



**A Study of Parent/Caretaker Perspectives on the Reasons their Children 0-5
Years Old were Disenrolled/Dropped Off of Medicaid Rolls in 1997-1998**

submitted to

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by

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Introduction

The declining enrollment of children in Medicaid is a relatively recent phenomenon. Both national and state statistics reflect a diminishing enrollment of children in Medicaid (United States General Accounting Office publication 99-163, 1999). While the reasons for this diminishing enrollment are likely manifold, a Families USA Foundation report (1999: 1) argues there is “a direct connection between the loss of welfare benefits and the loss of health insurance coverage.” It finds that approximately 675,000 people lost Medicaid coverage as of 1997 due to welfare reform. “The majority (62 percent) of those who became uninsured due to welfare reform were children, and most of those children were, in all likelihood, still eligible for coverage under Medicaid (Families USA Foundation 1999: 1). Loss of eligibility for Medicaid obviously interrupts low-income children’s access to and utilization of primary preventive health care.

Government agencies are beginning to recognize that welfare reform efforts may have had the unexpected and unwanted result of reducing the numbers of children and families with health insurance coverage. For example, the Health Care Financing Administration (1999) recently issued a guide to assist policymakers and others in understanding Medicaid statutes and regulations, and provided information to help facilitate broadening Medicaid coverage. However, as Rosenbach, Irvin, and Coulam (1999) point out, merely providing insurance without a system in place to serve the special needs of low-income children and their families may not result in expanding access to preventive health services. Clearly, this is a multifarious problem.

The Lawton and Rhea Chiles Center for Healthy Mothers and Babies, under contract with the Department of Health and the Agency for Health Care Administration, with support from the Robert Wood Johnson Foundation, is successfully engaged in two efforts to increase enrollment in Medicaid of children in whose parents were case assistance recipients. One effort is a massive, community-based outreach program that has reversed the downward trend significantly, and the other is the development of medical homes from children in three pilot communities. This later effort is aimed at insuring that health care is provided for children who are enrolled in KidCare.

Purpose of the Study

Access and utilization of primary preventive health care and Child Health Check-Ups for Medicaid eligible infants and young children is compromised if a portion of that population is inadvertently dropped or disenrolled from Medicaid. In the state of Florida, while the population of children age 0-5 increased from 1,141,239 in March 1996 to 1,152,202 in March 1998, the numbers of those children on Medicaid declined from 351,264 to 282,663. This drop occurred simultaneously with the implementation of welfare reform and the WAGES program in Florida. Since 1999 this trend in disenrollment of children has been reversed, however, it is not clear if the increase in enrollment is new children or the children who were dropped off previously. While there is an explanatory administrative code for each child dropped from the Medicaid rolls, the perceptions and experiences of the parents/caretakers as they relate to the disenrollment during this time period may provide insight and direction for policies and processes to stem

further unwarranted disenrollments. This exploratory study will attempt to discern the process of disenrollment and/or dropping off of children from Florida Medicaid rolls 1997-1998, as understood and experienced by their parents and caretakers.

Limitations

This study is limited insofar as it depended upon the ability of parents/caretakers of children disenrolled or dropped from Medicaid to recall what was going on in their lives at the time of the alleged disenrollment, approximately two to three years ago. In addition, since it was rarely the child's family that initiated the dropping/disenrolling, the reasons they gave for it happening may be purely speculative. Also, it is likely that responses were biased by participants from more stable and secure families, meaning they were more likely to be married, older, and to have a higher income, hence these interviews may not be representative of the Medicaid population as a whole.

Population

The target population was families in Hillsborough, Pinellas, and Pasco counties who reportedly had at least one child between the ages of 0 and 5 dropped or disenrolled from Medicaid at some time in 1997 or 1998.

Methodology

The research protocol for this study was submitted to the University of South Florida IRB for exempt review and was approved. In January 2000, the Department of Children and Families provided data on 512,268 Florida children ages 0-5 dropped or disenrolled from Medicaid at some time during 1997 and 1998. Duplicate records of children who appeared to have been dropped/disenrolled more than once during that time period were removed from the database, resulting in a total of 438,067 children dropped or disenrolled in 1997-1998.

