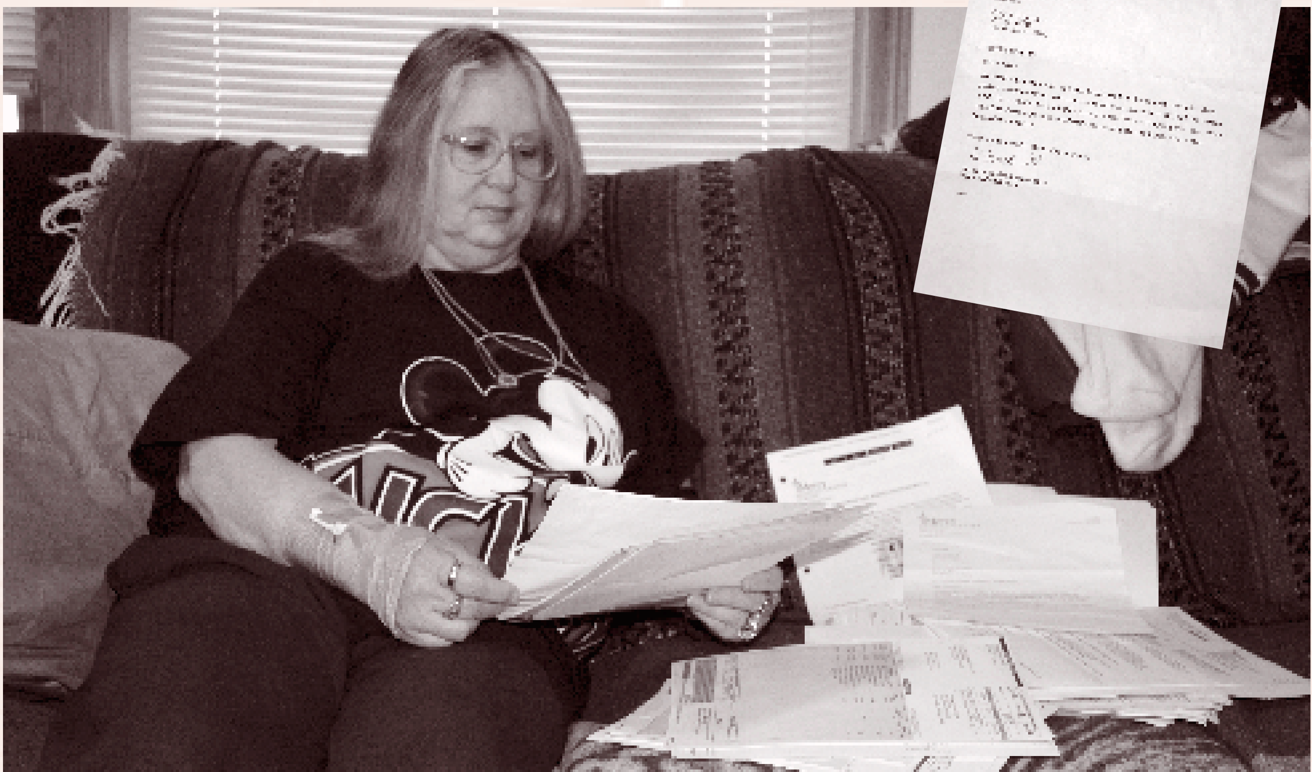
Easing the **Burden** of Medical Debt in Des Moines



Crickett Bozarth feared the bills from a kidney stone operation and infection, but a letter from the hospital told her that she qualified for assistance and owed them nothing. She credits AMOS's campaign.

More than one in three residents of ***Making Connections*** Des Moines neighborhoods struggle with medical debt. But a campaign led by a ***Making Connections*** partner – an organizing group called AMOS – helped thousands of Des Moines residents get free or discounted medical care.

Many worry that organizing is purely confrontational – yet the AMOS campaign showed that dialogue and negotiation are key elements in any successful organizing strategy.

By Kristin Senty

One survey found that more than half of the lower-income Des Moines residents who responded had medical debt.

To test the pulse of the members of its 23 congregations, the Des Moines organizing group known as AMOS — a Mid-Iowa Organizing Strategy — sponsored more than 200 house meetings in the fall of 2004.

One thing that emerged from these meetings was a little unexpected: people kept talking about their struggles with medical debt. In many cases these medical debts had become all-consuming, preventing people from meeting other needs.

At about the same time, a survey of residents of *Making Connections*' neighborhoods in 10 cities also brought attention to the medical debt problem. This "cross-site" survey found that, while medical debt was an important issue in all *Making Connections* sites, it was considerably worse in Des Moines. More than one in three residents of *Making Connections* Des Moines' 15 target neighborhoods had medical debt, a percentage that was more than twice that for residents of the city as a whole. This percentage was 10 points higher than that for the next highest *Making Connections* city.

Another survey, this one involving interviews of people who come to free tax help sites, suggests that the problem could be even worse in Des Moines and in other cities. Conducted by The Access Project, this survey found that more than half the people who responded in Des Moines (55%) had medical debt. Of all the cities surveyed, just over 46% reported medical debt.

This survey research coupled with the concerns expressed during the house meetings sparked a campaign in Des Moines to ease this medical debt crisis.

This campaign — which is continuing — has made impressive strides. In late 2005, Des Moines' two major hospital systems — Mercy Medical and Iowa Health Des Moines — agreed to scale down medical debt to an income-based amount that an individual could realistically pay.

For example, a family of four with a $20,000 medical bill that earns less than $20,000 will owe nothing. If a family with this $20,000 bill earns less than $50,000, they will owe either $4,000 or $2,300, depending on the hospital.

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Two Des Moines-area hospitals have increased the assistance they provide lower-income patients by $3 million each.

The hospitals also committed to making their charity care policies more clear and open. In the past, many patients didn't know they could ask the hospital for assistance, or that nonprofit hospitals were supposed to provide charity care. The Access Project survey found that, nationally, 77% of those who reported medical debt were not offered any form of financial assistance.

Mercy Medical Center also agreed to create a $1 million fund to help patients cover non-hospital expenses for specialists and medicines.

As a result, both Des Moines-area hospital systems report that the assistance they provide lower-income patients has increased by more than $3 million in the first year after they made these commitments. Both systems report that the demand for this assistance was far greater than they anticipated: 70% higher than Mercy had budgeted, for example. These changes made a big difference for several individuals (see page 34).

An editorial in the *Des Moines Register* called these changes "a good first step — a step that should make Iowans proud."

Jim Wallace, a minister who co-chairs the AMOS health-care committee, says it is just one step in addressing the health care crisis. But, he adds, "You have to climb the mountain one step at a time."

AMOS leaders are continuing to climb that mountain, monitoring the hospitals' policies and practices related to medical debt and working to change state and local policies concerning the responsibilities of nonprofit hospitals to provide affordable healthcare.

Mercy Medical Center agreed to create a $1 million fund to help patients cover non-hospital medical expenses.

One of the most interesting aspects of the AMOS campaign was the amount of common ground that was built between the organizers and local nonprofit hospitals.

This publication examines the process AMOS used to achieve these changes at Des Moines hospitals, provides guidance to others who want to organize around medical debt (see page 15) and discusses the implications of AMOS's success for a long-term change initiative like *Making Connections* (see page 28).

AMOS is an interfaith political action organization based in Des Moines. It organizes on issues that have the potential to build community and help its 23 member congregations bridge potential divisions. The organization tackles a number of significant community problems, yet avoids issues such as school prayer or abortion where building consensus is difficult.

The organizing principles and strategies that guide AMOS's work come from the Industrial Areas Foundation (IAF). Established by activist and writer Saul Alinsky, IAF is a nationwide network of mostly faith-based organizing groups.

These groups sometimes use "actions" or media campaigns to achieve change. But one of the most interesting aspects of the AMOS campaign was the amount of common ground that was built between the organizers and local nonprofit hospitals. Both parties were open to hearing each other's frustrations and focused on resolving the issue in an atmosphere of respect. Everyone involved said they came away from the experience with something positive.

AMOS member Rev. Jim Wallace found that active listening was important in succesfully negotiating with Des Moines hospitals.

“A lot of the work of organizing is convincing people that they actually have a story that matters — and everyone has one.”

—Paul Turner

While much can be learned from this experience, AMOS leaders caution that every organizing effort will vary, with many intangible elements. “It came together in the right way,” said AMOS organizer Paul Turner. “Timing, personality and even luck combined to make this happen.”

