

**Children's Medical Services:
Survey of Families Who Did Not
Renew Title XXI Coverage
2005**



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I. Executive Summary

The purpose of this study is to evaluate the experiences of families who did not renew their child's¹ health coverage following recent legislative changes in Florida. Specifically, this study focuses on those families whose children had been enrolled in the Title XXI-funded Children's Medical Services Network (CMSN) component of the Florida KidCare state children's health insurance program, but whose coverage was not renewed due to incomplete or noncompliance with new documentation requirements. Children's Medical Services (CMS) is a Title V program for children with special health care needs (CSHCN).

A comparison of administrative data covering the same time spans shows that CMS children had a disenrollment rate of 16 percent, while Healthy Kids children had a disenrollment rate of 23 percent.

Compared to respondents from the Florida KidCare Caregiver Survey and the Healthy Kids non-renewal survey, Title XXI CMSN parents who did not renew their child's coverage were more likely to have completed high school and more likely to have an Associates degree or higher.

Results of this study showed that 78 percent of Title XXI CMSN families that did not renew their children's coverage found the new renewal process to be much more to somewhat more difficult than it needed to be and that the majority of families found too much background paperwork was required to verify income.

The study also investigated the effectiveness of different activities to encourage families to renew their child's health coverage. The study found that the most effective activities (ranked by the number of families reached and the perceived helpfulness) were the Florida KidCare renewal organizer and a reminder flyer used by the CMS program.

The top three reasons cited for non-renewal by Title XXI CMSN non-renewers were:

- Didn't think child was eligible anymore because of income (24 percent),
- Sent in all materials but they said you did not (12 percent), and
- Never received renewal documents from the Florida KidCare program (11 percent).

Title XXI CMSN non-renewing families were satisfied with the program and their children's providers, and 92 percent felt that the CMS Network was the right program for their child.

¹ Each interview that was conducted was targeted at one child in the household.

Recommendations

Information learned from families and administrative data prompted a number of recommendations on how CMS and the Florida KidCare program can improve the renewal process.

Administrative Simplification

1. Reduce bureaucracy/paperwork. The Florida KidCare program should re-evaluate its renewal documentation requirements to ensure that the requirements are concise, clear, and specifically meet the statutory directive. Investigate the feasibility of using electronic verification of income or other methods whenever possible to cut down on paperwork required from families.
2. The CMS Program should work with Florida KidCare to identify ways that CMS field staff could have access to CSHCN family account information since families contact their care coordinators first when they have questions or need help understanding what renewal information is required.

Communication

3. Utilize electronic mail to send families information about the renewal process as well as reminders.
4. Target renewal information to families with adolescents or young teens and those who live in urban areas.
5. Modify the Florida KidCare application to ask for the parent's cellular telephone number, as well as a follow-up question asking if the State has permission to call them using their cellular telephone number.
6. Staff more customer service agents to answer phone inquiries.
7. Make the renewal forms shorter and in larger print.

Further Research

8. CMS should consider investigating why parents believe they are no longer eligible due to income. Results could estimate how often the parent's belief is not substantiated.

II. Background

Florida KidCare, the State Children's Health Insurance Program (SCHIP), consists of four program components:

- MediKids;
- Florida Healthy Kids;
- the Children's Medical Services Network (CMSN); and,
- Medicaid for Children.

Both MediKids and part of the CMSN are governed by Title XXI of the Federal Social Security Act. Federal Title XXI SCHIP eligibility requirements provide that a child must be uninsured, under age 19, have family income under 200% of the federal poverty level, be a U.S. citizen or qualified alien, not reside in a public institution, and not be eligible for Medicaid.

The CMS program is Florida's Title V program for children with special health care needs. The comprehensive health insurance component of the CMS Network is available to children with special health care needs who are eligible for Title XIX-funded Medicaid or Title XXI-funded SCHIP. Section 391.021(2), *Florida Statutes*, defines children with special health care needs as:

“those children younger than 21 years of age who have chronic physical, developmental, behavioral, or emotional conditions and who also require health care and related services of a type or amount beyond that which is generally required by children.”

To qualify for the Title XXI-funded CMS Network Florida KidCare program component, a child must meet all Title XXI eligibility requirements and CMS clinical eligibility requirements. A child must have a serious or chronic physical, developmental, behavioral or emotional condition that requires extensive preventive and maintenance care beyond that required by typically healthy children.

During the 2004 regular legislative session Florida policymakers passed two bills that made significant changes to the Florida KidCare program: Senate Bill 2000 and House Bill 1843. These laws increased the Title XXI eligibility redetermination period from every six months to every 12 months, instituted new income documentation requirements, required information about whether a child could be added to the parent's employer-sponsored health insurance and its cost, and assigned formal responsibility for Title XXI eligibility determination to the Florida Healthy Kids Corporation.

Prior to the passage of the legislation, Title XXI eligibility redetermination, or renewal as it will be referred to in this report, was a passive process. Families whose children were enrolled in the Florida KidCare program received a letter notifying them of the upcoming renewal date for their child's health care coverage. Families were instructed to report any changes that may have happened to their health insurance or income. Families who did not respond were allowed to continue their children's coverage as long as they paid their monthly premiums. Families who did report changes had their renewal applications determined for continued eligibility much like they did when they first enrolled their children in the program.

Beginning on July 1, 2004, the renewal process changed to an active redetermination. Families were required to complete a renewal request form and provide proof of income and information about their access to employer-sponsored health insurance. Failure to respond or provide all required information resulted in disenrollment. Families were required to provide three documents that proved their income: the federal income tax return, W-2 statements and pay stubs, plus other income documents. Due to the four hurricanes Florida experienced in the fall of 2004 however, no children were canceled from the Florida KidCare program for failure to comply with renewal requirements or for failure to pay the monthly premium. The first and largest group of children to lose Florida KidCare coverage due to non-compliance with renewal requirements was on December 1, 2004.

In response to growing concerns about the amount of paperwork needed to document income and declining Title XXI enrollments, during a special session in December 2004, the Legislature enacted Senate Bill 28-A, which changed the required income documents to the most recent federal income tax return. In the absence of a federal income tax return, a family may submit wages and earnings statements (pay stubs), W-2 forms, or other appropriate document. The legislation, however, did not change the requirement to pay a monthly premium for Title XXI-funded Florida KidCare coverage. Failure to pay the monthly premium on time continued to result in disenrollment for at least 60 days.

Few studies have been conducted that focus on how State's renewal policies affect SCHIP disenrollment rates; however, results from these studies suggest that on average, 30 to 50 percent of SCHIP enrollees do not renew coverage². A 2002 study by Dick et al., compared the effect of different disenrollment policies of Florida, Kansas, New York and Oregon on disenrollment rates in SCHIPs. The study showed that under passive renewal, which Florida had in 2002, the disenrollment rate was 5 percent as compared to the other states which had disenrollment rates as high as 50 percent³. A final study by Kempe et al., focused on Colorado's SCHIP program, which has had an active renewal process since inception. The study found that only one-third of families

² Sommers, B.D. From Medicaid to Uninsured: Drop-Out Among Children in Public Insurance Programs. Health Services Research. 2005 Feb. 40(1):59-78.

³ Dick, A. W. et al. Consequences of State's Policies for SCHIP Disenrollment. Health Care Finance Review. 2002 Spring 23(3): 65-88.

eligible for SCHIP successfully renewed their coverage in 2000⁴. It should be noted that these studies focused on SCHIP in general, while the focus of this report is the CMS population. However, these studies give an idea of what typical disenrollment rates in State public health insurance programs are under passive and active disenrollment policies.

