August 1984, p. B15.

<sup>8</sup>Conover, p. 3.

<sup>10</sup> Ibid.

<sup>11</sup> In 1987, Medicare covered \$2,391 of the \$5,360 in average personal health care spending by the elderly. Waldo *et al.*, "Health Expenditures by Age Group, 1977 and 1987," *Health Finance Review*, Vol. 10, No. 4 (Summer 1989), p. 118.

<sup>12</sup> E. Howell *et al.*, "Out-of-Pocket Health Expenses for Medicaid Recipients and Low-Income Persons, 1980," *National Medical Care Utilization and Expenditure Survey*, Series B, Descriptive Report No. 4, DHHS Pub. No. 85-20204, Office of Research and Demonstrations, Health Care Financing Administration, U.S. Government Printing Office, Washington, D.C., August 1985, pp. 21–22.

<sup>13</sup> Conover, p. 6.

<sup>14</sup> J. Holahan and S.R. Zedlewski, *Insuring Low-Income Americans: Is Medicaid the Answer?* (revised), The Urban Institute, Washington, D.C., July 1990, p. 3.

<sup>15</sup> All figures obtained from Center for Health Policy Research and Education analysis of 1988–90 Current Population Survey data for North Carolina.

<sup>16</sup> Data from May 1988 Current Population Survey, reported in U.S. Congress, Congressional Budget Office, *Rising Health Care Costs: Causes, Implications, and Strategies*, Washington, D.C.: Congressional Budget Office, April 1991, p. 75.

<sup>17</sup> The current minimum wage is \$4.25 an hour. A worker earning the minimum wage for 40 hours a week, 52 weeks a year would earn \$8,840.

<sup>18</sup> Conover, p. 19.

<sup>19</sup> Ibid.

<sup>20</sup>G.S. 58-51-30.

<sup>21</sup> Ibid., p. 20.

<sup>22</sup> Congressional Omnibus Budget Reconciliation Act of 1985, P.L. 99-272, 29 USC 1161.

<sup>23</sup> In 1989, average weekly earnings in retail trade were \$216.51, compared to \$366.10 for all privately employed workers in North Carolina. Employment Security Commission of North Carolina, *Employment and Wages in North Carolina, 1989*, 1990, p. 23.

<sup>24</sup> For more on how the lack of insurance affects decisions to seek health care, see Pam Silberman, "Health Care for the

# Health Care at the Margins: Three Families without Insurance

#### by Susan Dente Ross

Here are the stories of three North Carolina families without private health insurance. Gene Richards of Durham is the breadwinner for a family of four, but in a good month he earns only \$900. Using a combination of charity care and installment payments, his wife Carolyn struggles to finance health care for a child with special needs. Mary Hedgepeth of Rocky Mount wants to work, but her health problems frighten off would-be employers. Her Social Security disability payments make her ineligible for Medicaid, so she forgoes care and juggles bills to make ends meet. Nancy Smith is a single parent who depends solely on Medicaid to provide health care for herself and her family. So far the Smiths' care has been adequate, but it's never been tested by a longterm health crisis. In none of these cases has care been denied due to lack of insurance, yet they illustrate how inadequate insurance can have an impact on health.

Susan Dente Ross is a free-lance writer and a journalism instructor at Lynchburg College in Lynchburg, Va.

<sup>°</sup> Ibid.

Poor: Adequacy, Availability, Affordability," North Carolina Insight, Vol. 11, No. 2–3 (April 1989), pp. 122–137.

<sup>25</sup> Patricia M. Danzon and C. Johnston Conover, *Health Care for the Uninsured Poor of North Carolina*, Center for Health Policy Research and Education, Durham, N.C., August 1985, pp. 15–16.

<sup>26</sup> CRS: U.S. Congress, Library of Congress, Congressional Research Service, *Health Insurance and the Uninsured: Background Data and Analysis*, U.S. Government Printing Office, Washington, D.C., pp. 137–147. See also Danzon, pp. 15–16.

