals:

- 1. Define clear goals, roles, and strategies.** Think about what you want to accomplish; how it needs to be done; when it will be accomplished; and who will carry out each task. Be sure you are communicating these roles and strategies to your group's membership. Come up with a communication vehicle that works for all members of your group. This could be a newsletter or an issue-update session at meetings.
- 2. Agree on ground rules to guide your work.** For example, does your group want an open decision-making process, or, for the sake of efficiency and time, should some decisions be made by a few individuals? Taking the time to clarify ground rules and roles throughout your work together can go a long way to both preventing and resolving group conflict down the road. For example, it may be more practical to assign one person the role of speaking to a reporter on deadline.
- 3. Create opportunities to bring in new members and leadership into your work.** One of the key building blocks of success for developing a community-based response to healthcare concerns is using every opportunity to recruit new community members to support the work. New members help define goals as well as achieve them. Think about who should be involved in your group and pay attention to communities often overlooked by the mainstream—immigrants, people of color, people with disabilities, gays and lesbians and the working poor. Developing the leadership potential of new members will move the group's issues and agenda forward.

4. **Pay attention to results, but keep in mind that solid relationships are just as important as results.** Your group should always be thinking about whether all participants feel respected, valued and heard. The framework has your group define the results it wants to produce, a process for producing those results, and the quality and mix of relationships it needs to achieve its results.
  
5. **Ask for feedback on how you are doing.** Do ongoing assessment to evaluate your progress against your desired results, and then revise your goals or plan as needed. At the beginning of each step, your group needs to assess where it is, define where it wants to go, and plan how to get there. After implementing its plans, the group needs to evaluate the effectiveness of its work in order to plan the next phase. One method that works well for many groups is a quick review at the end of a meeting. They write “What worked” and “What needs to change” on a poster board and the group responds. Keep a record of these lists and be sure to follow-up on areas that need improvement.

The following **Checklist for Effectiveness** will assist you in applying these practical guidelines in your on-going evaluation of the group’s success. At the end of each step in the framework, you might find it helpful to turn back to this page and review the checklist.

### ***Checklist for Effectiveness***



1. **Define goals and strategies.** Does your group have a clear strategy?
2. **Agree on ground rules and clarify your decision-making process.** Do participants in your group feel respected and heard?
3. **Bring new members into the group.** What is your plan for engaging new members and developing leadership among current members?
4. **Pay attention to results, but don’t forget relationships.** Did members feel respected and heard? How effective was the strategy you used? Do you need to revise it?
5. **Ask for feedback.** What do members and others think about how you are doing your work? What’s working and what isn’t? What can you do differently next time?

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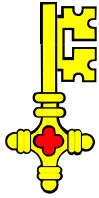
## Step 1: Identify Healthcare Issues

Communities face growing challenges to their healthcare resources as hospitals convert from non-profit centers of care with a charitable mission to for-profit institutions with a bottom line. Community hospitals and clinics are also merging with larger institutions to guarantee their financial stability. Other challenges you may face in your community include the push for Medicaid managed care, the loss of Medicaid as previous recipients enter the workforce, or the exclusion of immigrants from receiving healthcare. In doing community assessment and outreach, as described in step 2, you will often find how these various challenges directly affect people's lives.

*In **Pittsburgh, Pennsylvania**, concerns about the shift to mandatory Medicaid managed care prompted the Jewish Healthcare Foundation to work with constituency groups to form the Consumer Health Coalition and begin work to address inequities in the healthcare system. Another group in **Cottage Grove, Oregon** organized rapidly to address the potential loss of all hospital services when it was proposed that their community hospital be purchased by a competing hospital system.*

Changing times demand a strategic community response. The health of your community is at stake, and you feel compelled to do something. The best place to begin is by identifying what you realistically can hope to change. This is one of the most difficult tasks of organizing. You need to think about which battles you can really win and where the opportunities present themselves. To help clarify the process, community organizers often distinguish between a "problem" and an "issue." A concern that has emerged within a community—welfare reform, Medicaid managed care, or a hospital merger—is a "problem." A problem becomes an "issue," however, when you can identify a solution and begin to organize your community to act. It is worth taking the time to brainstorm problems, solutions, and issues with group members. Determine how easy or difficult it will be to enlist community support and what the chances are for successfully resolving the healthcare issue. The issue should affect people so strongly that they will commit to working together over a long period of time.

## Key Questions



- Is there something pressing in the community about which people have immediate concerns?
- Have community members identified an issue or opportunity that brings people together? What are people working on already?
- Are there policy changes occurring that could have a negative impact on community members?
- Are people beginning to see common issues and emerging concerns?
- What are the values, principles and assumptions that will guide your work on this issue? Has the group made these explicit and agreed on them?

## Activities

- ✓ Answering the key questions could assist you in identifying community healthcare issues. Listening to community members is also a way to begin identifying the issues.
- ✓ Develop a preliminary agreement on what the most critical issues are.
- ✓ Build your base of community support. By asking “Who is affected by this issue?” you can begin to identify community members who may want to work with you.
- ✓ Agree to test your group’s assumptions about the issues, its impact on your community, and factors in the broader environment that need attention to successfully address the issue.