The initial research protocol entailed randomly selecting 125 Hillsborough, Pinellas, and Pasco county children's names from a list culled from the larger database. From those 125 names, every fifth one was selected and mailed a recruitment letter. Follow-up phone calls were made to further explain the project and to schedule an interview with a parent/caretaker. Open-ended interviews were conducted only with parents/caretakers who agreed to be interviewed, either in their homes or at another public place. All interviews were tape-recorded and transcribed by the principle investigator; tapes were destroyed after transcription. A total of six interviewees were paid \$35 each for their participation.

An addendum to the research protocol was submitted and approved by the University of South Florida IRB. The addendum to the protocol entailed conducting short "snapshot" telephone interviews with additional parents/caretakers. Individuals not contacted to do an in-depth interview were contacted for a snapshot interview. An additional 130 names from the three county area were added to the potential contact list. The principle investigator and a nursing graduate student conducted the snapshot interviews. After obtaining verbal consent, individuals participating in the snapshot interviews were administered a five-minute survey consisting of 30

questions. Interview questions were developed based on discoveries from the in-depth interviews. Question areas included disenrollment experience, length of time without coverage, eligibility for other benefits programs, health care seeking behaviors, and demographic questions. A total of 28 individuals completed a snapshot interview. No names of interview participants or their families appear in any written or recorded reports of this study.

In-depth Interviews

Six parents of children disenrolled from Medicaid at some time during 1997 and 1998 were interviewed in-depth between March 10 and April 20, 2000. Each interview will be presented in a vignette style. All names are pseudonyms.

Lynn

Lynn lives on a dirt road that runs parallel to the main road through a small, rural town. A chain-link fence surrounds the tiny home and there are two satellite dishes on the property. The house belongs to her parents; she and her husband are separated. Lynn is 24 years old, white; she finished high school via an international correspondence school. She has two children, a 6-year-old boy and a 3-year-old girl.

When asked how she found out her child was no longer enrolled in Medicaid Lynn responded: "Got a doctor's appointment and after they checked the number on the Medicaid card they come back and told me my child was no longer enrolled in Medicaid and I said 'excuse me? Nobody told me this.'" I asked her what she did after she found out and she said: "in order for my child to see the doctor I had to pay cash which I didn't have so I had to obviously cancel my appointment until I could get cash for it." She added: "You know, it's not the child's fault that, you know, he had been taken off, 'cause he was sick. They could have at least went ahead and let that doctor see him."

I asked her what was happening in her family at the time of the disenrollment, hoping to find a pattern emerge after doing a few interviews. She noted that she wasn't working, but her husband was, and that "we were barely making it week to week." She expressed satisfaction with the medical coverage her children had received on Medicaid: "at the time my kids were covered I was very pleased with it because there were times like I say I didn't have money to take them, cash money, and you know all I had to do was show the Medicaid card. It was just a very nice experience, you know, to have something like that for the families that can't really afford it."

Currently Lynn's children have no health insurance coverage, although she is trying to get them back on Medicaid. As she puts it: "I go at least once a month to, you know, update whatever they think I have to update, you know, to try to get 'em back on there." She just found out the day before she was interviewed that she herself has limited Medicaid coverage via the family planning waiver.

Lynn had just started back to school in January; she is studying to be a licensed practical nurse. She had been told she had to go through WAGES before she could go to school. She went through the program, did the weekly job search, got a job, reported it, but it somehow didn't end

up in her file so she was sanctioned. She returned to the WAGES office to try to deal with the wrongful sanction and was then informed they could provide help for childcare and school expenses. I asked her if they told her she and her children might be eligible for transitional Medicaid and she said “no, she was just telling me about child care and my expenses to go to school and that was it.” Childcare is costly for Lynn. She pays \$90 a week for her two children to attend daycare.

When asked if she had anything else to say about her children being dropped from Medicaid, Lynn said:

the experience that I've had with this family and children's place, if you're a certain color you get in there right away. If you don't fit in that category you can wait up to two weeks before you get an appointment... And just like yesterday, the lady just kinda give me the impression that... I didn't deserve anything. She didn't come out and tell me that, but that's how I felt... it's just that kind of attitude she had towards me, like I didn't deserve it or I didn't need it, you know?

Mary and Herb

Mary and Herb live with Herb's mother in her comfortable house near a gulf coast suburb. Mary and Herb have three children (she has two others from a previous marriage) who live with them in the house; one daughter has juvenile brittle diabetes. Mary is 41 years old, white, has a high school diploma, and works as a secretary in a hospital. Herb is disabled and does not work outside the home.