<sup>27</sup> Danzon, pp. 15-16.

<sup>28</sup> Steffie Woolhandler and David U. Himmelstein, "Reverse Targeting of Preventive Care Due to Lack of Health Insurance," *Journal of the American Medical Association*, Vol. 259, No. 19 (May 20, 1988), p. 2873.

29 Danzon, p. 15 and CRS, p. 142.

<sup>30</sup> John Billings and Nina Teicholz, "DataWatch: Uninsured Patients in District of Columbia Hospitals," *Health Affairs*, Winter 1988, p. 160.

<sup>31</sup> Mike King and Hal Strauss, "Thousands in South Dying for Lack of Health Care," *The News and Observer* of Raleigh, Sept. 30, 1990, p. 1A.

<sup>32</sup> "State Health Plans for the Uninsured and Ranking of States' Percent of Uninsured," Public Citizen Health Research Group, *Health Letter*, Vol. 6, No. 11, November 1990, p. 7.

<sup>33</sup> Chapter 58 (HB 1037) of the 1991 Session Laws.

<sup>34</sup> Joe Dew, "Program Targets Medically Uninsurable," *The News and Observer* of Raleigh, March 7, 1991, p. 1–B.

<sup>35</sup> Karen Youngblood, "Plan Helps Children in Need," Winston-Salem Journal, June 12, 1991, p. 1.

<sup>36</sup> Chapter 754 of the 1991 Session Laws (S.B. 917).

<sup>37</sup> Robert Pear, "U.S. Moves to Cut Medicaid Payments for Many States," *The New York Times*, Sept. 11, 1991, p. 1A.

<sup>38</sup> Frank Newport and Jennifer Leonard, "The Health Care Crisis," *The Polling Report*, August 12, 1991, p. 1.

<sup>39</sup> Martha P. King, *Medical Indigency and Uncompensated Health Care Costs*, National Conference of State Legislatures, July 1989, p. 20.

<sup>40</sup> Jerry Berger, "Prognosis Poor for Universal Health Care," State Legislatures, June 1991, p. 35.

<sup>41</sup> Ibid., p. 36.

### **Carolyn and Gene Richards, Durham**

CAROLYN AND GENE RICHARDS find the money to provide health care for their children. As for themselves, they mostly do without. Gene earns about \$900 a month hanging sheet rock when he can find the work. That's enough to disqualify the family for Medicaid, but a far cry from what it would take to pay for a true medical emergency.

Still, Carolyn has made peace with what for most middle-income families would be a glaring gap—the lack of health insurance. "We're healthy," she says glibly. And the children, Tommy, 12, and Melissa, 11, have gained limited coverage under the N.C. Caring Program, a private insurance initiative that offers free primary and preventive health care to children of low-income families.

The Richards live in a frame rental house on the east side of Durham, a house jammed in so close to its neighbor that Carolyn can hear telephone conversations through an open window. The front door hangs loose. The porch sags. An oil-on-velvet portrait of Hank Williams Jr. graces the living room walls—a Christmas gift Gene got from his cousin. The Richards are no strangers to hard times, but the Caring Program has made things a little easier.

Until recently, the Richards had to struggle with medical bills for a child with severe health

problems. Tommy was born without either a hard or a soft palate, and when he was 10 days old—still in the hospital—his left leg was broken.

At 11 months, doctors surgically reconstructed his palate, but he's been seeing an array of physicians ever since. There are, of course, the routine medical needs of any growing child. But Tommy also regularly sees a speech therapist, a speech



Carolyn Richards helps daughter Melissa with her homework.

pathologist, a plastic surgeon, an orthodontist, a hearing specialist, and doctors at an ear and throat clinic.

He has had nine sets of ear tubes implanted surgically to correct a nearly constant string of ear infections that has left his hearing slightly impaired. His tonsils and part of his adenoids have been removed. And there's the specter of repeat surgery for his cleft palate and the certainty of dental braces in his future.

