

medicaid
and the uninsured

THE NORTH CAROLINA
HEALTH CHOICE ENROLLMENT
FREEZE OF 2001

Prepared by

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UNC at Chapel Hill

kaiser commission on medicaid and the uninsured

The Kaiser Commission on Medicaid and the Uninsured serves as a policy institute and forum for analyzing health care coverage and access for the low-income population and assessing options for reform. The Commission, begun in 1991, strives to bring increased public awareness and expanded analytic effort to the policy debate over health coverage and access, with a special focus on Medicaid and the uninsured. The Commission is a major initiative of The Henry J. Kaiser Family Foundation and is based at the Foundation's Washington, D.C. office.

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January 2003

Executive Summary

North Carolina was the first state in the country to impose an enrollment cap on its State Children's Health Insurance Program (S-CHIP), called North Carolina Health Choice for Children (hereinafter referred to as NC Health Choice). From January 1, 2001, until October 8, 2001, NC Health Choice capped enrollment.¹ Since North Carolina's imposition of an enrollment cap, two other states, Utah and Montana, have implemented caps in their S-CHIP program. Because of tight state budgetary constraints, other states may consider this action in the future. Little is known about the impact such enrollment caps have on low-income children's health, access to health care, and cost of care. By studying the experiences of low-income children affected by the North Carolina enrollment cap, we hope to inform policy makers as to the range of effects that caps on public insurance programs might be expected to have.

The Kaiser Commission on Medicaid and the Uninsured contracted with the Cecil G. Sheps Center for Health Services Research, at the University of North Carolina at Chapel Hill, to study the effect of the enrollment on children's access to and use of health care services. Our study has three components: 1) quantitative analysis of administrative data to determine the number of children affected by the enrollment cap and whether they eventually qualified for NC Health Choice or Medicaid; 2) focus groups with parents of children who had been placed on a waiting list when enrollment was closed; and 3) an analysis of the utilization data to determine whether children on the waiting list who eventually qualified had pent-up demand for services. The NC Division of Medical Assistance, within the NC Department of Health and Human Services, graciously agreed to provide enrollment and utilization data for the study.

This report contains the results of the first two analyses—the quantitative analyses of the administrative data and the focus groups. We chose to conduct focus groups rather than a survey because of the need to contact affected families as quickly as possible to minimize respondent recall bias. The focus groups were conducted within seven months after North Carolina lifted the enrollment cap for new applicants.

History of NC Health Choice program

The North Carolina Health Choice program began in October 1998. NC Health Choice is a separate state children's health insurance program, providing comprehensive health benefits for certain uninsured children. The NC General Assembly chose to create a separate state program, rather than expand Medicaid, because they thought that it would be easier to control program costs. To qualify, children must be ineligible for Medicaid

¹ North Carolina actually froze enrollment from January 1, 2001 to July 1, 2001; and put all new applicants on a waiting list. Beginning on July 1, 2001, the state started processing applications for the children who had previously been put on the waiting list, but did not completely open the program to new applicants until October 8, 2001.

and have a family income that is equal to or less than 200% of the federal poverty guidelines (or \$29,260/year for a family of three in 2001). The NC Health Choice program is administered jointly by the NC Division of Medical Assistance (DMA) within the NC Department of Health and Human Services (DHHS) and the Teachers' and State Employees' Comprehensive Major Medical Plan (hereinafter the State Employees Health Plan). DHHS has overall responsibility for the program—and must ensure it operates within state and federal budget parameters. DMA determines eligibility and the State Employees Health Plan administers the benefits. The State Employees Health Plan contracts with Blue Cross Blue Shield of North Carolina (BCBSNC) to pay claims.

The NC Health Choice program provides comprehensive benefits, including but not limited to: primary care and preventive services, inpatient and outpatient hospital services, prescription drugs, mental health and substance abuse treatment, durable medical equipment, therapy services, vision, hearing, and dental. Children with special health care needs may qualify for additional benefits. Children with family incomes in excess of 150% of the federal poverty guidelines (or \$21,945/year for a family of three in 2001) must pay an annual enrollment fee of \$50 for one child, or \$100 for two or more children. In addition, these families have co-payments for certain services, including \$5 for each physician, clinic, dental, or optometry visit; \$5 for outpatient hospital visits; \$6 for each prescription, and \$20 for use of the emergency room.

Early in the program's inception, North Carolina was recognized as one of the national leaders in enrolling uninsured children. The NC Department of Health and Human Services initially estimated that there were approximately 71,000 uninsured children who would be eligible for NC Health Choice, and budgeted accordingly. The program grew quickly, so that by the end of December of 2000, there were more than 72,000 children enrolled in the program (See Chart 2). The NC Department of Health and Human Services realized that the program would run out of funds by the end of the state fiscal year. Because of the way the program was established—the NC Department of Health and Human Services only had the discretion to limit enrollment; not reduce provider reimbursement rates or utilization (which was under the control of the State Employees Health Plan) or cut services (legislatively mandated by the NC General Assembly). As a result, DHHS, with the approval of the Governor's Office, froze enrollment beginning in January 2001 to assure that the program operated within its state and federal budget. Children who were enrolled in NC Health Choice at that time continued to receive coverage, and they retained their coverage even after their one-year enrollment period if they re-applied within the specified time period and were determined to be eligible. However, new enrollees, children who were no longer eligible for Medicaid due to increases in family income or because they "aged" out of coverage, and children whose parents did not seek to reenroll in the program within a specified time period were put on a waiting list if they were determined to be eligible for NC Health Choice. Children who were on Medicaid who would ordinarily be "rolled-over" into NC Health Choice were caught in the NC Health Choice enrollment cap.

NC Health Choice enrollment dropped from a high of 72,024 at the beginning of January, 2001, to 59,472 children by June of that year. Children lost eligibility due to

changes in family income, aging out of the program, or because their parents did not submit a form to renew their coverage within a specified time period. As a result of this decline in enrollment, the state began in July 2001 to process the applications of families on the waiting list prior to that date on a first-come, first-served basis. New applicants were put on the waiting list during this time period, but the children who had been waiting the longest started to have their applications processed. Despite the partial re-opening of NC Health Choice in July, enrollment continued to drop until it reached a low of 51,294 in October 2001. The enrollment cap was officially ended for new applicants on October 8, 2001.

Analysis of Waiting List Enrollment Files

We obtained application and eligibility files from the NC Division of Medical Assistance, to determine how many children previously enrolled in NC Health Choice ended up on the waiting list, where the other children on the waiting list came from, and the insurance status of wait list children after the cap was lifted. There were 53,340 children enrolled in NC Health Choice with re-enrollment dates that fell during the enrollment cap (January 1 – October 8, 2001). Approximately half of these children (49.0%) were recertified and remained on NC Health Choice. One-fifth of the children (20.9%) qualified for Medicaid. Almost all of these children were categorically eligible for Medicaid — that is, they qualified based on their family income; but a few (42) were able to qualify because of large medical bills. Only 1,537 children (2.9%) did not reapply in time, were found to be eligible when they did file their applications, and were placed on the waiting list. Some children (5.1%) reapplied but were found ineligible for NC Health Choice or Medicaid—presumably because their family income had increased. However, almost one-fourth (22.0%) of the children who were enrolled in NC Health Choice simply did not reapply for coverage. We have no information to know what happened to these children, or why they did not reapply.

During the time of the enrollment cap, there were 34,282 children who were found to be eligible for NC Health Choice but were put on the waiting list. Most of these (60.0%) were children who had been receiving Medicaid, but were unable to “roll-over” because of the enrollment cap. A little over one-third (35.5%) were new applicants to Medicaid or NC Health Choice. Only 4.5% (1,537 children) were children who had previously been on the program, but did not reapply for coverage in time.

Almost half of the children on the waiting list (47.2%) were ultimately enrolled in NC Health Choice when the program re-opened. Another quarter (24.5%) were enrolled in Medicaid, which means that their family income decreased after they were placed on the waiting list. The remaining 28.4% did not qualify for NC Health Choice or Medicaid when their application reopened, or could not be located.

Impact of the Enrollment Cap on Families

Participants in the focus groups reported that the enrollment cap caused significant hardship for their families. Children who were caught in the cap faced periods

of uninsurance that ranged from four weeks to more than a year, although most families reported that their children were uninsured for less than six months. Most of the children caught during the enrollment cap were the poorest of the working poor—those who were applying directly after losing Medicaid coverage. Many families reported trying to seek other health insurance coverage for their children when they were uninsured—but most were unable to afford the monthly premium costs—even when it was available through their or their spouse’s employer. Only 16% of the participants were able to get private health insurance coverage during the waiting period.

A lot of them (jobs) have the insurance, like where I work they have it but it’s too much for a family...I have it on myself but you feel bad you can’t get it on your kids. It just cost too much. You’d be paying them actually all of your paycheck.

Almost all of the participants needed health care for their children at some point during the time their children were uninsured. Their children’s health care needs ranged from common illnesses, such as colds, fevers, bronchitis and flu—to more serious concerns with asthma and potentially life threatening infections. Families struggled to meet their children’s health care needs during the cap. Although most families eventually were able to secure care for their children, they reported making substantial sacrifices to do so, often delaying needed care and/or incurring large bills.

My daughter had a problem in her ear and they had to do surgery on it ...We didn’t have insurance...(my) child suffered a month (before we finally had the surgery).