Mary's experience with disenrollment is a unique one: she took her children off Medicaid when she began working and put them on the insurance she received through her job. Previously, Herb had been working, but he became disabled, so Mary had no choice but to begin working.

It seems, however, that insurance through her job is a mixed blessing. When asked about their experiences with Medicaid, Mary said: “the Medicaid was fine... I never had no problem with it. I'd rather have the Medicaid than the insurance I have that I'm paying \$160 for a month.” Mary and Herb began talking about their insurance woes, when Herb said: “actually we were better off with Medicaid.” Mary elaborated: “We are because everything with insurance you've gotta always constantly pay even though you pay a month, you know? And it's hard with three little ones, and one's diabetic and all her needs. And him being disabled and me workin'... it's tough!”

When asked if she had ever tried to get back into Medicaid again, Mary said since she was working she never got around to seeing if her children were even eligible. Then she said: “I hate having anything to do with that kinda stuff. I hate getting food stamps, I hate that... it's just that I feel belittled because I've never ever had to stand in a line and beg for help.” When Herb interjected that “they don't treat you like you're begging” Mary retorted “yeah they do in that HRS office, don't give me that. They don't give you the time of day... they made me feel like they're doin' you a big favor.” She continued “And I just, I never pursued keepin' em on Medicaid. Maybe I should have, but I don't like dealing with people like that.”

Tina

Tina is a 25-year-old white woman who lives with her mother, stepfather, sister, niece, and two-year-old son in a house near a gulf beach. She completed her GED and is hoping to enroll in college soon to become an elementary school teacher. She opted to meet for the interview at a local college library rather than her own home.

Tina found out her child was disenrolled when Medicaid sent her a letter. The letter told her she and her son were being dropped because “they hadn’t heard from us or we hadn’t reapplied for AFDC or something like that.” When asked what she could remember about what was happening in her life at that time, Tina recalled receiving both AFDC and Medicaid, and that she was attempting to reconcile with her son’s father so she was “back and forth between my parent’s home and my son’s father’s home... I wasn’t planted enough to keep on with my appointments or whatnot with Children and Families.” Tina quickly learned that “they just need my work information... if I don’t give that information to them and I don’t reapply when I’m supposed to then I guess they’ll take him off, take us both off. That’s how it works.”

Tina has had a positive experience with Medicaid: “I would say pretty good considering that, you know, I had Medicaid through pretty much the whole time between his first year. I was able to take him to the doctor and I really didn’t have any problems at all, so I would say definitely good, my experiences were good... it’s been such a blessing to go to the doctor without, you know, worrying.”

Tina has participated in the WAGES program which she calls “a good overall idea... it’s just that I believe it’s a little bit unrealistic for some families... some families have the ways and means to participate in the program and others, I believe, don’t.” Tina quickly found a job within the first two weeks of her participation, and finished the 10-day program by reporting in and staying there for “a 4 or 5 hour day everyday.” She chalks up her success to having a vehicle and her mother around to watch her son. She noted that the WAGES program says they will help find childcare and transportation for its participants, but those services are not always easily accessible.

When asked if WAGES provided any information regarding Medicaid for herself or her son she said: “No. The only thing that they told me was that if I was gonna receive cash assistance that I had to go into the WAGES program... if you didn’t apply for cash assistance you didn’t have to go through the WAGES program.”

While Tina seemed very versed in what she needed to do to get Medicaid and food stamps, she characterized her life as “not very stable,” in part because she is living with her parents and her son’s father is not contributing financially to the care of their son. “I guess it’s just the stability of living from one day to the next not knowing, you know, what could happen because I, you know, tried really hard, you know, to get my life together and then something happens it causes me to... not be able to go to work because of childcare or something like that, you know, that has caused me many problems.” When asked if childcare had created a problem in trying to keep a

job she said: “Yes, that’s exactly what I’m getting at. I’ve lost two jobs because of childcare in the past, since my son’s been born.”

Susan

Susan lives in a run-down house 25 feet from the railroad tracks in a rural area. She lives with her two sons (ages 6 and 8), her three-year-old daughter, and her grandmother who at the time of the interview was in the hospital. Susan says she is married, but in further discussions with her it seems she and her trucker husband have separated. She is 37 years old, white, one credit away from obtaining a Bachelor’s degree, and works as a pre-kindergarten teacher.

