

ACCESS TO HEALTH CARE FOR ALL VERMONTERS

Beginning the Dialogue and Action

What is Access to Health Care?
Is Health Care a Right, Responsibility or Privilege?
Establishing Priorities, Making a Difference.

A Report of the Vermont Ethics Network's
Study Circles Project on Access to Health Care for All Vermonters
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Introduction and Overview

Access to health care is at its core a medical ethics dilemma, believes James Bernat, MD, a medical ethicist and former member of the Vermont Ethics Network's board of directors. This realization led him and the VEN board to pursue a project to help Vermont citizens engage in the deliberations on health care access. The Vermont Ethics Network's mission is to promote better understanding of the ethical issues, dilemmas and choices in modern health care.

Vermont has tried to address the problem of access to health care for all Vermonters for over a decade. Ideas have emerged, been developed, and put out to the public for consideration. Some progress has occurred, yet the issues are far from resolved. Many groups -- advocacy, special interest, government, business and think tanks -- have sought to define it and solve it. Providing citizens (including members of the above groups) safe, impartial, independent settings in which to come together to listen, learn and labor as equals brings a fresh approach to the process and movement toward the goal. Study circles are designed for that purpose.

This report first explains what study circles are and how they engender deliberative conversations. Then it conveys the essence of those discussions. Participants knew their work would be featured in the report, with less emphasis on quantifying and interpreting the data. As people registered, many wanted to know that their concerns would be heard, that this project would focus on making a difference. They did not want to come just to complain; they wanted to know they were not alone in their concerns, that they were valued, and that there was real hope for change: they did not want to waste their time.

The layout of the report reflects both the process and the content of the study circles. It uses a chart-like format, with segments that describe the purpose and approach for each session, echo discussions, and summarize major points. It shows how each meeting built on previous ones to move participants forward, gain trust and respect for one another, elicit thoughtful responses, think openly, and engage group members in the problem solving process.

Project Background

Purpose

VEN undertook this study circle project to educate Vermont citizens and involve them in access to health care issues. Its Board of Directors indicated three goals they wished to pursue. These were:

- 1) to ***raise the public consciousness*** about the many dimensions and ethical implications involved in access and choice decision-making at the societal level;
 - 2) to develop a consensus among a broadly diverse and representative group of citizens which will ***feed into the development of public policy***,
- and
- 3) to stimulate citizen input and participation to ***create initiatives for action at the local and regional level***. VEN brings these discussions to the public because it believes solutions must come from informed citizens, via a democratic process.

Rationale and Conduct

To accomplish the above goals, VEN felt it important to use a participatory process. The study circles model provides that process and moves people towards the board's goals. Often people come to understand the ethical choices and dilemmas best when they have the opportunity to examine the issues

on a personal level, hear other people's ideas, and struggle with case scenarios together in small, private, nonjudgmental groups. Once people have an understanding of the issues, they tend to be motivated to work on solutions, whether those solutions are making personal changes, working locally to improve a service, or getting involved in the political process. This project then, was a nonpartisan, open sharing among equals about matters that affect us all. Its deliberative process gets at the *broadest range of access issues*, not just the cost of health care and whether people have adequate insurance coverage. Though the cost of health care will be among many people's concerns, "It's not just about money."

Initially the project hoped to offer 40 study circles across the state to get a broad representation of Vermonters. Over the summer of 2001, a discussion workbook was developed and two pilot study circles were held. Facilitators were recruited from VEN's network of volunteers, professional social workers and graduates of the Snelling Center for Government's Leadership Institute. They received a day and a half orientation and training for this project. Each facilitator had leeway to use the discussion guide as a starting point, and to deviate from it as long as the conversations stayed productive.

A kickoff news conference, designed to be the cornerstone of the participant recruitment process, was scheduled for September 11, 2001. Because of the tragic events of that day, and the following weeks and months of societal grief, confusion and readjustment, the project was revised. A much subdued recruitment process was developed and implemented, focusing on reaching out to groups more individually, such as business and professional groups, public health providers and advocacy groups. Originally, all groups were to be held in the fall, as that was identified as the most opportune time for people to participate. Instead, five groups met then, and the remaining that we were able to field held their sessions in the new year, 2002.

After all the groups ended, an Action Forum convened on March 19, 2002 to bring together representatives from all the study circles. VEN board members, political and governmental leaders, and interested advocacy and health groups attended, as well.

Scope of the Information

Because this project employed a citizen education and involvement model, and not a research model, the questions posed prompted discussion, not concrete "most, least important" type opinions and ideas. VEN hoped to capture the breadth and quality of people's ideas, experiences, wants, and potential directions for future solutions. Though there was no attempt to quantify people's comments, the report will show what common themes emerged and what types of action citizens wish to see happen and in which they are willing to be involved.

Many who participated work in the health care field. While this may influence their views, the emphasis was on their personal experience and ideas, not their professional work. Some participants were not associated with health care professions, and no matter what the professional background, there were diverse ideas about what makes good health care, who is responsible for it and how we should strive to achieve it.