In August 1990, when one of Tommy's ear tubes fell out, Carolyn just crossed her fingers and hoped for the best. She had no choice because the Richards had no medical insurance. Then came the Caring Program for Children. It offers free primary and preventive health care to children of low-income families. A collaboration of Blue Cross and Blue Shield of North Carolina and the N.C. Council of Churches, the program covers routine immunizations, doctor visits, emergency and accident care, x-rays and other diagnostics, and outpatient surgery for children under 19.

But for a child with the health problems Tommy has, there are still gaps. The program does not cover prescriptions, speech and hearing services, dental braces, or in-patient surgery. Still, Carolyn is grateful for the help. "I'm glad they have the program," she says. "Even if it's just for check-ups, those are still expensive."

1

Without missing a beat, she recites some of the specific costs of routine medical care. An office visit runs \$22. Septra, a frequently prescribed treatment for ear infections, costs \$15 to \$20. The Richards rang up a \$75 bill in a hospital emergency room when Melissa got strep throat. The bill along with a \$10 prescription totaled \$85 nearly one-eighth of the family's monthly income.

Despite the Richards' limited means, Carolyn is a careful health care consumer. For example, she entrusts the care of her son primarily to Duke University Medical Center and avoids the public clinic. "They seem to rush you right through," she says. "Sometimes with a child with special needs or even one without special needs—you have to make sure they get that extra care. I'm very particular about the children's doctors because I've seen so many. I know it makes a difference. With Tommy's needs, he's strictly Duke. From when he was three until he hit second grade, I was at Duke every week. Those doctors have seen him grow up from my arm baby."

Richards concedes that the family cannot afford this kind of care for Tommy. His annual daylong visit to various specialists at Duke costs \$150. "Still, it's for my sanity," says Richards. She also takes Tommy to Duke twice a year to get his hearing tested, rather than relying on the public schools. She pays on the bills not covered by the N.C. Caring Program "a little at the time. That's all you can do," Carolyn says. "I'll just have to pay it off."

The Richards also have gotten help from time to time from Medicaid and the state Crippled Children's Program in the Division of Health Services. But when Gene is working they don't qualify for Medicaid, and there are gaps in all of these programs.

With so little money to begin with, and so much of it going to medical costs, a lot of things just have to wait—like new clothes and a bike for the children. "And they've learned like I learned," says Richards. "When you need something or you really want it bad enough, you just have to put it on hold for awhile."

## Mary Hedgepeth, Rocky Mount

MARY HEDGEPETH is stuck between a rock and a hard place when it comes to health care. She needs a job so she can get health insurance to help pay her many medical bills, yet no one wants to hire her for fear her medical problems will interfere with her work. Hedgepeth is legally blind and her vision is getting worse.

"I have a good resume, and my record shows I can work," Mary says, "but nobody will trust me. They think because I can't see well, I can't work well. But a person who is vision-impaired is more careful because we know we have to watch ourselves."

Still, Mary's vision problems are only the beginning. She has ulcers and rheumatoid arthritis. She suffers from anxiety and high cholesterol. And with no job, she has no health insurance for herself or her sons—19-year-old twins and a 15-year-old.

Mary's Social Security disability payment of \$429 and her child support of \$200 a month push the family income above Medicaid's eligibility limit. There is no room in her budget for private insurance.

So Mary scrimps on medical care. When she was covered by Medicaid, Mary's prescriptions cost about \$250 a month. Now she tries to hold expenses for prescriptions to below \$125 to leave about \$500 for the family's other bills, including \$311 a month for rent. She avoids or postpones medical care whenever possible. Her physician has substituted less expensive and sometimes less effective drugs, and she takes them less frequently than prescribed.

"I can't afford to take prescriptions as I should," Hedgepeth says, "and I get sick from not taking them. I'm in pain. My stomach bothers me. Then too, I can't get a lens implant that would really help me see because I can't afford it. And we all need dental work.