My problem was prescriptions. (There were times I couldn’t get asthma medicine for my child because of the cost)...Even if you get to take the child to the doctor, you might not have the money for the medicine...I had to wait until payday or something.

Several took their children to the emergency room for care; others sought out low-cost options through community health centers or health departments. However, these low-cost options were not available in every community, and even when they were available, the participants did not always know the services existed. Some families reported that they could work out payment arrangements with their private providers. Even if the families were able to obtain needed medical services for their child’s acute or chronic health needs, they reported problems getting the needed medications. Some were able to obtain free samples from their doctors or from pharmaceutical assistance programs—but others reported the need to share medicine between children or use old prescriptions they had at home.

We did something I wouldn’t recommend but I had old antibiotics that I had had for an infection and I gave them to the older one who was sick...that was my prescription... I gave it to her. So I think you are also making bad choices when you don’t have money. I mean it could have been the wrong antibiotic but you’re desperate to do whatever you have to do.

Obtaining needed medical care caused great financial hardship to the families, as all of the families had modest incomes (below 200% of the federal poverty guidelines, or \$30,040 for a family of three). Participants reported juggling payments, borrowing money from friends or family, buying basic or lower quality food, and going without food. Because of the difficulty in paying the bills on time, they incurred late fees and received calls from creditors. Many reported that they were still paying for some of the health care bills incurred during the time their children were uninsured.

Almost universally, participants reported an overall appreciation for the coverage offered their children through NC Health Choice. Participants lauded the low costs and generally comprehensive coverage. They appreciated the similarity between NC Health Choice and private insurance. As several respondents noted—NC Health Choice was a “godsend” for families that had incomes that were too high to qualify for Medicaid, but not high enough to afford private coverage.

There’s so many of us that fall into that middle income range...not poor enough (for Medicaid) but not rich enough (for private insurance).

I was on welfare for so long. I said if God would bless me with a job, I’d make sure my kids are taken care of. It was hard to seek help again...I said I wouldn’t go back to Social Services, but then the kids got sick and I got to where I couldn’t afford insurance. My income is above the level for Medicaid, so this program helps me. It doesn’t seem like a welfare program.

While the participants were generally positive about the program, they did note various ways in which the program could be improved. One of the striking findings throughout all of the focus groups was the general lack of understanding about the program—what it covered, the eligibility rules, and the differences between NC Health Choice and Medicaid. Another common complaint that surfaced in these focus groups was the inability to find a dentist willing to treat NC Health Choice children; and the limits on coverage for orthodontia. Participants also were concerned that the state might impose another enrollment cap, —given the state’s current financial troubles. Despite these concerns, almost all of the participants were planning on reapplying for the program.

In sum, many families faced significant hardships as a result of the enrollment cap. Children were uninsured for a period that ranged from four weeks to more than a year. Most families in the focus groups “did what they needed to do” to secure care for their children while on the waiting list, but they often had to make considerable sacrifices to do so. Many reported delaying needed care, and in some cases their children endured unnecessary pain and suffering as a result. In a few cases, families told about surgery or tooth extraction that might have been avoided with earlier care. Many reported problems obtaining needed medications. Nearly all families experienced financial hardship due to out-of-pocket expenses for medical and dental care while their children were uninsured, and reported buying less and lower quality food, delaying rent and utility payments, and

incurring late fees or calls from creditors. Most of the children caught during the enrollment cap were from among the poorest of the working poor families, those who were applying directly after losing Medicaid coverage. These are the children with the least resources to pay for ongoing health care needs.

The North Carolina Health Choice Enrollment Freeze of 2001: Health Risks and Financial Hardships for Working Families

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Purpose of the study

North Carolina was the first state in the country to impose an enrollment cap on its State Children's Health Insurance Program (S-CHIP), called North Carolina Health Choice for Children (hereinafter referred to as NC Health Choice). From January 1, 2001, until October 8, 2001, NC Health Choice capped enrollment.¹ Since North Carolina's imposition of an enrollment cap, two other states, Utah and Montana, have implemented caps in their S-CHIP program. Because of tight state budgetary constraints, other states may consider this action in the future. Little is known about the impact such caps have on low-income children's health, access to health care, and cost of care. By studying the experiences of low-income children affected by the North Carolina enrollment cap, we hope to inform policy makers as to the range of effects that caps on public insurance programs might be expected to have.

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History of NC Health Choice program

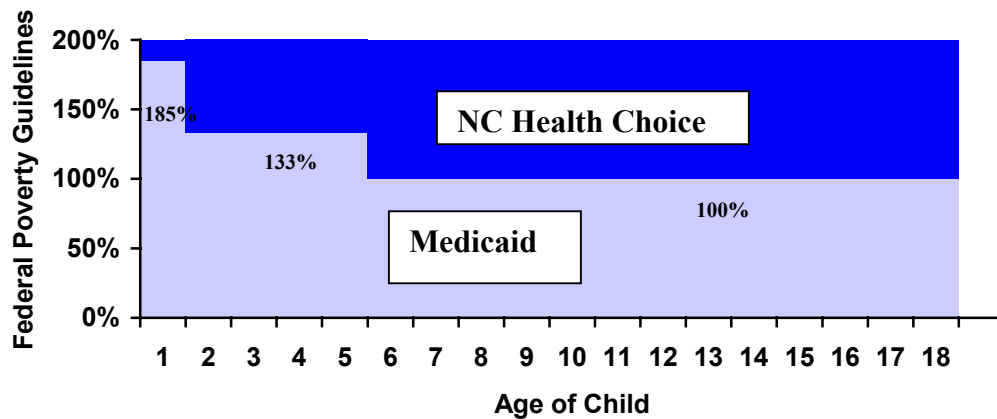
The North Carolina Health Choice program began in October 1998. NC Health Choice is a separate state children's health insurance program, providing comprehensive health benefits for certain uninsured children. The NC General Assembly chose to create a separate state program, rather than expand Medicaid, because they thought that it would be easier to control program costs. NC Health Choice must operate within specific budget parameters. To qualify, children must be ineligible for Medicaid and have a family income that is equal to or less than 200% of the federal poverty guidelines (or \$29,260/year for a family of three in 2001). The NC Health Choice program is administered jointly by the NC Division of Medical Assistance (DMA) within the NC Department of Health and Human Services (DHHS) and the Teachers' and State Employees' Comprehensive Major Medical Plan (hereinafter the State Employees Health

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Families who are interested in applying for NC Health Choice must fill out a two-page application form. The form is available at local Departments of Social Services (DSS), health departments, community health centers, many private providers, some schools and daycare centers, through a toll-free hotline, and on the DMA's website. Families may apply in person at the local Department of Social Services or health department, or may mail in an application. Local DSSs determine eligibility, first by examining the child's eligibility for Medicaid, and if not eligible, determining eligibility for NC Health Choice. Eligibility for Medicaid is based on the child's age and family income, with higher income eligibility thresholds for younger children (See Chart 1). Because of this "stepped" eligibility system, Medicaid may cover the younger children in a family, while NC Health Choice covers their older siblings. Children who are eligible for Medicaid are eligible for one-year continuous enrollment, unless the child ages out of a particular income eligibility category. In this event, DSS must assess the child's eligibility for NC Health Choice, based on the income and other eligibility information already contained in the file. If the child is determined to be eligible for NC Health Choice, he or she will be automatically "rolled-over" into the program.²

Chart 1
Income Eligibility Guidelines for Medicaid and NC Health Choice
(By Age)

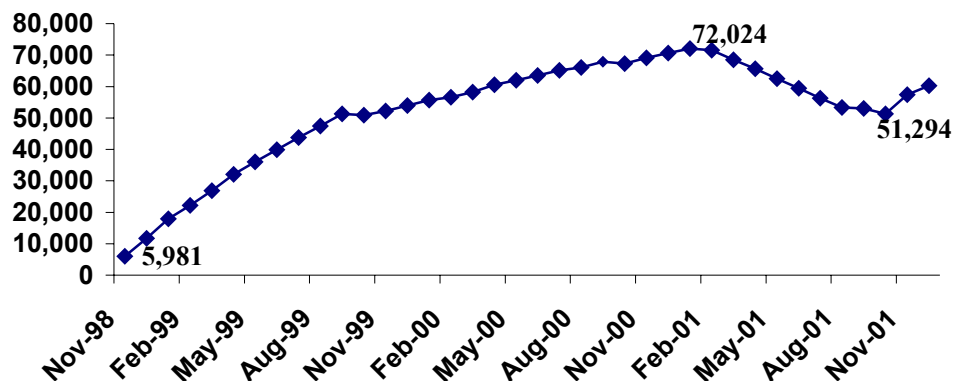


Children who are determined to be eligible for NC Health Choice receive one year of continuous enrollment. During the eleventh month of coverage, the family is sent a mail-in application form to renew coverage. To continue to receive benefits, the family must send in the completed form, be determined to be eligible, and pay the annual enrollment fee (if applicable).