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## **Step 2: Do Community Assessment and Outreach**

### ***A. Gather Further Information About Healthcare Issues and Opportunities***

To address healthcare issues in your community, your group must first listen to and gather information from community members about what they believe to be the most pressing issues and potential solutions. This listening process yields a wealth of information that can be used to guide your group's strategies and planning. The process also creates a sense of community responsibility—an “ownership” of the issues—and recruits new members to be a part of your efforts. By listening to your community's opinions, your group can test initial assumptions of what the issues are and make good decisions that will guide your plan of action. In brief, you will gather information about three things: the healthcare issues or needs your community cares about; the community's recommendations for solutions; and resources your community has to respond to the issues. Research and information gathering are on going and should occur throughout your efforts.

*In Pittsburgh, Pennsylvania, a conference held to hear the varying perspectives of community members who were feeling the impacts of managed care led to the founding of the Consumer Health Coalition. One-to-one interviews with a broad section of underserved groups over the following months helped focus the new coalition's plan of action and future decisions.*

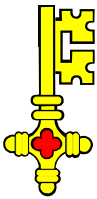
In addition to listening to the views of your community members, you also need to collect facts, policy information, and/or quantitative data about the issues. This type of research may include a hospital financial analysis; an analysis of hospital free-care policies; or information on applicable laws, regulations, and policies.

A good place to begin your research is your state's public health department or appropriate regulatory authority. A state university might also be helpful. One of the most useful resources is the Internet, where you can search web sites of states, municipalities, and counties as well as of non-profit organizations that might have the data you

need. A knowledgeable reference librarian may also be able to assist your search.

*In Cottage Grove, Oregon, community activists held a series of intensive meetings with civic groups, attorneys, and public officials. Through these meetings, the activists learned new ways Cottage Grove Hospital could get more funding to improve its financial ability to stay open. This information helped inform the strategy they decided to undertake in the months ahead.*

## Key Questions



- What is the health status of the community? What are the demographics of your community?
- How do underserved or low-income people get access to healthcare services? What are some of the barriers to care—transportation, childcare, language, or other barriers—that people experience? What are the community's assets and strengths?
- How do the health institutions in your community treat the populations who are culturally and linguistically diverse?
- What is the public's experience and perception of access issues and problems? What kind of health care do people want?

## Activities

- ✓ Identify current events and trends that your group may need to pay attention to in order to address its healthcare issues. Some of these may include: healthcare legislation, new regulations, economic policies, or changes in healthcare delivery.
- ✓ Keep up-to-date by reading relevant newspaper articles and newsletters published by local hospitals, trade associations, or non-profit organizations.
- ✓ Determine where there is support and willingness in your community to fight for these issues. In both steps 1 and 2 of this framework, as you talk with community members, you will begin to identify support.
- ✓ Develop an understanding of community member's and allies' perception(s) of the issue. The process outlined in steps 1 and 2 will also give you a chance to identify those who may disagree with your position.

- ✓ Determine whether you have the right mix and number of people to support your group to be successful in getting the work done and moving forward. Ask if you have included those with an interest in addressing the issue and those who have the influence to effect change?
- ✓ Collect data to assist the group in developing strategies and alternative courses of action, including data about the target populations affected by this issue, the health status of your community, and the economic structure of your community. A good resource for making use of data is *Using Data: A Guide for Community Health Activists*, published by The Access Project.
- ✓ Consult health studies from national and local organizations about your state and community.
- ✓ Talk to policy-makers in the community about the issues in order to gain information and also to inform them of your concerns. Good contacts can often be found in your state's Department of Health and Human Services, Department of Public Health, or Office of Minority Health. You can also contact the chief executive officers (CEOs) of local healthcare institutions and local and state representatives.

## **B. Initiate Community Outreach and Participation to Address Healthcare Issues**

Building a community-based, grassroots healthcare movement involves developing community participation and community ownership of healthcare issues. Although you may have been successful in attracting committed and hard-working members to your group, you must continue to expand your base of support to accomplish the work that lies ahead. Start by connecting to people you have not yet involved: those who are most affected by the issues as well as those who have resources to support your group's efforts. Outreach usually includes one or more of the following techniques:

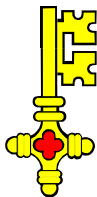
1. Building on existing community networks;
2. Connecting one-on-one;
3. Using questionnaires;
4. Responding to calls for assistance to advocacy groups; and
5. Sponsoring community forums.

It is important to keep an eye open for potential community leaders who will be effective spokespeople. Leaders can be identified by their willingness and interest in the issue, and not necessarily by their track record or experience. A key to strategic community-building is putting the people most affected by healthcare issues in the forefront. These are the leaders who will speak at demonstrations and give testimonies and newspaper interviews.

*In **Cottage Grove, Oregon**, community residents organized a public forum to assess current health needs when they heard that the Cottage Grove Hospital might close when it went under new management. The forum was a vehicle for publicizing the issue and creating community support for further action.*

*In **Hartford, Connecticut**, healthcare advocates endeavored to reach out to parents and develop leaders within communities while they worked to improve health services for area children. Community outreach took the shape of eight monthly workshop sessions that would train parents to participate in healthcare decision-making. Participants came from a range of racial and cultural backgrounds and learned valuable advocacy skills while becoming more unified as a group. During the training, when an issue emerged involving the possible loss of Blue*

## Key Questions



*Cross/Blue Shield's charitable assets from a proposed merger, parents felt confident enough about their knowledge and skills to take it on.*

- Who in your community is interested in addressing this issue?
- How are you going to listen to the community members who are affected by this issue? Are you open to hearing perspectives that are different from your own?
- How will you ensure that affected community members have ownership and control of the process?
- What activities will help people “own” what may be a new issue for them? (Examples include training sessions, planning committees, one-on-one interviews, and a founding convention. A founding convention occurs when interested parties gather to formally establish their organization and its platform.)
- What other organizations are working on this issue? How can you link with them?
- Who needs to be involved in your group but isn't yet? How will you include people of color, people with disabilities, immigrants, and others if they are not already in the room?
- How does the issue you have uncovered affect different populations?
- Are there organizations that you might *not* want to involve? If so, how will you deal with them?