"I know my frame of mind would be much better if I had these services available to me. Right now, the only thing I can do is go to the emergency



Mary Hedgepeth at her desk in Rocky Mount.

room, and I can't do that because I can't afford to pay for it. You can cut back on groceries, but that affects my cholesterol. There's only so much that you can rob Peter to pay Paul."

She wonders whether her ulcers and anxiety wouldn't subside if she didn't have to worry so much about making ends meet. "My God, I just can't think about if I don't pay my light or phone bill what will happen," she says. "Do you know what it's like to come home and flip the switch to see if you've got lights or pick up the phone to see if it still works? It's nerve-wracking."

Hedgepeth's vision loss began in the mid-1980s. She says her vision loss stems from detached retinas, cataracts, a weak—or lazy—right eye and dry-eye syndrome. She isn't certain what caused what, but she suffers progressive vision loss, and the treatments are expensive and experimental.

The contact lens that improves the vision in her strong eye has long needed replacement, but a new lens costs money. She risks additional vision loss and a dangerous eye infection because she cannot see well enough to remove the contact lens and clean it herself. She simply leaves it in, day and night, because she cannot afford to have it removed and cleaned.

The vision in her right eye might improve through an experimental lens implant. "The doctor couldn't guarantee better sight or for how long, but it's possible," she says. "And I want it if only for cosmetic reasons. I don't like to have my picture taken anymore because of the way it looks." But until Hedgepeth's financial situation improves, she has given up on the operation. "I didn't make any plans for it because I couldn't afford it," she says.

Her twins already exhibit some of her vision problems. Both have partially detached retinas. And 15-year-old Lionel has arthritis problems with his back and an ailment called loose body osdeochondritis disease that caused him to require arthroscopic knee surgery in September 1991.

Hedgepeth holds small hope of getting a job that would enable her to pay for private health insurance. She continues to take training programs virtually whenever and wherever available and to try to find a job. But she fears there is no work for her in Rocky Mount. "A woman at Social Services here said I had more going for myself than most of the people there, but I'd have to relocate because businesses wouldn't hire me because I'm a safety hazard... and a black lady with education," says Hedgepeth. "I'll do anything I think can help me," she says. "I would leave Rocky Mount in a heartbeat if I could get a job. I enjoy working."

Hedgepeth has an associate degree in business administration. She has worked for most of the past 20 years, nine of those years in a fast food restaurant and six as a nurse's aide. While in college, she was a work-study student, and for a time she did bookkeeping for the city of Rocky Mount.

"Society has me stereotyped, and I can't be very productive—as productive as I could be if I had my medicine and some insurance. I could work around my problems if I could pay for my medicine, and I can get any equipment I need to do a job from Services for the Blind."

Still, she's had no luck finding a job. And so Hedgepeth demonstrates her productivity as a volunteer for the guardian ad litem program and for Big Brothers and Big Sisters. She serves on the boards of the National Federation for the Blind and of N.C. Fair Share, a grassroots organization that helps promote better health-care benefits. Hedgepeth also works with a health-care steering committee in Rocky Mount that is trying to open a public health clinic for Edgecombe County residents. The city lies in two counties, and a health clinic would save Edgecombe residents from having to go to Tarboro to get services.

All this volunteer work is important to Hedgepeth, but it won't help her pay her bills. "I don't like living off the system," she says, "and here I have strived to get an education and to instill the importance of education in my kids, but they see me with no job and they say, 'You got an education, and it didn't do no good.""

## Nancy Smith, Raleigh

THE BIGGEST COMPLAINT NANCY SMITH has about being on Medicaid is the application process. Eight years after getting up the nerve to walk into the Wake County Social Services Department and apply for the program, the humiliation of the interview still burns in her memory.