What are study circles

Study circles are small group, democratic discussions that involve community members in dialogue and action on important social and political issues. They usually have 8 to 12 participants, meet over a period of weeks, are led by impartial facilitators who help manage the deliberation process, but are not experts or teachers in the traditional sense, and look at issues from many points of view. They do not require consensus, but they do uncover areas of agreement and common concern. A culminating event generally is held to bring together all participants, facilitators and recorders, as well as staff and community people to look at common themes and directions for action.

The key concept of study circles is to promote dialogue, not debate. Several comparisons below illustrate the difference.

In dialogue, one listens to the other side(s) in order to understand, find meaning and find agreement.

In debate, one listens to the other side in order to find flaws and to counter its arguments.

Dialogue opens the possibility of reaching a better solution than any of the original solutions.

Debate defends one's own positions as the best solution and excludes other solutions.

Dialogue creates an open-minded attitude: an openness to being wrong and an openness to change.

Debate creates a closed-minded attitude, a determination to be right.

Dialogue assumes that many people have pieces of the answer and that together they can put them into a workable solution.

Debate assumes that there is a right answer and that someone has it.

Dialogue remains open-ended.

Debate implies a conclusion.

The Study Circles Project: Process and Content

During the four sessions of each study circle, group members examined their own concerns and experiences, looked at the issues from a broader, policy perspective, discussed how they thought our health care system should be designed. They struggled with a case study, established their priorities for action and took steps towards those priorities. In using a model that allows and supports "cordial disagreement," people found it is possible to move beyond politics and rancor, to realize that all perspectives and efforts are needed to progress towards an improved health care system. They also realized that, as individuals and small groups, they can and must be engaged in action on the individual, community, system, and societal levels.

Session One: How have you been affected by health care in Vermont?

At this first session, participants had a chance to get to know one another, learn about study circles and this specific project, agree on some ground rules on how to talk about the issues, and start to get comfortable with participatory discussions on public issues. They shared personal experiences they had had in the health care system .

Each group suggested modifying the ground rules, which gave them the opportunity to make the group safe and respectful for themselves, and to emphasize the importance of the upcoming conversations, to test out speaking up, and whether or not the facilitator really was going to stay out of content areas, and let the group take responsibility for itself.

They considered what experiences they had, what made them good or bad, and how those experiences influenced their general opinions about Vermont's health care. This allowed participants to see where they had common perceptions, and what they thought were some of the serious challenges we face with access to health care. They did not mince words.

"The hospital was short staffed and I became a 'thing'."

Many of the negative experiences were related to impersonal treatment, due to not enough time in a doctor's day, being short staffed, lack of insurance. Participants reported being yelled at by a nurse, having a doctor be rude, or use a paternalistic 'doctor knows best' attitude. Some people noted that their level of care was directly related to whether or not they had insurance, and what that insurance covered.

"You have to advocate for yourself. You need to know the tricks, how to play the game."

"I did medical billing. If I put a dot in the wrong place, they'd send paperwork back to me."

Dealing with bureaucracy was a common theme. Whether it was a voice mail service that never allowed conversation with a human, or being denied care and having to appeal, or bills not being paid in a timely manner by the insurance company, frustration with 'the system' ranked high among many people's concerns.

"Billing is a secret code that no one understands." "Administrative bloat sucks up dollars." "Even insiders have to advocate for themselves."

Participants related positive experience as well.

"The VA staff is committed to serving you, honoring your service to the country." "My son got bitten by a dog. The owner walked away, the police weren't responsive. The doctor from urgent care called to see how he was." Being treated professionally, with kindness and sensitivity, as a partner in health care made a big difference. Having a professional available to advocate was seen as a plus. Having choices for preventive and complementary care, as well as conventional/western treatments, was mentioned by quite a few people as being good experiences. ***"Home health nurses are like a second family. They were very responsible -- acted as though they couldn't do enough for me. They respect people, no matter what their circumstances"***

"The genetics/cancer center in Burlington gave very conscientious care and followed up with me"

Interestingly, most of the noted experiences, good or bad, were more about how people were treated. Quite a few items in the "good" category included actual health care services or outcomes; only a few of the "bad" category items related to medical care and outcomes. Those, however, were quite serious problems. One involved disregarding a living will and advance directives, another involved what was to have been minor topical surgery and aftercare for three weeks, and resulted in two years of painful treatment and an addiction to pain killers because of bad care, and a third involved administering procedures insensitively. Affordability and availability of insurance concerned many. By the end of the session there was a genuine interest in people's stories and a common bond within which they could move forward.

"I am deaf, without a hearing aid and couldn't get it taken care of while I was in a hospital. There was no one to tell. I was afraid and I won't go back to (that facility) -- I would die first." Doctors who participated acknowledged that their degrees opened doors. Others noted that because they had good insurance or not many health problems they were unaware of the problems others encounter. One participant noted a quandary: we spend a million dollars on treatment for complex health care when death is inevitable and natural. ***"I've witnessed a peaceful death at the hands of the system, and a violent death in the system."***

"It is an illness treatment system, not a health care system." "It is a group of fiefdoms, not a system."

