# SYMPATHY AND EXCLUSION

## ACCESS TO HEALTH CARE FOR UNDOCUMENTED IMMIGRANTS IN THE UNITED STATES

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When the editors approached me about writing this essay, I had already been researching immigrants' access to medical services for my book on the history of the right to health care in the United States. Initially, I expected to show how the Jesica Santillan case fits into that history. It turned out, however, that Jesica's story does not actually fit very neatly. First of all, the Santillan family came to the United States to seek medical care for Jesica; most undocumented immigrants avoid the health care system as much as possible, and very few migrate solely for medical reasons. Second, Jesica's family had the financial means to purchase her transplant because her mother had health insurance through her job, and because a private organization raised thousands of dollars on her behalf. Even though the undocumented are eligible for transplants under United Network for Organ Sharing (UNOS) rules, the only public insurance program that covers indigent immigrants (Emergency Medicaid) specifically excludes organ transplants, and most undocumented workers lack private health insurance.[1] Jesica's case, therefore, was far from typical.

But there was one crucial way in which the Santillan case did typify the history of immigration and health care in America, and this was in its ongoing tension between the impulses of exclusion and generosity. Strict immigration laws prevented Jesica from entering the country legally or receiving a humanitarian parole and forced her family to make the dangerous, expensive, and unlawful journey across the border. National organ transplant rules then made Jesica eligible for a transplant despite her immigration status, but Medicaid rules forbid the government from paying for the transplant. The INS tried to deport the Santillans, but local citizens and even a conservative senator intervened on the family's behalf. Duke University, businessman Mark Mahoney, and the employer of Jesica's mother were praised for their generosity when they helped Jesica get her first transplant but were later castigated by immigration opponents for "wasting" precious medical and financial resources on a noncitizen.

These seemingly contradictory impulses of sympathy and exclusion have historically been embodied in the nation's immigration policy, which has veered between exclusion, quotas, amnesties, guest worker programs, deportations, raids, employer sanctions, and border crackdowns, and sometimes several of these at once.[2] It is perhaps not surprising that attitudes toward health access for the undocumented have reflected the nation's erratic immigration policies. As I outline below, U.S. policies on immigrant health care have been fragmentary, contradictory, or nonexistent. Although the general trend has been to officially exclude undocumented immigrants from every type of health care except emergency care, this history is punctuated with examples of great generosity toward individuals. In this way, the Santillan case *is* reflective of the history of immigrants and health care in America, and indeed of the paradoxes of the American health care system itself.

Access to health care in the United States rests on a basis of categorization and exclusion, of defining who is deserving of and able to receive what services based on income, insurance coverage, past health conditions, and myriad other factors, and the nation is notorious for its growing number of uninsured. At the same time, Americans are proud of the generosity of their health care system, with its long history of charity and voluntarism. Private medical philanthropies, individual giving, the coin box on the convenience store counter raising money for a local child's leukemia treatment, are just as integral a part of the American health system as hospitals, the American Medical Association, and insurance companies. While seemingly paradoxical, these impulses of exclusion and charity together drive the engine of American health care, allowing Americans the comforting notion that "we don't let people die in the streets" even as universal access to care grows increasingly elusive. Similarly, the clashing notions of welcome and exclusion in U.S. immigration policies serve to maintain our economic system, with its cyclical increases and decreases in requirements for immigrant labor and concurrent demands that this labor be bought as cheaply as possible. The apparently baffling contradictions of the Santillan case, then, make it not a historical curiosity but a window onto the complex workings of American immigration and health care policy.

## ACCESS AND RIGHTS TO HEALTH CARE BEFORE 1986

The history of undocumented immigrants' access to health care is particularly elusive for several reasons. By definition, the undocumented leave few written records. The term "undocumented" itself is a recent one, and throughout the twentieth century it was often difficult to distinguish "legal" from "illegal" immigrants and migrants to the United States. In the Southwest, for example, all residents of Mexican descent were referred to as "Mexican," including those who had been in the United States for generations.[3] This led to great fluidity in border areas; longtime residents might be treated like foreigners in their own land, but Mexican migrants could also be treated like locals. Mutual aid societies, founded throughout the Southwest in the 1870s, intended to serve both immigrants and longtime residents of Mexican descent, and membership in the societies usually included some health care provision. In the mining community of Bisbee, Arizona, the company-owned Copper Queen Hospital treated numerous workers with Spanish surnames; its records from the 1910s did not distinguish between citizens and noncitizens.[4] At the same time, when access was restricted, the restrictions applied to longtime "legal" residents and recent arrivals alike. While some county and private hospitals in the Southwest and California seem to have treated both Mexican and Anglo patients, other health facilities were strictly segregated by national origin. In Los Angeles in the 1920s, for example, separate public health clinics were established for "Americans" and "Mexicans," the latter ones intended to serve both U.S. citizens and Mexican nationals.[5]

Migrant farmworkers, undocumented or not, historically have endured the poorest health conditions and the least access to health care of all socioeconomic groups in the United States. However, because of their importance to the agricultural economy and the fact that they by definition crossed state boundaries, their health problems have received the attention of the federal government. The Migrant Health Act of 1962 originated in concerns about migrants' supposed propensity to contagious disease. Mexican workers entering the country to work in the bracero and other contract labor programs were required to pass through Public Health Service stations at the border, where they were "dusted with an insecticide, vaccinated, examined for evidence of venereal disease, given a . . . chest X-ray, and examined for any other condition which would make the laborer inadmissible or unfit for agricultural work."[6] Once workers had passed through the stations, the government turned over responsibility for their health to employers. Reliance on employer voluntarism predictably proved ineffective, and by the early 1960s health conditions among migrant laborers had become a national scandal.