## Activities

- ✓ Engage community members who are affected by the issue and have a strong interest: hold a community forum; write and distribute a newsletter on the issue.
- ✓ Engage institutional allies who may have the resources to help define and move your healthcare issue. These allies could be hospital CEO's, community relations departments, doctors, nurses, outreach workers, and community health educators.
- ✓ Increase community members' knowledge of the healthcare issue that has been identified.
- ✓ Build community ownership of the issue.

- ✓ Build your base of community support and use a process that will help your group be successful in the next step.
- ✓ Create a plan to develop the leadership capacity of the community members you have recruited.

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## Step 3: Develop Goals and a Plan of Action

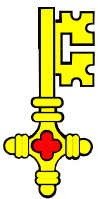
### A. Set Clear Goals

Your group has probably already defined its healthcare issue and has initiated community participation to gauge the range of responses to the issue. With this information, you can begin to set specific goals that produce the results you need to achieve. Goal setting should focus on:

- (1) External or “policy” goals based on the health needs and barriers in your community;
- (2) Internal or “community” goals such as increasing participation and leadership by group members; and
- (3) Distinguishing between short-term and long-term goals. Be clear about the difference between what needs to be accomplished right away and what may need further, long-term development. For example, a short-term goal would be to raise funds to keep a clinic open, whereas a long-term goal would be to establish a continuing relationship with a hospital.

*In its effort to maintain its hospital, the **Cottage Grove, Oregon** community first established short-term goals such as winning the state attorney general’s attention, getting the bankruptcy court to give the community standing in the proceedings, and increasing community participation. The group then established long-term goals: to make the hospital a financially viable institution, and to create a formal organizational structure to manage ongoing community involvement.*

### Key Questions



- Given the healthcare issue(s) your community has decided is important to address, what must be accomplished to bring about the desired change? What specific results does your group want to produce?
- Do your group’s external goals address the key challenges and opportunities presented by the healthcare issue(s) that most affect your community? Have these goals been informed by the information and data your group has collected?

- Do your internal goals include increasing the diversity and leadership development of your group so that it reflects the target population(s) whose healthcare your group seeks to improve?
- Are your goals SMART (**S**pecific, **M**easurable, **A**chievable, **R**esults-oriented and **T**ime-bound)?

### Activities

- ✓ Involve all group members in the process of goal setting.
- ✓ Document your goals (and the process you used to identify them) and post them so that everyone has a clear idea of what they are.
- ✓ Publicize your goals to new members.

## **B. Define Your Action Agenda**

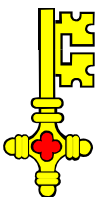
Moving from broad goals to a concrete action plan is a difficult but essential step in turning ideas and possible solutions into reality. The best action plans are developed collaboratively with all allies on hand working together to agree on an agenda and specific objectives. An action plan should frame clear objectives and outline specific steps needed to achieve them. In addition, it should identify:

- (1) All the tasks needed to implement a strategy, program, or activity;
- (2) Who is responsible for carrying out each task;
- (3) A time frame for completing the tasks; and
- (4) How you can go about evaluating your effectiveness in carrying out the action plan.

At the same time you need to consider the strategy you will be using to carry out your goals and action plan. Think about your potential allies and who has a common interest or a conflicting interest in your issue. You should identify who has the power to give you what you want, such as a government official, hospital, or institutional board. Usually the power connection is an individual, and you must analyze how you can influence that person and decide who will be responsible for doing so. Be aware of the barriers to the change you seek, from both your group's point of view and that of the person you are trying to influence.

*In **Pittsburgh, Pennsylvania**, organizers were able to engage the Regional Hospital Association in conducting an aggressive outreach and enrollment campaign for the Children's Health Insurance Plan (CHIP). The extent of the outreach would not have been possible without the Association's efforts. Enrolling low-income children accomplished the Consumer Health Coalition's goal of guaranteeing that communities receive the healthcare to which they were entitled.*

### **Key Questions**



- Given the healthcare issue your community has decided is important to address, what must be accomplished to bring about the desired change? What specific results do you want to produce?
- By when must these results be produced?
- Who will be responsible for producing these results?
- What are potential barriers to producing the results you want?

- What needs to be done to overcome these barriers?
- Who do you need to work with to produce the results you want?
- What are key arenas where decisions are being made about the issue?
- Where and how can you get involved to influence decision-making in those arenas?
- Are there organizations that have particular expertise or knowledge that could assist you?

### **Activities**

- ✓ Confirm the issues or opportunities and identify possible solutions and barriers to action.
- ✓ Develop an action plan with clear objectives, time frames, and assignment of responsibilities.
- ✓ Commit to an evaluation plan: review time frames and assigned tasks and roles.
- ✓ Document your plan so that all members know about it and can contribute to changes and assessments.