When participants were asked to identify what they thought of as the most serious concerns we face in the health care system, the following items were mentioned: capital expense for new technology, general overall costs, prescription costs, bureaucracy, dental care, staff shortages, finite resources, follow up care, changing public perception of rights and responsibilities -- the need for a culture shift, long term care for catastrophic injury and illness, need to broaden health care to include holistic, preventive, home care, patient education. ***"One size does not fit all -- for care, for outreach, for health promotion."***

Session two: Core questions about health care and access

In session two, participants moved from personal experiences to the challenge of examining complex policy issues and (tolerating) differing opinions. Drawing on their common bonds and expanded awareness, they struggled to decide if health care is a right, responsibility or privilege, to define health, health care and access, and to look at what realities exist in their communities. Questions promoted critical thinking, consideration of difficult issues beyond the personal level and how to minimize political "hot button" terms.

Is health care a right, responsibility or privilege?

"It's all three." "It's a right that needs stewardship." "A privilege is something you can live without ... if I'm having a heart attack, it's not a privilege to have health care." "It's a responsibility, and people need to maintain a healthy lifestyle."

"They are interconnected." "Health care is a right and society has to find a way to provide it. Personal responsibility is essential." This last comment illustrates how important many participants felt it was to link rights and responsibilities.

Discussion included the following points: health care should be a right without discrimination; several people felt it should be ***"like Act 60", where everyone has some basic level of care provided by state funding and should pay for anything above that.*** Analogies also were drawn to other societal infrastructures such as highways. Others were not so sure: ***"Universal access is an extraordinary goal -- there needs to be continued discussion and debate."***

"Does a healthy democracy require enhanced health care?" asked one participant. Some people felt that the responsibility belongs to the community and to society. Schools were seen as a place where much could happen for providing health education and preventive care.

"Communities, regions, states, the country have a responsibility to take care of their citizens so as to not be a drain on the system."

"Some limits help me take responsibility. For example, if I know bypass surgery will be available, I might not eat as healthily."

Other participants focused on the individual responsibilities each member of society has to take care of him or herself. Though people acknowledged that it would be difficult to monitor, evaluate and judge people's right to access based on personal behavior, they did feel emphasis should be placed on this aspect. Concern was expressed especially around drinking, drugging, nutrition and exercise. A few people mentioned physically risky activities such as riding a motorcycle without a helmet, skydiving, and dangerous sports.

"Where do we cut back? We have to accept that we can't get everything we want."

Many of the study circles looked at rationing -- that is, making rational, thoughtful decisions about where society's health care dollars should be spent, both in a general and specific sense. This applied to many areas such as hospital expenditures, preventive care, research, unproven/new treatments, and

end-of-life care. Preventive care and primary care should be accessible to all; beyond that, there is no consensus as to where to allocate our health care dollars.

Other factors affect access, as well. The more common barriers participants identified included transportation, lack of doctors (and other providers) in their area, providers who did not take their insurance or Dr. Dynosaur (a Vermont health insurance for children), lack of interpreters (for people who use sign language or speak another language), and cultural practices, such as the stoic New England attitude of not seeking help until a major problem has evolved.

Knowledge of available services, programs and health care information, how things work now, and of government processes varied among people. All felt it was useful to share what they knew, and several people found ways to meet their needs as a result of the discussions. In some groups there was disagreement as to what the correct information was, and in most groups there was a lack of awareness of where to get information.

Session three: What structures, principles and values does our health care system need?

During the third session, participants worked to identify structures, principles and values needed in our health care system through two activities. First they discussed a case study crafted to touch on many of the ethical dilemmas facing us individually, and as a society. Then they articulated what features the "ideal" health care system would have. These opportunities not only allowed them to voice their wishes, but to experience the difficulties in planning for health care needs.

We asked about an ideal health care system:

What services and facilities should be in it?

Where should they be located?

What hours should they be open?

Why should the services be part of the system?

What organizations should administer the system?

How should the services be paid for?

Who gets to use the services?

How do you literally move through the system?

How should the parts be connected?

How would someone know how to use it?

How do you resolve conflicting values?

Given realities of choice, limits and cost, what would the best possible health care system look like?

Common themes included that a broad spectrum of preventive and primary care, and health education services should be available to all. Some believe it is especially important to include dental, vision and eye care, hearing, mental health and substance abuse treatment among these core services. Most people mentioned that some sort of an advocate, or case manager or primary care provider, whose responsibility was to the consumer, and not the organization providing or paying for the service, was very important, as was consumer autonomy in choosing providers and making health care decisions.

A variety of specific ideas came up that would provide topics for further discussion.

Several dilemmas arose:

Having to choose between health care and heat or having a family or food.

How do we, as a society, deal with young people who feel invincible? They won't purchase insurance, and they engage in risky behaviors.

Most people felt health care should not be tied to employment, yet how to fund, manage and provide it is not clear to some.

How much should we focus on life saving, versus life enhancing, care and services?

A broad spectrum of ideas emerged regarding an improved health care system:

There should be choices for Western, Eastern and alternative/complementary medicine.

Subsidize schooling for providers (Medical/Nursing School Education) so they aren't burdened with debt.

Model a new system after the original health maintenance organizations (HMO) of the 1940s and 1950s.

Establish statewide standards of care.

Reach out more to men.

Provide more hospice, long term care services.

Family lodging, other services, available on site, especially for hospital care.