Congressional sponsors of the Migrant Health Act of 1962, which provided federal grants to local health providers willing to care for migrant workers, argued that the legislation was intended to protect American citizens from contagious disease, sustain the agricultural labor force, and even to fight the Cold War. "[Q]uite apart from humanitarian considerations," the act would "help assure in the national interest the continued availability of an essential labor supply." One New York congressman told a committee hearing that "the plight of the migrant worker is foreign to our American institutions. This long-festering sore in our society and our economy provides a propaganda weapon for those who oppose our traditions and ideals." Arguments about national interest and labor demands, rather than the health needs or rights of the migrants themselves, helped the Migrant Health Act pass in 1962.[7] Currently, over 100 migrant health centers receive federal funding, but advocates estimate that only 10 to 15 percent of migrants ever use the services. Undocumented workers fearing deportation are reluctant to attend these clinics, and, due to low literacy levels, many are not even aware of the clinics' existence, which are advertised primarily through pamphlet literature.[8]

Sometimes, undocumented workers in need of medical help turned to local indigent care services. Medical care for the poor in the United States was traditionally a county responsibility that in the twentieth century became guaranteed by state statutes. County and municipal health systems were required to provide care to local indigent residents; the statutes made no reference to citizenship requirements, and most public hospitals and county welfare programs did not inquire into immigration status. In general, communities with public hospitals (such as Los Angeles and Chicago) seemed to offer greater access than those who relied on private practitioners and institutions to provide indigent care (such as in most rural areas). Local taxpayers occasionally objected to the use of county funds to pay for immigrants' health care. In 1940, an anti-immigrant Mexican American newspaper complained about "county charities" that "provide aliens and their families food, clothing, shelter, and medical care without work." In 1980, a taxpayers' group sued L.A. County to "stop the expenditure of public funds to pay for non-emergency health care for undocumented persons," but lawyers argued successfully that the state of California required counties to "provide health services to *all* indigent residents," including the undocumented.[9]

But basing access on local residency was a double-edged sword for migrants and immigrants. Local indigent care facilities had strict requirements for proving residency, usually demanding not only a local address but also utility bills, employment verification, and other documents. Such requirements likely prevented many undocumented immigrants from ever approaching the local hospital or health center. In some communities, residential requirements were "durational," meaning a patient was required to have resided in the county for at least six months before becoming eligible for indigent medical care. In the absence of a citizenship requirement for indigent care, residency requirements provided a legal basis for hospitals and other county and public health facilities to deny care to recent immigrants, or to deny reimbursement to providers willing to treat them.

In 1971, a Mexican-born migrant worker launched the first successful constitutional challenge to residency requirements for medical care. Henry Evaro, a legal resident of Arizona, traveled to Phoenix to find work as a welder. He had been there less than a month when he had a severe asthma attack and went to the emergency room of the private Memorial Hospital. Evaro was so sick that he needed admission as an inpatient; Memorial called Maricopa County Hospital and asked them to take him, since he was indigent. The county hospital refused because Evaro had not resided in the county for at least a year, as required by Arizona State statute. The welder remained at Memorial for eleven days, and the hospital sued the county to pay for Evaro's care. On February 26, 1974, the U.S. Supreme Court ruled in *Memorial Hospital v. Maricopa* that durational residency requirements for medical care were an unconstitutional violation of the equal protection clause of the Fourteenth Amendment since they "impinged on the right of interstate travel by denying newcomers basic necessities of life."[10]

It was not *Memorial*, however, but another Arizona case the following year that would firmly establish a legal right to emergency care for the undocumented. On February 10, 1972, two young children at home in the border town of Naco, Sonora, Mexico, were severely burned when a stove exploded in their kitchen. Relatives rushed the children across the border to the nearest hospital, Phelps Dodge Company's Copper Queen Hospital in Bisbee, Arizona, but a nurse refused to even allow them into the emergency room. Instead, she glanced at the burned children crying in the back seat of the car and told the driver to take them to the county hospital in Douglas, Arizona, eighteen miles away. The boy and girl both survived, but their parents sued Copper Queen, alleging that the hospital's refusal of care had aggravated the children's injuries and prolonged their convalescence. When the case reached the Arizona Supreme Court, the resulting decision, *Guerrero v. Copper Queen*, stated that "nonresident aliens" could not be excluded from hospitals' duty to provide emergency care. The justices based their decision rather narrowly on the existing Arizona State statute regarding private hospitals' requirements to provide emergency care, which did not exclude noncitizens. Until state legislators chose to make an exception in the case of immigrants, the *Guerrero* decision concluded, hospitals would be required to treat all emergency cases.[11] The *Guerrero* decision is still cited today as a major precedent for the federal, universal right to emergency care in the United States.