Legislation aimed at the Florida KidCare program affects all of its Title XXI program components, including the CMS Network. Continuity of care is important for any child, but the issue becomes even more important when a child has a special health care need. Understanding the critical need for continuity, the CMS program undertook several activities to help families with children enrolled in the Title XXI CMS Network understand the revised renewal requirements and how they should go about meeting the requirements. Examples of these initiatives included:

- Contacting families by letter;
- Contacting families by personal telephone calls;
- Opening up fax lines for families to send documents to the CMS Headquarters Office in Tallahassee for hand delivery to Florida Healthy Kids;
- Contacting families with flyers; and,
- Providing CMS Area Offices with Florida KidCare renewal organizer booklets to help families understand the documentation requirements.

Each of these initiatives is further explained in Section VI of this report.

The CMS Program contracted with the Institute for Child Health Policy (Institute) to evaluate the effects of the new renewal process on Title XXI CMSN families. The purpose of this evaluation is to present the findings of a statewide survey targeted at CMS families who were affected by the recent changes in the Title XXI renewal process. Specifically, this report addresses the renewal experiences for those Title XXI CMSN families who *did not* ultimately renew their child's coverage. A companion report detailing the renewal experiences of those Title XXI CMSN families who *did* successfully renew their child's coverage is forthcoming. This evaluation covers the period of July 1, 2004 through June 30, 2005 - State Fiscal Year (SFY) 2004-2005.

It should be noted that the Institute conducted a similar renewal study targeting children enrolled in the Healthy Kids program entitled, "Renewal Policy Changes and Enrollment in the Florida Healthy Kids Program". Healthy Kids is a Florida KidCare Title XXI statewide program that provides health care coverage to children who meet certain income requirements and do not have a special health care need. Throughout this report comparisons will be made to the findings from the Healthy Kids study. Although the two programs serve markedly different populations, the Healthy Kids study provides a baseline for comparison. In addition, the Institute annually conducts a Florida KidCare Caregiver Survey. This statewide survey assesses the general satisfaction of parents

⁴ Kempe, et al. Disenrollment from a State Child Health Insurance Plan: Are Families Jumping S(c)HIP?. *Ambulatory Pediatrics*. 2004 Mar.-Apr. 4(2):129-30.

and guardians with the program and caregivers in each component of the Florida KidCare program, including Title XXI CMSN families. When applicable, comparisons are made throughout this report to those from Title XXI CMSN families that were surveyed in the 2004 Florida KidCare Caregiver Survey.

The following sections are contained in this report:

- An overview of the data collection and evaluation methods;
- A description of families' sociodemographic characteristics who *did not* renew their child's coverage;
- A description of the renewal experiences of families who *did not* renew their child's coverage;
- A description of the attitudes towards premiums for families who *did not* renew their children's coverage;
- A description of the satisfaction with the overall CMS program for families who *did not* renew their children's coverage; and,
- Conclusions and recommendations.

III. Data Collection and Evaluation Methods

Four sources of data were used to evaluate the experiences of families who did not renew their child's Title XXI CMSN coverage: administrative data (which includes claims and encounter data), enrollment files used for the telephone surveys, telephone survey data from families who did not renew their children's Title XXI CMSN coverage, and results from Florida KidCare Caregiver survey conducted with Title XXI CMSN families whose children were enrolled at the time of the survey and for 12 months preceding the survey. Data files were obtained from CMS data specialists and these files were used to select the sample of families that would be interviewed. The enrollment files contained information on the child's age, gender, number of months in the program, and whether or not they renewed coverage during the first passive renewal cycle.

The enrollment files from the CMS Program consisted of 1,388 Title XXI CMS Network children in 1,249 families whose Title XXI coverage was canceled between December 2004 and June 2005 for one of two reasons: (1) renewal documents incomplete and/or not returned, or (2) non-response to renewal, later replied, but subsequently not re-enrolled. Based on administrative data provided by the CMS data specialists, less than 10 percent of these children were re-enrolled in Title XXI CMSN or Title XIX Medicaid in July 2005 (7.2 percent) or August 2005 (6.1 percent).

Telephone surveys conducted with families who did not renew their child's coverage were administered from 10 AM to 9 PM, 7 days per week from July 2005 to August 2005. Families were contacted a minimum of 30 times and searches were conducted in an attempt to update contact information. Surveys were conducted in English and Spanish. The respondent was chosen by asking to speak to the individual in the home most familiar with the targeted child's health⁵. In total, 148 families completed the survey.

Overall, 47 percent of the telephone numbers provided were disconnected, fax numbers, or numbers to businesses. In addition, 19 percent of the telephone numbers were associated with respondents who did not meet the screening criteria to participate in the survey (i.e., eligible for renewal but had not renewed coverage). Of the families who were located and eligible to participate in the study, 12% refused to participate. Overall, there was a 36% response rate.

In addition to the enrollment files and the survey data, the Institute also analyzed administrative data for children enrolled in Title XXI CMSN who were up for renewal from September 2004 to February 2005. Children were partitioned into 3 groups: Continuously Enrolled, Disenrolled and Reinstated, and Disenrolled and Never

⁵ Surveys were targeted to one child in the household even if the household had two or more children enrolled in CMS.

Reinstated. Each child's Clinical Risk Group (CRG), gender, age, urbanicity, and federal poverty level were analyzed.

The Clinical Risk Groups (CRGs) were used to classify enrollees' health status. This system classifies individuals into mutually exclusive clinical categories by reading ICD-9-CM diagnosis codes from all health care encounters, except those associated with providers known to frequently report unreliable codes (e.g., non-clinician providers and ancillary testing providers)⁶. It assigns all diagnosis codes to a diagnostic category (acute or chronic) and body system, and assigns all procedure codes to a procedure category. Each individual is grouped to a hierarchically defined core health status group, and then to a CRG category and severity level, if chronically ill.

Chronic and acute illnesses are generally classified only if there has been at least two outpatient encounters for that diagnosis separated by at least a day. Enrollees in the program for 6 months or longer are included in the analyses. Some continuity of enrollment is required to classify individuals accurately. The health status classifications of children meeting the enrollment criteria are reported in these analyses. The health status of children not meeting the enrollment criteria is reported as "not classified."

For the analysis, the CRG categories were grouped as follows: (1) Healthy (children who were seen for preventive care and for minor illnesses, including children who were enrolled but did not use health care services during the classification period), (2) Significant Acute (acute illnesses that could be precursors to or place the person at risk for developing a chronic disease), (3) CSHCN – Minor Conditions (single minor conditions and multiple minor conditions), (4) CSHCN – Moderate Conditions, (moderate chronic conditions), and (5) CSHCN – Major Conditions, (major chronic conditions, multiple chronic conditions, metastatic malignancies, and catastrophic conditions).

⁶ Neff, J.M., Sharp, V., Muldoon, J., Graham, J. Popalisky, J., Gay, J. 2001. "Identifying and Classifying Children with Chronic Conditions Using Administrative Data with the Clinical Risk Group Classification System. *Journal of Ambulatory Pediatrics*. 2(1): 72-29.

IV. Health and Sociodemographic Characteristics

Administrative Data Analysis

Results from the administrative data analysis are shown in Table 1. A census of children enrolled in Title XXI-funded CMSN and scheduled for renewal between September 2004 and February 2005 was included in the analysis. Of the 9,334 children: 80 percent (7,513) were continuously enrolled, 16 percent (1,516) were disenrolled and never reinstated, and 3 percent (302) were disenrolled and subsequently reinstated.