Susan found out her children were disenrolled when she received a letter: “It just said that my three children were no longer eligible. And as of, it was like a month prior to the time I got the letter. So I had no insurance on those three children for a whole month and didn’t know it.” I asked her how long the children went without coverage and if she tried to get them back on Medicaid or some other type of insurance. She replied: “It took a couple of weeks, I don’t remember exactly how long. But it was a lot of running to the HRS building, which they call it now Children and Families, and arguing with people.” She continued:

It was like at least two times a week, and either the social worker was busy or wasn’t available, or just didn’t plain want to talk to me. ‘We haven’t got our records up yet’, ‘the computers aren’t up’, or ‘we haven’t got everything in the computer’... it was just a round and round thing. And it was like, you know, my son has asthma, I’ve got to have insurance, you know? He could go in the hospital at any time.

She eventually received a letter reinstating her children, but it took “months for them to say definitely yes.”

I asked Susan if there was anything going on with her family situation at the time her children were disenrolled. She wasn’t sure if it was at the same time, but recalled that she and her husband were separated then, “I had three children that I had to tend to for myself, I had no job, and just the money wasn’t... it just wasn’t here.” She elaborated further: “And then see, they wanted to fight with me over the fact that I was still legally married, therefore his income was still my income. And he has his own business, and so being self-employed they wouldn’t accept my application.”

I also asked Susan why she thought her children had been disenrolled. She said:

The reason that they told me was because I did not renew my application. It’s supposed to be done ever six months, whatever, but I never got a letter stating that it was going to be coming up. And you have to have an appointment with your social worker/caseworker in order to get in to do this, and I was busy having children and taking care of children and you know, six months goes... you know? So I basically forgot that they never reminded me. So they came down and said it was my fault because I failed to come in and update.

Interestingly, Susan's children had been dropped again the week before she was interviewed. This time they were dropped because of her income: "I just got a job, I've been working since October, and they said because my income is too high now" they were dropped.

Susan has not had good experiences with Medicaid. She related a story of one of her children ripping off the roof of his mouth with a straw: "it was very painful for him... *very*. It ended up down hanging into his throat and it took Medicaid three days to finally get him into emergency surgery to get it sewn back up. Three days!" I asked her what they did for him in the meantime, and she said:

Nothing! No pain medicine, nothing. I spent four hours at the first hospital where the doctor looked at it and said 'oh it'll be fine, don't worry about it.' And I was so angry I wouldn't even sign the release forms to leave, I just left, caught a cab and went to [another hospital]. Stayed there 6 hours, they said you need to see eye throat nose doctor in the morning. Well then I got there he was booked and had emergency surgery so I didn't get to see him 'til late that afternoon. And that afternoon he said 'well he's gonna have to have surgery.' So they got him in for emergency surgery the next day.

Susan also mentioned that being on Medicaid meant she couldn't have certain medicines for her children. One of her children has a skin condition that requires a particular, expensive prescription lotion, however, Medicaid only provides for its generic equivalent. She found out, however, that the generic was not as good as the other stuff when she had to pay out of pocket once and received the brand name medicine: "it works so much better! I mean, you put one application on and he's cleared up in one day. This other stuff you put three, four applications on, and he screams for about an hour, you know?"

Juanita

Juanita is a 37-year-old Hispanic, born in Cuba, who moved to the United States at age 7. She completed her high school education and currently works as night supervisor for a small office cleaning business. She has two daughters (ages 11 and 16) from her first marriage and a son (age 7) from her current marriage. Juanita and her family live in a suburban neighborhood house, close to a major city.

I asked Juanita how she found out her children were no longer covered by Medicaid. She found out when she took one of her children to the doctor:

They told me she was too big for Medicaid, and that my husband was getting too much money. My husband was working in Miami, self-employed. So it wasn't his kids... he only had the boy. So I went to apply, everything went perfect until we moved here, talking about now six years ago. Everything was perfect until that just one time and they took her's away because my husband he's an electrician and he was making good money.