The power of stories leads to a call to action

In 2004, many personal stories showing the impact of medical debt emerged from AMOS’s 200 house meetings. According to Turner, they served as an important catalyst for direct action. “There’s a power in stories and the chance for pain to be publicly processed,” he said. “A lot of the work of organizing is convincing people that they actually have a story that matters — and everyone has one.”

The house-meeting stories led to a call to action. Several pastors, AMOS lay leaders and key meeting participants formed a team. Their focus was to define and clarify the issue, set a goal and develop a strategy for organizing.

What is Making Connections?

Making Connections is a long-term effort in 10 cities to pull residents and institutions together to improve the lives of families living in specific low-income neighborhoods. Established in 1999, this initiative is supported by the Annie E. Casey Foundation along with many local funders. A statistical profile of *Making Connections* Des Moines’ neighborhoods is on page 18.

AMOS organizer Paul Turner says that there is “a power in stories and the chance for pain to be publicly processed.”

The group spent time researching the issue of medical debt and its connection to poverty. They used statistics and technical assistance from The Access Project, a health research and advocacy organization. They read up on local activity involving area hospitals on the issue of medical debt, and met with local health insurance providers to understand how this industry operates.

The AMOS group discovered that individuals who are uninsured and hospitalized are typically charged the most, while an individual with insurance is provided a sizeable discount for the same services. Said Turner, “People who can afford medical care the

Two-thirds of people with a medical bill or debt problem went without needed care because of the cost — nearly three times the rate of those who don't face medical debt.

MEDICAL DEBT:
A Growing Problem Is Emerging as a National Issue

One consequence of so many Americans not having health insurance — an estimated 46 million in 2005 — is that increasing numbers of people are struggling with medical debt. A 2005 study by the Commonwealth Fund found that around 77 million Americans ages 19 or older struggle to pay medical bills and have accrued medical debt.

All this debt has a big impact on millions of people. Studies from The Access Project, a health research and advocacy organization, show that significant medical debt affects an individual's credit, employment and housing. The Access Project's "Homesick" study found that more than a quarter of the people who reported medical debt had housing problems (27.2%).

Debt psychologically limits a patient's access to needed care because they fear the additional financial burden. The Commonwealth Fund found that two-thirds of people with a medical bill or debt problem went without needed care because of the cost — nearly three times the rate of those who don't face medical debt.

Over the past several years, the issue of medical debt has started to gain national attention. In March 2003, The Connecticut Center for New Economy released a report that showed the nonprofit Yale New Haven Hospital had access to $35 million in free care for uninsured patients — yet instead of informing patients in need, they chose to bill and then collect.

In July 2003, Connecticut passed legislation to require hospitals to cap patient interest rates at 5% and notify patients of charity care options before filing lawsuits to collect debt. Illinois and California followed with similar efforts to protect uninsured patients. By 2006, hospitals in no less than 22 states feel pressure to consider similar reforms.

In September 2006, the Senate Finance Committee held a hearing to focus on the community benefits and free or low-cost care provided by nonprofit hospitals. The hearing came after a long review by Senate Finance Committee staff of charity care provided by nonprofit hospitals.

At the hearing, a legal service attorney from Virginia said that one nonprofit hospital in Norfolk had 100 separate actions to collect debts.

Further attention to this issue came when 40 class action lawsuits were filed against nonprofit hospital systems around the nation. Initiated by Richard Scruggs, the attorney who successfully sued big tobacco companies, the lawsuits clearly have a credible ring.

A few local governments are also challenging local nonprofit hospitals. In October 2006, the state of Illinois ruled in favor of Champaign County removing an Urbana, Ill. hospital's tax-exempt status because of its aggressive attempts to collect money from poor and uninsured patients. That hospital has had to pay more than $5 million in property taxes since 2003.

The Urbana hospital officials contend that government officials are ignoring the community services the hospital provides, such as health fairs, immunizations and disease-prevention programs.

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—Don Aten

The Anatomy of Medical Debt

All Respondents	1,692
Number with Medical Debt	784
Percentage with Medical Debt	46.3
Of Respondents with Medical Debt:	
Health Insurance at time debt acquired	
Yes	41.0 %
No	40.1
Other*	8.9
Type of provider owed	
Hospital	70.3
Doctor	44.3
Clinic	18.7
Lab	19.8
Ambulance	14.9
Dentist	9.4
Pharmacy	4.2
Provider offered financial assistance	
No offer	77.7
Payment plan over time	13.6
Informed of public programs	7.5
Discount on bill	5.5
Help applying for loan	1.3
Amount of debt	
< $500	28.7
$500-< $1,000	21.9
$1,000-< $5,000	33.8
$5,000 +	15.6
How long had debt	
< 1 year	36.4
1 to 2 years	36.4
> 2 but < 5 years	18.7
5 years or more	8.6

*Includes both "Don't Know" and families with both insured and uninsured among family members with medical debt.

From Homesick: How Medical Debt Undermines Housing Security (see page 14).

least pay the most. When hospitals raise their charges for those without insurance, it really traps those with low incomes."

"If insured individuals can receive a 60% to 70% discount on their rate, it doesn't make sense that you are charged the full amount if you're not [insured]," commented Margaret Wright, *Making Connections* Des Moines Site Coordinator. "Individuals who are uninsured should not be subsidizing the government or private insurers."

The group noted that many hospitals were going after individuals with medical debt more aggressively, even though those individuals often have the least ability to pay. "We heard about two hospitals in other states that were really going after medical debt," said Dan Aten, AMOS group chair. "They had gone so far as to put some people in jail for contempt of court after failing to pay court-ordered amounts. It almost seems like they were going back to Dickens' day in England when there was a debtors' prison."

Power recognizes power

With solid research on medical debt and ample stories in hand, the AMOS group approached Des Moines-area hospitals to ask for more specific information on their billing policies for uninsured and low income patients.

In order to approach a powerful and established entity, AMOS leaders felt it was important for the group to demonstrate its credibility. One of the organizing principles developed by Alinsky and the Industrial Areas

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>
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Foundation is the recognition of power as the essential ingredient in social change. Explained Turner, "Power recognizes power, and it comes in two forms — either organized people or organized money."

AMOS had already gained a measure of credibility with the hospitals by lobbying on a shared issue of concern. It had organized a rally of more than 650 leaders at the State Capitol to support an increase in the tobacco tax as a way to fully fund the state's Medicaid budget. This stance helped the hospitals' bottom lines. Said Turner, "We had already demonstrated our power around a vital issue of concern to the hospitals, which ratcheted up our clout quite a bit."

The group's power was also in its people. AMOS congregations represented a broad range of churches and synagogues throughout Des Moines, some with personal ties to area hospital CEOs themselves. Another key connection came through group chair Dan Aten, a retired health clinic administrator. His knowledge of hospital politics, their inner-workings and his relationships with insiders were invaluable in establishing a dialogue.

Aten placed a call to one area hospital requesting a meeting with top CEOs. "They took my phone call because they knew who I was," he said. "They also knew how many congregations we were representing, and the fact that we had 23 was critical…there was a realization that each of these pastors is speaking to a large congregation each week. Our organization was reaching a broad base of people."

Staging the meeting — setting the tone

Building mutual trust and respect was an important part of staging a meeting with each hospital. The hospitals understood that the AMOS group was approaching with a clear objective in mind, and Aten said it was important to show they had no hidden agendas. "Hospitals asked us if they would be blind-sided. We reassured them that our objective was to learn," he said. "We did not want to go to war with them."

AMOS also tried to hear the hospitals' perspective about medical debt and charity care. "There's a lot going on in healthcare right now, and it's understandable that every hospital

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hasn't figured out their best approach for charity care," is how Mercy Medical Center's senior vice president, Joe LeValley, put it. "But even if you believe that hospitals aren't doing a lot, the fact is they're giving away millions of dollars every year in free care."

The importance of including an insider such as Aten in the process was yet again obvious. Said AMOS organizing partner Jim Wallace, pastor of Central Presbyterian Church in Des Moines, "It sure helps when you've got someone who is perceived as a peer."

The AMOS group planned to meet with all area nonprofit hospitals. When meeting with top hospital CEOs in its first round of discussions, the group spent time telling stories from the original house meetings. They also brought along an individual who had been greatly affected by medical debt to share her personal story. Hospital officials listened openly and respectfully — then the group turned and listened to what those officials had to say.

After a thorough airing of perspectives, AMOS asked to see the hospital's financial assistance and charity care billing policies. Turner said many nonprofit hospitals around the country tend to keep such information under wraps. However, the hospitals' CEOs in this case were cooperative.