Early in the program's inception, North Carolina was recognized as one of the national leaders in enrolling uninsured children. The NC Department of Health and Human Services initially estimated that there were approximately 71,000 uninsured children who would be eligible for NC Health Choice, and budgeted accordingly. The program grew quickly, so that by the end of December of 2000, there were more than 72,000 children enrolled in the program (See Chart 2). The NC Department of Health and Human Services realized that the program would run out of funds by the end of the state fiscal year. Because of the way the program was established, —the NC Department of Health and Human Services only had the discretion to limit enrollment; not reduce provider reimbursement rates or utilization (which was under the control of the State Employees Health Plan) or cut services (legislatively mandated by the NC General Assembly). As a result, DHHS, with the approval of the Governor's Office capped enrollment beginning in January 2001 to assure that the program operated within its state and federal budget. Children who were enrolled in NC Health Choice at that time continued to receive coverage, and they retained their coverage even after their one-year enrollment period if they re-applied within the specified time period and were determined to be eligible. However, new enrollees, children who were no longer eligible for Medicaid due to increases in family income, and children whose parents failed to reenroll during the appropriate time were put on a waiting list if they were determined to be eligible for NC Health Choice. Children who were on Medicaid who would ordinarily be "rolled-over" into NC Health Choice were caught in the NC Health Choice enrollment cap.

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Chart 2
NC Health Choice Bi-Monthly Enrollment
(Nov. 1998-Nov. 2001)

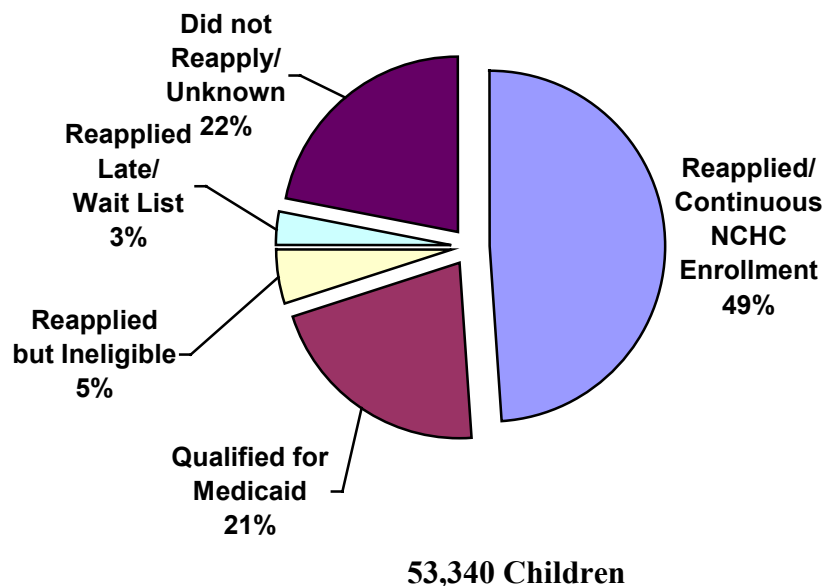


Analysis of the Administrative Data

We obtained application and eligibility files from the NC Division of Medical Assistance, to determine how many children previously enrolled in NC Health Choice ended up on the waiting list, where the other children on the waiting list came from, and the insurance status of wait list children after the cap was lifted. There were 53,340 children enrolled in NC Health Choice with re-enrollment dates that fell during the enrollment cap (January 1 – October 8, 2001). Approximately half of these children (49.0%) were recertified and remained on NC Health Choice. One-fifth of the children (20.9%) qualified for Medicaid. Almost all of these children were categorically eligible for Medicaid—that is, they qualified based on their family income; but a few (42) were able to qualify because of large medical bills. Only 1,537 children (2.9%) did not reenroll in time, were found to be eligible when they did file their applications, and were

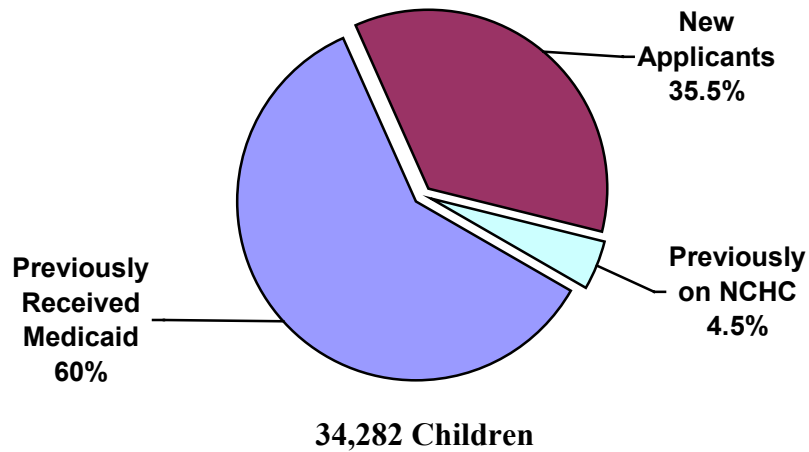
placed on the waiting list. Some children (5.1%) reapplied but were found ineligible for NC Health Choice or Medicaid—presumably because their family income had increased. However, almost one-fourth (22.0%) of the children who were enrolled did not submit applications to renew their coverage. We have no information to know what happened to these children, or why they did not reapply.

Chart 3
NC Health Choice Children with Reenrollment Dates
During Enrollment Cap



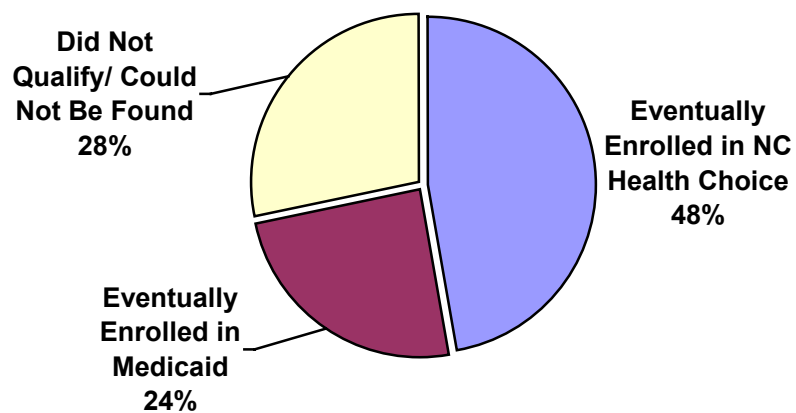
During the time of the enrollment cap, there were 34,282 children who were found to be eligible for NC Health Choice but were put on the waiting list. Most of these (60.0%) were children who had been receiving Medicaid, but were unable to “roll-over” because of the enrollment cap. A little over one-third (35.5%) were new applicants to Medicaid or NC Health Choice. Only 4.5% (1,537 children) were children who had previously been on the program, but did not reenroll in time.

Chart 4
Children Eligible for NC Health Choice
Placed on Waiting List



Almost half of the children on the waiting list (47.2%) were ultimately enrolled in NC Health Choice when the program re-opened. Another quarter (24.5%) were enrolled in Medicaid, which means that their family income decreased after they were placed on the waiting list. The remaining 28.4% did not qualify for NC Health Choice or Medicaid when their application reopened, or could not be located.

Chart 5
Program Coverage When Enrollment Cap Lifted



Focus Group Methodology

We conducted six focus groups over a two-month period (March 18 – May 2, 2002). The focus groups were conducted within seven months after the enrollment cap was fully lifted. We contracted with First Research, of Greensboro, NC, to lead the focus groups. Four focus groups were in urban areas, and two were in rural areas (defined as non-Metropolitan Statistical Areas). We obtained enrollment data from the NC Division of Medical Assistance to identify potential focus group participants. Potential participants were screened, by telephone, to determine if they knew about the enrollment cap. Only individuals who knew about NC Health Choice and about the enrollment cap were invited to participate.⁴ Parents were given \$20 as an incentive to participate.

Participants were asked a series of questions about the enrollment cap including how they first learned about the cap, what information they were told, whether they were encouraged or discouraged from applying, how they learned that the enrollment cap had been lifted, the length of time they were uninsured, and whether the parents were able to obtain other health insurance coverage for their children during the enrollment cap. The participants were also asked about their children's health care experiences while they were uninsured, including whether they were able to obtain needed health care for their children while they were uninsured, whether they were able to see their existing provider or had to change providers, and whether they made any economic trade-offs to pay for health care services for their uninsured child(ren). Finally, participants were asked about their experiences on NC Health Choice and whether their perception of the program changed after experiencing some time on the waiting list.

Forty people participated in the six focus groups. Of these, 90% (35) were females and 10% (5) were males. Forty-one percent (16) were white, 54% (21) were black, and 5% (3) were Asian. In contrast, DMA reported that 51% of the children in NC Health Choice were white, 36% black, 3% Asian or Indian, 3% were other races, and 7% were Hispanic during Federal Fiscal Year 2001 (which included the time of the enrollment cap).⁵ Four families were represented by both parents. Altogether, the 36 different families represented in the focus groups had 79 children who were in the age group to be eligible for NC Health Choice.

More than two-thirds of the participants' children were on NC Health Choice at the time of their focus group. The remainder were either on Medicaid (20%) or had private insurance (9%). Only one child (1%) was uninsured, and the reason was unclear, as she had two siblings covered by NC Health Choice.

Participants reported that their children were uninsured for periods ranging from four weeks to more than a year. Although the enrollment cap was officially in place between January and October, 2001, most families that we talked to spent less than six months on the waiting list, because the state started reviewing the applications of families on the waiting list beginning in July. However, some of the participants' children were uninsured for longer periods of time because they had been uninsured for some time prior to applying for NC Health Choice.