The *Memorial* and *Guerrero* decisions laid the groundwork for a legal basis for immigrants' right to health care. However, they also coincided with a growing backlash against immigration. In the severe economic downturn of the 1970s, politicians and some of the public blamed immigrants for taking American jobs and burdening the welfare state. The 1965 amendments to the Immigration and Nationality Act drastically reduced the number of Mexicans eligible for legal residency, forcing many more immigrants to enter illegally; between 1968 and 1976, the number of annual deportations of undocumented Mexicans increased from 151,000 to 781,000.[12] When Congress added the Supplemental Security Income program to Social Security in 1972, it explicitly denied coverage to undocumented immigrants. Then, in 1973, the U.S. secretary of health, education, and welfare issued a regulation denying Medicaid eligibility to any alien who was not a permanent resident or "otherwise permanently residing in the United States under color of law."[13] For the first time, undocumented immigrants were specifically excluded from Medicaid.

## THE BACKLASH: IRCA AND WELFARE REFORM

The Immigration Reform and Control Act of 1986 (IRCA) further restricted immigrants' access to health care. The law excluded some categories of *legal* immigrants from Medicaid during their first five years in the country, and new sanctions against employers undoubtedly made it harder for the undocumented to get jobs that might provide health insurance. That same year Congress amended the federal Medicaid statute to bar aid to undocumented immigrants for "any condition short of a medical emergency," thereby creating the program known as Emergency Medicaid. Emergency Medicaid continued the nation's trajectory of setting apart emergency care for special coverage.[14] The program is extremely restrictive, excluding single adults over eighteen and childless couples under sixty-five, and covers nothing outside of acute care in the hospital for sudden-onset conditions.[15] As mentioned before, Emergency Medicaid does not cover organ transplants.

In the early 1990s, some states continued to provide undocumented immigrants with nonemergency services such as prenatal care and immunizations. Politicians sought to remove the supposed "immigration incentive" of such care through measures like California's Proposition 187, which attempted to bar undocumented immigrants from using nonemergency health services. The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA), the 1996 "Welfare Reform" passed by a Republican Congress and signed into law by President Clinton, dramatically cut back on immigrants' (including legal immigrants) access to health care and welfare programs. PRWORA declared all state aid to the undocumented illegal unless states chose to pass new enabling legislation. Some states attempted to continue offering care, but others took the opportunity provided by PRWORA to eliminate most health services to the undocumented. In 1996, for example, California governor Pete Wilson ordered state employees to stop giving prenatal care to undocumented women, and in 2003 a Texas district attorney began a criminal investigation of local hospitals that offered such care.[16] Both of these actions were successfully challenged by health care providers and advocates for immigrants, as was Proposition 187.

State attempts to either end or provide nonemergency care continue to be mired in legal challenges and confusion, and Emergency Medicaid remains the only federal health program officially available to undocumented immigrants. Unofficially, many locally funded health clinics offer some nonemergency care for immigrants. At Alivio Medical Center in Chicago, for example, which provides $1 million a year in uncompensated care, more than half of the patients are undocumented.[17] School-based clinics are an important source of care for children of undocumented parents. This contradictory and patchwork system of care—official policies of exclusion and cutbacks coupled with tolerance of provision at the local level—reflects the nation's inability to come to terms with the realities of immigration and the health needs of undocumented workers.

## IMMIGRATION AND HEALTH CARE IN NORTH CAROLINA

Until Jesica Santillan's case, most of the debate and legislative activity around immigrants' access to health care took place in areas of the country with traditionally large Spanish-speaking immigrant and migrant populations: the Southwest, California, and New York State. Jesica's story highlights one of the major shifts in immigration patterns in the last decade. Fewer Mexican nationals are heading for the heavily immigrant neighborhoods of the urban West and Southwest; their destinations increasingly are small, rural towns in the Midwest and Southeast. In North Carolina, the immigrant population increased by 72 percent between 2000 and 2004.[18] According to a federal estimate, the state currently has 206,000 undocumented residents.[19] As a heavily agricultural state, North Carolina has long been dependent on migrant labor, but the composition of the migrant workforce has shifted dramatically in the past twenty years, from primarily African American to primarily Mexican.[20]

Immigrants to North Carolina face extreme difficulty in obtaining health care. In 2003, 69 percent of Hispanics in North Carolina whose primary language was Spanish had no health insurance. In comparison, 32 percent of English-speaking Hispanics, 19 percent of African Americans, and 13 percent of whites in North Carolina lacked health coverage.[21] Immigrants lack health insurance primarily because they are concentrated in job sectors that do not provide health coverage, such as agriculture, and in jobs with wages insufficient to purchase health insurance or health services.

Although the private Duke Endowment was renowned for its health care philanthropy in the state, at the time of the Santillans' arrival the Duke University Medical Center was not actually the top provider of charity care in central North Carolina. That distinction went to WakeMed, a community hospital in Raleigh, and the University of North Carolina hospitals.[22] While Duke was not known primarily for its indigent care or its care for immigrants or migrants, its transplant capabilities were world famous. It was also one of the few hospitals in the country providing heart-lung transplants for children. This is what Jesica and her family had heard about Duke in Mexico.