The group met with other area hospital CEOs, moving through a similar process of telling stories, listening and gathering information. In his own time, Aten read through each hospital's policy and devised a way to compare them side by side on a spread sheet to show how billing policies stack

AMOS member Dan Aten (left), a retired health clinic administrator, used his connections to help establish communication and negotiations with hospital officials, including Mercy Medical's Joe LeValley (right).

"Our role was to remind the hospitals that they were a not-for-profit. I think we really could emphasize the need to help people and be of service to the community. In a sense we were able to reacquaint them with their mission."

—Jim Wallace

This is one of many churches in the *Making Connections* Des Moines neighborhoods. Not all of them are part of AMOS.

up against each other. The result was quite dramatic. Said Turner, "No one had ever taken that information and put it on a single piece of paper. When we sent it back to the CEOs, it got quite a reaction."

Negotiating

The group then shared their findings with the CEOs and told them they planned to make it available to all AMOS congregations. Essentially, the chart showed that area non-profit hospitals had less than charitable practices toward uninsured patients. AMOS turned up the pressure and decided to use this to their advantage.

"We said we would let our member congregations know that if you're sick and you don't have insurance, these are your options," explained Turner. "This got their attention, and they said 'Wait, wait, let's talk.' It was a real point of leverage."

The AMOS group told hospital officials they wanted the same discounts applied to individuals without insurance as those offered to individuals with coverage. Said Aten, "We told them, 'We are your constituency and you are an important asset — we want you working with us.'"

Two nonprofit hospitals involved in the negotiations were church-founded. Wallace said AMOS's faith-based presence at the table played an invaluable role in emphasizing the need for a like-minded institution to show greater compassion. "Our role was to remind the hospitals that they were a not-for-profit," he said. "I think we really could emphasize the need to help people and be of service to the

“AMOS actually helped us to bring focus, and really dig down to explore how we could improve. We were then able to make a commitment to do more.”

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Why Should Nonprofit Hospitals Offer “Charity Care”?

The issue of medical debt has been getting more attention, not just because it affects so many people — 77 million according to a 2005 study — but also because it offers organizers and advocates a potentially powerful “hook.”

Despite the growth of for-profit health care in this country, two thirds of hospitals remain nonprofits. And nonprofit status confers a set of obligations. In exchange for the considerable benefits of being able to receive tax-deductible contributions and not having to pay income or property taxes, nonprofits must clearly benefit the public in some way.

This is very similar to the idea that has been at the core of the three-decade-old movement to force banks to lend money in low-income communities that they once shunned. Banks get huge benefits conferred by the federal government, such as federal deposit insurance.

The difference is that federal laws (the Community Reinvestment Act and the Home Mortgage Disclosure Act) spell out the obligations of banks to lend to all parts of the communities they serve. This has led to “CRA agreements” that have caused tens of billions of dollars to be directed to mortgages and other loans in communities that had once been excluded from this capital under a practice known as “redlining.”

In relation to medical debt and charity care, the law is much less clear. Senate Finance Committee investigators found that a 37-year-old IRS rule implementing the law that requires charity care in exchange for tax-exempt status to be “so vague that nonprofit hospitals have been able to exploit it by offering some free services but often little aid to the poorest people in their communities,” according to *The Washington Post*.

These investigators also found that reporting by hospitals of their charity care is very inconsistent, making it hard to measure whether a particular hospital is fulfilling its obligations. Some simply count all bad debt as charity care. Others count the maximum of what a particular service costs, an amount that insured patients never pay because of the big discounts that insurance companies receive.

In the community reinvestment field, achieving consistent reporting was the goal of the Home Mortgage Disclosure Act, which has been used for decades by organizers and advocates to identify and challenge banks that weren’t meeting their “CRA” obligations.

One result of the vagueness of the charity care requirements is a plethora of lawsuits. Lawyers for the poor have filed federal lawsuits in at least 22 states accusing nonprofit hospitals of failing to meet their tax-exempt obligations to provide care to the poor.

community. In a sense we were able to reacquaint them with their mission.”

Hospital leaders, in turn, said that AMOS helped them to reconnect to their mission of charitable service. “AMOS actually helped us to bring focus, and really dig down to explore how we could improve,” said Joe LeValley, Senior Vice President of Mercy Medical

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—Margaret Wright

Mercy Medical Center's Diane Daspit explains the hospital's financial assistance policies.

Center in Des Moines. "We were then able to make a commitment to do more."

Making Connections' Wright said the AMOS group's expectations pointed to a larger issue that hospital officials could not ignore. "I think it points to partnership at the highest level — for decision makers to do the equitable thing for a community. It's not typical, but if any of us really stop and step back for a minute, we know this type of decision is the right and just thing to do in a community. That's the measure of a good action: that it's the right and just thing to do."

The first area hospital to meet with AMOS agreed to take the request back to their board, which quickly capped the total amount billed to uninsured patients based on their income. Few hospitals around the nation had established discounts for uninsured patients, yet many were aware of the growing national climate of change on the issue of medical debt billing and payment.

AMOS leaders felt the hospital CEOs were able to sense a potential public relations disaster in the making should they not adopt some changes. Rather than apply direct pressure, leaders allowed this possibility to work in their favor naturally, letting hospitals mull the possibilities and make the first move.

Understandable tensions came out during these discussions, yet AMOS leaders said that relations with the hospitals remained overwhelmingly positive. Hospitals perceived a credible threat when they considered that hundreds of parishioners across the city would

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—Joe LeValley

realize the inadequacy of existing charity care policies.

To involve the media at this point was always an option, yet the group chose not to "blind side" the hospitals and stayed with the negotiation process to its conclusion.

"There was a lot of bad press for nonprofit hospitals (in Minnesota) for exhibiting behavior that was really not charitable," said Turner. "We could have contacted the press, but it was clear that we did not want to do that when we were in the middle of negotiations. We wanted to pursue a relationship with the hospitals to convince them that we had something of value to offer on the question of accessibility and affordability."

Said Aten, "We were torn when it came to the question of publicity at this point. We wanted it, but we didn't want to embarrass the hospitals when we thought we were making progress."

LeValley said the diplomatic approach paid off. "It helped that they approached us as a colleague, and not as an enemy or opponent.... My advice to anyone working on this issue is to approach the hospitals as nonprofits with a common message to work together," he said.

Turner said that one victory provided leverage to persuade other hospitals to adapt similar policies. "The hospitals are very competitive with each other, which worked in our favor. Once we got one to say yes, it would have been awfully hard for the others to say no."

Going Public

All area nonprofit hospitals agreed to modify their existing charity care policies to make charges more affordable for individuals lacking insurance. "Once they knew there was a watchdog group, the hospitals themselves actually came up with a better policy than what we had even expected," observed Dan Aten, chair of AMOS's Medical Debt group.

AMOS then contacted local press with the decisions that area hospitals had made. A front-page story in a state-wide newspaper, the *Des Moines Register*, opened the issue to the public at a point of resolution rather than conflict.

AMOS organizing member Tim Diebel, a pastor at first Christian Church in Des Moines, said that conducting negotiations privately helped the process work in everyone's favor. "The hospitals got some great PR and came away with the ability to say that they're making a positive contribution," he said. "They had a sense of pride in doing good."

"This is an equity and justice issue that the community has addressed, and I applaud the hospitals for balancing things out for the uninsured," said *Making Connections*' Wright. "It's significant because it evens the playing field for people. That's significant just from a pocketbook standpoint for households in the *Making Connections* neighborhoods."

Turner said he understands that hospitals will lose money by offering charity care discounts. "But at least they won't be chasing as much bad debt," he said.

“We want to hear the hospitals’ stories about people utilizing their policies. We know that knowledge of these policies has not been widely disseminated.”

—Pastor Tim Diebel

“Of course, hospitals that commit to do more will spend more money,” said LeValley. “However, as not-for-profit organizations, and as faith-based health care providers, we cannot and do not shy away from making these investments. Meeting people’s needs is why we exist.”

The Ongoing Work

Despite all the concessions made, nearly a year later the AMOS group is following up with hospital CEOs to track their progress on these changes. Pastor Diebel said that superficial reports from parishioners who had contact with hospitals for their own care have shown only modest improvements. “We want to hear the hospitals’ stories about people utilizing their policies,” he said. “We know that knowledge of these policies has not been widely disseminated.”

Pastor Diebel said AMOS is also monitoring Mercy Medical’s $1 million endowment fund to help patients cover non-hospital expenses for specialists and medicines. “We know this information is printed in a brochure, but we want to really hear it from their mouths that patients are learning about this easily,” he said.

Aten said that some AMOS group members visited various hospitals and satellite clinics asking staff members to provide information on charity care. “Access to that information was mixed. Most people we asked didn’t know what we were talking about or who we could talk to,” he said. As a result, the AMOS group will ask hospital CEOs to formally educate staff to ensure patients get the information they need.

