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# How Grassroots Efforts Turned Tobacco Tax Money into Transplants:

## *Social Workers as Advocates*

*Charlie Thomas*

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Poor workers rarely obtain health coverage through employment. They are more likely to be covered through Medicaid...

### **Introduction and Background**

Social workers utilize specific practice methods in working with clients and their environments. This article addresses the experience of social workers in Arizona that combined group work and community organization practice methods to resolve problems of access to organ transplantation for the "working poor."

Only half of poor workers, those individuals employed full- or part-time who remain below the official definition of poverty, are covered by health insurance. In 1990, poor individuals who worked full-time, year round, were less likely to be covered by health insurance than individuals aged 16 to 64 who did not work at all (54% vs. 68%). This imbalance was largely due to the Medicaid program, which guaranteed coverage to TANF (Temporary Assistance to Needy Families) and SSI (Supplemental Security Income) recipients.

Poor workers rarely obtain health coverage through employment. They are more likely to be covered through Medicaid or another family member's policy.<sup>1</sup> This has potentially severe consequences for their health and has created a disincentive to work, especially for those with chronic illnesses, because they would probably lose their publicly funded health insurance if they became employed full-time.

Medicare covers health services for the aged and disabled. Most disabled individuals wait for 2 1/2 years before receiving Medicare benefits. The one

exception is end-stage renal disease, which essentially covers these recipients from the 3rd month of initiating hemodialysis or from the month of initiating home dialysis or receiving a kidney (or combined kidney pancreas) transplant. However, those individuals needing heart, lung, liver, and bone marrow transplants must first survive the 2 1/2-year wait to enroll in Medicare. Most do not survive the waiting period. This is a critical problem for the working poor who are uninsured and need a life-saving transplant. They are too young for Medicare, not poor enough for Medicaid, and too poor for private insurance. They may also not qualify for private insurance due to preexisting conditions clauses and because high-risk insurance plans are expensive.

Medicaid coverage of transplantation varies widely from state to state. Most states only cover transplants for those individuals receiving Temporary Assistance to Needy Families (TANF), Supplemental Security Income (SSI), or other federal entitlements. The working poor that become eligible for Medicaid as a result of uninsured medical expenses or "spend down" are usually denied access to medical care that involves transplantation.<sup>2</sup>

In 1999, Congress commissioned the Institute of Medicine (IOM) to study the impact of the Department of Health and Human Services "Final Rule" regarding organ allocation.<sup>3</sup> Congress instructed the IOM to study the impact on access to transplantation for low-income populations and

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racial and ethnic minorities. The IOM reported that “the most important predictors of equity in access to transplant services lie outside the transplantation system—that is, access to health insurance and high quality health care services.” The report also acknowledged that minorities are “less likely than whites to be referred for evaluation and are placed on waiting lists at a slower rate, as are all low-income patients of all racial and ethnic groups.”

The Arizona Health Care Cost Containment System (AHCCCS), Arizona’s managed care alternative to Medicaid, was developed in 1982.<sup>4</sup> Kidney transplants and posttransplant medications were a covered service for all enrolled clients. However, lifesaving heart, heart-lung, lung, liver, and bone marrow transplants were only covered for those beneficiaries of federal entitlement programs (i.e., TANF, SSI). The working poor and the disabled (those waiting 2 1/2 years for Medicare) were often eligible for AHCCCS but were not covered for organ transplants. This resulted in a 2-tier AHCCCS policy regarding transplantation.

The state would only approve transplants for beneficiaries of federal programs, usually the most poor. But the state denied transplants to those not also enrolled in a federal entitlement program. This was a result of federal-state revenue sharing where the federal government contributes two-thirds and the state matches with one-third of the funding. The federal government could only require the state to cover transplants for federal beneficiaries. The state elected not to fund transplants for all enrolled AHCCCS clients. The transplant centers identified more than 50 working poor, as well as disabled individuals waiting for Medicare eligibility, who were denied transplantation and died as a result of this policy.

### Methods

This was not a research-based project. Instead it involved application of some theoretical principles of group work and community organization. In October 1994, transplant social workers decided to organize an advocacy effort to expand AHCCCS coverage of transplantation to the working poor. A proposal was developed and submitted to the transplant administrator. The administrator was skeptical at first, but after considerable discussion, she re-

ferred the social workers to the hospital’s government relations department. The director of government relations quickly agreed to support the advocacy proposal. It was discovered that several county health departments were also interested in changing the law. One county had even developed policy that covered transplantation to those residents denied transplantation by AHCCCS. Many of the AHCCCS patients that were denied a transplant had turned to their legislators, the governor, and the media. They had also turned to support groups for assistance, and the social workers were involved with the groups. However, most of the advocacy had involved individual cases only. There had not been an effort to organize all the cases into one effort.

