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The Unrealized Hope of Welfare Reform

Implications for Health Care

Cecilia, a young biracial (African American and Hispanic) mother of two, identified herself as African American. She was introduced to us by another of our San Antonio respondents. We conducted a number of interviews with her over the course of a year and a half, during which her second child, a daughter named Annika, was born. When we met Cecilia, she was living with Annika's father. Her older child, a two-year-old boy named Kevin, was from a previous relationship. Cecilia's own childhood had been chaotic. Her father had thirteen children with various women, but Cecilia only knew two of her siblings and was not particularly close to either of them. One lived in another state and although Cecilia had talked to her on the phone, they had never met in person. Cecilia lived near her mother, but they were not close and Cecilia received little help from her. She described her mother as "remote" and unwilling to provide child care or other assistance to the family.

Cecilia's grandmother also lived nearby, and Cecilia's relationship with her was much warmer than her relationship with her mother. Her grandmother provided what support she could, and Cecilia greatly appreciated the help. When we met Cecilia, she was estranged from Kevin's father and would not allow him to have any contact with the boy. She felt that the father no longer had any right to see his son because he had stopped paying child support. Cecilia seemed resigned to the realities of her life and told us that she had always known that

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she was going to have to raise her children alone. As she explained,

> I made it [the decision to raise the children alone] before my first son was born and I knew I wasn't going to have their dad because he wasn't there when I was pregnant. He wasn't there really. . . . I wanted to show my mom that I can do it as a teen parent. . . . If my partner left me today I'll be alright because I feel like I can do it by myself even though I'm going to still struggle. I can do it myself.

After the birth of her first child, Cecilia quickly discovered that life with an infant was a real struggle. Although Kevin was bright and active, he developed behavioral problems at a very early age and acted up at the day care center where he stayed while Cecilia worked at a fast food restaurant. After he bit several other children, the center staff told Cecilia that she could no longer leave him there. Without child care for Kevin, Cecilia lost her job, and without a job she lost her apartment. She was forced to move back with her mother for a short time before she found another subsidized apartment. Luckily, early in the study, Cecilia was able to move to her own apartment away from her mother and the dangerous neighborhood in which her mother lived. Cecilia expressed great relief at being able to move away from what she described as the ill-behaved children and drug culture of her mother's neighborhood. Her new home was in a pleasantly landscaped compound with electronic access gates.

Cecilia and both children suffered from acute and chronic health problems for which Cecilia struggled to obtain treatment. Cecilia suffered from arthritis, and Kevin experienced frequent asthma attacks. Cecilia's second pregnancy had ended with a protracted labor and a complicated delivery that left her with ongoing medical problems. Like so many of the parents we met, Cecilia had to make difficult choices about who would get health care first, and she devoted much of her time and effort to getting care for her children, while she often delayed attending to her own health care needs.

Cecilia and her children were welfare "cyclers." They applied for Temporary Assistance to Needy Families (TANF) whenever the partner with whom Cecilia was living at the time was laid off or moved out or when Cecilia herself lost whatever job she periodically held. The family cycled off the TANF rolls when Cecilia's partner found a new job and was able to support the family and when her child care arrangements and her own health allowed her to work. The health care problems that

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resulted from her difficult second pregnancy, including weakness and ongoing infections, made it hard for Cecilia to maintain continuous employment, however, and her unstable employment and cycling in and out of jobs became a continuing reality that affected many aspects of the family's life.

Cecilia could not always understand or comply with the TANF regulations, and the state had sanctioned her for noncompliance several times by reducing or cutting off her benefits completely. She had been sanctioned when she did not report child support from Kevin's father. It was shortly thereafter that the boy's father stopped paying child support, but it was some time before her full TANF benefits were reinstated. At one point, Kevin was dropped from Medicaid when Cecilia missed a well-child checkup for him. On another occasion, the state lowered her food stamp allotment when she could not provide her caseworker with an address for Annika's father. Cecilia told us that on one occasion when she was particularly stressed by her case manager's strident questioning she broke down and cried in his office. The case manager was unmoved and told her that he did not believe that she had no income and threatened to sanction her for not reporting it.