There should be a health care bill of rights and responsibilities.

Primary care services should be located in or near shopping areas, and be open more hours.

People should have a case manager or advocate for their needs.

Use more telemedicine.

Educate people better about health care costs and other factors involved in policy development.

Streamline the bureaucracy.

Warm, sensitive environment provided for care settings.

Second opinions should be easier to get.

Single point of intake, information and referral.

Promote more neighbors helping neighbors.

Use the existing public health system structures; improve and expand them.

Use schools for prevention, screening, education; have healthy food in schools.

Conflicting ideas about how to pay for and ration care were suggested.

Principles and values people wanted to see reflected included the following:

Prevention, wellness promotion and primary care available to all.

Everyone needs to help pay for the system.

The system should be citizen controlled -- there should be a statewide public process that includes a vote, to set health care priorities.

Support patient decision making.

Research should be guided by other than market value.

Death is a natural part of life, not something to be avoided at all costs.
Each person needs to make a difference; for example, taking responsibility for behavior, practitioner accountability.
Privacy and confidentiality protected.

Session four: Establishing priorities and making a difference

For the final session, questions led participants to think about and own what THEY would like to do to move the issue forward. Because this project is based on citizen involvement, it needed to end in a way that "left the ball in their court". While VEN can help communicate the results of the project to government officials and health care organizations, ultimately citizens must become more involved. Focusing on citizen action, therefore, was the most important aspect of this meeting. We asked:

- Who would you want to talk to about improving access to health care and what would you want to say?
- Of all the concerns raised in your study circle, what would you most like to work on?
- What can you do as an individual to make a difference? Why is this important to you?
- What can you do if you work together as a group?
- How can you build on existing efforts to make health care accessible to all Vermonters? Who is involved? Who else should be involved?
- What knowledge and information do you want to have? How might you go about getting that? What help do you need to get it?
- What two or three ideas for addressing access to health care for all Vermonters does your group want taken forward to the forums, to policy makers, and to be included in the final report?

Here are the summaries from each study circle:

Each study circle was asked to come up with a few main points to be included in the final report and brought to the action forum. Participants were assured their reports would be reproduced here as closely as possible to the original they supplied.

Barre

1. Start with a truly universal health system.
2. Establish a single payer, tax supported system.
3. Prevention and health promotion.
4. Develop a public process for setting health care priorities.
5. Disentangle employment and health care, business and health care.

Bellows Falls

1. There is a need for concrete information in all aspects of health care: services in area, choices in treatment, health education, insurance
2. People should have access to a spectrum of health care -- complementary, preventative, urgent care, etc.
3. Communication needs to be improved, especially between consumer and provider. A concern is arising about ethical conflicts between communicating information quickly and globally to the benefit of health care consumers and providers on the one hand, and right to privacy and confidentiality on the other.

Bennington

1. There needs to be access, education and cooperation among all providers so people can have choices including western and complementary options.
2. Case management /advocate/resource educator who is on the consumer's side, not a bureaucrat or gatekeeper, who can bring information to consumer and provide guidance and individualized support to the consumer so he/she may make informed decisions and get the care needed.
3. Increased funding to provide adequate reimbursement to providers to cover costs for everyone including the general population, the untended population and marginalized folks no matter the source of payment.

Brandon

1. Strongly support universal health care -- see it as a federal issue though: Vermont is a small state, and if we try to tackle it ourselves may have too many problems, such as providers leaving.
2. Pharmaceutical expense makes medication not accessible due to insurance not covering them, especially for the elderly, and people with mental health difficulties
3. Concerned about health care for prisoners: do they get adequate care, especially for mental health needs and, substance abuse problems
4. Limited access to and choice of doctors in small communities
5. Access to dental care is a concern -- don't have insurance, can't afford out of pocket

Brattleboro

1. Influence policy makers: invite politicians to meetings of concerned citizens and business people. Pressure, education, information dissemination and accountability are key efforts in this area
2. Personal action plans:
 - a. create a local newspaper column devoted to the real life stories of folks struggling with the current system. This has been implemented and is happening with two group members.
 - b. Mobilize people to engage in the efforts towards health care improvement before it affects them personally.
 - c. Mobilize members of the nursing profession to advocate for change
4. Create a viable mechanism to reach out to non-engaged groups

Burlington (summer)

1. Action after the study circle can take many forms. For some it means volunteering in agencies. Others want more time to ponder the questions raised in the discussions, especially, what is the value of life? Political activities -- serving in the legislature, lobbying the legislature, are important to a few.
2. Communication and education between patients and providers, especially, but also insurance companies, needs to improve.

Burlington (fall)

What do we want?

Healthcare in Vermont will be provided as universal comprehensive coverage, probably through a state government administered single-payer method that coordinates care utilizing a network of primary care practices. Personal decision-making will be preserved in the health care process. Dignity and respect will be key values in the delivery of quality services. A successful health care system will include a strong prevention and education focus. Pharmaceutical, mental health, chiropractic, and nontraditional options for care need to be elements of comprehensive coverage in one-way or another. Long-term care must be an element of comprehensive coverage. It is a key health care challenge both for quality and cost. On-going administration of a Vermont Health care plan needs to provide for a clear avenue of public assessment and citizen participation in the process. Vermont health care cannot be second rate. First-rate health care will measure success by the quality of care for the majority of people and not by an assessment of the pinnacle of care possible in a few cases or specific medical procedures.