It was decided to hold a meeting of patients who had been denied transplants, their families, transplant recipients, and support group leaders. The social workers identified surviving family members of individuals that had died as a result of AHCCCS policy, and they were also included. The social workers functioned as community organizers. The meeting discussed AHCCCS policy and generated enthusiasm and a positive sense that the group could make a difference.

The outcome of the meeting was to hold a second meeting to which every transplant support group, the four state transplant centers, the major metropolitan counties, the National Kidney Foundation (NKF), the American Association of Kidney Patients, the American Liver Foundation, the Coalition on Donation, and the local organ procurement organization were invited. The state AHCCCS was also invited, and they participated by sending program and legislative staff. The transplant centers and the counties also sent their government relations directors. The local NKF sent their volunteer lobbyist.

Those in attendance at the second meeting agreed to form a committee and engage the legislative and public relations arena and to name itself the Arizona Public Policy Forum on Transplantation. The committee’s agenda included the development of a policy brief that could be distributed to policy makers and the media, the conducting of legislative training for volunteers, and soliciting media attention. The policy brief declared that AHCCCS (and the state of Arizona) discriminated against the peo-

The brief documented that more than 50 Arizona citizens had died after being denied a transplant by [the state of Arizona].

ple who had paid for the program with their work and taxes by only funding transplants for the poorest. It emphasized the problem with waiting 2 1/2 years for Medicare coverage. The brief documented that more than 50 Arizona citizens had died after being denied a transplant by AHCCCS. It also demonstrated the cost-benefit to the state, that transplantation was more cost-effective than denying a transplant and caring for that person while he or she died. One case in particular was a 30-year-old single mother who was diagnosed with leukemia and needed a \$130,000 bone marrow transplant. She eventually died after AHCCCS denied her transplant, and it cost Arizona more than \$750,000 to care for her. The brief also cited the experience of the Oregon Health Plan in documenting that transplantation was more cost-effective than denying the procedure.<sup>5,6</sup>

There were 3 possible sources of funding to cover transplantation:

1. additional federal Medicaid funds,
2. unused AHCCCS funds (\$10 million had been returned to the general fund), and
3. revenue from Arizona's new tobacco tax.

More than \$130 million was generated in the first 6 months, and none had been appropriated for programs. The brief urged immediate, emergency action or more people would die. The brief was revised several times as the committee gained additional information. It was eventually distributed to every constituency represented on the committee, to every legislator, and the governor. It was also helpful in educating the media.

The committee planned a legislative workshop for early February 1995. However, the committee learned that the Senate Health Committee and the House Health Committee had scheduled hearings 3 days before the training on how to spend the \$130 million in tobacco tax. A subgroup of the committee formed, called the Social Action Group. This smaller group attended and testified at both hearings. The group members were AHCCCS patients that needed transplants, transplant recipients, family members, and support group leaders. They had been preparing for more than 3 months. The testimony was very compelling, and several legislators voiced concern about the AHCCCS pol-

icy. AHCCCS officials were in attendance, and they verified the accuracy of the committee's statements. This launched the committee into full involvement with the legislature and the governor. The Social Action Group was energized by the hearings, and by the time of the legislative training, the issue had been on the front pages of the state's major newspapers.

The legislative training was an opportunity to launch the letter writing and telephone calls campaign. Committee members attended every relevant legislative committee meeting and testified. Additional private meetings were held with Senate and House leaders as well as with both the Republican and Democratic caucuses. The campaign grew and became a formidable effort, especially after the media became involved.

### The Role of the Media

The lobbyists on the committee had advised that presentations be made to the newspaper editorial boards. However, the committee consisted of individuals who had previously contacted reporters regarding their own AHCCCS denial and the group naturally approached the reporters they had relationships with. In fact, one reporter was in the middle of writing a special feature on AHCCCS transplant policy when the group testified before the Health Committees. That story was on the front page of the state's largest newspaper the following morning, and by the next day television and radio were providing extensive coverage.

The role of the media was very important as well as strategic. For years, the media had been covering individual AHCCCS clients that had died after being denied a transplant. Utilizing the tactic "the threat is more terrifying than the thing itself,"<sup>7</sup> the committee promised media coverage every time another AHCCCS client was denied a transplant and died. There were several such individuals on the committee, and the threat was very real. The extensive media coverage generated support in the general public to expand AHCCCS coverage of transplantation. The media coverage also functioned to attract other individuals that needed transplants. During one radio talk show interview, a committee member encouraged listeners to call their legislators and the governor. The radio show was also simulcast on statewide television, and many he-

In March 1995, 5 months after organizing the committee, the Arizona state legislature passed emergency legislation authorizing the immediate appropriation of \$8.2 million from the tobacco tax to pay for 63 heart, liver, and bone marrow transplants.

modialysis patients were watching while receiving treatments at their centers. The response overwhelmed the Capitol switchboard so much that the governor's staff asked us to "back off" because they couldn't use their fax machine for a period of time.