The family depended on Medicaid for whatever care the children received and on a local program that allows family members to receive care for a predetermined minimal payment on their accumulated bill. Because this program did not provide free care but only allowed Cecilia to continue receiving care by making small regular payments on what she owed, there was no real possibility that she could ever pay off her medical debt completely. The more realistic outcome was that the debt would simply grow. Cecilia, like so many other impoverished women who accumulate medical debt, owed hundreds of dollars to the program. Our research with low-income mothers revealed just how difficult it is for them to maintain health care coverage for their families and how much time and attention they must devote to finding and keeping their children's health insurance. It also revealed the nearly impossible task these women, many of whom have serious chronic health problems of their own, face in paying for their health care. Most were unable to do so, and Cecilia's case was again typical. Early in her second pregnancy, the family lost all of its TANF, food stamp, and Medicaid coverage because Cecilia had missed a meeting with her caseworker that was required for recertification. Having

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missed the meeting, she had failed to file the required "proof of pregnancy" forms that would have allowed her to retain TANF and the other benefits for herself and had also failed to provide the information necessary for her children to continue receiving TANF and Medicaid.

In response, Cecilia resubmitted her documentation and began working with an advocacy organization to regain her welfare benefits. The difficult pregnancy made Cecilia's situation urgent, and Cecilia worked hard to try to regain Medicaid coverage before her second child's birth. It was unclear from our interviews exactly when she did regain coverage (Cecilia herself was not certain), but she had the coverage by the time of the delivery, and she and the newborn received the care they needed. She recounted with some irony how even when she was visibly in the later stages of pregnancy she had to provide "documentation" that she was in fact pregnant.

While waiting for her Medicaid coverage to resume, Cecilia delayed medical care for her son, who needed both dental work and treatment for a hernia. Luckily, her son's hernia receded without treatment, and Cecilia was relieved that he did not need expensive medical care that would have inevitably increased the family's medical debt. The dental care was simply put off. Unfortunately, a few months after Annika's birth, Cecilia again lost her son's Medicaid. Evidently, she was not up-to-date with his inoculations, and his Medicaid coverage was again canceled. As a result, Cecilia again plunged into a time-consuming flurry of activity to get her son's coverage reinstated.

During the periods when she was well enough to work, Cecilia held a series of short-term jobs, none of which offered health insurance. Her partner never received medical insurance from any of his jobs when he was living with her. Because nondisabled and nonpregnant adults who are not receiving TANF do not qualify for Medicaid or any other public program in Texas except under special circumstances, Cecilia and her partner had no coverage even when they were employed. Like other uninsured Americans with low incomes, when they suffered from health problems they had no options other than charity, going into debt, or simply forgoing care. For the family, the system of health care financing for the poor resulted in coverage for the children that was episodic and difficult to maintain, and coverage for the adults in the family was nonexistent, except for Cecilia herself when she was pregnant and eligible for Medicaid.

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Toward the end of our time with Cecilia, she was hospitalized twice, once shortly after the birth of her daughter, when an incision opened and became infected, and again a month or two later, when she developed a strep infection and there was concern that the infant might also be infected. Because she did not have health insurance, she again used CareLink, which added to her outstanding medical debt. Cecilia's struggle to provide medical care for herself and her family was a never-ending battle, and after the year and a half we were in contact with the family, we left with no sense of how things could ever improve. When the study ended, Cecilia was continuing to work whenever her health allowed her to do so, but her health remained precarious and maintaining steady employment was difficult. She kept her children enrolled in Medicaid when she could make all of the appointments and could provide the necessary documentation. Often, doing so meant missing work. As with the other families in our study, there was no happy ending to Cecilia's story, nor any sense of closure or resolution. As the children get older and as their eligibility for Medicaid changes, Cecilia's struggle for health care will change as well, but it will never end.

In the following chapters, we tell the stories of other low-income families and their encounters with the health care system and their attempts to obtain and keep medical care coverage. As with Cecilia, most of the stories we heard were confusing in many ways, largely because the lives of the people we worked with were often confusing and chaotic. Unlike fictional accounts, the story plots are not complete and there are often large gaps in the narratives. Although for the most part the mothers we interviewed were remarkably candid about their lives and were forthcoming with information, we could not always be sure when members of the family were employed and when they had health insurance because their lives were simply too complex and confusing to be easily entered into the sort of time and activity matrix that researchers often use (or that a well-crafted novel might portray). Even in directed interviews, the sequence of events and the identification of who did what when was often unclear to us and probably to the mothers themselves.