Diebel said the AMOS group is planning to push hospitals to extend these policies statewide to other hospitals within their network. They also plan to approach individual doctors to offer similar discounts to patients who need them.

Pastor Wallace explained how important it is to continue to push for system change. “We’ve got to get it ingrained in the system. If it doesn’t get down to the person who works in the cubicle, it’s lost. Now we’re having conversations to see how we can make sure that the hospitals really to stick to it.”

Resources:

- **The Affordability Crisis in US Health Care: Findings from the Commonwealth Fund Biennial Health Insurance Survey**, Sara R. Collins, Ph.D., Michelle M. Doty, *http://www.cmwf.org/Publications*.
- **The Hospital Billing and Collections Flap: It's Not Over Yet**, by Carol Pryor, The Access Project, (30 p., ©2005).
- **Homesick: How Medical Debt Undermines Housing Security**, by Robert Seifert, The Access Project, November 2005.
- **Seeing Red: Americans Driven into Debt by Medical Bills: Results from a National Survey**, Michelle M. Doty et al., *www.cmwf.org/usr_doc/837_Doty_seeing_red_medical_debt.pdf*

“Stories enabled us to move from a topic to something that affects real people.”

—Pastor Tim Diebel

A Tool-Kit for Organizing Around Medical Debt

The people involved in AMOS's successful campaign around medical debt learned a lot from the experience. Many also have learned from other organizing campaigns. This “Tool-Kit” communicates some of what they've learned.

Gathering Stories

Stories have an immediate power to connect one person to another. They create an intimacy for the listener and open a door for understanding a problem.

Stories are also an important part of an effective organizing strategy because they connect a larger issue to very real situations, making them less abstract. They help bring an issue down to a personal level, where the potential for empathy can bring about meaningful action. “Stories enabled us to move from a topic to something that affects real people,” explained Pastor Tim Diebel.

How do you cultivate useful stories for organizing? Opening a public dialogue, as in the case of AMOS, is an effective way to identify stories as well as passionate participants who can be useful to your organizing effort. Public feedback can also help you gain clarity and vision on an issue. Churches and civic organizations are often ready-made sources that you can tap into for assistance in facilitating these dialogues.

Organizations that specialize in facilitating public dialogues have useful tools. The National Issues Forums and Study Circles Resource Center are two such national organizations. Some of these organizations develop guides and materials specifically designed to explore issues like medical debt.

Pastor Tim Diebel says that, if new financial aid policies “don't get down to the person who works in the cubicle, it's lost.”

Recording allows you to capture the details of a person's story, details that can make the story real to someone hearing it. Recording can also capture the compelling way that people often tell their own stories.

Recording public conversations (through notes or audio/visual tape) can be valuable. Recording allows you to capture the details of a person's story, details that can make the story real to someone hearing it. Recording can capture the compelling way that people often tell their own stories. They can also help identify individuals who have a good story that could be used in negotiations.

An example of an effective personal story: Caryn and her grandson Max

To look at 6-year-old Max, Caryn said most people would regard her grandson as a normal little boy. However, his developmental delays in eating, walking and speech require ongoing medical care to help him grow in the best possible way.

Max's parents were self-employed and could obtain health coverage, yet insurers would not cover their son because they considered his issues a preexisting condition. Paying for his care directly out of pocket, Max's parents have taken on enormous debt, live in substandard housing and navigate a maze of bureaucracy to gain only a small amount of assistance through Medicaid.

After participating in the AMOS house meetings, Caryn realized there were many families from diverse socio-economic backgrounds who struggle with the same kinds of problems as her children and grandson.

"Everyone would be insured if I could wave a magic wand," she said. "Especially children who don't have as much natural family support as Max."

Individuals with a strong story can be some of your most effective organizing allies. They often have the passion needed to see a problem through to its resolution because they have been so deeply affected. To uncover stories:

- **Engage churches and civic organizations** that have the experience, critical mass and the desire to host a public forum.
- **Use materials and technical support from organizations that have expertise with facilitation** to deepen and refine the conversation. Look to organizations like the Study Circles Resource Center (*www.studycircles.org*) or the National Issues Forums (*www.nifi.org*) for such resources. The Study Circles website has a book that lays out the process it uses to develop community-wide dialogue about issues, which can be downloaded for free: *http://www.studycircles.org//en/Resource.39.aspx*
- **Record conversations for later use**. Inform participants and gain permission in the event that an audio or audio-video recording would be used at a later date.
- **Look for individuals who can tell compelling, realistic stories in a practical context that helps illustrate the overall problem within the system**. Something to the effect of, "This is what happened to me. I wouldn't want this to happen to anyone else, so now how can we solve the problem?"
- **When you get to the negotiation stage, include individuals with personal sto-**

"AMOS's success around medical debt reinforces the idea that an organizing strategy has tremendous potential to achieve results that will change people's lives."

—Ira Barbell

ries. Select individuals with a passion for the issue and the ability to stay the course through uncertain and complicated negotiations. "Opt for people who have the ability for the passionate, stronger tell," advised Pastor Diebel.

Organizing

Some people get involved in organizing because they've been let down by the system and they're fed up. While passion about an unfair situation can provide good energy for getting started, it isn't nearly enough to get this situation changed.

On its surface, organizing can seem pretty simple. Pull some people together who care about a certain issue, reach agreement on what's needed, then push government or business to respond to this need. But organizing has a long history, during which a lot has been learned about how to engage people and bring about change. Within community organizing, there are several "networks" of organizing groups, each with its own history and approaches.

One of the first people to take the principles of union organizing and apply them to bringing about community change was Saul Alinsky, who began the Industrial Areas Foundation in a community near the Chicago stock yards. His book, Rules for Radicals, is the best known guide to organizing. The Industrial Areas Foundation continues to provide support and technical assistance for organizing efforts throughout the world. For more information go to *www.IndustrialAreasFoundation.org*.

Mercy Meidical Center's new financial aid policies have been summarized in a brochure.

Most cities have an infrastructure of organizing groups, though many are quite small because they struggle for resources. Connecting with one or more of these local groups can be a critical step. Some of the most impressive results in the *Making Connections* initiative, according to Casey Foundation staff person Ira Barbell, have involved situations where the local *Making Connections* initiative teamed up with a local organizing group. Barbell says that AMOS's success around medical debt reinforces the idea that "an organizing strategy has tremendous potential to achieve results that will change people's lives" (see page 28).

Not only is there much to learn about organizing, there is also a tremendous amount to learn about medical debt, which is one part of the complex system of health care that has evolved in this country.

To learn enough to talk competently about a particular issue is one level of knowledge; to negotiate with experts is something altogether different. Individuals who are committed to organizing on this or any other complex issue must develop the kind of knowledge that can

A Statistical Portrait of
Making Connections Des Moines' Neighbo

M*aking Connections* focuses on a 15-neighborhood area that stretches from the west central part of the city to the east side of Des Moines. Together these neighborhoods have a population of 32,000. Des Moines' population is nearly 200,000 while Polk County, which includes several fast-growing suburbs, has about 375,000 residents.

Facts about these neighborhoods come from a report prepared in 2003 by Making Connections' Neighborhood Learning Partnership and the Neighborhood Information Service.

Nearly two thirds of all children in the *Making Connections* neighborhoods of Des Moines are non-white or Hispanic, compared to one third within the Greater Des Moines area. Races represented include African American, Asian, Hispanic, Native American and multi-racial. In recent years, African refugees from Sudan, Somalia, Nigeria and Liberia have broadened this diverse racial and ethnic mix.

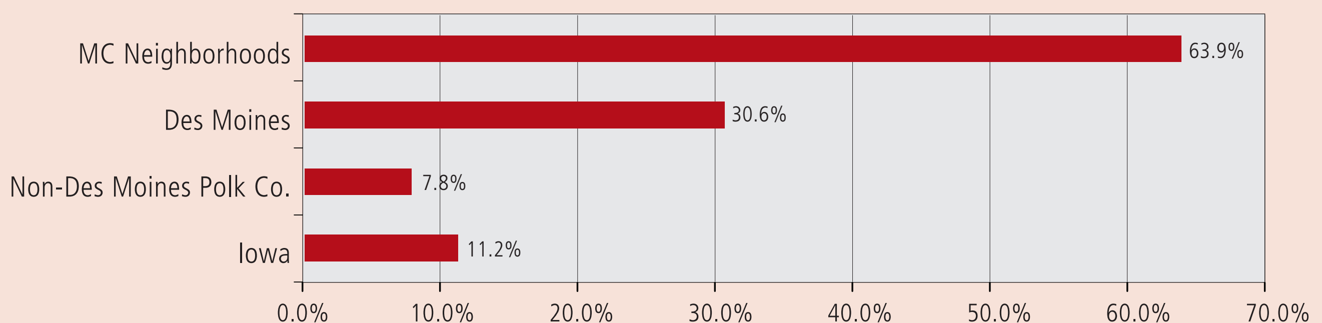
Children make up a large portion of the residents in the *Making Connections* neighborhoods of Des Moines. At 30%, there are higher concentrations of children here than in any other part of the Greater Des Moines area.

rhoods

The entire Greater Des Moines area has grown in diversity in recent years. This diversity is concentrated in the *Making Connections* neighborhoods, where the number of persons of color has increased the most. They are the most diverse neighborhoods in the Greater Des Moines area and indeed in the entire state.