## A RIGHT TO ORGAN TRANSPLANTS?

At the time of Jesica's arrival, the UNOS policy of allowing (or limiting) 5 percent of organs to go to noncitizens had been in place for over a decade. The 5 percent policy originated in the mid-1980s, when public outrage was sparked by media coverage of wealthy foreigners, including members of the Saudi royal family, traveling to the United States to receive transplants. At one Pittsburgh transplant center, for example, 28 percent of donated kidneys went to wealthy foreigners between 1984 and 1985.[23] UNOS was urged by some to ban transplants to noncitizens altogether, but experts argued that immigrants were an important source of organ donations (see Eric Meslin's essay in this volume for more discussion of this argument, and see Jed Adam Gross's essay for more on the Pittsburgh case). The UNOS guidelines refer only to noncitizens and do not explicitly mention undocumented immigrants.

Following the Santillan case, letters to newspaper editors nationwide railed at the unfairness of scarce organs going to someone who had deliberately violated U.S. laws by entering illegally, but others pointed out that undocumented immigrants actually donate *more* than the 5 percent of organs they are entitled to receive.[24] "In North Carolina, Latino families are among the most likely groups to say yes to donating a family member's organs," reported the Raleigh *News and Observer*. "Latino consent rates ran about 78 percent during the first six months of [2002], compared with 62 percent for other groups."[25]

Not only do immigrants donate more organs than they are entitled to receive, they actually end up receiving far fewer than the 5 percent designated by UNOS. Only slightly over 1 percent of organs actually to go undocumented immigrants annually.[26] Transplant centers are not required to provide organs to noncitizens and many refuse to do so. A Raleigh newspaper found at least two cases of undocumented immigrants who died after being refused transplants at U.S. hospitals.[27] Children's Memorial Hospital in Chicago underwent a storm of negative publicity when it refused a liver transplant to eleven-year-old Ana Esparza in 2001. Ana, who was near death, finally underwent the transplant at a Florida hospital, and Children's agreed to pay for her follow-up care and also offered transplants to two other undocumented children.[28] As for Duke, it was far from being a center of transplantation for the undocumented. According to UNOS data, "Of 2,541 people who received transplants at Duke from Jan. 1, 1988, to Nov. 30, 2002, there were no 'nonresident aliens' recorded, although eight people did not specify their citizenship status."[29] The UNOS 5 percent marker, then, clearly has not established a guaranteed right to organ transplants for noncitizens. And Emergency Medicaid's denial of reimbursement to hospitals performing such transplants made immigrants' access to organs even more elusive (this was the reason given by Children's Memorial for refusing Ana Esparza's transplant).

When Jesica Santillan arrived in North Carolina, then, she was ostensibly eligible for an organ transplant, and Duke did indeed put her on the waiting list for a heart and lungs. However, Duke wanted to be paid, and as an undocumented immigrant Jesica had no right to government assistance and Duke had no right to government reimbursement for her care. But because of her unique situation as a young female with a devastating illness, Jesica was able to tap into two other funding mechanisms for her care: employer health insurance and private charity. Jesica's plight led to widespread sympathy for her family among locals in their town of Louisburg, sympathy that helped Jesica's mother find a job with health insurance and led businessman Mack Mahoney to begin aggressive fund-raising on her behalf. Had Jesica relied only on official governmental and organ network policies, she would likely not have received a transplant. Instead, like many Americans (especially children) who cannot afford catastrophic medical expenses, she ended up relying on the charitable impulses of private citizens.

## THE POLITICS OF CHARITY AND SYMPATHY

Jesica's second transplant and her subsequent death led to extensive discussions in the media about immigrants' "deservingness" of organ transplants and of U.S. health care in general. As Leo Chavez shows in his essay in this book, immigration opponents capitalized on Jesica's tragedy to demand further restrictions on immigration and on health services for the undocumented. The Santillan case and its aftermath, however, also elicited extensive public and media sympathy for Jesica and her family. The Santillan tragedy led to powerful outpourings of both compassion and anti-immigrant invective, highlighting Americans' continuing confusion, unease, and ambivalence about the country's immigration policies and its health care system.

As Eric Meslin points out, there is widespread acceptance of the "idea that charity and humanitarianism are necessary features of the U.S. health care system that result from inequities generally." The Santillans themselves were aware of this. Jesica's family came to the United States not to seek Medicaid but because they had heard about the Children's Miracle Network, a private charity that helped pay for children's organ transplants at major hospitals, including Duke.[30]

It was not this national charitable network, however, that enabled Jesica to receive a transplant. Rather, the Santillans ended up relying on a particularly southern tradition of local benevolence. The family settled in Louisburg, North Carolina, and Jesica was accepted onto the transplant waiting list at Duke, with the knowledge that a heart-lung transplant would cost around $500,000, not including follow-up care. When Louisburg home developer Mack Mahoney read Jesica's story in the local paper, he decided he had to help. Mahoney created a private charity, "Jesica's Hope Chest," solely to raise money for the transplant. When traditional fund-raising efforts fell short, Mahoney enlisted building suppliers and contractors to donate materials and labor to build houses that then would be sold and the proceeds donated to Jesica's cause. According to Mahoney, "Soon, the whole community was involved in the effort. Individuals, local business groups, churches and many civic organizations were working to raise money for the first 'Jesica's House.' "[31] Mahoney also helped Jesica's mother find a job at the local college—a janitorial position that, amazingly, included health insurance coverage.