Burlington (winter)

1. A statewide, comprehensive, long term process needs to be designed and implemented to educate citizens and have them come to a consensus about what the health care system should be in Vermont.
2. Our group thinks there should be a real system that provides health care for all that maintains quality and has economic efficiency.
3. There needs to be public accountability of health care in Vermont.
4. Consumers need better information/education and advocacy
5. The "industry" of health care and pharmaceuticals gets in the way of sound decision making
6. Alternatives to treating people with pharmaceuticals should be emphasized, covered
7. Resources need to be shared and we all need to make sacrifices.

Essex Jct.

Every person in Vermont should have an individualized health plan.

1. Characteristics:

- a. focus on building health
- b. identify risk factors
- c. identify wellness goals
- d. screen for pathology as well as strengths
- e. plan moves people toward optimal functioning (physical, mental, spiritual)
- f. the plan is not static - "continuous quality improvement"
- g. plan develops in partnership with individuals and experts
- h. personal ownership of the plan is vital

2. How to implement:

- a. should be multiple ways to access/develop a personal wellness plan
- b. most people develop these plans with their primary care providers
- c. other ways to develop a wellness plan could be through the internet and other computer technology/resource center at libraries/informal support groups
- d. wellness model currently being developed by Vermont pediatricians could be expanded to include adult patients
- e. pilot this approach to study the effects on a small population
- f. medical leadership needs to endorse idea of an individualized health plan and organize providers
- g. the concept probably requires a cultural change (beginning with children)
- h. can build on self-help models and computer/internet technology for some adults.

Fairlee

1. Our current system focuses on providing insurance, not providing health care
2. Legislators are a "weak link" and yet they control the decision making.
3. Need easier public access to data -- not buried in agency "protection"
4. Need further information (in a matrix) to compare various health care systems around the world.

UK Canada Iceland Sweden Norway etc.

Issues of care

Self-employed

Long term care

Funding - % of

Health care of GNP?

Drug addiction

Public/private funding
Hospice- end of life
Taxation: gas,
Tobacco, alcohol
etc.

Irasburg

Problems with the health care system are numerous and diverse; ideas to address these problems are likewise. The task at hand – generating ideas to improve access to health care – requires an understanding of the fundamental features of the health system that leads to these problems and not responding to each problem, one at a time, without an awareness of the fundamental causal relationships.

1. The goal of the health care system should be optimal health for all citizens. The current health system is primarily focused on responding to disease and important factors that promote health extend well beyond the domain of the health system.
2. Everyone will need the health system at some time so there must be universal access.
3. Moving beyond the current system and its numerous limitations requires change and change requires leadership.
4. Leadership should have face-to-face accountability to its citizens.
5. We would like to see the following three structural changes:
 - a. An accountable leader, a *Physician General*, to steward the changes necessary to pursue optimal health for all citizens.
 - b. A health care information system that will provide accurate and relevant information to all decision makers: providers, patients, policy makers, managers.
 - c. A health policy council to weight the costs, risks, and benefits of health policy decisions in pursuit of the goal of accessible health care for all citizens.

Montpelier

1. Our society needs to adopt a more expansive view of what constitutes “health care”.
 - a. Current system focuses too heavily on treatment of disease.
 - b. We need to individualize care and increase prevention, maintenance, complimentary services and education.
2. We need to view health care as both a collective and an individual responsibility.
 - a. Collective Responsibility

- i. We need to recognize that, in the end, we all pay for the health care of each other either through increased insurance premiums, out of pocket expenses and/or taxes.
 - ii. The public good is served by having all individuals covered with, at the least, a catastrophic policy with a substantial deductible (e.g. \$2000.), with a share of the premium paid with state funds. An individual or family's ability to pay would form the basis for the amount of the state subsidy.
 - iii. In concert with that, we need to have a public discussion regarding what we, as a society can afford to pay for health care for our citizens. That discussion should not be any different than the type of discussions we have at Town Meetings about town and school budgets. Some members expressed a willingness to adopt explicit rationing of health care, similar to Oregon, but that did not target the poor only.
 - iv. The group felt that consumers, employers, hospitals and providers could probably agree on 80% of what needs to happen to fix the system if they put aside their various fears and competition, and focused on their common needs and goals.
- b. Individual Responsibility
- i. There needs to be more emphasis placed on health care education, prevention and maintenance.
 - ii. Consumers also need to be more informed about the costs and quality of a particular procedure, medicine, or practitioner in order to fulfill their fair share of responsibility.

Randolph

1. In a rural state, transportation needs must be addressed as part of access to health care.
2. Prescriptions are not affordable.
3. We believe the system is reaching a breaking point.
4. A grass roots process needs to happen to bring about change.
5. Real planning for funding needs to be done.
6. The public needs better education about healthy choices.