These families' efforts to obtain and keep continuous health care coverage represent only one of the many domains in which they faced daily struggles. In addition to health care, they had to worry about food, clothing, housing, education, employment, child care,

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transportation, and much more. Each of these domains presented multiple problems, and they could not be sure from month to month that their needs would be met. It was almost impossible for most to maintain long-term daily routines. Like Cecilia's, the problems they dealt with were rarely fully resolved and they fed upon one another. Our families cycled in and out of jobs and on and off welfare, Medicaid, private insurance, and other programs as numerous other problems impinged on their efforts to maintain their households. We came to realize that even they were frequently unsure as to which members of the family were covered by which programs or whether they were covered at all. Some, for instance, thought their children were covered by Medicaid only to find when they attempted to use medical services that the child was in fact not covered.

The stories we recount represent the best summaries of the lives of these families that we could compile from lengthy narrative interviews. Narrative lacks the neat structure of surveys in which every respondent is asked the same question in the same order and in the same way. It requires interpretation and judgment and in the end provides information that may not be statistically generalizable like that of a survey. On the other hand, narrative provides otherwise unavailable detail on the human experience of dealing with serious adversity in physical and social environments that seem to attack and undermine an impoverished family's every effort to get ahead. These stories are not verbatim transcriptions of what our respondents told us. The narratives were often too long and difficult to follow and much of the verbatim conversation too rambling and unstructured to make sense out of context. The stories we recount summarize, paraphrase, and characterize the lengthy conversations that we had with our respondents. We believe we have stayed true to the content of what our respondents wished to communicate. Of course, we also conducted a survey, and that information tells a similar story, but the narratives provide insight into what lies behind the numbers in a way that only intensive and free-flowing narrative can do.

The Three City Study

The chapters that follow focus on the system of health care coverage for the poor in the United States as it affects families like those in our

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study. As part of the discussion, we place that system in historical perspective and elaborate the unique situation of the United States among developed nations in not providing health care to all of its citizens as a basic right. As part of the development of our argument in favor of such a universal system, we draw on many data sources. The core of the presentation draws on information from the Three City Study, a large, multidisciplinary examination of the consequences of welfare reform for children and families. The two components of the study that we employ in this book, a survey of 2,400 families in poor neighborhoods in Boston, Chicago, and San Antonio and intensive ethnographic interviews with over 255 families from these same neighborhoods, provide detailed information on health insurance and health care and are described in the context of the larger study.

The larger study consisted of four components: (1) the survey, which was developed by anthropologists, economists, sociologists, and developmental psychologists; (2) an intensive developmental assessment of young children in those same families; (3) an intensive ethnography based on a separate sample of poor families similar in income to those in the survey and who lived in the same neighborhoods from which the survey sample was drawn; and (4) a similar ethnographic study of families that included someone with a significant disability. The logic of this design was to understand the lives of the poor and the potential impact that welfare might have on children from as many salient perspectives as possible. Each discipline and approach provided useful information and insights that informed the interpretation of the data we collected. The study represents a new and powerful approach to understanding complex social phenomena and provides important information that can inform public policy.

The survey consisted of two waves, the first of which was carried out from March to December 1999 in preselected low-income neighborhoods in Boston, Chicago, and San Antonio. As part of the selection criteria, each household contained at least one child younger than four or one child between the ages of ten and fourteen, ages that the developmental psychologists on the team deemed to be of particular developmental importance. Most households, of course, included other children as well. Forty percent of the survey families were receiving cash assistance at the time of the initial interview and, as we will see, very few had private or nongovernmental health insurance. We collected

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in the survey extensive information on income, education, earnings, employment, health, private health care coverage, Medicaid, welfare use, social program participation, and much more for each household. The second survey was conducted between September 2000 and May 2001 and collected information concerning changes in such factors as household structure, insurance coverage, and health care since the first interview. A third wave is in the field as this book goes to press. In what follows, we use information from the first and second waves of the survey to frame and generalize the discoveries from the ethnographic component.

The ethnography included a series of open-ended interviews and observations in the homes of mothers and their children in the same neighborhoods in which the survey was conducted, although the ethnographic families were not among those surveyed. The families that participated in the ethnography had household incomes of no more than 200 percent of the federal poverty line (FPL). The ethnographic sample design called for interviewers to recruit sixty families in each city from among each of three racial and ethnic groups: African Americans, Hispanics, and non-Hispanic whites. A smaller group of families that included someone with a serious disability was also selected. The study plan called for each interviewer to work with about six or seven families, visiting each family once a month for discussions of a variety of issues, including child-rearing practices and family rituals, the education and work histories of household members, and health and medical care coverage. Data were collected over a three-year period from 1999 to 2002. Interviews and observations were transcribed and coded and then entered into a qualitative database.