The participants in these focus groups were not scientifically selected to represent all of the families on the waiting list. Thus, the participants may not have reported on the full range of experiences that families on the waiting list faced. This report reflects common themes across focus groups—when a particular issue is unique to a particular group, it is so noted. Nonetheless, because this is not a scientifically valid sample, these data cannot be used to quantify the percentage of families that had particular experiences.

Enrollment Cap

Awareness of Enrollment Cap

Most of the respondents first learned about the enrollment cap when applying for NC Health Choice or Medicaid. The participants who applied directly for NC Health Choice learned about the program cap from the DSS, from health department staff, or after receiving information about the enrollment cap in the mail. Other participants found out about the NC Health Choice program after losing Medicaid eligibility⁶ or after applying for Medicaid and learning they were ineligible. Families were informed that their child was eligible for NC Health Choice, but they would need to be placed on a waiting list until the program re-opened enrollment.

When I went to try to get insurance for my daughter, I thought she was eligible for Medicaid. I didn't know she wasn't. I didn't know there was an age cutoff and the lady told me that she may qualify for Health Choice but there was a cap right now and there were no funds for it and she put her in the system.

My husband changed his job and last year we used to pay \$150 for private insurance for the whole family. When we moved here it was \$360. It's very high and I cannot afford it. I said at least I would go apply for Medicaid for the children. We went and they said because of (our) income, only two of our children would qualify for Medicaid. The caseworker advised me to apply for Health Choice and I waited about two months (before my child received coverage).

I didn't really know about it before. I went to DSS because I was pregnant and without insurance. I needed to get some kind of coverage or I wouldn't be able to afford the hospital bills. When I was in there getting Medicaid for me...I asked them about getting my four-year old on Medicaid...She said that he couldn't get Medicaid but (that they would) put him on the waiting list for Health Choice.

Well my kids were on Medicaid at first. Then she redid my income and she said that I was making too much...I was rejected so my kids were without insurance for about six months. I went to the Health Department to get the NC Health Choice forms and I sent it off. I just got the forms and mailed them off because one of my friends told me what I needed to do. (DSS) sent me a note that said I was rejected because of the waiting list and (later)...they sent me a note that it was (opened back up)...and that the kids were enrolled.

When I spoke to the lady she mentioned (the waiting list) and I think that was a good thing. She really didn't have to do that. She could have said the funds are not available.

Although most of the applicants were placed on the waiting list because they had filed new applications for NC Health Choice or had recently lost Medicaid eligibility, some of the participants reported their children had been enrolled in NC Health Choice but were placed on the waiting list because the parents reenrolled late or problems arose with the renewal application. One woman reported that her child lost NC Health Choice eligibility because her husband worked overtime around the Christmas holidays. In one focus group, the participants reported that DSS hired temporary workers who lost their applications—causing some individuals to lose continuous NC Health Choice eligibility.

In November, when it came time for our review... my husband's boss had given him a few extra hours (of work) so we'd have extra money for Christmas. (The NC Health Choice recertification) happened (at the same time) so the extra money for the Christmas present (made my child ineligible, when we reapplied) then we had to wait... They said it would probably be about four months. (They told us) to save up the money (for the enrollment fee) because when the time came (for my child to get enrolled) there wouldn't be but about five days (to pay the enrollment fee).

(I found out about the waiting list) only when I called to find out what happened (to my application). I didn't get my renewal card and I called to find out what was going on and they told me because they had not received my application (for NC Health Choice), that the kids were pretty much bumped out of the system.

One of my daughters is diabetic and I got a letter in the mail for re-enrollment. This was in April...it was running out in June but from April to June I called constantly but I never heard anything so finally someone called me back...the worker I had...she never returned the call. I went to everybody I could. I got no response. So I went to the director of the Social Services department...and (found out) the people (taking the Health Choice) applications were temporary and (DSS found out) they had trashed the mail...it was when they had a cap on so ...my daughter was really, really sick...(I applied first) in April. When I applied again it was like July. (She was off the program with no insurance.) Well my worker did (encourage me to apply)...She encouraged me to wait and be patient...she told me as far as she knew from their meetings it wouldn't be long...but it was still some months, maybe about six months...seven months.

Information about the enrollment cap

Participants complained that they were not given a lot of information about the enrollment cap, particularly about when the cap would be lifted. Some of the participants filed applications by mail, and consequently did not have a chance to talk with a caseworker. Their only source of information was correspondence from DSS informing

them that their child had been placed on a waiting list. Even some of the participants who talked with caseworkers expressed frustration about not knowing when the cap would be lifted, or that their applications were going to be processed on a first-come, first-served basis.

(I was told) it was just a waiting list and there were hundreds of children on it and they didn't know when the cap was going to be raised. No, (they didn't tell me I'd get processed quicker if my name was on the list). It was just a waiting list. She didn't even say 'first come first served'. She just said it's a waiting list and I was concerned.

I asked ...specifically and that's when she told me about the cap...she told me the program had been put on hold, something about the funds on hold and I could put him on the waiting list. She said it could take anywhere from six months to a year before he got on the program.

Encouraged or Discouraged from Applying

Participants in five of the six focus group locations reported that they were actively encouraged to submit their application—either by a DSS or health department worker, a doctor or other health professional, or a friend. In two of the focus groups, participants were told to save money for their enrollment fee because once the enrollment cap was lifted they would be given only a few days to submit their enrollment fee. None of the participants reported being discouraged from filing an application, although some noted that they had not been actively encouraged or discouraged from applying—that the decision was left to them.

Well the supervisor that I talked to, she was very encouraging because she was genuinely concerned about my daughter's health needs. She kept in touch with me (during the enrollment cap).

She (the worker) said if I was interested in (NC Health Choice) that it would be best if I get on the waiting list.

Well my worker had just told me when she sent me the letter, she called me and she told me the state was having some money problems and she told me to stay on the list and she said in a couple of months she would call me back to let me know if they still had a cap. They were calling it a cap on NC Health Choice and the next thing I know she wrote me a letter that the cap was off and my card was on the way.

Well actually I had a friend who had it for her son and she was telling me about it and she had gave me a number and kind of like kept referring me until I finally got a live voice...a live person to talk to and she told me she could send me some forms and (I was) to fill them out and get them back as quick as I could. That's what I did.

I wanted to get on the waiting list regardless (others agree). You know I hated not to know how long I'd have to wait. That's the only thing that irritated me but I was going to put him on the list regardless.

We applied ... and qualified, but there was a cap. They said it was probably (going to last) about four months and (we should) just save up the money (for the enrollment fee) because when the time came there would only be about five days (to pay it).

Confusion Caused by Having Different Children Eligible for Different Public Programs

Several respondents reported problems that occurred because some of their children were eligible for Medicaid, and others for NC Health Choice. Several families had (younger) children who received Medicaid, but older children who lost their Medicaid eligibility as they aged out of a specific income eligibility group. Other families, those with children from different marriages, could have children on different programs.⁷ Having children in multiple programs can lead to different application and recertification dates. Participants reported that this caused hardships in remembering to fill out the various recertification forms, and in having some children with health insurance coverage but others who were caught under the enrollment cap.

I have (two older children) who are on Medicaid. They were never switched over (to NC Health Choice). I don't know why...I know they do my kids' applications separate at Social Services because they're from my previous marriage...My younger son kicked over to Health Choice ...it just happened. It was like you no longer have this ...He (received NC Health Choice) but there was...a lot of confusion about my daughter. I called and they said she was no longer on that (Medicaid) because she had turned five or six...she now needed to be on Health Choice but there was a waiting list or there was a cap.

It was all a step-by-step (application process)... all my kids didn't get it at the same time. I would fill out one child's application, and then a month later it was time to do the next one, and a month later the next ones. You have to reapply exactly one year from that child's (original application). When I reapplied, my husband made too much money for Medicaid. They said that my daughter had...qualified for North Carolina Health Choice but that she couldn't get it at that time because ...there was a waiting list. My oldest ones went to live with their dad so I didn't have to have insurance for them, but my youngest one, when her time came it was the same thing.

My two older children are on NC Health Choice but my youngest currently doesn't have anything... For my first two children I applied for Medicaid and qualified for NC Health Choice... When I first applied for them they were (put on the waiting list) and then about four months later I got a letter saying that the

program had re-opened and then they got in...My (youngest) daughter had ... Medicaid while I was pregnant with her so she was automatically covered on Medicaid for the first year but then after the first year because of our income she no longer qualified for Medicaid. I sent the papers in for the NC Health Choice and I got a letter back saying that the program was full at this time and that she couldn't qualify. (Later) I just got a straight rejection...I didn't get them on the waiting list during that time. It just said that you fail to qualify...(because the family income) went up about five thousand dollars ...(I didn't try to get other insurance because) I can't afford any other insurance.

I applied for Medicaid but we couldn't get (it). My daughter was too old for Medicaid. She was already on Health Choice. My son was on Medicaid but they had to take him off because of our income. He was approved for Health Choice and they said he was on a waiting list...my daughter had health insurance but my son didn't.

Well, I feel like if one (of my children) was already on (NC Health Choice), then both of (my children) should have gotten it. Both (of my children) were in the system (on Medicaid)...they (should have been able to go straight) from Medicaid (to NC Health Choice).