These neighborhoods are also the poorest areas, with three times more families living below the poverty level than in the county as a whole. Their rates of FIP (TANF) participation, adolescent parenting, individuals on probation or parole, and infant mortality are also higher than for the county as a whole.

Percentage of Child Population Either Non-White or of Hispanic Origin



"Throughout this process, I really feel we became experts who gained the ground to have the conversation. The value of doing that was priceless."

—Pastor Tim Diebel

Pastor Jim Wallace says, "You've got to know your stuff. There's no time for stumbling around."

withstand the pressures of an individual or entity with potentially a great deal to lose.

"You've got to know your stuff," said Pastor Jim Wallace. "Hospital CEOs are a highly paid and trained group of people. If they offer you 45 minutes of their time, you've got to get in there and say what you need to say efficiently and quickly. There's no time for stumbling around." Hospitals also can call on national associations that focus on issues such as medical debt and charity care. These trade groups can be very effective in helping hospitals respond to efforts to change their policies.

The only way to build enough knowledge to confidently interact with experts like these is to spend time studying the issue inside and out. "Throughout this process," reflects Pastor Diebel, "I really feel we became experts who gained the ground to have the conversation. The value of doing that was priceless."

To gain a strong overview of the subject of medical debt look to organizations like The Access Project (*www.accessproject.org*) or the Hospital Accountability Project, which is part of the Service Employees Union (*www.seiu.org*). These organizations have taken on the issue of medical debt and have statistics, resources, case studies and even technical assistance to offer.

Just as important, understand an issue like this one in your own backyard. As you research things locally, find answers to these questions:

- What recent issues related to medical debt and hospital collections policies have shown up in your local press?
- Which hospitals are for-profit and which are public or operating as a 501(c)(3) charity? A nonprofit hospital is required to have a policy for providing charity care (see page 11).
- What are the collections policies and practices of your local hospitals? Is there evidence that certain hospitals go after debt collections more aggressively than others? Consider replicating The Access Project's survey of people who came to a local, no-cost tax service operated by Volunteers In Tax Assistance (VITA). These surveys dramatically illustrated how big a problem medical debt is locally and documented the small number of people with medical debt who were told about financial assistance.

AMOS spent two full years building a power base and establishing a citywide network of congregations before they made a decision to concentrate their resources on the issue of medical debt.

- Where does medical debt stack up against other types of debt locally, and what are the consequences and implications for people in your community?
- Have any local hospitals faced financial difficulties?

Because medical debt is but one symptom of the crisis affecting this country's health care system, it's important to also develop an understanding of the entire medical industry. Learn about medical insurance. Gain a perspective on the pressures and financial challenges hospitals face.

Nationally, the medical debt and charity care issues are on the radar screen of hospitals that operate as charities (see page 6). With some of their own energy already invested, these hospitals may be at a positive tipping point for change in the face of a solid, educated appeal.

Building a power base

The primary purpose of organizing is to build a power base. An organized body of people is an important show of strength, which translates into citizens who are well informed, connected and tactically able to influence.

In the case of AMOS, two full years were spent building a power base and establishing a citywide network of congregations before they made a decision to concentrate their resources on the issue of medical debt. Interestingly, this base did not come together with the intent to attack this specific issue. Instead, the issue of debt became an obvious focus for AMOS. This shows the importance of developing issues based on what residents are experiencing and what they care about.

In developing a base, AMOS's leaders suggest several steps:

- **Find out if a local entity exists that could serve as a natural base of support for organizing on the issue of medical debt?** If so, what is their potential reach and influence? Consider utilizing faith-based institutions, especially on issues that involve questions of justice and equity.
- **Inventory your own connections to power**. As the saying goes, there are generally only six degrees of separation from one person to another. Inventory your own connections and develop a detailed list of individuals and organizations that you're connected to. Seek to include individuals who can add to your forward momentum.
- **Try to include insiders within the medical field who have connections to people with power and are sympathetic to your issues**. Enlisting their assistance may open the doors and start conversations. Mercy Hospital Senior VP Joe LeValley responded positively to the AMOS group's members. He advises: "Select the leadership within your group carefully. Choose non-confrontational individuals who can articulate well with the media and with doctors. Choose people who are open, collaborative and energetic."

But keep in mind that AMOS's experience with its local hospitals will not mirror

"There were confrontations and tensions through the whole process. There's no way to get away from that."

—Paul Turner

other groups' experiences with their hospitals. They may resist negotiations that will lead to significant policy changes. Many organizers would argue that public confrontations with hospitals may be needed. Even the AMOS story had "confrontations and tensions through the whole process," said organizer Paul Turner. "There's no way to get away from that."

- **Find out if you and the hospital share issues in common**. While tensions may be inevitable, the AMOS experience suggests that there may be opportunities to ease those tensions by finding common issues. AMOS had an opportunity to assist the hospitals with a mutual issue prior to organizing. While this kind of mutuality would be hard to premeditate, check to see if there is a history of shared support for an issue — any common ground always works in your favor.
- **Work to build a team that has the right elements needed to make organizing a success** — above all, seek out individuals who embody ethical principles above ego and personality.

Making Your Case

AMOS didn't have to take the issue of medical debt public before it completed negotiations with the hospitals. But this will often not be the case. You may need to clearly make a case publicly that medical debt is an important issue to many local people and that local nonprofit hospitals have an obligation to change their policies about medical debt.

Working with The Access Project allowed AMOS to develop local data about the extent of the medical debt problem in Des Moines. It also helped them understand how medical debt can have a broad impact on a family, keeping some from decent housing and causing others to put off needed healthcare. Getting this kind of data can be very useful.

There are many resources that can help you make a strong argument that local nonprofit hospitals have an obligation to provide assistance to people who need it. The article on page 11 lays out at least part of this argument.

The debate about medical debt may hinge on how well local hospitals inform patients of the possibility of financial aid. This continues to be a concern in Des Moines. Once again, it may be critical to gather information that can clearly make the case that your hospitals aren't doing enough to get the word out about their charity care policies.

In Virginia, for example, a team of legal aid attorneys conducted a survey of 20 hospitals across the state regarding charity care. They found that these attorneys could not get even basic information from many of these hospitals. "In almost every instance, it took repeated phone calls to contact anyone who could offer us any information," stated the director of one Legal Aid office, Raymond Hartz, in testimony to Congress. "Lawyers on our staff found the experience very frustrating. Imagine what they might be feeling if they had a devastating debt motivating this search."

Clear expression can also be critical in the negotiating stage. Dan Aten's spreadsheet

"Lawyers on our staff found the experience [of searching for hospitals' charity care policies] very frustrating. Imagine what they might be feeling if they had a devastating debt motivating this search."

—Raymond Hartz

comparing billing policies of Des Moines-area nonprofit hospitals was an invaluable tool for AMOS. Any group organizing around this issue can request this same information, find someone competent to interpret it correctly, and then find a way to communicate it visually. Aten's spreadsheet compared the hospitals policies in 21 ways. These included:

- Whether an application for financial assistance was required.
- Whether there was a residency requirement.
- Who qualifies for 100% assistance.
- How much assistance people at various income levels could receive.
- If there was a cap on how much patients could be charged in a year as a percentage of their income.
- Whether the value of a person's home would be taken into account.
- Whether there was a discount for paying cash.
- What happens to people who don't or can't pay their bills.

Negotiating

You've studied the subject matter, built a base, developed connections and are prepared to negotiate. The AMOS experience shows that the negotiation process can be done fairly amicably, in an atmosphere of mutual respect, with the goal that every party will gain something.

Negotiations don't always work out this way. In another *Making Connections* city that

To help engage residents around issues they care about such as medical debt, *Making Connections* employs three resident organizers, all of whom have been trained by an AMOS organizer. Here, resident organizer Dora Sedeno (right) talks with neighbors.