Rutland (fall)

1. Universal coverage is a priority
2. Work on a benefits package allowed by available funds. Assumption that savings are available if we move to single payer and if Vermont covers basic package. Expenses over and above will be covered by insurance. Unresolved: whether there should be a gradual or radical approach in implementing the change.
3. Concern about the overlap among nonprofit and other service providers

Rutland (winter)

1. There should be basic care for everyone, based on medical needs, especially routine and preventive health services, regardless of ability to pay
2. Intake should be centralized: one stop shopping for any medical or related need from which assessment and appropriate and timely referral would be made
3. Education should be offered at all levels to emphasize personal responsibility about health care and insurance or coverage
4. Health care should be acknowledged as a major economic component of our society without judgment as to whether that is bad, good or indifferent.

Shelburne

1. Everyone get access to some basic level of care with some cap; people should be able to buy any higher level they wish to and can afford.
2. People need to be responsible for their care and healthy behaviors. People should be screened very thoroughly before granting transplants.
3. Health education should be emphasized (and providers need more education on this themselves)
4. We are concerned about lack of choice in a system similar to Canada or the United Kingdom
5. Everyone needs to pay into the health care system, similar to social security.
6. Reinstigate physical education as it was taught in the 1960's in schools.

Stowe

The Stowe study circle sent a letter to their local hospital. The following points were in it.

1. Care
 - a. The process the patient goes through is as important as the outcome.
 - b. Patients want the system to treat the whole person; a more holistic approach.
 - c. A warmer, more patient and family centered environment is needed.
 - d. There is a feeling that care out of state is a higher quality.
2. Access:
 - a. More convenient clinic hours
 - b. Option of affordable clinics for uninsured
3. Education:
 - a. More public awareness of available social services programs
 - b. Support of nursing programs (to help offset the low enrollments)
 - c. Physician and Hospital waiting rooms should display patient bill of rights
 - d. Health education/prevention brought into schools earlier
4. Cost:
 - a. Though this was seen as one of the largest problems, it was difficult to pinpoint due to the complexities of today's systems.
 - b. Current cost is prohibitive for small employers and therefore a large percentage of Vermonters.
 - c. Growing legal issues and high cost of liability insurance seen as a large part of the cost problem.
5. Process:
 - a. Health care has become a service industry.
 - b. Both patients and providers overwhelmed with paperwork, where can it be streamlined and made more efficient?
 - c. The need to maintain more privacy and confidentiality (especially given the small community environment).

Swanton

(No written report submitted.)

White River Jct.

1. We would like to speak to Vermont Association of Health Care Systems, the Vermont Medical Society, academic institutions, consumers of health care. We need to ask candidates for state offices and the legislature to be explicit about what they will do to change health care systems.
2. Public health education at an early age should be part of the school curriculum. Laura Bush needs to lead the new Public Health curriculum.
3. School should model health behavior and bring this education to families. We should try to impact the critical decision making skills to affect lifestyle choices: target media by reducing media's ability to stimulate unhealthy behaviors by manipulating children's choices, and reduce direct marketing of pharmaceuticals to consumers.
4. Get fresh ideas from younger and newer health care professionals. Stimulate them to think about changes needed to the health care system and the effects on their careers.
5. Community health care centers staffed by Physician Assistants, Nurse Practitioners, and Nurses for primary care services.

Wilmington

1. We want a UNIVERSAL, SINGLE PAYER, PRIMARY HEALTH CARE SYSTEM to be established.
2. We will achieve this through ground level lobbying to our neighbors and friends in terms that can be understood fully by all.
3. We want there to be education for the public about preventative health care, and for our community through public forums.
4. We are embarrassed at the alarmingly high number of Vermonters who do not have health care coverage.

Action Forum held at the Vermont Technical College Old Dorm Conference Room – March 19, 2002:

Approximately 100 participants, facilitators, recorders and invited guests came together in Randolph, the geographic center of Vermont, to share their points from their final sessions, to network, and to identify what common themes they found among their groups.

Several areas emerged as important to the participants: **1) Need to increase citizen participation; 2) The lack of a true health care system; 3) Some basic coverage for everyone; and 4) Prevention services and a focus on health and well-being.** Below are reflections of the ideas and discussions for each of these topics.

CITIZEN PARTICIPATION INCREASED

"Is the goal to engage the public or to pick a goal to advance?"

Citizen participation focused on two areas: having more study circles type meetings around the state where people can become more informed and discuss ideas, and having people work toward specific goals through political action. Some people know already what they'd like to see, and want to work for, while others believe more discussion and education about access to health care is needed.

"When is it time to have a single voice?"

For those who did have specific ideas and solutions to promote, action ideas centered around communicating with legislators, working on political campaigns, forming a citizens' lobby, and sending letters to local health care institutions stating values and concerns

People who wished to see increased public dialogue want a formal, comprehensive process created that gives citizens an ongoing voice. People want to have a say in deciding priorities, examining issues and holding the system accountable. They want an informed dialogue with hard data. Some of the questions they'd like discussed are: What do we wish for in a health care system with no limitations? What don't we like? What are the real costs? What is working in the health care system? Many participants felt the study circles model should be used. They also want to hear candidates discuss the Lewin Report (about the feasibility and cost savings of a single-payer health system) and have them be able to debate it from either side to show they understand the complexities.

"Why engage more people?" "How should we get more people involved?"