Jesica's case appealed not only to Mahoney and other local supporters but even to North Carolina senator Jesse Helms, no supporter of immigration, who "reportedly interceded on [Jesica's] family's behalf when INS officials considered deporting them."[32] Such a remarkable outpouring of support seemed to be the polar opposite of the anti-immigrant reactions to Jesica's case that later emerged. This might be understood, then, as a story of American acceptance of immigrants and of Jesica's right to medical citizenship. But the public support for Jesica was based not on her immigration status but on other factors that made it possible for her supporters to ignore or downplay that status. These factors were Jesica's youth, her gender, and the severity of her medical condition (and probably her beauty as well). Mahoney repeatedly referred to Jesica as a "little girl," a "baby girl," and "my baby." Mahoney himself had lost a baby years earlier, making these pronouncements about a seventeen-year-old a bit more understandable.[33] Mahoney also seemed to play the role of the southern patriarch whose benevolence was rooted in paternalism (a paternalism that emerged quite harshly as a desire to control Jesica in the Mahoney interview cited by Carolyn Rouse in her essay in this volume).[34]

Sympathy for children plays an important role in America's welfare state and private charity systems. Government programs are more popular when they are aimed at children rather than able-bodied adults; such programs as Head Start and, more recently, the State Children's Health Insurance Programs expansion of Medicaid, and children's charities (particularly medical charities) are extremely well funded and generate much publicity. And not only was Jesica a young female whose teenage dreams could be embodied by a "Hope Chest"; she was placed in an even more vulnerable condition by the nature of her illness, which would shortly kill her if she did not receive the transplant. As an increasingly familiar member of the local community, Jesica was an "identified life" of the type discussed in Nancy King's essay in this book, a known individual who elicited public sympathy even as the broader social problems she embodied (immigration, the high cost of health care, organ shortages) went unaddressed.

Jesica's age, gender, and medical condition added up to a state of "innocence" that trumped her illegal status. It is difficult to imagine such an outpouring of public support on behalf of, for example, a forty-five-year-old undocumented Mexican male farm laborer in need of a liver transplant (especially if the liver disease were due to excessive drinking). The confluence of factors in Jesica's favor made her unusually well positioned to attract charitable support—support that was significant enough (alongside her mother's insurance) to convince Duke to go ahead with the transplant.

## AFTERMATH: BACKLASH RHETORIC VERSUS POLICY REALITY

Although her local supporters never wavered, much of the broader public sympathy for Jesica seemed to evaporate after she received the second transplant, and media coverage became increasingly critical. As Leo Chavez's essay details, the Santillan case quickly became a flashpoint for anti-immigrant sentiment. John A. Mulhall of upstate New York wrote in a newspaper editorial, "Why were Jesica Santillan and her mother, illegal aliens from Mexico who knowingly broke our laws, even at Duke University and not in an INS holding cell?"[35] Feelings against Jesica and her family reflected anxiety not only about unchecked immigration but also about the scarcity of organs and high medical costs. Sixty-five-year-old Jackie Mills of Raleigh, North Carolina, told a reporter, "I definitely would not want [my organs] to go to an illegal alien. I don't think they should be able to come in here and take our hospital and take our medicine and turn around and sue us."[36]

The image of illegal immigrants using up precious health care resources came to a head in the aftermath of the Santillan case, but such arguments were not new. Since the 1970s, hospitals in U.S.-Mexico border areas had claimed that immigrants were "swamping" emergency rooms and "flooding" local health facilities, and they used these images to argue for increased federal funding to hospitals.[37] In 2003, shortly after Jesica's death, the Bush administration finally agreed to include $1 billion for uncompensated emergency care for undocumented immigrants in its Medicare Modernization Act.[38]

The new legislation infuriated immigration opponents who saw it as a subsidy for illegal immigrants. California congressman Dana Rohrabacher introduced a bill requiring hospitals accepting the funds to report undocumented patients to the Department of Homeland Security, which would then begin deportation proceedings. Rohrabacher used the Santillan case to argue that immigrants were depleting crucial health care resources that should be reserved for U.S. citizens. "We all remember Jesica Santillan, said Rohrabacher. "She was an illegal alien who died after receiving not one, but two, heart and lung transplants in North Carolina. . . . There are American citizens who desperately need organs, and they are being knocked out of line by a family who broke the law to come here. . . . If we cannot provide medical care for our senior citizens, we cannot provide them medicines, how is it that we can provide $1 billion to treat illegal immigrants. . . ? My bill . . . is meant to deal with this travesty. If passed, it will signal to the leadership that the American people no longer will stand for this type of providing services for illegal immigrants."[39]