“A not-for-profit hospital has thought about these issues forever. Many of us are currently talking about what we can do to better fulfill our charitable obligations.”

—Joe LeValley

was working on a different issue, negotiations came close to breaking off several times. The organizing group felt that the other negotiators were stringing them along at times. Many of the others felt that the organizing group was often intransigent, bringing an attitude that they represented “the people” and thus they should have a special place at the table. Indeed, one of the key roles that this other *Making Connections* site played in this story was keeping everyone at the table long enough to do a deal.

This transition from agitating outsider to negotiating party can be tricky. AMOS’s experience demonstrates the possibility of a relatively smooth negotiation that respected all parties involved.

It helped a lot that the hospitals were open to negotiating. “When AMOS asked us to meet, it never occurred to us not to — it was a perfect fit for what we had been talking about all along,” said Joe LeValley, Mercy Medical Center Senior Vice President.

He thinks many hospitals across the country are similarly open to negotiating. “People need to understand that a not-for-profit hospital has thought about these issues forever. Many of us are currently talking about what we can do to better fulfill our charitable obligations.”

To help insure that these negotiations go well, the AMOS group has several suggestions:

- **Get very clear on the issue you are meeting about and what your ultimate goal or objective is**. Streamline this down to a clear and simple statement that you

Mercy Medical Center’s Joe LeValley said that, “When AMOS asked us to meet, it never occurred to us not to.”

can say confidently without a lot of additional explanation. Simple language helps to maintain everyone’s attention and focus on the issue. Unnecessary wording, gratuitous apologies and explanations can sap energy and give you less credibility.

- **While it is not always possible, try to meet only with top decisionmakers**. Interacting with middle managers may keep you away from those who have the power to make decisions. Use any connections you have to leverage these meetings.
- **Include individuals with a solid story to tell who can communicate their difficulties with facts and a sense of passion**. While an emotional component to these stories is important for creating a personal connection to the issue, too much of it without

"The hospitals are very competitive with each other, which worked in our favor. Once we got one to say yes, it would have been awfully hard for the others to say no."

—Paul Turner

a focus on the facts can leave your audience feeling coerced and less receptive.

- **Listen. Hospitals have their own side of the story to tell**. If you've done your homework right, you should already understand the stresses and frustrations they're facing. Time at the table actively listening to their perspective builds an atmosphere of respect. Show affirmation and understanding for what you hear. Listen in the same way that you would want others to hear you.
- **Ask hospital CEOs some tough questions**. Dan Aten's inside expertise as a former clinic administrator helped guide the AMOS group in their preliminary questioning of hospital CEOs. He suggests you ask the following:
  - ***Ask for a copy of a hospital's existing charitable care policy***. These policies are typically lengthy and will require someone with expertise to interpret them. If a hospital presses you on why you want this information, tell them you want to understand it. If they're hesitant to provide you with a copy, ask them why a charity care policy exists if they're not going to educate people about it.
  - ***Ask to see a public posting of the charity care policy that a hospital currently offers***. Aten said that nonprofit hospitals around the nation are required by the Joint Commission on the Accreditation of Hospitals to inform patients in writing that charity care is available. Ask to see where that information is posted and whether it's in a brochure or on a poster.
  - ***Ask hospitals how much charity care they provided last year***. If a hospital indicates that they are giving away so much that they can't afford more, ask them how they define charity care. Sometimes hospitals will include the amount of unpaid debt they simply wrote off. If these two figures are lumped together, it may inflate how much charity care the hospital is actually giving out.
  - ***Ask hospitals the percentage discount they offer to insured patients for individual services***. Follow up with a request that the hospital consider a similar discount for an individual who is uninsured.
- **Don't get tricky**. Express your expectations openly and follow through with what you say. For example, if you go into your first meeting asking for access to the hospital's charity care policies in order to compare them to the policies of other hospitals, then do that. Don't suddenly run off and leak the information to the press. If you've established a respectful dialogue, work within those parameters.
- **If and when you're ready to make a threat, make it a credible one**. AMOS came up with a dramatic way to present hospital charity care policies on paper, showing these institutions were not quite so charitable. They also had a large and influential audience of religious congregations to share this information with. Bottom line: mix information with audience, and you've got a recipe for a negative public image that any hospital will want to avoid.
- **Use one victory to leverage another**. Aten said that hospitals are naturally competitive with one another. If one agrees to adopt more generous charity care policies, use their willingness to influence others.

Monitoring is a critical step that often isn't accomplished. A written agreement, even a change in policy, is only as good as its implementation.

Several state governments have become involved in the charity care issue. This is the Iowa State Capitol Building in Des Moines.

Changing roles — Negotiator to Watchdog

If and when you do gain a victory, realize that the real work of change has only just begun. Words and commitments are one stage in the process, but actions that match those words mean that your organizing has transformed words into reality.

Hopefully, hospitals will actively move ahead on their own to implement agreed-upon charity care policies. It's realistic to assume that these new policies will take some time to saturate into a hospital's culture. To make sure this happens, it's wise to shift your efforts from being a negotiator to a watchdog, monitoring hospitals for compliance and educating the public on their right to seek affordable care.

This is a critical step that often isn't accomplished. There is great energy at the beginning of a campaign, energy that often carries the campaign to success, but then people's energy wanes as they get back to their lives or move on to the next campaign. A written agreement, even a change in policy, is only as good as its implementation. If a hospital agrees to make its charity care policy more public but then does nothing to change how front-line staff interact with patients, the agreement can become meaningless.

The idea is to leverage your initial victory so that it becomes a standard way of operating throughout the entire medical industry.

- **Work actively with hospitals to develop a strategy for educating patients on their options for affordable care**. Approach this in the same constructive way you approached organizing, working to solve the problem with the desire to help individuals in need.
- **Suggest campaigns for public education and outreach**. Collaborate on developing simple materials in various languages that will educate patients about their options. Encourage hospitals to provide information from their first point of contact to every level of care so patients know their options.
- **Monitor hospitals for effective education**. Make periodic checks to see if policies are open and available. If you have worked with a larger body such as a church congregation, poll members to find out what kind of information they're receiving when they go to the hospital.
- **Make your own independent effort to educate the public about their right to affordable care**. Utilize the media as one method for getting the word out. Create your own set of public education materials. Distribute these materials through social service agencies, churches and other charitable institutions. Develop public service announcements.
- **Seek ways to influence other health care providers**. Individual doctors, clinics, testing services and satellite hospitals should adopt similar discounts. The idea is to leverage your initial victory so that it becomes a standard way of operating throughout the entire medical industry.
- **Consider policy-making opportunities**. Contact state legislators and congressmen to find out who shares a supporting view on the issue. Begin a dialogue with the goal to affect policies so that more hospitals are required to do more for the medically needy.
- **Seek to empower as many individuals as possible with this new information**.

The AHA's Prescription for Hospitals

In 2003, The American Hospital Association issued the following recommendations as hospitals nationwide faced mounting criticism for their debt collection practices.

- Make charges for services public and available.
- Review current charges to ensure that they are "reasonably related to both the cost of the service and the community's health care needs."
- Provide financial counseling to patients on how to pay hospital bills.
- Have understandable written policies to help patients determine if they qualify for public assistance or hospital-based assistance programs.
- Consistently apply policies for assisting low-income patients, and share them with appropriate community health and human services agencies and other organizations.
- Educate hospital staff about these policies.

"Making Connections' research was really, really helpful. Just having access to data that shows that Des Moines has some of the highest levels of medical debt was a big, juicy piece of information that was critical in approaching the hospitals."

—Paul Turner

What Can Other Community Change Efforts Learn from Des Moines' Success on Medical Debt?

"What this story reinforces is that an organizing strategy has tremendous potential to achieve results that will change people's lives. There are now literally millions of dollars in people's pockets that previously would not have been there."

—Ira Barbell, Site Team Leader, *Making Connections* Des Moines

Ira Barbell of the Annie E. Casey Foundation was the "Site Team Leader" for Des Moines *Making Connections* for more than six years. Before coming to the foundation, Barbell directed South Carolina's child, family and adult services agency.

From the perspective of a long-term community change initiative like *Making Connections*, Des Moines' medical debt story is quite interesting on many levels.

The organizing on this issue was led by AMOS, a congregation-based organizing group that is working more and more closely with *Making Connections* Des Moines. *Making Connections* is a long-term effort in 10 cities to pull residents and institutions together to improve the lives of families living in specific low-income neighborhoods.