Over one-half of these children were female, and the majority was between 12 and 20 years old. In all strata, over 80 percent lived in urban areas, and over one-half had incomes less than 150 percent of the federal poverty level (FPL). Focusing on the Clinical Risk Groups (CRGs), the greatest percentages of children were classified as “healthy”. Children in the “healthy” category all met the CMS clinical eligibility criteria for enrollment in the program. As previously described, children classified as “healthy” are those children who were seen for preventive care and/or minor acute care needs or not seen at all during the classification period. A higher percentage of those who disenrolled and were never reinstated were classified as “healthy” compared to those who stayed continuously enrolled (40.5% and 37.9%; respectively).

The child’s age also was associated with failure to renew. A higher percentage of those in the 12 to 19 year old age cohort disenrolled and were never reinstated compared to those who were continuously enrolled (51.4% and 46.1%; respectively). Finally, a higher percentage of families with incomes below 150 percent FPL disenrolled their children compared to those in higher income categories.

Analysis of the administrative data are encouraging, considering that typical disenrollment rates seen in other states with active SCHIP renewal policies are 30 to 50 percent. Direct comparisons with other states are difficult because the studies conducted in other states do not focus on Title XXI enrollees enrolled in a CMS-like program. However, the results may suggest that the activities that CMS staff undertook helped to abate the disenrollment of eligible CMS children. CMS can use the results of this analysis to further lessen disenrollment rates by targeting CMS children who are: low income, ages 12 to 19, and live in urban areas.

The same analysis performed for this study also was performed on children enrolled in the Healthy Kids program scheduled for renewal between September 2004 and February 2005⁷. Of those 270,333 children in the Healthy Kids Program: 77 percent renewed coverage and 23 percent did not. Although both analyses focus on a snapshot in time, the results show that fewer CMS children disenrolled. This difference may be

⁷ The Healthy Kids analysis can be found on page 16 of the aforementioned report.

related to differences in populations or to efforts by the two programs to reduce disenrollment rates.

Table 1. Title XXI CMSN Demographic and Health Characteristics

	Children up for Renewal		Enrollment Trend					
			Continuously Enrolled		Disenrolled and Reinstated		Disenrolled and Never Reinstated	
	N	%	N	%	N	%	N	%
Total	9,334		7,513	80.5%	305	3.3%	1,516	16.2%
Health Status Categories (CRGs)								
Healthy	3,582	38.4%	2,847	37.9%	121	39.7%	614	40.5%
Significant Acute	181	1.9%	144	1.9%	7	2.3%	30	2.0%
Minor Chronic (Single & Multiple)	571	6.1%	483	6.4%	16	5.2%	72	4.7%
Moderate Chronic (Single)	1,847	19.8%	1,515	20.2%	40	13.1%	292	19.3%
Major Chronic (Dominant/Multiple Chronic, Malignancies & Catastrophic)	1,423	15.2%	1,190	15.8%	40	13.1%	193	12.7%
No CRG	1,730	18.5%	1,334	17.8%	81	26.6%	315	20.8%
Gender								
Male	4,028	43.2%	3,264	43.4%	133	43.6%	631	41.6%
Female	5,306	56.8%	4,249	56.6%	172	56.4%	885	58.4%
Age								
1-4	840	9.0%	662	8.8%	23	7.5%	155	10.2%
5-11	4,101	43.9%	3,388	45.1%	131	43.0%	582	38.4%
12-19	4,393	47.1%	3,463	46.1%	151	49.5%	779	51.4%
Urban/Rural								
Urban	8,122	87.0%	6,552	87.2%	259	84.9%	1,311	86.5%
Rural	1,118	12.0%	887	11.8%	44	14.4%	187	12.3%
Unknown	94	1.0%	74	1.0%	2	0.7%	18	1.2%
Federal Poverty Levels (FPL)								
<150% FPL	5,462	58.5%	4,334	57.7%	178	58.4%	950	62.7%
>150% FPL	3,872	41.5%	3,179	42.3%	127	41.6%	566	37.3%

Survey Results

The remainder of the findings presented in this report focus on the results from the CMS non-renewing families survey, the Florida KidCare Caregiver survey, and the Healthy Kids non-renewer survey⁸. Table 2 shows the sociodemographic characteristics of Title XXI CMS Network and Healthy Kids children whose eligibility was scheduled for redetermination during the renewal cycle but who did not renew coverage, as well as sociodemographic characteristics for CMS children whose families participated in the 2004 Florida KidCare Caregiver Survey.

As seen in Table 2, the mean age of children for whom Title XXI CMS Network coverage was not renewed was 14.5. Results from the Florida KidCare Caregiver Survey show that the mean age overall of Title XXI children served in the CMS program is 12 years. The mean age of the non-renewers in the Healthy Kids study was 14 years.

Table 2 also gives the results of the child's race/ethnicity. Ethnicity/race is categorized by: White non-Hispanic, Black non-Hispanic, Hispanic, and Other. Overall, 57 percent of the Title XXI CMS Network non-renewers were White non-Hispanic, 24 percent Hispanic, 12 percent Black, and 7 percent Other. In the Florida KidCare Caregiver Survey conducted with families whose children are enrolled in Title XXI CMS for 12 months or longer, 60 percent of the enrollees were White non-Hispanics, 13 percent were Black non-Hispanic, 22 percent were Hispanic, and 4 percent were classified as Other. More information about the racial and ethnic differences between those who renewed and those who do not will be available when the surveys with families who renewed coverage are completed. Of the non-renewers from the Healthy Kids study, 42 percent were White non-Hispanic, 17 percent were Black, 35 percent were Hispanic, and 6 percent Other.

Of those non-renewing Title XXI CMS Network families who indicated they were Hispanic, the majority had Puerto Rican lineage (43 percent), whereas in the Florida KidCare Caregiver Survey the majority of families were of Mexican descent.

Next, the table illustrates the level of parental education. Compared to respondents from the Florida KidCare Caregiver Survey, CMSN parents who did not renew their child's Title XXI coverage were more likely to have completed high school and more likely to have an Associates degree or higher. Fifteen percent of Title XXI CMSN parents who did not renew had less than a high school education, as compared with 24 percent of the overall Title XXI CMS sample from the Florida KidCare Caregiver Survey. Thirty-one percent of the Title XXI CMSN non-renewing parents had an Associates degree or higher, compared to 10 percent from the Florida KidCare Caregiver Survey. Twenty-nine percent of non-renewing Healthy Kids families had an Associates degree or greater, while 18 percent had less than a high school education.

⁸ Each survey was described in Section II.

The survey next asked non-renewing families about their household type. Sixty-eight percent of the Title XXI CMSN non-renewal families were married and over 73 percent had a two-parent household. These results are consistent with the families from the Florida KidCare Caregiver Survey and the non-renewing Healthy Kids families. National data have shown that the number of single parent families in the United States has been rising⁹, even though divorce rates have recently fallen. Results from this survey are indicative of national trends.

Fourteen percent of the Title XXI CMSN non-renewer families were self-employed, 65 percent were employed, and 22 percent were unemployed. In regard to the spouse or other parent of Title XXI CMSN non-renewer families, 26 percent were self-employed, 58 percent employed, and 15 percent unemployed.

Table 2. Comparison of Sociodemographic Characteristics

	Title XXI CMSN Non-renewers (%)	Healthy Kids Non-renewers (%)	Florida KidCare Caregiver Survey (%)
Mean Age	15	14	12
Child's Race:			
White Non-Hispanic	57	42	60
Black Non-Hispanic	12	16	13
Hispanic	24	35	22
Other	7	6	4
Parent's Education Level:			
Less Than High School Education	15	20	24
Associates Degree or Higher	31	29	10
Married			
	68	66	54
Two-Parent Household			
	73	69	74

In conjunction with the sociodemographic characteristics that the survey data yielded, administrative data were analyzed to determine how many of the Title XXI CMSN non-renewers had siblings in another Florida KidCare program component. Of the 1,388 Title XXI CMS Network children whose Title XXI CMSN coverage was canceled between December 2004 and June 2005, 49 of their siblings were enrolled in Healthy Kids and two siblings were enrolled in MediKids during the same time period. These results suggest that retention efforts made by either the MediKids or Healthy Kids programs were unlikely to have a significant impact on Title XXI CMSN families that did not renew their coverage, because there was so little overlap of enrolled children in the Florida KidCare program components.