Behind closed doors, the public policy leaders of Arizona were scrambling. The committee had identified 3 possible sources of funding. The first 2, additional federal funds and unused AHCCCS appropriations, were ruled out by legislators. Federal funds were ruled out because the conservative legislature opposed increasing federal funds for perceived new "entitlements" and the unused AHCCCS funds were already targeted for other use in the proposed budget. However, there was a consensus among legislators and the governor to use tobacco tax dollars to expand AHCCCS coverage of transplants. The voter-approved tobacco tax had generated more than \$130 million in less than 6 months, and it continued to grow. None of it had been appropriated. The media continued to cover individuals from the committee that needed transplants, and the letters and calls continued to the legislators. It seemed that success was very near.

### Results

In March 1995, 5 months after organizing the committee, the Arizona state legislature passed emergency legislation authorizing the immediate appropriation of \$8.2 million from the tobacco tax to pay for 63 heart, liver, and bone marrow transplants. This allowed those individuals who needed these transplants to begin their evaluations immediately. In October 1995, the committee persuaded the governor to call the legislature into a special session. Legislators agreed to appropriate an additional \$2.7 million from the tobacco tax to fund 17 heart-lung and lung transplants. One unexpected outcome of this process was the creation of policy that allowed AHCCCS clients on the transplant waiting list to remain on the list even if they lost their AHCCCS eligibility. Whereas the committee was originally able to document the deaths of more than 50 AHCCCS clients that had been denied transplant, this policy change has actually provided access to transplants for approximately 70 working poor AHCCCS clients.

The success of the committee also helped to expand the state funding of the kidney disease medication program (administered by the NKF Affiliate) from \$100,000 to \$350,000 per year and the development of a new nonrenal transplant medication program, which received \$200,000 in its 1st year. These new medication programs serve those working poor individuals that eventually lose their AHCCCS eligibility.

### Discussion

This case reflects how social workers utilized group work and community organization skills to change the AHCCCS policy regarding transplantation. It involved working with existing support groups and developing a social action group. It also included the development of a broad-based coalition of individuals and institutions, which significantly increased the social action group's effectiveness. The principles of community organization and social justice were intertwined with group process and resulted in success. This action was based in social work literature and from social work practice.

As the IOM reports, the factors affecting access to transplantation for low-income populations reside outside the transplant system. However, that does not mean such solutions are beyond the impact of the transplant system. This experience demonstrates how social workers in transplant programs directly changed some of those external factors.

Each transplant center and hospital has internal or external government relations resources. If transplant centers can use these resources to advocate their positions regarding organ allocation, why not do the same regarding access to transplantation for low-income populations? The transplant system has a moral obligation to help expand access to transplantation to all individuals regardless of their socioeconomic situation. The poor and working poor often donate their loved one's organs. They should therefore have equal access to transplantation. If access to transplantation for the working poor is not increased, the benefits of transplantation will remain skewed toward the more affluent and the most poor at a deadly cost to those "in the middle" left behind.

Table 1 | ARIZONA HEALTH CARE COST CONTAINMENT SYSTEM—TOBACCO TAX TRANSPLANTS AS OF APRIL 1, 2000

ORGAN	WAITING	COMPLETED
Heart	2	5
Heart-Lung	3	2
Lung	1	3
Liver	4	5
Bone Marrow	2	41
Total	12	56

### Update...

AHCCCS has approved more than 70 people for a transplant as a result of the policy changes noted in this article. The actual cost to the state of Arizona has been much less than originally estimated. Instead of spending the \$11 million first appropriated by the legislature, the actual annual cost has been closer to \$4 million. There are several explanations for this. First, the original estimates were based on the number of AHCCCS patients that needed *referral for transplant evaluation*. After AHCCCS began to authorize evaluations, it became clear that not all of these were candidates for transplant. Second, as a result of limited organ availability, several AHCCCS patients died while on the waiting list. Both of these factors translated into fewer transplants and less cost for the AHCCCS program. And 3rd, the initial projections of need may have been too high. However, the most significant unexpected outcome was the large proportion of bone marrow transplants performed (see Table 1). This was probably due to the ready availability of marrow (compared to organs) for donation, primarily autologous.

Arizona will address increasing AHCCCS coverage further in the 2000 fall election. There are two voter initiatives on the ballot that will use *tobacco settlement* funds to take AHCCCS coverage from the current 32% of the federal poverty level to 100% of federal poverty if passed—an expansion that is long overdue. This could potentially add 50000 people to the AHCCCS program. The good news is that this will also extend coverage of transplants to even more uninsured Arizonans. The not-so-good news is that all *tobacco tax* programs (excluding AHCCCS) will need to be reappropriated by the legislature. This will directly affect the 2 medication programs for renal patients (dialysis

and transplant) and nonrenal transplant patients funded by the tobacco tax. The committee will need to advocate for continued funding along with more than 20 other programs doing the same. The committee and the coalition have already begun to strategize and organize for the legislative session.

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