Juanita says she rectified the situation for her daughter by making a phone call explaining the problem and was quickly reinstated. When she later went in for a re-determination meeting "they told me that I wasn't eligible... so then I just got up and said 'I don't want nothing else.'" She recalled that her son was still covered by Medicaid at that time and that she was really trying

to get coverage for her daughters. Eventually her husband got a different job that offered health insurance, so as she puts it: “it was expensive but we’re hanging in there.” I asked her how much it cost: “we pay about \$90 a week for all five of us.”

Juanita’s experience with Medicaid has been mostly good; she felt that she had no real problems until her daughter was dropped: “it wasn’t something perfect, but it helped me for the while that I had it.” However, she was less happy with her dealings with the Medicaid system:

Once in a while when you go in there and they look at you like if you’re from outer space that you’re trying to get help. I mean a lot of people... for me, it’s hard to go get that kind of help, but I needed it at that moment. I wasn’t there because my husband was making good money and I wanted to get some more health care or more money. I was there because I needed it, you know? But sometimes you see that the people in there that they have like an attitude like you know, you’re goin’ in there... ‘hey why are you coming in here?’ I’m going in there because I need help. But some of them have an attitude problem toward people that go in there. I don’t think that it’s fair.

In spite of this she told me she hopes “everybody that needs Medicaid, you know, they have it, because they’re there for a purpose. There’s a lot of people that I know that sometimes in a way they abuse, but there are other people that really, really need the help.”

Tamara

Tamara is a 31-year-old African-American, with a 2-year college degree. She is disabled and does not presently work outside the home. She lives with her 5-year-old daughter in an apartment and is currently separated from her husband. Tamara chose to meet in a park for her interview rather than her home.

Tamara found out her daughter was disenrolled when she received a letter, but as she puts it “they didn’t particularly give a reason” why she was dropped. She relates that her daughter was dropped after being on Medicaid for about four months. When asked why she thought her daughter may have been disenrolled she said: “I’m thinking that they probably dropped her because my husband still has insurance under her, and that’s it. But that’s the only thing I can think of.” After being dropped, her daughter luckily had some coverage under her husband’s insurance; her daughter got back onto Medicaid in November 1999.

While Medicaid was serving as a secondary payer for her daughter’s health insurance (she says her husband’s insurance is the primary payer), she was “kinda glad I had the Medicaid to fall back on because we were separated and you never know what a person is going to do.” She related that if her husband didn’t have insurance to cover their daughter she would be hard-pressed to finance co-pays or take her daughter in for emergencies when necessary: “because we’re separated that’s hard on me because he’s the one with the job. And I’m only getting a certain amount for disability and that takes care of everything else, you know, the bills that I pay.”

Tamara's experience with Medicaid for her daughter has been mostly good. In particular, she thought things seemed to be enhanced from the days of "straight Medicaid." She said: "they give you more variety to choose from, because I had to sit there for a while and read all the different plans that they have for Medicaid." On the downside, however, "you pick a plan and [your] doctor is not on any of those plans. And you have to change doctors, and you have to ship medical records all around to all these different doctors." She also noted difficulty getting her doctor's office to accept Medicaid (and Medipass), and told me she was allowed to continue with the only doctor her daughter has ever had because she was not a new patient.

At the close of our interview Tamara said, talking about health insurance and the treatment she has received because of being on Medicaid: "some people can't afford their insurance... and they have to get on Medicaid, and they need some help sometimes. That does not mean that they're sitting collecting AFDC and all that, you know what I'm saying?"

Snapshot Interviews

In an effort to talk to a wider group of parents/caretakers, and after getting a sense of some of the possible reasons for disenrollment from the in-depth interviews, a short telephone interview was constructed and administered to 28 people. The interview consisted of 30 questions that addressed the following topics: discovery of and reasons for disenrollment, eligibility for AFDC, SSI, and Medicaid, current health coverage, health seeking behavior, and demographics. Three of the questions allowed for an open response from the interviewee. Results from the selective response questions are listed in the table below.