Communication

Table 3 illustrates the results of various communication questions that were asked of Title XXI CMSN and Healthy Kids non-renewers. Title XXI CMS Network non-renewers were asked questions about their language preferences. Eighty-six percent of the respondents spoke English at home, 11 percent Spanish, 0.7 percent Creole, and 2.7 percent Other. When asked what language the child spoke at home, respondents indicated that 94 percent of the children spoke English, 3.4 percent Spanish, and 2.7 percent Other. Seventy-one percent of non-renewing parents in the Healthy Kids survey spoke English, 25 percent spoke Spanish, 2 percent Creole, and 3 percent Other.

Of the surveyed Title XXI CMSN families who did not renew coverage, 80 percent have access to a computer at home and 76 percent have access to the Internet at home. In addition, 52 percent have access to the Internet at work and of those, 82 percent believe their employer would allow them to use the Internet to access health information. In order to increase renewal rates, email addresses could be used by CMS to communicate with families. For the non-renewers in the Healthy Kids survey, 86 percent had a computer at home, 77 percent had access to the Internet, 47 percent had access to the Internet at work, and 79 percent indicated that their employer would let them use the Internet to access health information.

Another possible point of contact for families is by cellular telephone. Seventy-eight percent of Title XXI CMSN non-renewing families and 81 percent of Healthy Kids non-renewing families had a cellular telephone. It may be feasible to increase the contact rate of parents in this population by using cellular telephone numbers; however, two issues must be considered. First, it cannot be assumed that families with cellular telephones do not also have land telephone lines. Therefore, contacting them via a land line may still be a reasonable method. Second, contacting families via cellular telephone imposes a charge to the family. It is recommended that the Florida KidCare application ask for the client's cellular telephone number, as well as a follow-up question asking if the State has permission to call them using their cellular telephone number.

Table 3. Communication

	Title XXI CMSN Non-renewers (%)	Healthy Kids Non-renewers (%)
Parent's Language		
English	86	71
Spanish	11	25
Creole	0.7	2
Other	2.7	3
Child's Language		
English	94	82
Spanish	3.4	17
Creole	0	0.3
Other	2.7	1
Access to Computer at Home		
Yes	80	86
No	20	14
Access to Internet at Home		
Yes	76	77
No	24	23
Access to Internet at Work		
Yes	52	47
No	48	53
Can Use Internet at Work for Health Information		
Yes	82	79
No	18	21
Has a Cellular Telephone		
Yes	78	81
No	22	19

V. Impact of Child's Health on the Family

This section of the report summarizes the answers given by respondents concerning how their child's health has impacted the emotional well being of the family. Again, questions were asked about the impact of the targeted child only, and how the child's health directly affects the respondent and other family members. As this section is unique to the CMS Title XXI non-renewer survey, no comparisons are made to either the Florida KidCare Caregiver Survey or the Healthy Kids survey of non-renewers.

During the four weeks prior to being interviewed, 24 percent of respondents indicated that they had no emotional worry caused by their child's physical health. However, 24 percent indicated that they had a lot of emotional worry. In relation to how much emotional worry their child's behavioral health caused: 24 percent said none at all and 21 percent said a lot.

Next, respondents were asked if the child's physical health limited the amount of time for their own needs. Sixty-three percent said no. However, when asked if the child's emotional health limited the amount of time for their own needs 59 percent said quite a lot and 17 percent said none at all.

Respondents were then asked a series of questions related to how the child's health impacts the family. Forty-five percent indicated that the child's health almost never to never limited what the family could do. Likewise, 53 percent indicated that the child's health almost never to never interrupted everyday family activities, whereas 29 percent indicated that the child's health sometimes did. Overall, when asked to rate how well their families get along responses were, 32 percent Very Good, 28 percent Good, 22 percent Excellent, 14 percent Fair, and 4 percent Poor.

Sixty-six percent responded that the burden of their child's health on the family was none or a little. Seventy-three percent said they felt they were living day-to-day because of their child's health. When asked if fatigue was a problem in caring for their child seventy percent of respondents said not at all or a little.

Focusing on other family members, seventy-seven percent said that the lack of time that they had for other members of the family due to their child's health was none or a little. When asked if their family has had to give up things as a result of their child's health, 42 percent said not at all, 24 percent a little, 22 percent a medium amount, and 11 percent a great deal.

VI. Renewal Experiences

This section of the report focuses on two important areas related to renewal: experiences and the renewal process in the Florida KidCare program, and reactions to the specific CMS renewal information and education tools.

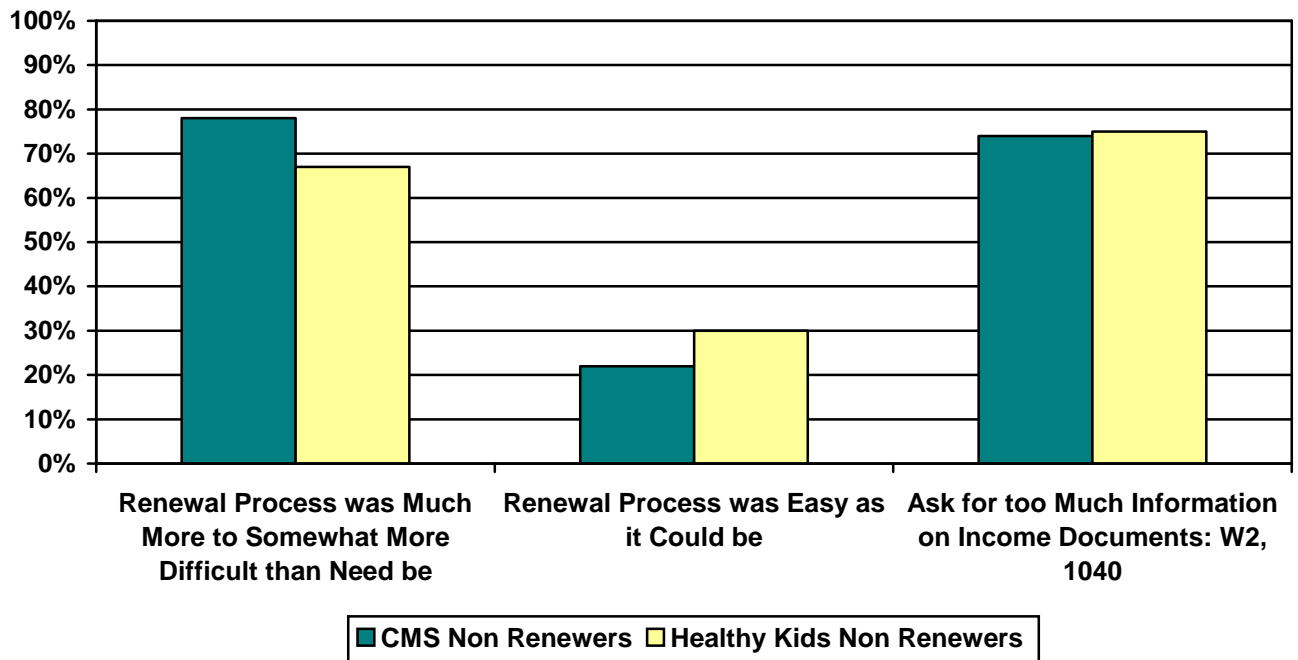
Florida KidCare Renewal Experience

Results from survey questions regarding CMS and Healthy Kids family's attitudes toward the renewal process are illustrated in Figure 1 below. The survey asked families about how difficult or easy they found the Florida KidCare renewal process. Seventy-eight percent of Title XXI CMSN families who did not renew coverage stated that they found the renewal process to be much more to somewhat more difficult than it needed to be. Only 22 percent reported that they thought the renewal process was as easy as it could be. In the comparable non-renewing group from the Healthy Kids study, 67 percent found the process much more to somewhat more difficult than it needed to be, while 30 percent thought it was as easy as it could be.