The ethnographic families were contacted between June 1999 and December 2000. About 40 percent of the families researched were Hispanic, 40 percent African American, and 20 percent non-Hispanic white, and roughly equal numbers came from the three study cities. To the extent possible, ethnographers met with each family an average of once or twice a month for between twelve and eighteen months and then again approximately six months and twelve months later. Although most meetings occurred in respondents' homes, the ethnographers also accompanied members of the families to the grocery store, family celebrations, welfare offices, and on a number of other family errands and activities. Topics addressed during these ethnographic

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visits with families included health and health care access, experiences with social welfare agencies, education and training, work experiences and plans, family budgets and economic strategies, parenting and child development, and support networks, among other issues. The work with families was accompanied by extensive neighborhood ethnographies in which ethnographers collected information on neighborhood resources (Burton et al. 2001; Winston et al. 1999).

The location and recruitment of families, the interview process, and the efforts to retain the families' involvement throughout the project illustrate many of the difficulties of intensive research with families in poverty as well as the nature of their life circumstances. We recruited families in neighborhoods that were home to impoverished families, and the families themselves had household incomes below 200 percent of FPL. In earlier work, we learned that families are most likely to participate fully in research of this nature if they are introduced to the project and the researchers by a trusted intermediary (Edin and Lein 1997). For that reason, the interviewers recruited families through public housing offices, day care centers, clinics, educational programs, and other contacts in the community.

We did not, however, recruit among the poorest of the poor. Interviewers did not seek out families in homeless shelters, in halfway houses, at centers that provided services for victims of domestic violence, or in situations where the children had been removed by the authorities. The mothers who participated in the study were women who were likely to have at least temporarily stable addresses, ties to at least one community organization, and a family consisting of at least the mother and a child. Many of the families in the study were struggling, but they were not the truly down-and-out. On the other hand, because we were recruiting families in low-income neighborhoods, neither did the study include families who were financially successful enough to move out. However, other studies of low-income families, particularly those drawing on large administrative databases, find that very few families actually move out of poverty in the years after they leave the welfare rolls (Isaacs and Lyon 2000; Schexnayder et al. 2002). In many ways, the families we studied resemble the more narrowly defined group of welfare leavers described in these studies in that they usually had some experience with one or another welfare program, they lived in a poor neighborhood, and

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their work experience was characterized by unstable jobs and low wages.

We can usefully describe our sample of families as a "middle cut" of low-wage and unemployed families. The families we describe were certainly struggling. Most were barely making ends meet, they were cycling between jobs and unemployment, and most were often behind in paying their bills. As we shall see, they often experienced lapses in health insurance, they had problems with housing, and they had difficulty paying for food, utilities, and transportation. However, in most cases, mothers and children were still together, and many found periods of stability that punctuated the periods of crisis and ongoing chaos that permeated much of their lives.

Even this middle-cut group of families experienced pressures, tensions, and discontinuities that took them out of the research process for a time, often leaving us with an incomplete record of their experiences. As we noted earlier, our original plan called for interviewing families on at least a monthly basis for eighteen months. However, only a minority of the families were available on a regular basis over the entire eighteen-month period. Thus, there are often blanks in our record of the families' life experiences. Families that experienced a sudden eviction (a more common event in Texas than in the other states because of the lack of tenant protection regulations), a sudden critical medical crisis, or any of a number of other setbacks were often difficult to find and unavailable for participation in the research project for a period of time. However, it was important to the nature of this research to keep these families in our sample. If we had excluded all families for whom there were discontinuities and missing data, our conclusions would have been based on an atypically stable group of poor families.

We also found that family life was sufficiently complicated that, on occasion, families did not know the answers to questions that, at least during the planning phase of the project, had seemed straightforward. These included such questions as whether the respondent was employed. The women in our study, like those in other studies of marginal workers, experienced frequent periods of unemployment and job hunting. For days, or even weeks, they might have been under the impression that they had their next job lined up. In such situations, they may well have told the interviewer that they were employed, even though they had not yet worked or received their first paycheck. Health

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