Despite strong anti-immigrant sentiment in his home state, Rohrabacher's in the measure in the U.S. House of Representatives was defeated in May 2004 by a vote of 331 to 88. One year later, on May 9, 2005, the Centers for Medicare and Medicaid Services announced that hospitals would not be required to ask patients about their immigration status in order to be eligible for the new federal funds. Instead, reimbursements to hospitals would be based on statistical estimates of state and local undocumented populations. For each of the next four years $4.9 million from this fund has been allocated to North Carolina.[40]

In this case, at least, anti-immigration rhetoric failed in the face of other forces: the power of the hospital lobby, which used immigrants' medical needs to tap into a new source of funding; pressure from medical practitioners and immigrants' rights groups, who argued that demanding to know patients' immigration status would discourage seriously ill people from seeking care; and finally, acknowledgment of the reality that the population of undocumented immigrants is large and growing and that ignoring their health needs is not in the nation's best interest.

Jesica Santillan's tragedy both highlighted and obscured central themes in U.S. immigration and health care. Most significantly, her case reflected the historical ambivalence and contradictions of U.S. attitudes and policy toward immigrants. Jesica and her family experienced the clash between generosity (employer benefits, private charity, a policy allowing immigrants to receive organ transplants) and exclusion (a dangerous border crossing, threats of deportation, Medicaid limitations). In the media and in public opinion, Jesica was portrayed as both a deserving innocent and a callous lawbreaker—the "angel" versus "thieving immigrant" dichotomy analyzed by Susan Morgan et al. in this volume's opening essay. Her case represented the continuing irrationality of the U.S. health care system, in which spectacular technology and expensive medical miracles flourish alongside the denial of basic health coverage and services to millions. It is notable that while health care "rationing" is supposedly anathema to Americans, during the Santillan case rationing was discussed explicitly and openly. The case lay at the intersection of two areas—organ transplantation and immigrant health access—where shortages and scarcity are endemic and are explicitly acknowledged. In discussions of Jesica Santillan, Americans were able to express—sometimes openly, sometimes in more coded terms—their own anxieties about scarcity and rationing in health care.

In other, significant ways, Jesica's story was highly untypical and thus obscures as much as it reveals. It is extremely rare, for example, for undocumented immigrants to get employer health insurance, to have local Anglos create a charity on their behalf, or to receive an organ transplant. It is also very rare for Mexicans to enter the United States solely to seek medical care. Perhaps the most important way that the Santillan case obscures the typical immigrant experience is that it focused the debate around a highly unrepresentative case of medical immigration (see the cartoon in Leo Chavez's essay showing immigrants coming for "free health care"). In doing so, it distracted from the major reasons people come to the United States: poverty in their home country and unceasing demand for their labor in this country.

These realities were vividly depicted in a news article that appeared shortly after Jesica's death. Alfredo Corchado, a reporter for the *Dallas Morning News,* traveled to the Santillan's home village of Arroyo Hondo in Jalisco, Mexico. Corchado found that Jesica's was only one of many desperate journeys that the villagers of Arroyo Hondo had taken over the northern border. Jesica's great-uncle, Bernardo Torres, had been a farmworker in the United States in the 1940s, when the U.S. government created the bracero guest worker program to meet a severe shortage of labor in the Southwest. After Torres returned to Mexico, over the next decades he saw more than one of his fellow villagers depart for the United States, only to come back in coffins—"people who died at the hands of smugglers, fell victim to the heat and brutality of the deserts or drowned in the Rio Grande." Jesica Santillan was in many ways an untypical immigrant, but her determination, her desperation, and her sad end made her not so different from many others who seek work and dignity in the United States. " 'Sometimes we search for a better life, only to find death,' said Torres, 70, as he quietly sobbed. 'That's life.' "[41]

## NOTES

1. Undocumented immigrants actually use less health care (apart from labor and delivery care) than nearly every other group in the population. They fear that using the health care system will require them to disclose their immigration status, that it will

open them up to accusations of being a "public charge" if and when they apply for legal status, and that it will be unaffordable. Undocumented immigrants tend to live in agricultural areas and inner cities, the parts of the country that are most likely to be strapped for health services. Workers' dependence on employers is another factor limiting access to health care; some employers may take workers to a doctor, but many workers are also afraid to tell employers about illness or injury for fear of losing their jobs (or even, as Leo R. Chavez describes in *Shadowed Lives*, of being dumped at the border by the employer.) And undocumented immigrants are, of course, overwhelmingly concentrated in low-wage jobs that do not provide health insurance. See Marc L. Berk, Claudia L. Schur, Leo R. Chavez, and Martin Frankel, "Health Care Use Among Undocumented Latino Immigrants," *Health Affairs*, July/August 2000, 51–64; Leo R. Chavez, "Undocumented Immigrants and Access to Health Services: A Game of Pass the Buck," *Migration Today* 11 (1) (1983): 15–19; Leo R. Chavez, Estevan T. Flores, Marta Lopez-Garza, "Undocumented Latin American Immigrants and U.S. Health Services: An Approach to a Political Economy of Utilization," *Medical Anthropology Quarterly* 6 (1) (March 1992): 6–26; Leo R. Chavez, *Shadowed Lives: Undocumented Immigrants in American Society* (Fort Worth, Tex.: Harcourt Brace Jovanovich College Publishers, 1992), 74–75; and "Increasing Share of U.S. Uninsured are Immigrants," *Wall Street Journal*, June 14, 2005, D6.