Making Connections provided a small grant to support AMOS, though not specifically its work on medical debt. *Making Connections* also paid AMOS for some of the time of organizer Paul Turner so that he could train *Making Connections*' own resident organizers and help them move into the community.

AMOS's focus on medical debt emerged from the more than 200 house meetings it held in 2004. But it was also influenced by a *Making Connections* "cross-site" survey that found that medical debt is a particular

"With the survey, you got data straight from residents about the issues they were handling. Both sets of information [the survey and AMOS's house meetings] complemented each other."

—Margaret Wright

problem in Des Moines' target neighborhoods. More than one in three residents of these neighborhoods reported having medical debt.

AMOS's Turner says that this research "was really, really helpful. Just having access to data that shows that Des Moines has some of the highest levels of medical debt was a big, juicy piece of information that was critical in approaching the hospitals."

"*Making Connections* offered us some useful assets that we could draw on" in addition to its research, Turner adds, such as "the relationships and partnerships *Making Connections* formed with community-based health organizations."

For Ira Barbell, *Making Connections* Des Moines' long-time Site Team Leader, the fact that *Making Connections* survey data became useful in a campaign like this one demonstrates a core MC principle: that data is critical in transforming a neighborhood and the lives of its residents. Barbell believes the medical debt story "shows how survey data can surface something that we didn't know was going on when we reached out and started talking to families."

"With the survey, you got data straight from residents about the issues they were handling," noted Margaret Wright, *Making Connections* Des Moines' Site Coordinator. "Both sets of information [the survey and the concerns expressed during AMOS's house meetings] complemented each other. They came together to move the AMOS initiative forward, which is a prime example of how *Making Connections* can support work already taking place in the community."

Barbell also thinks this story demonstrates that a key *Making Connections'* role is to help initiate and then support efforts led by others. "To me this is a great sign that there are organizations that have an alignment with *Making Connections*' priorities, organizations that have the capacity and willingness to act on these issues and that aren't necessarily looking to *Making Connections* to lead them.

"It's a great sign that the principles, values and ideas of *Making Connections* have permeated other organizations."

A demonstration of the power of organizing to help achieve measurable results

Barbell sees another critically important lesson in the medical debt story, which is the key role that organizing can play in helping an initiative like *Making Connections* achieve the kind of concrete results it wants.

"We have had examples in Des Moines of success around organizing strategies," Barbell says. One is the work that Citizens for Community Improvement did to stop predatory lending practices in Des Moines [see "Stopping Predatory Lending" on www.DiaristProject.org].

"This AMOS story reinforces this idea. They were successful in engaging the hospitals. There was never a demonstration, picketing or anything. It showed the power of consumers,

"This is a great sign that there are organizations that have an alignment with Making Connections' priorities, organizations that have the capacity and willingness to act on these issues."

—Ira Barbell

AMOS's medical debt group included Don Aten, a retired health care administrator, along with several leaders and members of AMOS's 23 congregations.

residents and the community to remedy something unfair that was hindering low-income families' ability to succeed.

"What this reinforces is that an organizing strategy has tremendous potential to achieve results that will change people's lives. It is literally millions of dollars that are back in people's pockets that previously wouldn't have been there."

Despite this clear success, organizing strategies still are not widely embraced by *Making Connections* or most other community change initiatives, Barbell says.

"My frustration is that we have not been able to capture this experience. We haven't been able to communicate that an investment in an organizing strategy can produce tangible, concrete results for families without threatening the community's institutional infrastructure."

Despite *Making Connections*' strong commitment to engage residents of its target neighborhoods, Barbell thinks that one of this initiative's biggest challenges nationally is the reluctance of its institutional partners to fund community organizing as a core strategy to engage these residents and achieve results.

"My frustration is that we haven't been able to communicate that an investment in an organizing strategy can produce tangible, concrete results for families without threatening the community's institutional infrastructure."

—Ira Barbell

"If we had created a health program that had the same impact on people's lives as this organizing strategy has had, we would have had all of these institutional partners funding it. But if we had gone to them and said, 'Look, we want to raise $100,000 to fund this organizing strategy to moderate the health care system's policies to improve families' financial stability and help them access the health care system, I don't think we would have gotten a dime out of any of them.

"I am convinced that there are other issues where we can apply this strategy. We want resident capacity, but resident capacity for what? What residents want are changes in their lives that impact what's happening to them on a daily basis. We need to be able to say to residents, 'Look, here are tangible examples of where the community has come together and brought about changes that improve the quality of life for children and families in Des Moines. You too have the capacity to bring about change in the things that impact your lives.'"

Barbell thinks that *Making Connections* should also be able to "have a conversation with our institutional partners as well" about how an organizing strategy can help them achieve results around whatever set of issues they care the most about.

Barbell acknowledges that many institutional partners worry about being a target of the organizing around a particular issue. "I think there is some anxiety at the institutional level that we need to understand. We need to peel this away and give people like Paul [Turner, an AMOS organizer] a chance to lift this up."

In Denver, for example, *Making Connections*' organizing partners trained its other partners in the history, principles and varying strategies of community organizing. Some of *Making Connections*' institutional partners talked about the positive experiences they had had working with organizers, who had helped them achieve much greater and more informed participation in their mandated community meetings, for example.

Barbell believes that the main point that needs to be communicated is that organizing can be "a powerful tool that can produce substantive results if we are serious about engaging families and communities to bring about change."

The unease with organizing strategies extends to national foundations as well, Barbell adds. "I don't know why organizing hasn't become as mainstream as some of the human service programs that we fund on a regular basis. We have a lot of programs we fund that are lurking around the margins and not dealing substantively with the major changes that families want.

"Maybe that is the issue — organizing has become driven by families and individuals and not by the funders and institutional partners. So they feel less certain about where this is going to end up. This is a very different way of doing business with a community."

"I don't know why organizing hasn't become as mainstream as some of the human service programs that we fund. We have a lot of programs we fund that are lurking around the margins and not dealing substantively with the major changes that families want."

—Ira Barbell

Barbell keeps coming back to the idea that, "We need to capture the success we have had in getting substantive changes for families." If people saw these concrete results on important issues, he thinks they would eventually be insisting, "If it's a big issue like jobs and people are disconnected from the workforce, wouldn't an organizing strategy that could help connect people to jobs be the answer?"

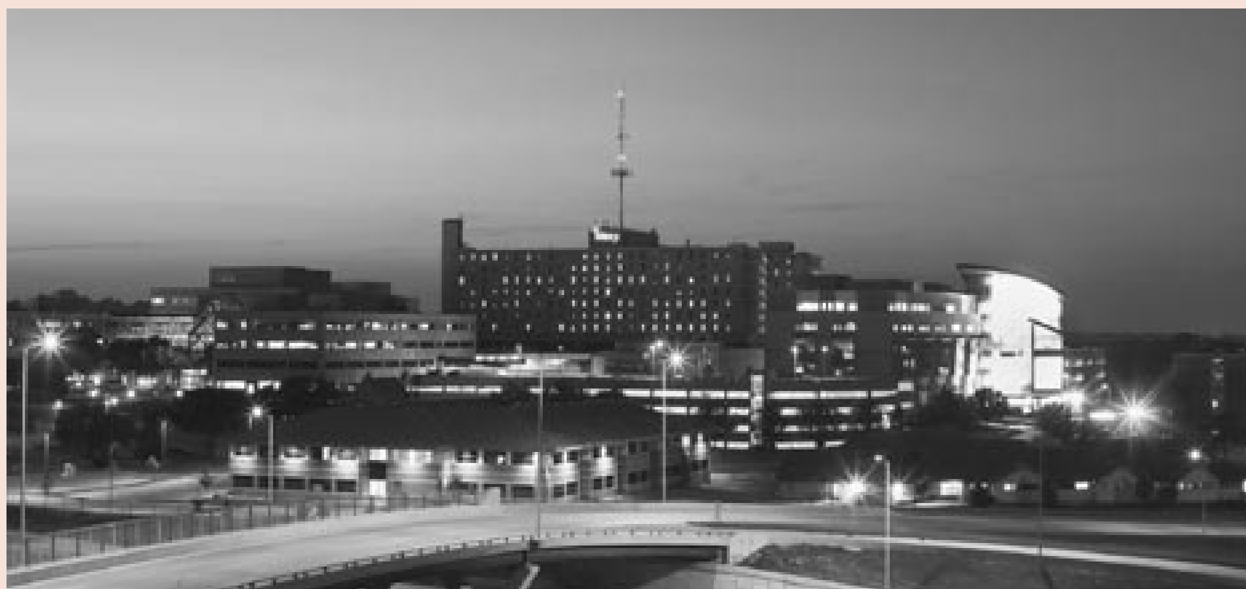
"But that question isn't even on the table," Barbell adds. "People just talk about a job-training program or a pipeline to business. It's all service program strategies that seem to be on the table first and solely. That's what I've taken away from this."