Respondents were asked about the amount of paperwork required to document their income. Almost three-fourths, or 74 percent, of Title XXI CMSN non-renewers strongly agreed or somewhat agreed that too much background paperwork was required such as pay stubs, 1040 forms, or W-2 forms. The identical question posed to the non-renewers in the Healthy Kids study showed that 73 percent somewhat agreed to strongly agreed that too much background paperwork was required to justify income such as pay stubs, 1040 forms, or W-2 forms.

When asked about the amount of paperwork required to document other forms of unearned income, such as child support, Social Security income or Unemployment Insurance, 47 percent of the Title XXI CMSN non-renewing families strongly agreed or somewhat agreed that too much paperwork was required, while 59 percent disagreed that too much was required. When asked if too much paperwork was required to document income from self-employment (i.e., business ledgers and work calendars), 41 percent indicated this did not apply to them. Of the approximately 60 percent that were affected, 37 percent strongly agreed or somewhat agreed that too much was required and 22 percent somewhat to strongly disagreed that too much was required. Healthy Kids families were not asked these two questions.

Figure 1. Attitudes Towards Renewal Process



Florida KidCare Letter, Telephone Contact, and Toll Free Number

As a part of the renewal process, the Florida Healthy Kids Corporation sends a letter and Florida KidCare renewal request form to all families whose children’s coverage is due for renewal. The corporation also contracts for automated telephone calls to be made to the families reminding them about renewal, as well as for the Florida KidCare customer service toll-free number (1-800-821-5437).

Respondents from Title XXI CMSN non-renewing families were asked if they received a letter in the mail about renewing their child’s Florida KidCare coverage¹⁰. Seventy-five percent recalled receiving the letter, and 52 percent found the letter to be helpful to very helpful. Seventy-five percent of non-renewing families from the Healthy Kids survey recalled receiving the renewal letter; of those, over one-half (52 percent) found the letter to be helpful to very helpful.

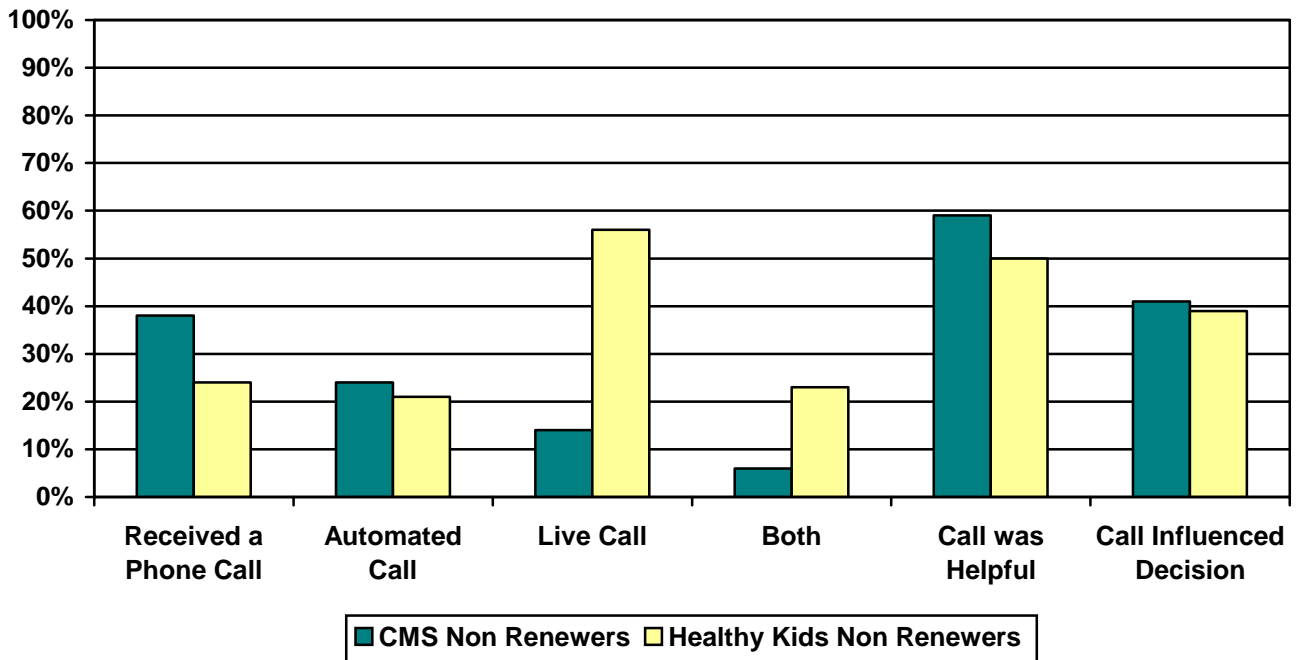
Florida KidCare also contacted families about renewal via a live or automated telephone call and results are seen in Figure 2 below. Thirty-eight percent of non-renewing Title XXI CMSN families recalled receiving a telephone call about renewal. Of those, 24 percent received an automated call, 14 percent a live call (from either a CMS nurse or other staff member), and 6 percent received both. Fifty-nine percent found the

¹⁰ An example of this letter and renewal request form can be found in Appendix A of this report.

telephone call(s) to be very helpful to helpful and 41 percent indicated that the call influenced their decision to renew coverage.

Twenty-three percent of non-renewing Healthy Kids families recalled receiving a telephone call about renewal. Of those, 21 percent received an automated call, 56 percent a live call, and 23 percent received both. Fifty percent found the telephone call(s) to be very helpful to helpful and 38 percent indicated that the call influenced their decision to renew coverage.

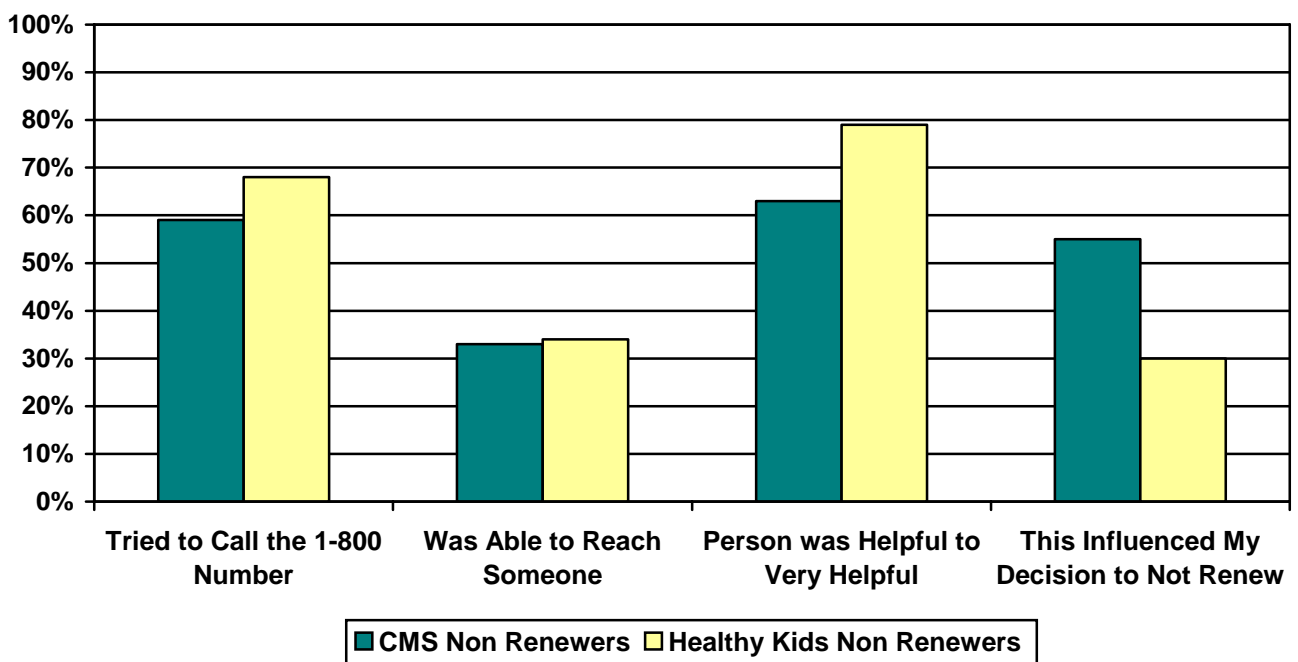
Figure 2. Attitudes Towards Florida KidCare Calls