2. Mae M. Ngai, *Impossible Subjects: Illegal Aliens and the Making of Modern America* (Princeton, N.J.: Princeton University Press, 2004).

3. David G. Gutierrez, *Walls and Mirrors: Mexican Americans, Mexican Immigrants, and the Politics of Ethnicity* (Berkeley: University of California Press, 1995), 91; Ngai, *Impossible Subjects*, 8.

4. Gutierrez, *Walls and Mirrors*, 75, 96; Admissions Log, Copper Queen Hospital, Cochise County Historical Society, Bisbee, Arizona. On mutual aid societies, see also Jose Amaro Hernandez, *Mutual Aid for Survival: The Case of the Mexican American* (Malabar, Fla.: Robert E. Krieger Publishing Company, 1983).

5. Emily K. Abel, "'Only the Best Class of Immigration': Public Health Policy toward Mexicans and Filipinos in Los Angeles, 1910–1940," *American Journal of Public Health* 94 (6) (June 2004): 932–39. On the bracero program, see Ngai, *Impossible Subjects*.

6. Norma J. Robinson, "The Public Health Program for Mexican Migrant Workers," *Public Health Reports* 73 (9) (September 1958): 851–60.

7. "Health Clinics for Migratory Farmworkers: Hearing before a Subcommittee of the Committee on Interstate and Foreign Commerce, House of Representatives," February 13, 1962 (U.S. Government Printing Office, 1962), 13.

8. Tina Castañares, M.D., "Outreach Services," *Migrant Health Issues Monograph Series*, No. 5, April 2002, National Center for Farmworker Health, Inc., Texas.

9. Mexican American Movement newspaper quoted in Gutierrez, *Walls and Mirrors*, 137; "Access Upheld for California Undocumented," *Health Advocate: Newsletter of the National Health Law Program*, No. 124, September 1981.

10. *Memorial Hospital v. Maricopa County*, Supreme Court of the United States, 415 U.S. 250; 94 S. Ct. 1076; 39 L. Ed. 2d 306; 1974 U.S.; *Memorial Hospital and Henry Evaro v. Board of Supervisors and Maricopa County*, Case No. 251236, Maricopa County Superior Court, Clerk's Office; Interview Transcript, Augusto Ortiz, M.D., May 26, 1994, 5, *Medicine and Health Care Delivery in Southern Arizona*, Arizona Historical Society Oral History Project, Arizona Historical Society. Since the 1996 welfare reform legislation, discussed below, states are again allowed to impose residency requirements for welfare services; see David A. Donohue, "Penalizing the Poor: Durational Residency Requirements for Welfare Benefits," 72 *St. John's Law Review* 451, Spring 1998.

On the residency debate in California, see Chavez, "Undocumented Immigrants," 18.

11. Deposition of Katie Perazzo (nurse), Bisbee, Arizona, May 18, 1982, Superior Court of Cochise County; *Guerrero v. Copper Queen Hospital*, Supreme Court of Arizona, 112 Ariz. 104; 537 P.2d 1329; 1975 Ariz. (July 18, 1975).

12. Ngai, *Impossible Subjects*, 261.

13. 38 Fed. Reg. 30, 259 (1973), reprinted in *Lewis v. Grinker*, 965 F.2d at 1212.

14. See Beatrix Hoffman, "Emergency Rooms: The Reluctant Safety Net," in *Bringing the Past Back In: History and Health Policy in the United States*, ed. Rosemary Stevens, Charles Rosenberg, and Lawton R. Burns (New Brunswick, N.J.: Rutgers University Press, forthcoming 2006).

15. The Omnibus Budget Reconciliation Act of 1986, Pub. L. No. 99–509, 100 Stat. 1874, 2057 (1986). The program was preserved by Congress in the 1996 welfare reform; Lucette Lagnado, "Emergency Medicaid Policy Binds Sick Immigrants Without an Exit," *The Wall Street Journal*, October 18, 2000, A1.

16. Katherine Eban Finkelstein, "Medical Rebels: When Caring for Patients Means Breaking the Rules," *The Nation*, February 21, 2000, 11–17; Jeffrey T. Kullgren, "Restrictions on Undocumented Immigrants' Access to Health Services: The Public Health Implications of Welfare Reform," *American Journal of Public Health* 93 (10) (October 2003): 1630–33.

17. Ana Mendieta, "Hospitals Pay Medical Costs of Undocumented," *Chicago Sun-Times*, December 11, 2001, 8.

18. Joel Millman, "Low-Wage U.S. Jobs Get 'Mexicanized,' But There's a Price," *Wall Street Journal*, May 2, 2005, A2.

19. Sarah Avery, "Hospitals Face Care Quandary," *News and Observer* (Raleigh, N.C.), September 25, 2004, A1.

20. For an illuminating study of immigrant labor in rural North Carolina, see Leon Fink, *The Maya of Morganton: Work and Community in the Nuevo New South* (Chapel Hill: University of North Carolina Press, 2003).