"They wanted to know everything but basically your shoe size," says Smith. "I don't think because you're poor or in a transition period is a crime, and I needed some health insurance.... They didn't need to treat me like a criminal." Smith, 42, and her three children have been covered by Medicaid since 1983, shortly after she fled home and her abusive husband. "We ran away from home and gave up everything," she says. "I thought Medicaid would help me through the transition."

Smith didn't realize that eight years later she would *still* be in transition—still making do with Medicaid. "The biggest problem is [that Medicaid] does not pay the full cost of medications," says Smith. "And if the pharmacy I use is closed, maybe another pharmacy won't take the prescription because I've used the Medicaid prescription card somewhere else.

"Or you get a prescription, and the pharmacist will tell you Medicaid doesn't cover this. There's been some medicines I couldn't afford, and sometimes I had to go back and get another prescription I could afford. I didn't mind. You better not mind or else."

Finding doctors who accept Medicaid also can be difficult. "Medicaid is like food stamps, only worse, because not every doctor takes Medicaid," Smith says. "You have to hunt a lot, and you may not find the doctor you want or like.

"I go through the Yellow Pages. It's almost like a crossword puzzle. You have to search them out. For example, the kids go to the Wake Teen Clinic, and I feel they have gotten the quality of care they would if we had paid privately. But you can't always get the same doctor—the one that's been used to you. I don't have a regular doctor at all.

"When you go to the public health clinic, it's like a factory. They don't know you, and you have to wait and wait. I hear war stories of waiting half a day."

٠.

In the years immediately following her marriage, Nancy was agoraphobic, overweight, and had bad teeth. "I needed to re-establish myself as a person," she says. "I knew I was OK, but I didn't know how I fit together."

The first thing she wanted to do was be able to smile again. "I had left the marriage with broken teeth," says Smith. Medicaid paid for her dental work. "But you have less choice of a dentist, and you can't, at least I couldn't, get a root canal, so some teeth I wanted to save I couldn't because it would take too much work. But they did realign my jaw, and now I can smile."

Nancy could never determine whether Medicaid would pay for personal or family counseling. "At first it seemed like they would in a limited way and not for long," she says. "Then it seemed they didn't cover counseling at all. Then, who knows? I'm to the point on a lot of things where I say, 'Why bother?""<sup>1</sup>

But counseling was important to Smith. "I believe in preventive care," she says. "My mother taught me that. I had gotten my kids and myself into family counseling before we decided to run away. I didn't want my kids to become alcoholics like their daddy, or drug addicts or abusers. So I



wound up paying for the counseling on my own. Thank goodness it was on a sliding scale. Think about it: counseling weekly for four people for five years! But that counseling has helped me more than anything."

At the time, Nancy was supporting her three boys—now 19, 20, and 25—on \$266 a month from Aid to Families with Dependent Children and \$50 a month in support from their father.

By and large, the family's medical needs have been routine. "All we ever did was go in for yearly exams and to the dentist," Nancy says. But the routine medical needs of growing boys do include emergencies. There was the time four years ago that Ryan's appendix ruptured in school. He had to have an emergency appendectomy and spent almost three weeks in the hospital. Or the time last December when Robert had to have minor, sportsrelated surgery. Or the time he got cut with pliers. Medicaid covered it all. "I never even saw the bills," Nancy says.

"But," says Nancy, "we're not sickly people. We're very lucky. I've met people with a lot worse problems than I have with Medicaid. I know people who use up the limit" of 24 paid doctor's office visits a year.

The one medical condition Nancy wanted to tackle in 1983 but has yet to address is her weight. "I have wanted to go into counseling for weight and exercising," she says. "I really want to do that."

"And," she adds, "my mother taught me to smother. Now I'm trying to learn to be a mother and keep my hands off my kids and let them grow."  $\square$ 

<sup>1</sup>Dennis Williams, assistant director for medical policy in the Division of Medical Assistance, N.C. Department of Human Resources, says Medicaid generally does pay for counseling at Area Mental Health centers but not in every circumstance.

47