To the best of your knowledge, have any of your children been dropped from Medicaid in the last three years?	Frequency (percent)
Yes	21 (75)
No	7 (25)
How long did your child go without medical coverage after being dropped?	Frequency (percent)
Less than a month	4 (14.3)
1-3 months	4 (14.3)
3-6 months	5 (17.9)
1 year or more	2 (7.1)
Child is still without medical coverage	6 (21.4)
Child wasn't dropped	7 (25)
Have you changed addresses in the last 3 years?	Frequency (percent)
Yes	6 (21.4)
No	15 (53.6)
Not asked the question	7 (25)
Did you ever receive a letter or notice telling you your child was no longer eligible for Medicaid?	Frequency (percent)
Yes	11 (40.7)
No	8 (29.6)

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Not asked the question	8 (29.6)
Did you receive AFDC cash benefits during 1997 or 1998?	Frequency (percent)
Yes	6 (21.4)
No	14 (50)
Not asked the question	8 (28.6)
Did you become ineligible for AFDC between 1997-1998?	Frequency (percent)
Yes	3 (10.7)
No	4 (14.3)
Not asked the question	21 (75)
Did any of your children become ineligible for SSI between 1997-1998?	Frequency (percent)
Yes	1 (3.6)
No	21 (75)
Not asked the question	6 (21.4)
Are your children currently covered by Medicaid?	Frequency (percent)
Yes	15 (53.6)
No	13 (46.4)
Does any other type of insurance cover them?	Frequency (percent)
Yes	9 (32.1)
No	5 (17.9)
Not asked the question	14 (50)
About how much do you spend per month on health care for your children?	Frequency (percent)
Less than \$20	10 (35.7)
\$20-\$49	7 (25)
\$50-\$99	5 (17.9)
\$100 or more	6 (21.4)
About how often do you seek health care services for your children?	Frequency (percent)
1-2 times/year	1 (3.6)
3-4 times/year	7 (25)
Once per month	3 (10.7)
Twice or more per month	4 (14.3)
Only when sick and for check-ups	13 (46.4)
Where do you usually take your children for health care services?	Frequency (percent)
Private doctor	21 (75)
Public health department clinic	3 (10.7)
Private clinic	2 (7.1)
Hospital	2 (7.1)

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Do you take your children to the doctor for check-ups even if they are not sick?	Frequency (percent)
Yes	24 (85.7)
No	4 (14.3)
Within the last three years, have your children had to go without medical care when they needed it because you could not afford to pay for it?	Frequency (percent)
Yes	7 (25)
No	21 (75)
How would you rate your satisfaction with the Medicaid system itself?	Frequency (percent)
Very satisfied	2 (7.1)
Satisfied	10 (35.7)
Somewhat satisfied	10 (35.7)
Not very satisfied	1 (3.6)
Not at all satisfied	4 (14.3)
No answer	1 (3.6)
How many adults live in your household?	Frequency (percent)
1	3 (10.7)
2	21 (75)
3	2 (7.1)
4	2 (7.1)
How many children live in your household?	Frequency (percent)
1	(7.1)
2	15 (53.6)
3	5 (17.9)
4	6 (21.4)
How old are you?	Frequency (percent)
20-24	7 (25)
25-29	6 (21.4)
30-34	3 (10.7)
35 or older	12 (42.9)
What is your race?	Frequency (percent)
White	14 (50)
Black	8 (28.6)
Other	6 (21.4)
Are you Hispanic?	Frequency (percent)
Yes	6 (21.4)
No	22 (78.6)
What is your marital status?	Frequency

	(percent)
Married	16 (57.1)
Never married	6 (21.4)
Divorced	3 (10.7)
Living with partner	3 (10.7)
What is the highest level of school you have completed?	Frequency (percent)
Less than high school	7 (25)
High school grad or GED	10 (35.7)
Some college	9 (32.1)
College grad	2 (7.1)
Do you work outside the home full-time, part-time, or not at all?	Frequency (percent)
Full-time	14 (50)
Part-time	6 (21.4)
Not at all	8 (28.6)
Which of the following ranges best describes the amount of your household's annual income?	Frequency (percent)
\$0-4,999	1 (3.6)
\$5,000-9,999	4 (14.3)
\$10,000-14,999	10 (35.7)
\$15,000-19,999	2 (7.1)
\$20,000-24,999	4 (14.3)
\$25,000-29,999	1 (3.6)
\$30,000 or more	5 (17.9)
No answer	1 (3.6)

Findings

In-depth Interviews

The parents interviewed at length about their disenrollment and Medicaid experience revealed two basic ways of finding out about their child's disenrollment, either by letter or by a visit to a provider; one of the parents self-disenrolled. Two of the interviewees are currently covering their children through private insurance, two enrolled in and are still in Medicaid, and two re-enrolled in Medicaid but are now without insurance because their children were recently dropped again from Medicaid. All but one of the interviewees was generally satisfied with the health care their children had received from Medicaid. Aside from the interviewee who had difficulties getting emergency care for her injured child, others characterized the health care their children received from "fine, no problems," "good," "not perfect, but helpful," to "it is a blessing."