21. Harry Herrick and Ziya Gizlice, "Spanish-Speaking Hispanics in North Carolina: Health Status, Access to Health Care, and Quality of Life Results from the 2002 and 2003 NC BRFSS Surveys," State Center for Health Statistics (Raleigh, N.C.) Study No. 143, *SCHS Studies*, July 2004. This study also found that only 12 percent of Hispanics in North Carolina received Medicaid.

22. In fiscal year 2004, WakeMed claimed to spend $68.2 million for charity care; UNC, $48 million; Duke, $28.8. See Avery, "Hospitals Face Care Quandary."

23. Lindsey Gruson, "Some Doctors Move to Bar Transplants to Foreign Patients," *New York Times*, August 10, 1985, 1.

24. Diana Washington Valdez, "Mexican Teen's Death Stirs Debate," *El Paso Times*, March 2, 2003.

25. Christina Headrick and Vicki Cheng, "Some Link Citizenship, Transplants," *News and Observer* (Raleigh, N.C.), March 4, 2003, A1.

26. "Undocumented Immigrants in U.S. Donate More Organs Than They Receive," *Transplant Week*, March 9, 2003, <www.transplantweek.org/members/Vol14?News/041001.htm>.

27. Headrick and Cheng, "Some Link Citizenship, Transplants," A1.

28. Mendieta, "Hospitals Pay Medical Costs," 8. The other children were Samira Ocampo, age thirteen, and Jesus Ramirez, age twelve, who both received stem cell transplants. Ocampo died of complications from the transplant.

29. Headrick and Cheng, "Some Link Citizenship, Transplants," A1.

30. Apparently the Santillans heard about the Children's Miracle Network from Jesica's aunt, an undocumented worker in the North Carolina tobacco fields. See Avery Comarow, "Jesica's Story," *U.S. News and World Report*, July 28, 2003, 51. According to the organization's Web site (<www.cmn.org>), "Children's Miracle Network Hospitals . . . provide $2.5 billion in charity (uncompensated) care each year; Treat 98% of all children needing heart or lung transplants."

31. "What Is the History of Jesica's Hope Chest?" <www.4jhc.org/index.html>.

32. Allen Johnson, "Who Lives, Who Dies, Who Pays? Jesica's Sweet Sad Song Plays On," *News and Record* (Greensboro, N.C.), March 9, 2003, H2.

33. It is also notable that most of the media, and some of the authors in this volume (including me), refer to "Jesica" rather than "Santillan" or "Ms. Santillan." This familiar usage of her first name emphasizes her youth, even though she was nearly eighteen.

34. The literature on the history of southern benevolence and paternalism is large; a few examples include James C. Cobb, *The Most Southern Place on Earth: The Mississippi Delta and the Roots of Regional Identity* (New York: Oxford University Press, 1994); Bertram Wyatt-Brown, *Southern Honor: Ethics and Behavior in the Old South* (New York: Oxford University Press, 1983); and Eugene D. Genovese, *Roll, Jordan, Roll: The World the Slaves Made* (New York: Vintage, 1976).

35. John A. Mulhall, "How Many Died While Illegal Alien Got Two Heart-Lung Transplants?" *The Post-Standard* (Syracuse, N.Y.), February 27, 2003, A13.

36. Headrick and Cheng, "Some Link Citizenship, Transplants," A1.

37. A 2002 Border Counties Coalition study, funded by the U.S. Department of Health and Human Services after pressure from influential Arizona senator John Kyl, determined that 25 percent of uncompensated care costs ($190 million) to border hospitals were attributed to undocumented immigrants; See MGT of America, Inc., and U.S. Border Counties Coalition, "Medical Emergency: Who Pays the Price for

Uncompensated Emergency Medical Care Along the Southwest Border?" 2002, available at <www.bordercounties.org>. Since all such statistics must be estimates due to the fact that hospitals do not ask patients about immigration status, it is impossible to determine their accuracy; see Lisa Richardson, "Immigrant Health Tab Disputed," *Los Angeles Times*, May 18, 2003. Other studies have found that undocumented immigrants' use of emergency rooms is minimal; Chavez, Flores, Lopez-Garza, "Undocumented Latin American Immigrants"; Veronica Bucio, "Misperceptions Won't Cure Our ER Crisis" (op-ed), *Houston Chronicle*, January 7, 2002, A24.

38. I have found no evidence that the Santillan case played a role in the passage of this legislation.

39. Speech by Dana Rohrabacher, "Stemming Uncontrolled Illegal Immigration," House of Representatives, May 12, 2004, available at <www.votesmart.org/speech—detail.php?speech—id=40989>.

40. Centers for Medicare and Medicaid Services, <www.cms.hhs.gov/providers/section1011/state—alloc.asp>.

41. Alfredo Corchado, "Village Shocked Over Transplant Death," *Salt Lake Tribune*, February 24, 2003. The article by the reporter for the *Dallas Morning News* was picked up by the Salt Lake City paper.