Study circle participants believe a greater number of people should be involved because the larger the public voice, the greater the impact on policy and legislation. They want politicians to get their information from citizens, not lobbyists. They agreed with the saying, "A leader is someone who finds a parade and goes to the head of it," and felt it was important to have many citizens in the parade so politicians would want to lead it. Some suggested that a variety of methods be used to get people interested. Though the study circles model was seen as a good one, not everyone wants to come to a structured discussion. Preventing the marginalization of certain voices was important. People felt whatever the methods, a long period of time would be required to promote more in-depth thinking, and to get people connected to one another. In pursuing something over time, however, people still felt the discussions should be focused and time limited. Finally, they wanted a way for all groups interested in access to health care to stay connected in some sort of a collaborative consortium. ***"With greater numbers, we can discover what our shared goals are, and we can shift the balance of power."***

PREVENTION - EMPHASIS ON HEALTH

Create a comprehensive health information system.
Use schools as focal points for health education/info.
Expand public nutrition programs through schools.
Educate public re: healthy lifestyles.
More emphasis on holistic health.

Health Promotion Subgroup:

CREATING & MAINTAINING WELL BEING

Participants in this group discussion focused on actions they could take individually and locally. They suggested the following :

1. Go back to communities and get dialogue started.
2. Go to groups we belong to.
3. Go to places of employment.
4. Go to schools & school boards.
5. Go to Health Department.
6. Involve youth.

Accomplishments they would strive for included:

Dissemination of information to general public. (Healthy Vermonters 2010)
Feedback - longitudinal study (follow up)
Influence fast food places to offer more healthy choices.
Begin good health education at early age.
Offer incentives
Understand diverse belief systems and cultural differences.
Identify target populations and develop messages and approaches specifically for them.
Support groups
Improve quality of school lunches -- get junk food vending machines out of schools
Collection of data on each issue - knowledge, attitude, practice
Local dialogue
Community approach, community run.
Getting involved in environmental improvement issues (individuals & communities)
Support movement for preventive approach and alternative approaches to medical treatment via medical school curricula.
Dialogue about death and quality of life
Education support - durable power of attorney and living will.
Re-education of physicians to address sensitive issues.

LACK OF A SYSTEM - EVERYONE COVERED

Many of the thoughts presented at the action forum referred to the sense that health care currently is not organized in a system. From the different group ideas, the following concepts and questions came together.

Specific features a system might have:

Create a personal health plan for every Vermonter.

Case manager for every person.
Elect a Physician General for state of Vermont.
Set targets and goals for the health care system.
Establish communication access for all Vermonters.
Create a plan to reduce administrative cost.
Set up drop-in centers for non emergency care.
Separate insurance and health care from employment.
Create a single-payer system. (H.54) would establish 3 person panel to design a system.

Questions to answer:

Who is everyone?
What are health services?
What is the system?
Service provided how?
Single payer?
What are Core Services?
Should core services decisions be evidence based, focused on prevention and early life, and the total burden of an illness considered?
Who decides?
What are the criteria?
Rationing -- how are priorities set? Age? Risk?

Information needed:

Priority List - Oregon
Use for selection of service
Primary Care Needs

Standards of care vary.

Processes:

Decisions

Commission

Elective process

Public needs ability to inform the legislature

Next steps:

Small group to determine priority list of core benefits - doctors, public, people with disabilities, cross-section like study circle.
From small group move to legislature, public forums.
Time limit to small group process.

Small Group

Propose highest priority service (2 to 3) to be implemented by legislature within 2 years.

Formally recognized major statewide *study circle project* undertaken, perhaps by the legislature to provide support and visibility

Agree to process before discussion begins

Leadership needed.

Invite candidates for governor into the discussion.

The final exercise in the action forum was to look to the future. People decided what actions made sense for each of them to take on and to share those decisions with someone else in the room. Then they reviewed the various areas people could make a difference -- individual, community, systems and societal levels, and asked them to indicate which areas they were going to work within. All sectors were indicated. Pointed out that it takes all to make changes.

"Just because action starts doesn't mean dialogue should stop."

Discussion and Conclusion

Accomplishing the three goals identified by the Vermont Ethics Network comprehensively across the state is an ambitious project. VEN sought to:

1. *Raise the public consciousness* about the many dimensions and ethical implications involved in access and choice decision-making at the societal level.

Participants delved into the subject matter, had respectful disagreements, and came to appreciate the complexities of and difference of opinions on access to health care issues. Many felt that this project should serve as a beginning and that much more conversation, information and movement is needed for themselves as well as the rest of their fellow Vermonters.

2. Develop a consensus among a broadly diverse and representative group of citizens which will *feed into the development of public policy*.

There were several factors on which many participants were able to reach general agreement. Access to some basic level of care (on which they could not come to a common definition) they accepted almost unanimously. Realizing that access is connected to employment troubled most people. That health care is both a right and a responsibility made sense to just about everyone. Paperwork, bureaucratic processes and difficulty in navigating the system vexed and angered people.