Title XXI CMSN and Healthy Kids non-renewing families were asked about their experiences using the Florida KidCare customer service toll free telephone number to obtain help in renewing coverage and the results are presented in Figure 3. Fifty-nine percent of the Title XXI CMSN non-renewing families attempted to contact the 1-800 number, and 33 percent of those were able to reach someone easily. For those who did reach someone at the 1-800 number, 63 percent found this person to be helpful to very helpful while 17 percent found this person to be not helpful at all. Fifty-five percent of Title XXI CMSN non-renewing families indicated that their experiences using the 1-800 number influenced their decision to ultimately *not* renew coverage.

Sixty-eight percent of the Healthy Kids non-renewers attempted to contact the 1-800 number, and 34 percent were able to reach someone. Thirty percent of Healthy Kids families that had problems in reaching someone at the 1-800 number indicated that their experiences using the 1-800 number influenced their decision to ultimately *not* renew coverage.

Figure 3. Attitudes Towards the 1-800 Number



CMS respondents also were asked if any other health care provider or social service agency (other than the 1-800 customer service number) assisted them in the renewal process. When asked who specifically assisted them in renewing coverage (respondents could choose more than one answer): 38 percent said a Healthy Kids representative, 38 percent said a CMS nurse or care coordinator, 36 percent cited Other, 13 percent said Department of Children and Families, 7 percent said a personal physician or nurse, and 7 percent said a social worker. When asked to specify who

“Other” referred to, respondents indicated that they, ‘spoke to someone at a Health Center’, or ‘called their Senator’s office’.

CMS Information and Education Activities

In addition to the renewal information and contacts the Florida Healthy Kids Corporation made with all families whose children were enrolled in Title XXI, the CMS Program initiated supplemental activities to encourage families whose children were enrolled in the CMS Network to complete the renewal process.

In early November 2004, the Florida Healthy Kids Corporation notified the CMS Headquarters Office that coverage for 1,866 Title XXI CMSN children would be canceled at the end of the month for not responding or failing to provide all of the necessary information for renewal. In response, the CMS Program initiated telephone calls and letters to these families through the CMS Area Offices to encourage completion of the renewal process. The CMS Headquarters Office in Tallahassee opened five fax lines and made daily hand deliveries of families’ renewal documents to the Florida Healthy Kids Corporation. As a result of these intensive efforts, 51.8 percent (966 children) successfully renewed their coverage and remained enrolled in the Title XXI CMSN in December 2004.

The CMS Program also developed a “Florida KidCare Renewal Organizer” booklet, which was provided to the CMS Area Offices to share with CMSN families on a voluntary basis. The renewal organizer was created to provide families with the pertinent information needed to renew their child’s coverage in a clear and concise format. The renewal organizer is brightly colored booklet, and is printed in English and Spanish. The same text in Haitian Creole is available on legal size paper. CMS Area Offices were encouraged to distribute this organizer to families, and starting July 1, 2005, distribution was required to Title XXI CMSN families with upcoming Florida KidCare renewal dates. A copy of the 2004 Florida KidCare renewal organizer can be found in the Appendix B of this report.

In early July 2005, the CMS Headquarters Office mailed a one-page flyer to the 1,249 families whose children’s coverage had been canceled for non-compliance with renewal. The flyer’s message printed in English, Spanish and Haitian Creole stated:

“If your child is uninsured, it’s not too late to renew your Florida KidCare health insurance coverage. Call this toll-free number to find out what you need to do. Please have your Florida KidCare Family Account Number ready when you call – 1-800-821-5437.”

This message was designed to encourage families to contact the Florida KidCare customer service number and find out what information was needed to complete their renewal package. A copy of the flyer can be found in the Appendix B of this report.

Title XXI CMSN non-renewing survey respondents were asked a series of questions to evaluate the effectiveness of the various activities. When asked if they recalled receiving a telephone call about renewing their children's coverage, 38 percent of non-renewers recalled being contacted by telephone for this reason. Of those who reported receiving a phone call, 50 percent received a call from their CMS nurse or other staff member, 24 percent received an automated call from Florida KidCare, 20 percent received a call from a person other than their CMS nurse, and 6 percent received both an automated call and a personal call. Conditional on receiving one of these types of telephone calls, 59 percent found the call to be helpful to very helpful. However, 59 percent also indicated that the telephone call did not influence their decision to ultimately *not* renew coverage.

Concerning the Florida KidCare Renewal Organizer, 24 percent of Title XXI CMSN non-renewer families indicated that they did receive the booklet and 88 percent found the information easy to understand. Of those who received the booklet, 67 percent stated that it was helpful to very helpful and 82 percent stated that it helped to understand the renewal process and all of the requirements. On average, 84 percent of the respondents indicated that the booklet was useful in understanding what income documents were needed.

Slightly more than one-third (35 percent) of the respondents recalled receiving the reminder flyer and 98 percent found it easy to understand. Sixty-seven percent found the information in the flyer helpful to very helpful.

To get an idea of the effectiveness of each type of activity among Title XXI CMSN non-renewing families, Table 4 summarizes the percent who received the information and the percent who found it helpful to very helpful. Respondents reported that the two most helpful tools were the renewal organizer and the green flyer; however, these did not reach as many families as the renewal letter.

Table 4. Comparison of Information Activities for Title XXI CMSN Non-Renewing Families

	Received Renewal Letter	Telephone Call about Renewal	Renewal Organizer	Reminder Flyer
Percent Received	75%	38%	24%	35%
Percent Who Found Helpful to Very Helpful	52%	59%	67%	67%

VII. Non-Renewal Experiences

The next phase of the study focused on reasons *why* families did not ultimately renew Title XXI Florida KidCare coverage (both CMS and Healthy Kids families). Respondents were read a list of reasons that typically cause parents not to renew coverage. They were instructed to indicate which reason best fit their situation and they were able to respond with more than one answer. Table 5 shows the responses.

Table 5. Reasons for Non-Renewal

	CMS Non-Renewers	Healthy Kids Non-Renewers
Didn't think child was eligible	*	*43%
Didn't think child was eligible anymore due to income	41%	*
Sent in all the materials, but they said the family did not send them	32%	24%
The program wanted background information that you could not get	27%	41%
Never received renewal documents from Florida KidCare	26%	24%
Planning on getting other insurance	21%	29%
Forgot or did not get around to doing paperwork	20%	25%
Other	16%	20%
Dissatisfied with CMS/HK Program in general	14%	17%
Didn't think child was eligible anymore because of access to employer-sponsored health insurance	12%	*
Did not want child in CMS/HK anymore	11%	11%
Dissatisfied with child's physician	10%	11%
Didn't think child was eligible anymore due to age	9%	*
Dissatisfied with monthly premium	9%	7%
Didn't think child was eligible anymore due to health reasons	5%	*
Didn't think child's condition required CMS/HK coverage anymore	3%	12%

*Denotes a question that was not asked on the survey.