How Participants Learned the Enrollment Cap was Lifted

Almost all of the participants received letters informing them that the enrollment cap had been lifted. Some also received phone calls from their worker telling them that their child(ren) were now eligible to receive NC Health Choice. Several reported checking periodically to find out the status of the waiting list. While most of the participants learned that the enrollment cap had been lifted, at least one participant in three of the locations noted that they never received any information from the Department of Social Services when the cap was lifted.

I got a letter (telling me about the enrollment cap). I think mine said that (if anything had changed I would have to fill out another form) and then...I got the letter (saying the cap had been lifted). I had to go in and pay the money and then after that it was maybe a couple of weeks and I got the card in the mail.

First I got a letter, then my card, and my worker called me also...to make sure I had gotten my card.

I had to call the Social Services because I didn't get a Medicaid card, I didn't get a Health Choice card and I didn't know what was going on. She said I was approved for it but I didn't get any information. I had to keep calling to Social Services to see what was going on and eventually they told me he was put on Health Choice and then I had to keep calling about that because they said he was approved...No (they didn't send me any information about it) so when they said he was approved for that I never got anything.

Difficulties Paying the Enrollment Fee When the Enrollment Cap was Lifted

Families with incomes above 150% of the federal poverty guidelines are required to pay a one-time enrollment fee of \$50 for one child and \$100 for two or more children. The enrollment fee must be paid in full before the child can begin receiving NC Health Choice coverage. Participants in one focus group noted that they had very little time to pay the enrollment fee once the enrollment cap was lifted, which caused a hardship in coming up with the necessary funds.

I was on the waiting list...for a whole year...and then when it reopened, they sent me a letter...but I had to pay (the enrollment fee quickly) and that was hard...I almost didn't get it. I really had to scrape. My worker said 'Try, try whatever you do...switch around your bills...make an agreement with the light bill ...and get them on (Health Choice) because once you're on – you are on the whole year...and even if your income goes a little above... there's an extended plan you can get. You might have to pay a little more premium but you can still get it' ...I'm relieved now, because I don't have to worry about the kids getting sick or hurt.

I got a letter in the mail and it said that he was in (NC Health Choice) and I just had three days...to go in and pay \$50 at Social Services...I didn't do it. I never did get him on Health Choice. I just let it go ...at the time I don't think I had \$50 and I remember calling... my husband to see what to do and he said 'Don't do it. If something comes up we'll handle it.' Then right after that we were approved for Medicaid...I knew Medicaid was going to come through eventually...my husband had got laid off and I went on maternity leave and I was not going back to my job so our income went way down to nothing...

Ability to Obtain Private Health Insurance Coverage

Most participants were unable to get private health insurance coverage for their children when they were uninsured. Many of these families talked about trying to get insurance coverage, but found that private insurance coverage—either through their work or by buying private insurance—was too expensive.

A lot of them (jobs) have the insurance, like where I work they have it but it's too much for a family. (Several respondents agree.) I have it on myself but you feel bad you can't get it on your kids. It just cost too much. You'd be paying them actually all of your paycheck.

The problem...I had with (the insurance companies) where I worked was (that they were) so expensive. It was free to me but so expensive for my child that I wouldn't have had any take home pay by the time (I paid for my daughter's insurance). As a single parent I (need the money) to pay my bills.

We were both insured through our respective companies but the insurance was too expensive to add the kids (to the policy). We did look into Blue Cross and a couple of other programs (but it was too expensive).

I had tried (to get my children on my insurance through) my job but they wouldn't take them back because of the lapse in coverage.

I had applied (for NC Health Choice) for all four of my kids because I'm a state employee and the insurance had gotten too expensive. It was almost four hundred dollars a month and I couldn't afford it for my family, so for about a year all four kids were not covered under any insurance.

Through my work it was just like four hundred dollars a month for both of my daughters. I mean that was unreasonable. You know I looked at other options. I tried to see if their dad could get coverage for them since we're divorced. He missed the deadline so that didn't work out.

I ...looked for all of the lowest insurance rates you can get for families, checked out all the brochures and things they sent me and talked to people over the phone (but couldn't find any affordable insurance)...My job offered insurance for me, but it was too high to cover the family...it was \$800 per month for the whole family. It makes you appreciate when they pay for your insurance on the job. That's a lot of money.

I called my insurance agent and she found two insurance (policies). The first one was called (Insurance Co. 1). It was for a family. There were four of us and it was \$53 a month, but it was no good. It was just paper...I went into the hospital and (the insurance company) turned me down and said they could not pay anything. Nothing...and we'd been paying premiums. The next insurance was (Insurance Co. 2). It cost \$73 for my whole family. But, it didn't work for me because you had to go into the hospital for them to pay you whatever... if you go to the doctor you have to pay yourself. ...It's hard. It's really hard trying to find insurance that you can afford when you know you're at the borderline and your husband is making just a certain amount of dollars and you really can't afford that insurance from his job to cover (the family).

You have to budget every check... Private insurance for my daughter and me would be \$85 a week. I can't afford that...that's a lot of your bill money right there.

Only six of the participants (17% of the families) were able to obtain private health insurance coverage for their children when they were placed on the cap. Four were able to place their children on an employer-based plan, although several of these families noted that this caused a financial hardship because of the high premiums. One respondent was able to get her ex-husband to pick up insurance coverage, and another could get military health insurance coverage. Several of the respondents with private

coverage noted that they wanted to enroll their child in NC Health Choice because the program was more affordable—but that the children’s private health insurance precluded or delayed them from enrolling. In addition to private coverage, one participant was able to get Medicaid to cover the child because of large medical bills.

My two oldest children were on (NC Health Choice) probably for about a year, and then I moved. They didn’t forward the letter to me and so I wasn’t able to re-enroll. When I called they said that I didn’t get my application in, in time, so then I had to add my children to my insurance. My insurance... was like two hundred and some dollars coming out of my check (every month), and that was bad.

My worker told me...to go to the drug store and double his medicine because she thought that I might be on the waiting list. She knew that my son’s medicine is like four hundred dollars a month and they’re only going to give him a thirty-day dose. So I went in there and did that. She told me I wasn’t eligible for Medicaid because I was working, but I went to Social Services and talked to a couple of workers and I explained to them that ...wouldn’t give me insurance for him because (he had) a pre-existing health problem. I told DSS that he needed his medication and I didn’t think it was fair if they had Medicaid...at the time he was fixing to go through surgery and I knew I couldn’t pay for the surgery. My worker said that she would see what she could do and...they gave me Medicaid (temporary)...I had to reapply every few months until the cap lifted. She sent me a letter.

No, I was going through a separation and I had to go to court so I kind of figured that once we got to court the judge would order (my husband) to (provide health insurance) so I didn’t even try anything else. I called and talked to someone in that department and she stated that she didn’t know how long it would be before they would be on. She said it could be three months, it could be six months, it could be a year. She said the older two would be on a waiting list and that was about all I heard so my husband ended up putting the oldest two on his (insurance).

When I reapplied, my husband made too much money for Medicaid. They said that my daughter...qualified for the North Carolina Health Choice but that she couldn’t get it at that time because...there was a waiting list...(When it was time for my youngest to reapply)...my husband got another job. He had a waiting period for insurance...we didn’t have NC Health Choice, and we didn’t have Medicaid because...he made too much money...About...two months later I got a note saying that my children were qualified for NC Health Choice now and asked if we were able to get insurance through his work. We said yes that we could get it through his work now after his waiting period was up...They said since we could get insurance through (my husband’s job), that we couldn’t qualify for NC Health Choice.

My oldest when I had him was on Medicaid, and after that first year they said we didn't qualify anymore, but I was never told about NC Health Choice, so I had to put him on my insurance...just him was eighty dollars a month...So when he was two years old, I was at a workshop, and that was when I first heard about NC Health Choice. And when...I asked 'how do I put my son on there' she told me there was a cap. I wanted to get him off my insurance because my husband had lost his job, and it was getting to be too much for me to pay all that...(but because of the cap) I had to keep him on my insurance...and then I had my other baby and he was on Medicaid, and again when we tried to do our re-certification, they said we made too much and that's when they said I could get on NC Health Choice. But when I tried to put my older child on there he couldn't get it. Before I applied I dropped him off my insurance. She did tell me he had to be uninsured for ninety days. But I took him off my insurance and it ended up being six months, not three months.

I had to fill out two applications, one because the paperwork didn't get there, from what I was told. I just got an application and I took it down to Social Services and dropped it off. Once I filled that out I was told there was nothing on file for my son so I had to fill out another application after two months of waiting and then I was told that there's a cap on so he's going to have to be on a list. I panicked about how long he was going to be on the list. (The worker didn't know.) That's when I ended up having to put him on my insurance and that really killed me because I mean I'm a single mother and that money coming out of my check was like 'oh, my God.' So after I added him on to my insurance...I'd say like a month later, here comes his card...and I couldn't take him off of my insurance because you have to wait until the new enrollment.

My youngest son is on his father's insurance and the oldest son is on NC Health Choice...It was kind of hard for me to have (only) one on insurance. I felt bad. I felt like I'm a bad parent and I'm not doing right by my son, but I couldn't apply for Medicaid because they claimed I made too much money.