3. Stimulate citizen input and participation to *create initiatives for action at the local and regional level*.

As evidenced by 1) serious conversations that took place in the groups, 2) over one third of the participants taking a full day to attend the action forum, and 3) ten percent (who could not attend the action forum) writing out detailed comments to contribute to it, the project did inspire participants to become more active. In addition to the efforts during the study circles project, several groups decided to meet at least once, and one ongoing, after the formal study circle ended. Several people wrote up their thoughts into essays and formal statements to share with others. During the action forum, quite a few of the participants connected with other organizations to join their efforts. Some participants agreed to stay in touch with each other.

Thematically, addressing issues of **respectful treatment**, providing **opportunities for participation** in ongoing system reform and **developing objectives for basic universal health care** appeared to be what most study circles participants want to see happen.

The challenge for policy makers will be to articulate strategies to help address these thematic concerns. Ongoing dialogues, such as study circles, can help bring people together in nonjudgmental and non-adversarial ways to craft solutions together.

If some form of rationing or limit-setting is required, the public clearly wants a deliberative, participatory role in the process that goes beyond incremental reform or subtle shifts in priorities at the legislative level alone.

If there is no other message readers of this report take, we hope they will come to appreciate and respect how important this type of project is as opposed to scientific surveys that catch people one moment in time, and do not ask them to make educated, deliberative responses, or participate in our democracy. This study circles project helped everyday people examine the health care problem, begin to understand the many aspects of the issue, and find out how they can have a constructive impact on addressing the problems as well as understand the realities, the imperfections, the joys and the incredible power of participatory democracy.

Acknowledgments

The Study Circles Project of the Vermont Ethics Network (VEN) would not have been possible without the commitment and enthusiasm of so many people, including the 142 participants. To them especially we dedicate this report and say thank you!

VEN thanks the volunteer facilitators and recorders who agreed to give of their time and skills for this study circle project. They were a resource and inspiration. Recorders and facilitators are listed in Appendix A.

We thank the many Vermont facilities and organizations which allowed us to use their spaces at little or no charge for our community study circles. All locations are noted in Appendix B.

Our major funding sources were: The Study Circles Fund (a Project of the Topsfield Foundation); the Vermont Community Foundation; the Vermont Health Foundation; the Commission on Public Health Care Values and Priorities (CPHCVP), the Pettus-Crowe Foundation and the Windham Foundation. Additional support for the Action Forum was received from Blue Cross- Blue Shield of Vermont, CIGNA, MVP Health Plan, the CPHCVP and the Vermont Medical Society.

Much appreciation is due the current and former VEN board members involved in the project for their inspiration, participation and support.

Deborah Lisi-Baker, Executive Director of the Vermont Center for Independent Living, Susan Gordon, Executive Director of the Alzheimer's Association, Green Mountain Chapter; Jacqueline Majoros, JD, Long Term Care Ombudsman and member of the CPHCVP, and Richard Davis, Chair, and Eddie Gale, staff, of the CPHCVP all assisted the project in its development and implementation.

A special thank you goes to Sarah Campbell of the Study Circles Resource Center (SCRC) as well as her colleagues, James Wolfe and Michael McCormick. Susan McCormack of Essex Junction, VT, helped plan and facilitate the Action Forum.

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We thank Andrea S. McAuslan, who served as Project Director and collaborated with VEN Executive Director, John Campbell.

Thanks are extended to Jim Mullally, VEN Staff Assistant for his many extra hours of administrative support.

APPENDIX A

FACILITATORS AND RECORDERS

Gloria Alexander
Robert Atherton
Lori Baker
Mary Belenky
Carol Bennett
John Campbell
Michelle Champoux
Lauie Crosby
Erin Dean
Jim Dean
Judy Edwards
Joanne Fedele
Jennifer Fitzgerald
Stuart Fiedman
Eddie Gale
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Arnold Golodetz
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Patrick McKee
Susan McCormack
Peter Myer

Ryan Murphy
Cindy Nease
Floyd Nease
Margaret Miller
Nancy Nye
Eric T. Osgood
Gayle Ottmann
Anne Peyton
Donna Reback
Mel Richardson
Steve Schapiro
Robert Swartz
Maureen Tremblay
Kevin Veller
Maureen Wilson

APPENDIX B

LOCATIONS/FACILITIES

Study Circles

Barre	Aldrich Public Library
Bellows Falls	Parks Place
Bennington	Second Congregational Church
Brandon	Neshobe Family Network and Brandon Public Library
Brattleboro	Brattleboro Senior Center and Brooks Memorial Library
Burlington (fall)	Lake Champlain Chamber of Commerce
Burlington (winter)	Fletcher Free Library
Essex Junction	Essex Jct. Recreation Center
Fairlee	Upper Valley Ambulance (Fire Department)
Irasburg	Office of Robert R. Holland, MD
Montpelier	Vermont Center for Independent Living
Randolph	Clara Martin Center
Rutland (fall)	Rutland Senior Center
Rutland (winter)	Community College of Vermont
Shelburne	Trinity Episcopal Church
Stowe	Stowe Elementary School
Swanton	Abenaki Learning Center
White River Junction	Bugbee Senior Center
Wilmington	Pettee Memorial Library

For planning and other meetings

Berlin	Central Vermont Medical Center
Essex Junction	Village of Essex Junction Offices
Montpelier	University of Vermont
Randolph	Vermont Technical College