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## Step 4: Develop Your Organization

### A. Build an Organizational Structure

***We started out as an ad hoc group and now we are running a hospital.  
--Cottage Grove, Oregon***

A burning issue within a community sometimes sparks the formation of an organization devoted to addressing that issue. Other times a community organization inspires and leads a community response. As your organization develops its plan of action, you will need to create an organizational structure that best suits the goals you wish to accomplish.

*In Cottage Grove, Oregon, community participants were quick to respond to merger threats that would end needed healthcare services at the community hospital. Using public meetings, newsletters, and television and other media interviews, an ad-hoc group was successful in fighting off a merge; but work was still needed to keep the bankrupt hospital running. The group opted for a traditional organizational structure and a new name, "Citizens Supporting Healthcare." They created articles of incorporation and organizational bylaws. Anyone who endorsed the new group could become a member and then be eligible to participate in electing the board.*

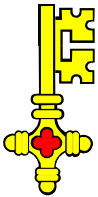
You may have to deal with paying salaries or consultant's fees, hiring, and supervising staff. Your group may want to become a nonprofit, community-based organization with a tax-exempt status or it may want to remain an informal voluntary group. Your group must be thoughtful in determining what kind of decision-making structure it will put in place. While groups often strive for consensus decision-making (where the whole group has to agree on a decision, without dissent), it is important to remember that democratic decision-making does not necessarily mean full agreement by everyone in the group. What it does mean is that the opinion of everyone is respected and listened to. Your group will need to decide what model of decision-making it will use.

*Parents in Hartford, Connecticut, who formed Building Parent Power were faced with the problem of finding a staff, an*

*office, and administrative assistance after their original supporter, the CHILD Council, had to suspend operations. They found a community organization that could provide in-kind office space for a year while they looked for funding. The group decided to use the consensus model of decision-making. They designated a planning subcommittee to recommend strategies for the larger group and an advisory committee of parents and supporters to guide collaborations with other area organizations.*

This step is a brief overview of things to consider as you begin to develop your organization. The tips offered here are far from exhaustive. Some of the resources included in the Suggested Readings will provide a more comprehensive overview of the process of creating a board, staffing your organization, and/or seeking funding.

### Key Questions



- If your group already has some kind of organizational structure, is it clear to all participants? Does it promote the kind of decision-making you want? Does it encourage discussion from all points of view, or does it avoid conflict?
- What kind of organizational structure will best enable your group to achieve its goals?
- What kind of budget, including in-kind contributions, do you have or need to achieve your goals?
- What resources are available or can be found to help the group do its work?
- Are there outside organizations that can provide you with resources and assistance to achieve your goals? How will you need to work with them to get the resources and assistance you want?

### Activities

- ✓ Develop an organizational structure to achieve the agenda and goals needed to address the identified healthcare issues and opportunities.
- ✓ Determine the information, staffing, and financial support needed for your group to achieve its goals.
- ✓ Identify organizations both inside and outside your community that could provide the resources your group needs to achieve its goals. Resources can include

funding information or contacts to funders, technical assistance, and in-kind support of people, money, material, or supplies.

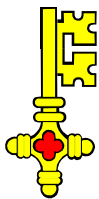
- ✓ Create a staffing and financial plan, plus a funding strategy, to achieve your group's agenda and goals.

## **B. Create a Plan To Assess Progress, Results, and Learning**

Throughout the framework, you have been evaluating your effectiveness and bringing new members into your group. You have assessed community needs and created an action plan and implemented it. Now is the time to stand back and look at your progress.

*Three years after its founding, **Hartford, Connecticut**-based Building Parent Power initiated a strategic planning process involving a survey of its constituency, a reaffirmation of its mission statement and an assessment of its organizational plan. An outside consultant helped the organization to form working groups and pose critical questions toward an overall assessment of its progress.*

### **Key Questions**



- Did you accomplish what you set out to do? What results did you actually produce?
- Are you making a difference?
- Which strategies or methods were most effective in helping you to produce those results? Which were least effective?
- What worked and what didn't work as you carried out your action plan?
- What new issues and goals have emerged since you started your work?
- What new relationships have emerged since the beginning of your work?
- What key opportunities and challenges do you now face?

### **Activities**

- ✓ Acknowledge your group's victories by holding a party or recognition ceremony that conveys appreciation to members.
- ✓ Keep track of individual members' contributions to the group's efforts. Make sure members know they are valued.

- ✓ Share and document amusing stories of your group's ups and downs.
- ✓ Highlight compelling, moving anecdotes that reveal the passion and heart of your group. Document these with photographs, video, or tape recordings.
- ✓ Develop a plan for evaluation of your group's performance and learning.
- ✓ Reach agreement on when your group will meet to review performance and learning.
- ✓ Measure the results of your group against your goals and action plan.
- ✓ Set new goals for the next phase of your work.

## CASE STUDIES

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### **BUILDING PARENT POWER (BPP)**

#### ***HARTFORD, CT***

#### **The Goal: Meeting the Challenge of Parent Participation**

The staff of Hartford-based CHILD Council had planned a short-term effort to educate parents and community members about the health care system and propose a community vision for health care. After learning about how the system worked, participants found themselves so involved with health care issues that eventually they formed their own formal organization, Building Parent Power.