In both the Healthy Kids and Title XXI CMSN non-renewer studies, respondents were asked which of the reasons cited in Table 5 was the *most important* reason for not completing the renewal process.

The top three reasons for not completing the renewal process cited by Title XXI CMSN non-renewers were:

- Didn't think child was eligible anymore because of income (24 percent),
- Sent in all materials but they said you did not (12 percent), and
- Never received renewal documents from the Florida KidCare program (11 percent).

Given that the most important reason for not completing the process was the parent's perception that the child was no longer eligible because of income, the CMS Program should consider conducting further research to determine if this perception is accurate or not. Since the Florida KidCare income eligibility calculation includes several income deductions which may be unknown or confusing to parents, this may lead to an unwarranted loss in coverage for children who are still eligible.

The Healthy Kids non-renewal survey asked the question in a different sequence. Healthy Kids non-renewer families that chose "Did not think child was eligible", were then asked a separate question, "Why did you think your child was not eligible?" These Healthy Kids families were then read a list of reasons and the results were:

- 68 percent due to income,
- 7 percent due to age,
- 6 percent due to access to employer sponsored insurance, and
- 19 percent said Other.

For non-renewers in the Healthy Kids study, the top three reasons cited were:

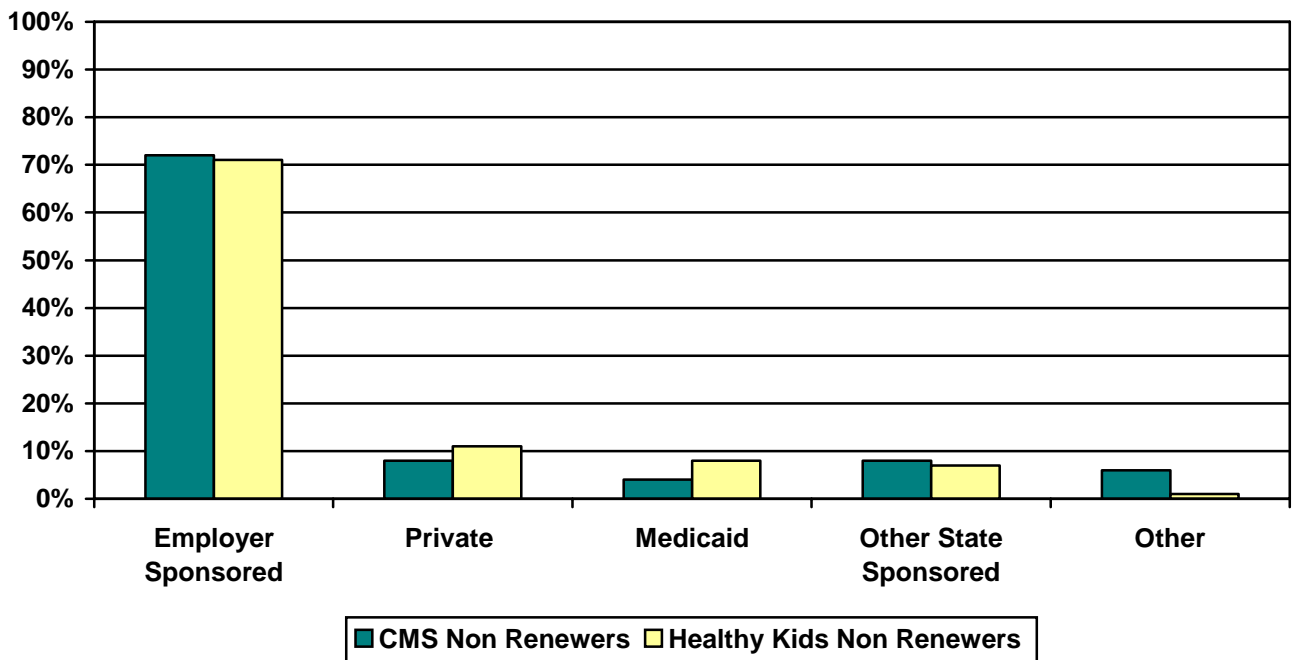
- Did not think child was eligible anymore,
- Could not get the background information that was required, and
- Sent in all materials but they said you did not.

Of the 65 percent of CMSN families who did not renew their child's Title XXI Florida KidCare coverage *and* did not obtain other insurance, the main reasons for not getting another health insurance policy were: premiums were not affordable (67 percent), were waiting to get back into Healthy Kids (41 percent), and child had pre-existing conditions that prevented coverage (19 percent). In comparison, of the one-half of families that did not renew their Healthy Kids coverage *and* did not obtain other coverage, 65 percent indicated that they could not afford other coverage, 38 percent stated that they were waiting to get enrolled into Healthy Kids again, and 20 percent said they did not believe in health insurance.

Thirty-five percent of CMSN parents who did not renew Title XXI Florida KidCare coverage obtained other health insurance coverage for their child. As seen in Figure 4, of those who did obtain other health insurance: 72 percent obtained private employer-sponsored insurance; 8 percent obtained private non-employer sponsored insurance; 8 percent obtained other public health insurance; 4 percent qualified for Medicaid or MediPass; and, 6 percent selected Other. Under their new insurance plan, 72 percent were able to keep their primary care physician (PCP) and of the 27 percent who were unable to keep their PCP, 79 percent had already selected another PCP.

The Healthy Kids study found that about 36 percent of the children who did not renew had obtained other insurance coverage. As seen in Figure 4, of these: 71 percent obtained employer-sponsored insurance, 11 percent obtained private insurance, 8 percent had Medicaid or MediPass, 7 percent had other state sponsored health coverage, and 1 percent had Other coverage.

Figure 4. Type of Other Coverage Obtained



VIII. Premiums

All families enrolled in a Title XXI-funded Florida KidCare program component, — including the CMS Network — are required to pay a monthly premium and failure to do so can lead to disenrollment for at least 60 days. However, children enrolled in the CMS Network are not required to pay copayments for services. Among CMSN families who did not ultimately renew their child's Florida KidCare coverage, the survey assessed their attitudes towards the premium, which is \$15 per family per month for families with incomes up to 150 percent of the federal poverty level, and \$20 per family per month for families with incomes between 150 percent and 200 percent of the federal poverty level.

Seventy-three percent of the non-renewing Title XXI CMSN families found the premium to be about the right amount, while 11 percent said it was too much and 16 percent said it was too little. Families also were asked how frequently they experienced difficulty paying the premium. Sixty percent never had difficulty paying the premium, 31 percent rarely had difficulty, 6 percent had difficulty every couple of months, and 2 percent always had difficulty.

Next, non-renewing Title XXI CMSN families were read a series of statements about the premium to see if they agreed or not. Results showed that:

- 99 percent strongly to somewhat strongly agreed that paying the premium gave them peace of mind that their child had coverage;
- 95 percent strongly to somewhat strongly agreed that the premium was well worth paying;
- 95 percent strongly to somewhat strongly agreed that they were happy to pay the premium because they felt better for paying part of their child's health care costs; and
- 91 percent somewhat strongly to strongly disagreed that paying the premium was a waste of money since their child was seldom ill.