My husband had good insurance that covered us both, but then he lost his job. My job picked up the slack, but when I lost my job we (needed) some insurance on our daughter. So then we went to the Social Services and they turned us down for Work First because I think they said we had too much (assets). Then they sent us into another office to apply for the Health Choice for our daughter and then they said there weren't any funds available but they thought that she was eligible. So they sent us a letter later telling us that she was eligible and that they didn't have any funds...by that time I had got the medical insurance from the military...he (my husband) was retired (military). I found out it was pretty good and that we could get it...but they don't offer dental.

Experiences While the Child was Uninsured

Participants in each of the focus groups reported being frustrated that they could not provide needed medical and/or dental care for their children. They reported a wide range of health care needs during the period of the enrollment cap. These included treatment for common illnesses such as colds, fevers, bronchitis, and influenza to more serious concerns with asthma and potentially life threatening infections that required hospitalization or extended follow-up. One respondent told of her daughter suffering for over a month with severe pain in her ear (from a condition that later required surgery). Others reported that their children needed preventive care, such as immunizations, physicals, or screenings during the enrollment cap period. Many of the respondents talked about delaying care they would otherwise have obtained, or treating the kids themselves with medications they had in the house, including using antibiotics that were prescribed for a different family member. People commonly postponed dental care, including routine cleanings and procedures such as fillings or extractions. When treatment could not be delayed, respondents sought low-cost care for their children either through the local public health department, community health center or with private physicians. Some reported going to their traditional providers for care, while others relied on the hospital emergency room when conditions were more serious or they did not know where else to obtain care. There were very few participants who noted that their children had no health care needs during the time they were uninsured.

Delayed Care

Respondents in each of the focus groups talked about how they delayed seeking needed health or dental care for their children. Instead, they treated illnesses such as colds, influenza, and sinus infections at home, delayed dental care and some medical exams (x-rays), and had to wait before filling medications. Some noted that they pulled their children out of school activities because they couldn't afford the needed physicals and because they feared injuries.

My daughter had a problem in her ear and they had to do surgery on it...We didn't have insurance...(my) child suffered a month (before we finally had the surgery).

My problem was prescriptions. (There were times I couldn't get asthma medicine for my child because of the cost)...Even if you get to take the child to the doctor, you might not have the money for the medicine...I had to wait until payday or something...(My son waited as long as) a week and a half...

Yeah, both of my daughters got the flu really bad last year and it lasted for about five days apiece. I was worried that it was turning into pneumonia and just waited it out. I tried to call (the doctor). I called an Urgent Care Center and I was going to take them there. It was going to be over a hundred dollars. Well at the time (that was a problem), because pretty much you have to pay up front...we treated them at home. My daughter needed a dental cleaning, a dental exam and

we paid for that and that was about ninety dollars for that. But other than that I mean we went without dental care. My daughter got hit in the ankle ...I was worried it was broken or fractured and just treated that at home. (If I had insurance) I would have taken her to get an x-ray definitely. I've always had health insurance since the day they were born so ... anything goes wrong I've been able to take them to a doctor. It's very disturbing not be able to take your child to the doctor when they're sick...when you're worried about how much it's going to cost. I mean it's very costly, you know.

My son had to have a tooth pulled and actually I had just been putting it off...and it happened that it came through just at the point where we couldn't put it off anymore. It got infected the day after I got the card in the mail and so we had to have it pulled and he probably could have kept from having the tooth pulled.

I put off taking my kids to the doctor...knock on wood. They were fairly healthy and other than allergies...my youngest had really bad allergies...I pretty much suffered through it and she suffered through it while we didn't have insurance...until we got insurance and then we went back to the doctor. (I held off going to the providers) until the insurance kicked in...dental appointments also. I had to cancel dental appointments because we didn't have the insurance. .

We got pretty lucky overall...we had two ear infections, an allergic reaction and an ingrown toenail...we paid out about three hundred and sixty dollars...even going to inexpensive places like the Health Department and getting prescriptions at a reduced cost ...(the costs) can rack up. ...We postponed a second trip to the children's pediatric clinic for the same toe...we had to postpone a semi-annual dental appointment...eighty dollars to get them cleaned ...that was really about it...making the hard choice—do we manage to come up with this money or do we put this off.

(My kids) had to have school physicals (to participate in) sports and stuff. They couldn't do it (participate) because I couldn't afford the physical... They got mad...it was kind of depressing.

Sought Out Low-Cost Care

Respondents in each of the focus groups reported that they tried to identify places where they could get the needed health services at a reduced cost. Many of the respondents relied on health departments or community health centers where they could obtain care on a sliding scale basis. However, not every community has access to a community health center, and not all health departments in North Carolina offer comprehensive primary care services. Low-cost primary care services were available in five of the focus group locations, although some participants did not know about these resources in the communities where they were available. In one community, the participants complained about having to rely on these community-based providers

because of the perception that these services were lower quality and the stigma associated with these clinics.

Before I got back on NC Health Choice I went to the Health Department and that was very helpful because the cost was based on income and the service was excellent. I did get a lot of the medications free...and that helped but...my little girl had an accident last year about this time and I didn't have insurance. (The emergency department charge was) \$800-\$900 and...I still (owe) for that. But when she got sick this winter, before she got back on (NC Health Choice) I took her to the Health Department. (The health department referred her) to a community health center...she referred me down there because I don't have anything (money).

We went to the health department when the kids were sick because it was low cost and the prescriptions were inexpensive or free. For the most part that's where we went... It was low cost based on income. ...They (the health department) have always gone above and beyond.

(We found out about NC Health Choice) through the health department. ...We fell just above the income limit for Medicaid. The health department said that there wasn't anything they could do except (reduce charges when the children visited the health department)...Even that was starting to rack up because my daughter was going (to the health department) about every week or two with strep throat, tonsillitis...it comes out of pocket and it's rough.

I went without eye care for my kids a year. I got a letter from the teacher (saying my child needed a vision screening). I went to the Health Department for a screening, but they don't (do comprehensive eye exams). The Health Department gave me a referral. I took the referral to school (to show them I had a vision screening, even if it wasn't a comprehensive eye exam)...parents have to do what they have to do... I had to tell my teacher we cannot afford these glasses at this point. We're working on it. So the screening is what I did.

I think I took her for some visits (to the community health center)... they charge on a sliding fee scale...The Community Health Center has a pharmacy and it's sliding scale too—so some of the medicine was discounted. But some medications are unavailable there so you have to go to a regular pharmacy to get it and there you have to pay full price.

My baby has asthma ...At the time that we weren't covered we would go to the (hospital pediatric clinic) when he had an attack ... (He went) twice a month (for two months) when he was uninsured.

(Our city) has the ...Community Health Center. You can go there. You pay a co-payment and they'll see your child or they'll see you...but I do not take my child because...if you go to (the Community Health Center) the care is not the same.

Ability to Keep Their Regular Doctor

Most of the participants reported that they were able to keep their child's regular doctor while their children were uninsured. The respondents did not notice a change in the providers' attitudes after their children lost insurance coverage, but a few respondents in one focus group noted a change in the attitudes of the office staff.

I went to the same (provider) and of course I had the cash so there was no difference. I had to pay cash...my momma's cash but cash just the same.

Once you get in to the doctors, they're pretty decent. It's just the people you got to go through.

Hospital Emergency Room

Respondents in each of the focus groups noted that they took their child to the emergency room for acute health care needs. Many reported incurring medical bills that they are still paying.

My son...when he catches a cold he has breathing problems. He has a machine for it...We had to take him to the emergency room and they billed (me) and I had to pay for it out of pocket...over \$200...I had to get the medicine for him and I had to pay for it out of pocket...almost a hundred dollars.

My son had a lot of problems with sinus so he had to go to the emergency room twice. Sometimes he can't breathe and so I'm stuck with the bill.

(My son had) one health need. I had to take him to the emergency room. He had bronchial spasms and so they billed me for that and I had to pay... four hundred and some dollars because he had to have a chest x-ray...Sometimes he would run a fever and it could be some virus and I would give him Motrin (instead of going to the doctor).

I had to take my son to the hospital. He's very susceptible to croup and almost died a couple of times...in December he had a bad bout...I'm still paying for all that...shot, breathing treatment and all that.

When my girl had that (accident) it was about twelve hundred dollars to go to the ER... I'm an LPN so I kind of knew what to do...took her to the ER, she had an allergic reaction to (the medicine), so they had to counteract that and medication was so high...I used my knowledge (as a nurse) because I couldn't keep going back (for more treatments).

This past December ...my kid got an infection...an ear and stomach infection. I took him to the hospital and they treated him...I have an amount I have to pay and I'm still paying...a lot for me.

Medication Needs

Respondents in each of the groups noted that they had particular difficulties obtaining the medications they needed for their children. For some, they were able to work with their providers to get free samples or medications through the pharmaceutical assistance programs. Others talked about sharing medications between children, or using medicine they had themselves and giving it to their children. One respondent noted that she was so desperate to address her child's health needs, that she gave her old antibiotics to her child, even though she knew it was potentially dangerous. Another participant had her physician prescribe medications for her, and then gave the medicine to her daughter.

We did something I wouldn't recommend but I had old antibiotics that I had had for an infection and I gave them to the older one who was sick...that was my prescription...I gave it to her. So I think you are also making bad choices when you don't have money. I mean it could have been the wrong antibiotic but you're desperate to do whatever you have to do.