Although the CHILD Council was founded to promote improved health services for Hartford children, its board consisted solely of representatives of major health care, insurance and funding institutions. The voices of Hartford parents were absent from the organization's decision-making process and from the health care system in general. The importance of parent involvement was acknowledged in the goals of many health organizations in the city (including the CHILD Council), but no plan existed to integrate an independent voice for the diverse mix of area parents.

In the summer of 1996, CHILD Council staff created an eight-month outreach and leadership development project called "Building Parent Power" to train parents to participate in health care decision-making. CHILD Council staff invested two to three days per week as well as logistical supports (food, transportation, child care), and resources for training consultants.

#### **Community Outreach**

The project was comprised of the following components:

- Eight monthly workshop sessions (facilitated by an organization hired to jointly design and conduct the training) on a weekday evening
- Participation limited to Hartford parents, grandparents, foster parents (agency staff and professional advocates were not permitted to participate in the workshops)
- Transportation, child care, and food were provided by the project
- Simultaneous Spanish translation (with radio headsets)

No plans existed beyond the workshop series so that parents could determine what, if anything, should follow the training

The CHILD Council did outreach for the project by making use of existing parent, neighborhood and community groups. An initial community meeting was used to present the overall project, to hear Boston area parent health activists discuss their local work, and to seek assistance in recruitment. Parents who attended recruited other new parents, grandparents, foster parents, working and homeless parents to create a core group of 50. Participants were an equal mix of parents active in other groups and parents new to any type of organizational effort.

The health care system training curriculum used adult education techniques built on the knowledge and experience of participants. The training was structured to develop group cohesion, elicit participants' major health concerns, and develop a vision of health care. Key to the training was new information about the current health system. During the course of the training, Blue Cross/Blue Shield proposed to merge with a large out-of-state insurance company. This new event raised serious questions about whether BC/BS would preserve its charitable assets. Parents decided to take on this issue and make use of what they were learning about health care advocacy. Parents testified at public hearings, sponsored community forums, engaged in local outreach and wrote articles for local media.

The latter sessions of the training series were designed for evaluation and discussion of possible next steps. Major themes of participant evaluation were:

- The racial, cultural and geographic diversity of the group was highly valued;
- Participant skills, knowledge and confidence were built;
- The experience of sharing and learning together, and the sense of unity this created, was appreciated and should be continued;
- Efforts to engage and retain involvement of Spanish-speaking parents needed to be expanded; and,
- Communication improvements such as creation of phone trees, personal follow-up, and minutes prior to meetings, were suggested.

## Developing an Organizational Structure

The group decided to establish itself as a citywide parent voice, “Building Parent Power” with the goal of improving health and to convene on a permanent basis.

By the end of 1997, a subcommittee of Building Parent Power was assigned to review structural options. The subcommittee explored three options – establishing an independent organization; linking to the CHILD Council; or linking with another parent organization. The group’s primary concern was full independence so that it could establish its own agenda. This desire raised some concerns about linking with other organizations. However, the group was unwilling to immediately take on the administrative burdens of establishing new administrative structures, tax exemption and funding sources. Given the CHILD Council’s history with the project, the group initially chose to work toward becoming independent while continuing to receive technical assistance and support from the CHILD Council.

Shortly after the above decisions were made, the CHILD Council board decided to suspend operations. Parents then began interviewing community organizations that were interested in providing an administrative and financial structure for the project until it could become independent. Many organizations were interested in providing a home for this active and dynamic grassroots group. An agreement was made with a state child advocacy organization to serve as the group’s fiscal agent. Another community organization agreed to provide in-kind office space for a year while the group sought solid funding support. Participants gained an understanding of financial requirements for part-time staff, phone, transportation, food, printing, etc. Staff then developed foundation funding proposals for general support of the group’s operations.

Building Parent Power decided to use a consensus model for its decision-making. A Transition Committee managed decisions that had to be made between monthly meetings. A Planning Subcommittee now meets regularly to prepare recommendations for the full group about issue-based work and strategy, as well as to address organizational development. An Advisory Committee comprised of parents and supporters from community, civic, and academic organizations provides planning and development recommendations and identifies opportunities for collaboration with other organizations and institutions.

## Identifying Issues and Developing an Action Agenda

Based on discussion throughout the workshop series, the group listed possible issue priorities and voted on them. The top three issues were Medicaid managed care, environmental health issues and BC/BS conversion. The issue of outreach and enrollment in new children's health coverage was added to this original list upon passage of new federal and state legislation. Building Parent Power places a strong emphasis on collaboration with other organizations and institutions so that there is a strong parent voice in all decision-making around health and community service issues. The Building Parent Power agenda and activities are designed to address issues while continuing to build parent membership and skills.

Major Building Parent Power activities in 1998 have included:

- Six focus groups of parents to discuss children's health with results to be presented to city Health Department for its planning work and to serve as benchmark for Building Parent Power's progress on the issues. (Work conducted with the Hispanic Health Council is under contract with the Health Department.);
- Community education about environmental justice issues through three community forums and a bus tour of city toxic sites for community members and local policymakers;
- Active participation in community-based coalition seeking to renegotiate contract conditions for city's trash sites, including gaining support from the City Council and the local state legislative delegation for a limit on the size of the landfill, hiring of city residents, and independent regular pollution testing and health screenings;
- Working with a state environmental group, Building Parent Power held a community forum on indoor air quality in schools and will now initiate establishment of indoor air quality committees in targeted schools;
- Through a joint project with the Urban League and the Hispanic Health Council, Building Parent Power hired staff to train parents to conduct outreach efforts to women about breast cancer prevention and the availability of free mammograms; and,
- Planning and implementation of an outreach campaign to increase parent and child participation in Medicaid and a new state health insurance program. (Building Parent Power negotiated to have this outreach project be a community placement site for the school of medicine.).