Next, the non-renewing Title XXI CMSN families were asked to indicate the amount they would be willing to pay if CMS had a full coverage option: 38 percent said \$20 to \$30, 23 percent said \$41 to \$50, and 12 percent said \$91 to \$100. The monthly capitation payment for Title XXI CMSN enrollees is approximately \$518 per child, per month. The survey responses indicate that, at least among non-renewing families, a full pay option for CMSN benefits without any additional subsidy would not be financially feasible.

Table 6. CMSN Full Pay Premiums

Monthly Amount Willing to Pay	Percent (%)
I Cannot Afford to Pay	2.9
\$20 to \$30	38.2
\$31 to \$40	8.8
41 to \$50	22.8
\$51 to \$60	4.4
\$61 to \$ 60	0.7
\$71 to \$80	1.5
\$81 to \$90	0.7
\$91 to \$100	11.8
\$101 to \$150	3.7
\$151 to \$175	0
\$176 to \$200	2.2
\$201 to \$250	0
\$251 to \$300	1.5
\$301 to \$499	0
\$500 or More	0.7

IX. Evaluation of the CMS Program

In the final section of the survey families who did not renew Title XXI-funded coverage were asked about their satisfaction with the CMS program. When asked how satisfied they were with their child's doctor, 91 percent were somewhat to very satisfied while 5 percent were very dissatisfied. In general, families felt that the quality of care their child received was: Excellent (53 percent), Very Good (25 percent), Good (13 percent), Fair (6 percent), or Poor (3 percent). Although families in this survey ultimately did not renew coverage, 92 percent felt that CMS was the right program for their child.

Results from the Healthy Kids non-renewers survey indicated that 88 percent of parents were satisfied to very satisfied with their child's doctor. In addition, 69 percent rated Healthy Kids as Excellent to Good and 70 percent said the quality of care was Excellent or Good.

Respondents to the Title XXI CMSN non-renewer survey were next asked to sum up in a word or two the best and worst aspects of the CMS Network. The most cited answers for the best part of the program were:

- Affordable/free coverage to parents who cannot afford it (21 percent),
- Good doctors/medical care (21 percent),
- Good coverage/comprehensive care (17 percent), and
- Access to doctors and specialists (13 percent).
- In addition, 37 percent provided other responses, such as: nice/diligent doctors and nurses (23 percent), helpful staff (7 percent), convenient (2 percent).

The most cited answers for the worst part of the program were:

- Renewal process is too complicated/bureaucracy/red tape (22 percent),
- Bad communication (9 percent),
- Program poorly run (5 percent),
- Workers treat you poorly (5 percent), and
- Eligibility criteria too strict (4 percent).
- In addition, 48 percent provided other responses, such as: limited number of physicians (8 percent), waiting too long (6 percent), high staff turnover (2 percent).

It should be noted that although families cited a complicated and bureaucratic renewal process as one of the worst parts of the *CMS program*; by state law, the CMS program does not control the Title XXI renewal process, but families may not differentiate between the program components.

X. Summary and Recommendations

Summary

Renewing coverage in public health programs can be a confusing process for some CMSN families. Recent changes in the Title XXI renewal process may have compounded this confusion. Understanding the serious issues associated with loss of coverage and disruptions to continuity of care, Florida KidCare and the CMS Program undertook a variety of activities in SFY 2004-2005 to help clients understand and successfully navigate the new requirements for renewal. This report contains the preliminary results related to how parents who ultimately did not renew coverage felt about the new process and how they were affected by the efforts to help them understand the process.

As compared to Title XXI CMSN families who participated in the Florida KidCare Caregiver Survey and the Healthy Kids Survey of non-renewing families, the mean age of the Title XXI CMSN non-renewers was slightly higher as well as the percent married. Household type and race/ethnicity were relatively consistent across all three groups, while respondents in the Title XXI CMSN non-renewer survey had greater levels of parental education.

In regard to their reaction to the active renewal process, more Title XXI CMSN non-renewing families found the process to be much more difficult than it needed to be than Healthy Kids non-renewers (78 versus 67 percent). Both groups of non-renewers, however, found too much background paperwork was required to document their incomes.

Focusing on the individual educational activities, the survey found that the original renewal letter and renewal form that was sent to families by the Florida Healthy Kids Corporation reached the greatest percent of families, but families found the Florida KidCare renewal organizer and the reminder flyer CMS developed for its clients the most helpful. Starting July 1, 2005, the CMS Program made the distribution of the Florida KidCare renewal organizers mandatory to Title XXI CMSN families. This change should result in more CMSN families with Title XXI eligible children successfully renewing their coverage.

Sixty-five percent of Title XXI CMSN non-renewing families in the survey did not obtain other health insurance coverage for their child. Of these, two-thirds did not obtain other coverage because the premiums are unaffordable, which is consistent with other study findings. Coupled with the relatively small amounts of money the non-renewing families said they could pay if the CMS Program offered a full pay option, these responses support the ongoing need for affordable health insurance for low and moderate income families.

Thirty-five percent of the CMSN families who did not renew their children's Title XXI coverage did so because they found other health insurance coverage. This is essentially the same percentage of Healthy Kids non-renewers that found other insurance coverage. The majority of those families who found other coverage obtained employer-sponsored insurance (72 percent of CMS families versus 71 percent of Healthy Kids families).

Comparing non-renewer results from the Healthy Kids survey shows that Title XXI CMSN non-renewing families are more satisfied with their doctor (88 versus 91 percent) and 92 percent of CMS non-renewers believed that CMS was the right program for their child.

Recommendations

Information learned from families and administrative data prompted a number of recommendations on how CMS and the Florida KidCare program can improve the renewal process.

Administrative Simplification

1. Reduce bureaucracy/paperwork. The Florida KidCare program should re-evaluate its renewal documentation requirements to ensure that the requirements are concise, clear, and specifically meet the statutory directive. Investigate the feasibility of using electronic verification of income or other methods whenever possible to cut down on paperwork required from families.
2. The CMS Program should work with Florida KidCare to identify ways that CMS field staff could have access to CSHCN family account information since families contact their care coordinators first when they have questions or need help understanding what renewal information is required.

Communication

3. Utilize electronic mail to send families information about the renewal process as well as reminders.
4. Target renewal information to families with adolescents or young teens and those who live in urban areas.
5. Modify the Florida KidCare application to ask for the parent's cellular telephone number, as well as a follow-up question asking if the State has permission to call them using their cellular telephone number.
6. Staff more customer service agents to answer phone inquiries.

7. Make the renewal forms shorter and in larger print.

Further Research

8. CMS should consider investigating why parents believe they are no longer eligible due to income. Results could estimate how often the parent's belief is not substantiated.

Appendix A

Florida KidCare Renewal Letter and Renewal Request Form

Appendix B

Renewal Information for Title XXI CMS Network Families

Appendix C: What Families Say

In general, families found the new renewal process to be time consuming, confusing, and required too much background information. The majority of specific complaints were directed toward the 1-800 number. Title XXI CMSN non-renewers had a negative experience from the 1-800 number as a result of long wait times and failure to have their phone calls returned.

Below are several excerpts from families who completed the Title XXI CMSN non-renewers survey, which asked respondents to indicate the areas of CMS that they think are the best and the worst.

Best:

- *The nurses at CMS were honest and upfront.*
- *His CMS nurse was wonderful, I would call her and she would immediately call me back.*
- *They always answered my questions, never made me feel stupid, and always got back to me.*

Worst

- *We never had the same doctor in his Mental Health group.*
- *We were not able to get anger management.*
- *Doctors were limited and sometimes very far away.*
- *His CMS caseworker changed all the time.*

Finally, families were asked about what they would do to change the renewal process. Excerpts were:

- *Have a way to email information.*
- *Reduce the paperwork.*
- *Staff more people to answer the phones.*
- *Make forms shorter and in larger print.*