We couldn't take him to his therapist (for Attention Deficit Disorder) because we couldn't afford it...but the nurse in his doctor's office would give me prescription sample packs (otherwise it would be) \$3-\$5 a pill.

One of my daughters is diabetic...I was going to (the local hospital) at the time and she was in a special clinic and they knew the medication was very high so what they did was they contacted the (pharmaceutical company) and they provided medication for her...I had to pay (for doctors).

I actually did (share medication) Both my three year old and my one year old got an ear infection at the same time and I just split the antibiotic between them. (Several respondents agree.)

I was coming out of my job where...they covered you free and there was a couple of times my kids didn't have any insurance...I would go and get medication...have my doctor prescribe some antibiotics for me and give it to them...I've done that before.

My aunt's kids have some problems like my kids did so we got some of her medicine.

Financial Hardship

Many of the participants sought medical care for their children's acute or emergency health needs. Several incurred substantial medical bills during that time, and most are still paying on them. This caused significant financial hardships.

Your whole lifestyle changes. If both in the house are working or one is working to make the ends meet you can sometimes buy these things but when one income is gone... you've got to step down. For me, it was both (unemployment and not having health insurance). Both of my girls had asthma real bad. We had to buy a nebulizer...The one we (bought) was \$125. At the time she had just come out of the hospital and \$125 was not easy for us...She stayed in the hospital (several) days and they said they would not let her go home without the nebulizer.

Well my daughter had a (problem)...and they (did) surgery ...it took them about four hours. When I got there I didn't have insurance but they called Social Services and they paid 85%. We had to pay the remainder - 15% - and still that's a lot...We had to buy all her medications... They say they gave me generics but generics to me are high priced.

My son has asthma and needed an asthma pump. He keeps getting an eye allergy that he needs eye drops for—I took him and am still paying a \$220 bill.

I had about four hospital bills. My daughter kept getting an infection and...she has to have surgery on her mouth and I couldn't afford that. My oldest son...he had an illness ...he was on life support for about two months. We've never found out why ...This time he was put back in the hospital and was in there for a week. Actually when I took him to the emergency room, they were the ones who told me (about NC Health Choice)...I had told them that I had applied so the supervisor of Social Services kind of worked with them.

Well I knew they had the Health Choice program and I knew that there was a waiting list and that she was eligible and that at some point in time she would get on it. I didn't know when. I didn't know what the criteria was exactly but I knew she was eligible. Meanwhile my daughter needed some dental work done and I had it put off because I couldn't afford it but I knew at the clinic that they accepted Health Choice...I thought it's like Medicaid because Medicaid is retroactive ...I kept putting off (the dental work) thinking we would get on NC Health Choice at any point in time. When our appointment came, I went ahead and had it done. It was about three hundred dollars worth of work that I still owe on (because NC Health Choice doesn't pay retroactively)...I took her to (the community health center) on several different occasions for work at the clinic on a sliding scale. I had to pay for some of that. She was seen at Chapel Hill by an orthopedic doctor... and I owed on that also. She didn't have Medicaid and she didn't have Health Choice, so at the end of the year they (University of North Carolina at Chapel Hill) took my state income tax (refund).

My son has had stitches four different times...it costs about \$60-\$75 (each time).

My son is ADD (Attention Deficit Disorder) and he's been tested for that and that's many trips back and forth to...(a city about 30 miles away) right in the midst of Health Choice being cut. That was two hundred dollars every trip

between the psychologist and the neurologist visits. They put him on a medicine and he had an allergic reaction and we had to take him to the emergency room and that was over three hundred dollars right off the bat...Those bills add up very quickly when you add in medications being over two hundred dollars for allergy and ADD...But, your kid has to have it for school because he needs it to focus...you're juggling bills around...you have to do what you can for your children.

I had two kids that needed to go to the emergency room. For whatever reason my daughter has gum problems...they keep getting infected. I kept taking her to the emergency room and get antibiotics. I called the supervisor at Social Services for Medicaid. I couldn't afford the hospital bills and they started reporting it on my credit and so it was a really bad situation.

My daughter is very, very healthy but that doesn't mean that she doesn't get sick. She got sick one time and the insurance hadn't kicked in yet...I had to have \$90 before (the pediatrician) would see her...

Respondents in each of the focus groups talked about the difficulties they had paying for needed health services when their children were uninsured. Respondents reported making economic trade-offs in order to pay for health care services. These included juggling payments or delaying bills (car, rent, utilities), borrowing money from family, paying for fewer leisure activities (renting movies, school activities), buying basic or lower quality foods, shopping for bargains and limiting the use of their vehicles. Two respondents admitted going without food. Others talked about paying late fees or getting collection notices from their creditors.

I juggled quite a few things but not just from the time I applied, but before that. I mean I (took my children to the pediatrician) three or four times...while they were uninsured. (Sometimes, we made partial) payments to the electric company instead of sending the full thing and...went without some things...It just meant we had to, you know, tighten our belts.

I had so many bills. My problem was because I had so many nasty collection notes.

I had to buy less food. Macaroni and cheese instead of potatoes, lettuce or fruit...I scraped by with what we could or borrowed from somebody.

I did have to juggle a lot...I'm sick of Oodles of Noodles...beans...

My child couldn't participate in school activities. I couldn't buy the food I like. I couldn't buy the clothes she would like to have... it was a struggle to provide just what had to be provided.

Well if mine got sick and I didn't get the money from my mother I would not pay my car (payment). I would rather have my child than drive the car.

Food...I mean for myself I would not eat but I would feed my child.

I bought the basics, but not ...what kids like. Their favorite cereal, that's going to go by the wayside and you're just going to get whatever and do what you can do. You're going to buy your clothes at the yard sale – not downtown. Stuff like that. You're going to sit at home and not go anywhere because you don't have the gas to do it.

In (this town) they let you extend your light bill...we did that...they give you up to four extensions a year.

Yes, I have quite a few bills for myself and I'm paying \$5 a month on everything to keep people off my back...

I had to pay my rent late because my daughter needed antibiotics for an ear infection. (My late fee was) twenty-five dollars.

Experiences on NC Health Choice

Participants were asked about their experiences on NC Health Choice. With only one exception, participants who had children on NC Health Choice had positive experiences with the program. They were pleased that their children had health insurance coverage and that the coverage was affordable, including low out-of-pocket costs. They also liked the small wallet-sized NC Health Choice card, which looks the same as a private insurance card. Medicaid, in contrast, is an envelope-sized paper card and is easily recognized. Few participants had problems finding health care providers who would take NC Health Choice, with the exception of dentists.

Participants did mention several ways that NC Health Choice could be improved. Several people complained that they were not given enough information about the program when they first applied. In terms of access to providers, the major complaint was the problem finding dentists who would accept NC Health Choice. Several of the respondents also complained about the limitations in dental coverage, especially the lack of coverage for orthodontia. In one focus group, a few of the participants talked about a stigma attached to the receipt of publicly-funded health insurance, although this was not noted in the other five focus groups.

While some of the participants were worried about whether another enrollment cap would be imposed given the state's financial crisis, almost all of the current NC Health Choice participants said that they would apply again in the future.

Affordable Health Insurance Coverage for Their Children.

Respondents expressed appreciation and relief that their children had health insurance coverage. The participants were pleased with the affordability (low or no-co-pay), the wide choice of physicians, and the scope of services (including dental and vision in addition to medical). Several people noted that NC Health Choice was a great option for people who had incomes that were too high for Medicaid, but not high enough to afford private insurance coverage. While several people noted the difficulty of paying the enrollment fee, only one person complained about the required co-payments. She acknowledged that the co-payments were generally reasonable, but she ran into a problem paying for two doctor visits and two prescription drugs on the same day.

There's so many of us that fall into that middle income range...not poor enough (for Medicaid) but not rich enough (for private insurance).

I was on welfare for so long. I said if God would bless me with a job, I'd make sure my kids are taken care of. It was hard to seek help again...I said I wouldn't go back to Social Services, but then the kids got sick and I got to where I couldn't afford insurance. My income is above the level for Medicaid, so this program helps me. It doesn't seem like a welfare program.

Well actually I think it's a pretty good program, because after you hit the salary cap (for Medicaid), then you still can afford the insurance for the other ones. I think it's a great program because a lot of people have kids and they can't cover them...As far as taking them to the doctors I haven't had any problems with that, but I just think it's great, because without it what would you do?

I think it's a good program...I lost my job and my husband lost his...at least my kids have insurance.

There is not that much difference between Medicaid and Health Choice. It's probably only a two or three thousand dollar difference in the eligibility and you're talking about people having a hard time making it even with the fifty dollar co-pay. That fifty dollars is nothing (to most people)...but to people that are poor and can't hardly make it and are struggling fifty dollars is a struggle...and if you have to do that yearly that adds up. And that sounds like a drop in the bucket in having to go to a doctor but that's still a hardship. It really is.

It was a blessing...we all work. We're not lazy but we're borderline...(we either) get Medicaid or Health Choice or we have no insurance.

There's one thing about Health Choice I like...I don't know if they do it to you all...is they send a reminder for the check-up thing. Now I think that's very good in case you forget.

It's more dignified than Medicaid. It's the size of that (Medicaid) card—the big blue card. This (NC Health Choice) looks like a normal insurance card. It feels better.