**Assessment and  
Learning:  
Current  
Challenges and  
Next Steps**

One of Building Parent Power's top organizational challenges at this time is to obtain funding to expand core staff capacity of a half-time coordinator through the addition of a full-time organizer and part-time development staff. As the organization has established a solid track record of informed parent leadership and successful issue work, more members have joined and demand for collaboration with other organizations has increased. This, in turn, increases demand for core staff to support basic functions, assist with issue research and develop leadership training opportunities. Current operating funding for Building Parent Power comes from the Haymarket People's Fund and the Public Welfare Foundation. Also, four foundations that previously funded the CHILD Council agreed to transfer remaining grant funds to Building Parent Power when the Council suspended operations.

A second challenge faced by Building Parent Power is integrating a strong parent voice at the health and child advocacy decision-making tables. Effective mechanisms do not exist at many of these institutions and coalitions. Creating the means for meaningful involvement of urban parents will require attention to scheduling, consistent information-sharing, power-sharing and cultural sensitivity. Building Parent Power is also committed to ongoing efforts to recruit and maintain the involvement of Latino parents.

After its first three years, Building Parent Power is addressing these challenges by engaging in a formal strategic planning process. Through a formal assessment of the organization's strengths and weaknesses Building Parent Power can identify new strategies for achieving a stronger parent voice.

**CITIZENS SUPPORT HEALTHCARE  
COTTAGE GROVE, OR**

In a matter of months, the rural community of Cottage Grove found itself moving quickly through all the steps in the framework and carrying out some of the steps almost simultaneously. The group moved from an ad hoc status to proposing to run a community hospital.

**The Issue:  
Hospital in Crisis  
Mobilizes a  
Community**

In the spring of 1998, the board of the small, nonprofit Cottage Grove Hospital (CGH) brought on a nonprofit hospital corporation to manage CGH and to purchase the facility by the end of the year. This hospital corporation already owned three other hospitals, including the large hospital in the nearby city of Eugene. Shortly thereafter, rumors of a possible hospital closure began circulating. In response to these rumors, CGH nurses worked with their labor union to initiate a public campaign to influence hospital decisions and oppose closure or cutbacks. They quickly gathered over 1,300 signatures for a petition that welcomed the new management company as long as its intent was to operate a full-service hospital.

By July, the rumors proved true when the management company announced that upon purchase of CGH, most, if not all, hospital services would be eliminated. A series of public forums were held by the hospital. Hundreds of community residents attended those meetings.

**Community  
Outreach**

Community support was further galvanized when residents organized their own public forum to assess current health services needs and develop a vision of a future community health system. Immediate concerns were with preservation of the emergency room, the nationally recognized birthing center (which requires a functioning hospital), and the long-term care/rehabilitation unit.

Community activists began an intensive series of meetings with civic groups, the Oregon Office of Rural Health, lawyers, advocacy groups and others. These meetings served to share community concerns and to gather information necessary to determine what realistic options existed to preserve the hospital and critical health services in the community. Through these meetings, activists learned about CGH's potential eligibility for a new federal rural hospital program that could

**Defining an  
Organizational  
Structure and  
Goals**

enhance payments. At meetings with local banks that were creditors of CGH, residents sought time to more thoroughly explore viable options for maintaining CGH.

A new state law initiated by statewide consumer advocates concerned about the need for community involvement in health system restructuring required the Attorney General to review any nonprofit hospital sale with a public hearing as part of the review. Through local media coverage, fliers, marching in a local parade and meetings with people and groups, over 350 people turned out for the Attorney General's five-hour hearing. Days after the hearing, the managing hospital corporation abandoned its merger plans and the CGH board filed for bankruptcy.

As activists continued to reach out to the community through the local media, public meetings, and a newsletter distributed through local businesses, the growing ad hoc group of residents moved to formalize their structure by incorporating. The group chose a name, Citizens Support Healthcare, and developed articles of incorporation, and bylaws. With the assistance of two volunteer consultants, the group began the internal transition from a coordinating group to a corporate board. Meetings became more structured and shorter. Stronger member participation was encouraged through committee level activities. Interim officers were elected at an open community meeting. Under the new structure, anyone endorsing Citizens Supporting Healthcare could become a member. The membership would then elect the board.

Today, all Citizens meetings are publicized broadly and open to the public. There is a high premium placed on openness since there had been bad feelings generated by the fact that the community had not been informed earlier about the seriousness of the CGH's financial situation. Through newsletters, forums and committee work Citizens has made its agenda and decision-making clear.