After being involved with *Making Connections* for seven years, Barbell says that he is "much more convinced that organizing has the potential to produce results." He says that Des Moines' work on predatory lending and medical debt "has literally put tens of millions of dollars in the pockets of low-income families.

"It dwarfs the EITC [an effort to get more families to file for the Earned Income Tax Credit]. It dwarfs other stuff that is going on. It has huge potential and we haven't been able to tap it." Organizing could help *Making Connections* achieve scale — one of its key goals — by being part of a strategy to modify state policies, "but we haven't been able to do that yet."

Barbell thinks one way the Casey Foundation could help is to look at the sites where organizing groups have helped *Making*

The size of the Mercy Medical Center is shown in this photo



"There are certain mythologies, beliefs and fears on both sides that keep organizing from becoming a more mainstream strategy for achieving change."

—Ira Barbell

Connections achieve specific successes and "distill out of that a more mainstream strategy for using organizing to achieve results."

Such a strategy would not just be an "against-the-establishment strategy" but one that "brings the establishment in as partners." Barbell acknowledges that this is not how organizing was seen in the past.

It is also not how organizers have seen their role in the past, nor is it necessarily how they see their role in the future, Barbell acknowledges. He says that, in the early days of developing MC in Des Moines, the two organizing groups he approached — AMOS and Citizens for Community Improvement — "were somewhat reluctant to get involved with our organization." Why? "They were setting their own agenda and they didn't want to move away from that base."

Barbell thinks that, "There are certain mythologies, beliefs and fears on both sides that keep organizing from becoming a more mainstream strategy for achieving change."

Perhaps the most common fear is that organizing inevitably means public confrontations. In its organizing around medical debt, AMOS did not go public with its challenge to the local hospitals, choosing a negotiating strategy instead, using its direct connections to these hospitals, some of which came through *Making Connections*.

Making Connections site coordinator Margaret Wright does not believe that organizing always implies confrontation.

AMOS has 23 member congregations including the Bethel A.M.E. Church, which is located in a *Making Connections* neighborhood.

"Organizing…is really about having a conversation to raise awareness of a policy or practice that is unjust or unfair. Once that awareness has been raised, good organizing asks, 'How can we solve the problem to everyone's benefit?' It's not punitive. It's about making people whole."

But the fact that there were no public confrontations in this medical debt campaign does not mean that there weren't tensions,

"A lot of people I know don't go to the doctor because they can't afford it. They stay at home until their problem gets worse, and then it's even more expensive."

—Crickett Bozarth

The Making of a Healthcare Activist

Crickett Bozarth is 60 years old, single and earns her living as an in-home day care provider. She is one of many individuals who can't afford health insurance, yet she makes too much to qualify for state medical assistance.

Bozarth recently rushed to the nearest hospital when pain from a kidney stone was too much to bear. "When you're hurting that much, you don't think about the cost," she said.

The kidney stone and a related infection left Bozarth with a bill that was over $11,000. During her stay at the hospital, a clerk had her fill out paperwork on her income. To her surprise, the entire bill was forgiven as part of the hospital's charity care. "I was grateful," she said.

She credits AMOS and its work with Des Moines-area hospitals to change charitable care policies. But Bozarth is also working for further system change, as a member of a local caregivers group that has joined AFSCME, the union for many government employees. She serves on a bargaining team that is taking their concerns on affordable healthcare to the governor's office.

"Everyone should have healthcare," said Bozarth. "A lot of people I know don't go to the doctor because they can't afford it. They stay at home until their problem gets worse, and then it's even more expensive."

"If there was a reasonable way to get healthcare based on your income, there would be a lot more healthy people," she said. "This experience has made me more active on this issue, and I believe that if people can come together and help each other, we might see a change."

Turner explains. "There were confrontations and tensions throughout the whole process from beginning to end, and there's no way to get away from that. Saying to the hospitals that we think you can do better and we expect you to do better created obvious tension. To their credit they responded."

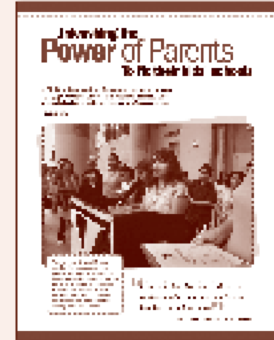
Turner says it's pointless to try to avoid conflict at all costs. "There is a time when confrontation is appropriate." He thinks the problem is that, when confrontation does occur, "It's the one thing people remember, or it's what the media cover. The media like conflict. But they don't cover the consensus building, the house-meeting process and the relationship-building aspects of organizing because it doesn't sell," he says.

"Compromise and tension are essential ingredients in all good organizing," Turner adds. "There is nothing new or different in how we approached this effort."

—Tim Saasta and Kristin Senty

Diarist Publications

Unleashing the Power of Parents to Fix Their Kids' Schools



A Making Connections Denver partner has found ways to engage parents in their children's schools and help them become articulate leaders in a district-wide school reform movement. This publication explains how this movement was built, what it's achieved so far and what others can learn from this experience.

Building a Pipeline to Success: A Look Inside the Making Connections Louisville Career Development Initiative

In Louisville, Making Connections has successfully connected residents from its neighborhoods to jobs in a nearby hospital complex. But it hasn't always been easy, and MC has learned a lot about what it takes to build a successful jobs pipeline.

Journey to Engagement:
A first-person reflection on how to engage residents

For more than 30 years, former Casey Foundation Senior Program Officer Garland Yates has been working with residents in low-income communities across the country. This publication—which is based on a series of interviews—lays out what he's learned about how to engage residents in trying to transform their communities. It also tells the story of how he came to this work.

The Gates Cherokee Redevelopment Project: "A huge step forward for low-income people in Denver"

After a three-year campaign, a broad coalition has helped establish a new standard for the community benefits that should be expected when government provides large subsidies to development projects in Denver.

For a complete list of Diarist Project publications, go to www.DiaristProject.org/pubs. Diarist publications are available at no cost on the Internet. Single copies of most publications are available from: The Diarist Project, %Charitable Choices, 4 Park Ave., Gaithersburg, MD 20877; Tim@CharityChocies.com.

"My frustration is that we have not been able to capture this experience. We haven't been able to communicate that an investment in an organizing strategy can produce tangible, concrete results for families without threatening the community's institutional infrastructure."

—Ira Barbell

The Diarist Project

This is one of a series of publications about the Annie E. Casey Foundation's *Making Connections* Initiative put together by The Diarist Project. The project is a new approach the foundation is using to learn from its efforts to strengthen families and transform struggling neighborhoods.

Diarists work to capture strategies and insights of the people who are leading the neighborhood transformation work. In *Making Connections*, the diarist works closely with the staff people who lead the work in each city, the Site Team Leader and Local Site Coordinator.

This article was written by Des Moines Diarist Kristin Senty. It was edited by Tim Saasta. Photos by Teresa Zilk (pages 1, 4, 5, 9, 12, 15, 20, 24, 30, 34) and Mary Ann Dolcemascolo (8, 10, 16, 23, 26, 28, 33).

Making Connections is a Casey Foundation initiative to support work that demonstrates the simple premise that kids thrive when their families are strong and their communities supportive. What began in 1999 as a demonstration project in selected neighborhoods in 22 cities is now an intricate network of people and groups committed to making strong families and neighborhoods their highest priorities.

Des Moines Site Team Leader Ira Barbell

The Annie E. Casey Foundation works to build better futures for disadvantaged children and their families in the United States. Its primary mission is to foster public policies, human service reforms and community supports that more effectively meet the needs of today's vulnerable children and families.

For more information about **The Diarist Project**, contact: Tim Saasta, c/o Charitable Choices, 4 Park Ave., Suite 200, Gaithersburg, MD 20877 (240-683-7100; Tim@CharityChoices.com), **www.DiaristProject.org**.

For more information about AMOS's medical debt campaign, contact Doug Peters, co-chair of AMOS's Health Care Research Team: 515-270-9226 or *doug@whumc.org*.

Making Connections Des Moines is a community-change initiative designed to make life better for people living in 15 of Des Moines' most challenging neighborhoods. Its believed that children do better when their families are strong, and families do better when they live in communities that help them succeed. The initiative seeks to close the gap in the results in employment and economic security, health, school readiness and education success.

For more information, contact Margaret Wright, 515-280-1502, *www.makingconnectionsdm.org*.