Satisfaction with Provider Access

Most participants were able to find doctors willing to accept NC Health Choice, although two of the participants did report some difficulties. Generally, the respondents who had ongoing relationships with providers said there was no difference in the way their child was treated when they started receiving NC Health Choice. However, a few of the respondents, primarily in one of the focus groups, thought that there was a stigma attached to NC Health Choice.

Access to dentists was the biggest access barrier discussed. In each of the focus groups participants complained about their inability to find dentists who would accept NC Health Choice. Many noted that this was not a problem unique to NC Health Choice, in that dentists were also unwilling to take Medicaid patients or even to file insurance for privately insured individuals. Some, who had dentists, complained about the limitations in dental coverage—specifically, that NC Health Choice would not cover orthodontia or tooth extractions.

I'm just glad for it. It's accepted in the places I've been, but I'm going to start checking...which dental offices will accept it.

My daughter wears glasses. I received a letter for the other one to have a vision check...(but the place that my daughter goes) no longer accepts Health Choice.

We are in that bracket where we make too much for Medicaid and on the border of Health Choice. So we were pretty much left hanging...my son has to have teeth extracted...he has extra teeth so I've been fighting with Health Choice over why you cover sealants and won't cover oral surgery that has to be done. We've had to ... come up with \$800 to get these teeth taken out.

She needs to go to the dentist. I've called a couple of dentists and they don't take it (NC Health Choice). That's the dilemma right now.

It's a wonderful program—the only thing is there needs to be more dental coverage...Three (of my children) really need braces and I can't afford it.

It's like levels...if you're on Medicaid you're right here (gesturing to the lowest point) in the health care providers' eyes. If you're on private insurance you are way up here (gesturing to the highest point) at the top on the treatment scale, the attitude scale. Health Choice, you're right (in the middle).

Worried about Future Enrollment Caps

Respondents in all of the focus group locations voiced concerns that the state might reimpose an enrollment cap, given the state's current financial troubles. They were concerned that their children might lose NC Health Choice—either because of another enrollment cap or if their family income changes. Despite their worries, most of the participants said they planned on reapplying for NC Health Choice. These respondents stated that NC Health Choice was their only real option to provide health insurance for their children, as private insurance was too expensive.

Well, she went without coverage the last part of last year and luckily my daughter didn't get sick or hurt. But I read the paper and listen to the news, and they're always talking about the Governor wants to cut this or cut that program. When my husband was working, I didn't really worry about it, because he had excellent insurance and we didn't sweat it. But when he lost his job and everything and we had to apply for NC Health Choice, the baby was okay but then I had to wait for her (because of the cap). So if it happens again and she gets sick or hurt...if you take them to the emergency room or something, that's expensive.

I was just thinking about that the other day because...every year my salary goes up so I was thinking well next year will they still be able to keep it? Because right now we're struggling, without my husband working, and to have to go get private insurance - there is no way (we could afford it). And my husband goes without insurance because we can't afford it for him...especially with just getting a new baby in the house. That makes it harder because she is so little.

Since I was treated the way I was last time, if my child was on Health Choice and it was time to re-apply, I would be very skeptical and afraid and worried that I would be put on another waiting list. If I needed to get health care past the enrollment date, what's going to happen? Am I going to be responsible again for more bills? What are they going to do to me next?

I think it's great, too. But I have a problem with this recertification. You are on it for one year and you don't know if you get it again (the next year). That (having to reapply) makes me nervous ...It's so confusing and it's really scary because I'm about to approach the time for them to be recertified and they already told me I didn't qualify for Medicaid.

For the coverage we've gotten before and after the enrollment cap...another cap doesn't matter. I will pay that money...and get them right back on again... (Private insurance) for just the two kids is a hundred and fifteen dollars.

Well yeah, with everything going on with the shortfalls and everything I wonder if they will just not have money for (NC Health Choice) and whether they will stop it completely. I worry about that sometimes.

One other thing, my oldest son has asthma ...if I had to insure him on my husband's policy, there would be a one year waiting period for asthma treatment...it's a pre-existing condition.

My son had Medicaid for a long time and suddenly it stopped. I worry ... he'll get a letter (saying he's no longer eligible for NC Health Choice).

Where is there to look (for alternatives)? All you can get is Medicaid or NC Health Choice. This was not a choice for me.

I have Health Choice for my daughter and I will continue to keep her on it until one day I can find a job and I'm able to afford my own insurance...

Conclusion

Although the NC Health Choice program did a good job re-enrolling children already on the program, the numbers show a large unmet demand for the program during the period of the cap. Children who were caught in the cap faced periods of uninsurance that ranged from four weeks to more than a year. Many families reported trying to seek other health insurance coverage for their children when they were uninsured, but most were unable to afford the monthly premium costs—even when it was available through their or their spouse's employer.

While their children were uninsured, families struggled to meet their children's health care needs. Most families were able to secure care for their children while on the waiting list, but they often had to make significant sacrifices to do so. Many reported delaying needed care, and in some cases their children endured unnecessary pain and suffering as a result. In a few cases, families told about surgery or tooth extraction that might have been avoided with earlier care. Several took their children to the emergency room for care; others sought out low-cost options through community-health centers or health departments, but these options were not always available. Obtaining needed medications was a particular problem—even when a provider saw the child, the family could not always pay for the prescribed medicine or supplies. Many families sought free medication samples from their providers, or tried to share medications within the family.

Moreover, nearly all families experienced financial hardship due to out-of-pocket expenses for medical and dental care while their children were uninsured – with many going without basic necessities in order to obtain their child's needed health care services. The families reported buying less and lower quality food, delaying rent and utility payments, and losing the use of their car due to an inability to afford repairs.

The focus group findings illustrate that families “did what they needed to do” to try to assure that their children received needed medical care while on the waiting list. However, it is clear that the enrollment freeze caused significant hardship for these families who participated in the focus groups. Further, most of the children caught during the enrollment cap were from among the poorest of the working poor families,

those who were applying directly after losing Medicaid coverage. These are the children with the least resources to meet ongoing health care needs.

¹ North Carolina actually froze enrollment from January 1, 2001 to July 1, 2001, and put all new applicants on a waiting list. Beginning on July 1, 2001, the state started processing applications for the children who had previously been put on the waiting list, but did not completely open the program to new applicants until October 8, 2001.

² If the child ages out of a particular Medicaid income category and has more than two months left in the twelve month continuous eligibility period, DSS will automatically assess eligibility for NC Health Choice or other Medicaid programs (such as the medically needy program) based on the records in the file. However, if the child has less than two months of the twelve months left, then DSS will require the child to bring in new income and eligibility information for a complete redetermination.

³ NC Health Choice enrollment grew rapidly once the program was reopened. By July 1, 2002, there were 84,286 children enrolled in the program. Because of the state's budget crisis, initially no new appropriations were provided to expand the program. DHHS was again faced with freezing the program, and announced that enrollment would be capped beginning September 1, 2002. At the same time, DHHS asked the NC Institute of Medicine to convene a Task Force to develop options to ensure the long-term financial solvency of the program—without the need for subsequent enrollment caps. The General Assembly initially considered several options to reduce overall program costs; but chose to delay implementing any of the proposed program changes until the Task Force could issue its report in early 2003. The General Assembly also appropriated an additional \$8.7 million in non-recurring funds to cover approximately 100,000 children. The Task Force's report is expected to be released in early February, 2003.

⁴ Initially, we intended to identify three different groups of focus group participants. Enrollment data from DMA were used to identify families that fell into the three groups:

- 1) Parents of children who applied for NC Health Choice and were put on the waiting list (this group included new applicants, children who were no longer eligible for Medicaid and who applied for NC Health Choice, and children previously receiving NC Health Choice whose parents reapplied late);
- 2) Parents of children who did not apply for NC Health Choice until the enrollment period was re-opened on October 8th (this could include some children who previously had publicly subsidized health insurance as well as new applicants); and
- 3) Parents whose children had been enrolled in NC Health Choice, but whose enrollment period ended during the cap and who chose not to reapply at all.

We were interested in determining whether the existence of the enrollment cap discouraged some people from applying until the enrollment cap was lifted (group 2) or from applying at all (group 3). However, during our telephone screens, we were unable to identify many families who knew about the enrollment cap and failed to reapply until after the cap was lifted (Group 2), or who lost coverage during the cap and had chosen not to reapply at all (Group 3). Therefore, our focus groups were made up almost entirely of individuals who were placed on the waiting list because they were new applicants, Medicaid rollovers, or families who reapplied for NC Health Choice late.

⁵ Johnston G. Special Data run for Federal Fiscal Year 2001 (October 1, 2000 through September 30, 2001). August 21, 2002. Children are categorized as one of the following racial or ethnic groups: Asian, Black, Hispanic, Indian, Other and White. Each category is mutually exclusive.

⁶ Children lost Medicaid eligibility generally for one of two reasons: 1) they aged out of a specific income category and their family income was too high; or 2) their family income increased, making them ineligible for Medicaid.

⁷ DSS counts the income of the child's parents who are living with the child and monthly support the family receives from a non-custodial parent in determining eligibility for Medicaid and NC Health Choice. A step-parent's income does not count in determining a child's eligibility, unless the step-parent has adopted and assumed financial responsibility for that child.

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