Citizens has supported its activities through individual donations, membership dues, local fundraising events, and extensive volunteer resources. Organizations from the local senior center to businesses to individuals and former employees have all contributed to Citizen's

## Defining an Action Agenda

Citizen's goals are explicitly to support and maintain CGH. Ongoing research about possible ways options to do this revealed new options. A regional nonprofit hospital system senior executive visited the community, met with the CGH board, and attended a Citizen's forum. The assessment of the executive was that the CGH could be financially viable. Another small rural Oregon hospital had been through a similar experience as CGH and was able to turn itself into a viable facility. A public opinion survey supported by the local newspaper indicated broad support for formation of a health district that could use taxes to partially fund the CGH.

As of November 1998, Citizens Supporting Healthcare had attained significant achievements including:

- Gaining formal recognition from the bankruptcy court with authority to present a plan for reorganization of CGH;
- Rejection by the court of CGH's reorganization plan calling for liquidation;
- Formation of a Citizen's advisory committee to work with the CGH management and board on a plan to reopen the hospital;
- Close working relationships and services from private and public interest attorneys, senior hospital executives and consultants, the Office of Rural Development and the Oregon Health Action Campaign;
- Specific strategies and options for a financially viable CGH, including application for federal rural hospital payment and formation of a local health district with taxing authority;
- Launching of a community fundraising campaign to raise \$3 million to "Jump Start" a reopened CGH.

By December the only bankruptcy plan submitted to the court was from Citizens Supporting Healthcare. The CSH proposed purchase of the hospital with \$2.5 million of accounts receivable and repayment of debt over time. (The old board did not file a plan on time saying it was delayed due to having the equipment evaluated.)

## Assessment and Learning: Current Challenges

The strong and broad community support generated by Citizens Supporting Healthcare has provided a reprieve from the proposed liquidation of the CGH. Time deadlines, however, offer the greatest

challenge to meeting the goal of a reopened CGH. Successful negotiation with creditors is required. The facility must be reopened before its hospital license expires in 1999. Oregon's Rural Health Plan, under which CGH could be eligible for greater reimbursements, must be submitted and approved by the federal government. Formation of a Hospital district to provide tax revenue will take at least three years. Funds must be raised for an operating cushion.

Sustaining and building greater community support, including more involvement from the Hispanic community, in the fast-paced and complicated world of bankruptcy courts and hospital finance represent the greatest challenge to Citizens Supporting Healthcare. The initial crisis response of the community must be channeled into the ongoing work of raising funds and the development of detailed plans for operation of the hospital.

**CONSUMER HEALTH COALITION**  
**PITTSBURGH, PA**

The Consumer Health Coalition began with particular advantages, including funding support and a highly structured approach to organizational planning. However, the group still struggled with becoming successful. A renewed focus on community participation and involvement became the ultimate key to success.

**The Issue: Local  
Foundation Sees  
Need for  
Consumer Voice**

Pittsburgh's history is marked by major economic and social transformations as its steel industry declined and the city rebuilt a different economic base. In 1995, a local private foundation saw a similar upheaval coming to the area's health care system. An anticipated shift to mandatory Medicaid managed care raised concerns about how vulnerable populations would fare, especially since access and quality problems were well documented in the Philadelphia area. Cost pressures were also certain to force restructuring of the area's large health industry with uncertain consequences for people most in need of health services. Familiar with consumer-based health advocacy efforts elsewhere, The Jewish Healthcare Foundation (JHF) determined that traditionally disenfranchised populations in the Pittsburgh area needed to know what was happening in the health care system and to have a voice in shaping changes. JHF also saw a need to have a unified voice across different constituencies because shifts in funding increasingly meant common issues for various groups.

JHF initiated The Constituency-Building Partnership with the United Way and the county human services department. The Partnership planned to conduct a conference for organizations of vulnerable constituencies to learn about managed care and the need to ensure that these constituencies would be appropriately served. The Partnership planned to continue the momentum generated through the conference by building a coalition of organizations with disadvantaged constituents. The coalition's purpose would be to monitor the impact of managed care and develop recommendations for improving care. This effort received funding support from JHF, the Robert Wood Johnson Foundation, United Way of Allegheny County, and The Allegheny County Department of Human Services.

**Community  
Outreach**

JHF provided direct staff support for the project and contracted with an established Massachusetts consumer health organization (Health

Care For All/HCFA) to provide consultation to the project, including sharing their experiences at the conference. A planning committee was composed of the project partners, constituency organizations, a policy expert, as well as a representative of the local Medicaid health plan. The committee focused on the conference itself and how it could lay the groundwork for building a coalition. Some key decisions about the conference and its relationship to the community/constituency were made before hand, including:

- The conference would target organizations, and constituents of these organizations who could become part of a regional consumer coalition;
- Health care providers, health plans and government officials would be invited to listen but not to make presentations;
- Conference organizers would enable people to attend with support for child care, transportation and outreach;
- The format would maximize participation and discussion by attendees in order to raise issues of concern and begin discussions about coalition formation;
- The experience of existing coalitions in the area as well as HCFA would be presented.

Although not in the original project design, an additional listening component was used at the suggestion of HCFA. About a dozen one-on-one interviews with a wide cross section of constituency groups were conducted by HCFA. These conversations focused on obtaining honest input around constituency health issues; current advocacy and collaboration; and thoughts about how best to develop a consumer coalition. Themes from the interviews were reported back and used in the planning process. (The interviews themselves were kept confidential.) Major issues raised in interviews included the following:

- The importance of building on good work already being done;
- Some resentment about not being aware of this new initiative (until the interview);
- The involvement of an organization from outside the community that raised concerns that a model might be imposed on the community rather than come from within;

**Determining  
Organizational  
Structure and  
Decision-making**

- Concern about sharing power between older, established organizations and newer agencies, including the need for diversity and cultural competence;
- Skepticism about the JHF's expertise and long-term interest in the development of consumer capacity; and,
- Importance of having an independent consumer-based effort separate from service providers.

A concerted effort was made to include under-represented communities in the conference. Workshops by geographic area and by constituency were used to solicit input on specific health issues and considerations in building a coalition. An organizing committee, open to consumers and existing coalitions, was formed to propose a structure for the coalition with the meetings open to interested parties.

With continued staff support from the JHF, the organizing committee used the conference proceedings to inform a relatively traditional organizational development approach of defining its mission, principles, and structure. The mission of the new organization would be to improve the health of vulnerable persons by insuring that the voice of the consumer is heard. In four meetings in as many months, the committee grappled with and resolved a number of issues about membership and collaboration, including that the new organization would:

- Become a nonprofit 501 (c) (3);
- Be a federation of organizations whose constituents are especially vulnerable;
- Have a governing board of half organizational representatives and half constituents;
- Define constituency organizations as those with constituents in major planning and oversight roles;
- Have a separate limited category of membership for other types of consumer advocacy organizations (in which constituents are not in major policymaking roles);
- Not have providers, insurers or government in its membership (although the coalition would work with these interests);

- Operate with a small staff and rely on its member organizations for issue identification and constituency involvement;
- Engage its membership through task forces, educational events, and formal participation in general council meetings.

*By March 1996 the Consumer Health Coalition's new board of directors held its first official board meeting as an independent organization. The board was composed of individuals from major community and constituency organizations. The JHF committed to providing three years of funding and helped to secure similar commitments from the Pittsburgh Foundation and United Way. Funding support for CHC was from the JHF, and the United Way.*

### **Setting Goals and an Action Agenda**

At a retreat, the board established an initial agenda intended to achieve some “quick wins” for the new coalition. However, a number of factors prevented the expected speed of action. It took 4 to 5 months to hire staff. The board and coalition were not a working coalition that carried out activities directly, but instead depended on staff. People on the board were new to each other and not yet used to working together. Also, the board members had not fully engaged their own organizations in the CHC agenda and work – the board participated more as individuals. Organizations did not have a commitment to work on the issues chosen by CHC. Finally, the timing of policy developments proved to be slower than anticipated. For example, implementation of mandatory Medicaid managed care in the area did not begin as originally scheduled.

As the board and staff worked for a year to address the challenges described above, a key funder was concerned about the organization's capacity to achieve its expressed goals. A portion of funding was conditioned on enhancing CHC's capacity through collaboration with a health policy and advocacy organization. Health policy developments in the state provided specific new opportunities for consumer action. New federal funding for state children's health insurance coverage (SCHIP) provided an immediate opportunity to address the problem of uninsured children. Pennsylvania already had a state-funded child health program, so one focus of advocacy was to utilize the full amount of available federal funds. A second focus was on outreach and enrollment.

CHC joined with area hospitals to launch a major campaign to enroll uninsured children in new health programs. In this effort CHC carved

out a role that was not being fulfilled -- building a grassroots base for the effort. Both individuals and over 180 grassroots community organizations were engaged in activities around addressing uninsured children. Mandatory Medicaid managed care is now moving forward in the Pittsburgh area and CHC is providing information and fostering input from community groups about this imminent development. These new campaigns have generated new financial support and increased support from existing funders for CHC.

Major activities and outcomes of the Consumer Health Coalition have included:

- Addressing Medicaid managed care marketing problems by collecting stories and information from the community; development and dissemination of a consumer handbook; establishment of standards for enrollment practices; meeting with state officials to advocate adoption of standards;
- Ensuring a sound governance plan for county behavioral health by collaborating with consumers, advocates and clinicians to make recommendations that were included in the county plan;
- Helping to prevent weakening of the definition of “medical necessity” for Medicaid recipients;
- Collaborating with consumers, community organizations and Child Health Insurance Program administrators to identify barriers to enrollment and develop a new outreach plan for 95,000 area uninsured children eligible for Medicaid and CHIP, but not enrolled;
- Spearheading a local children’s outreach and enrollment effort that demonstrated effective outreach and enrollment techniques reaching more than 1500 uninsured children with an 87% successful enrollment rate;
- Conducting a local campaign to inform legislators about the need to expand CHIP, helping to win 3,000 new slots.

**Assessment  
and Learning:  
Current  
Challenges and  
Next Steps**

One of the critical challenges now facing the CHC is how to define membership and how to make membership in CHC meaningful. CHC experienced success in its children’s health coverage work because of the extent to which both organizations and individuals engaged in the campaign’s activities. Many small community organizations now call

on CHC for information and support on health issues. Concerned individuals in the community have also found CHC to be a place in which they have a home base for activism. It will be critical for CHC to identify ways to sustain and build this type of active involvement.

CHC expects to expand its children's health access activities and to step up attention to mandatory Medicaid managed care using its expanded grassroots base to do so. Staffing at CHC will increase to carry out this work. CHC is working with individual members to evaluate the potential usefulness of a consumer helpline. The organization also wants to extend its grassroots reach into the outlying communities in the county.

## SUGGESTED READINGS

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