The most consistent finding from the in-depth interviews was the amount of dissatisfaction with the Medicaid system itself. Those who felt they were wrongly disenrolled related aggravation at not being able to get information about the reasons for the disenrollment and at roadblocks to trying to get their children reinstated. Beyond the irritation of dealing with the disenrollment

itself was the general frustration at the way they were treated by Children and Families eligibility staff. These parents discussed feeling belittled, being treated rudely, and experiencing “attitude” when they tried to deal with the system.

Snapshot Interviews

Caution must be used in interpreting numerical findings since too few people participated in the snapshot interview to insure statistical power, however, the results are suggestive of trends. Three-fourths of the parents/caretakers completing the snapshot interview said one or more of their children had experienced disenrollment in the last three years. Most respondents (46.5 percent) noted their child was without health insurance coverage for less than 6 months after being dropped, however, 21.4 percent said their child was still without any medical coverage at the time of the interview. Fifty-three percent of the respondents said Medicaid currently covered their children. On average, those interviewed were satisfied with the Medicaid system.

One hypothesis regarding children losing Medicaid coverage during 1997-1998 was that when parents became ineligible for welfare cash benefits (AFDC at the time) children were being disenrolled because of the linking of children to their parent’s eligibility status. These results cannot confirm or reject that hypothesis since only six of those interviewed said they received AFDC during 1997-1998, and only three of those remembered becoming ineligible for it during that time. Another hypothesis was that children may have been wrongly terminated due to changes in SSI eligibility, however, only one person said their child became ineligible for SSI during that time period.

Depending on how they answered other questions in the snapshot interview, respondents may have been asked up to three open-ended questions. The questions asked: how they found out their child(ren) had been disenrolled, thoughts on why they were dropped, and an example of what they did when they couldn’t get needed medical care for their children. About a third of those who said one of their children had been dropped found out when they went to the doctor’s office; another third found out by a letter from Medicaid. A couple respondents removed their children from Medicaid themselves; another couple simply didn’t reapply when it was time to do so. Two respondents mentioned going in for a re-determination meeting, but then being denied. One respondent called in to Medicaid after not receiving a Medicaid card and was told over the phone that her children were being dropped. One other respondent said she found out when she tried to get a prescription filled and the pharmacist told her she was no longer covered.

If they hadn’t already answered, respondents were further asked to tell why they thought their child(ren) had been dropped. Among some of the other reasons given: four said they didn’t go in to re-certify, three went to work and thought they made too much money, and five said they just didn’t know. One respondent who said she didn’t reapply related that she was told she would need to look for work two or three times a week to qualify for Medicaid, but that her husband didn’t want her to work. Another respondent said she had a re-determination appointment scheduled, but couldn’t make it; she called to reschedule but was told her caseworker wasn’t available. In spite of her efforts to reschedule, she was sent a letter saying she had failed to keep her appointment. The respondent who found out about the disenrollment from her pharmacist said she never received a letter about it or even a reminder to come in for re-determination. She

also said she should try to get her daughter back on Medicaid, but that she was too busy working and couldn't take the time off work to reapply. Three respondents specifically mentioned that one child was dropped while their other children were not.

Respondents were asked to share how they handled times when they couldn't get needed medical care for their children. A couple respondents remembered just purchasing over the counter medicines and toughing things out. One respondent said two of his four children have asthma and without health insurance the family can't afford medicine, therefore, his wife's uncle mails medicine from the Dominican Republic. Another respondent's daughter had an asthma attack and had to go to the hospital. She said the hospital didn't want to admit her because she was without insurance; they eventually admitted her, but the family was stuck with a large hospital bill. Another respondent related having difficulties getting her injured daughter admitted to the hospital without insurance.

Discussion and Interpretations

The results of this study found two main avenues for parents/caretakers to discover their children's disenrollment from Medicaid: receiving a letter from the Medicaid agency and finding out when presenting for a doctor's appointment. Parent/caretaker-initiated reasons include removing the children from Medicaid on their own and assuming they are earning too much money to qualify, therefore failing to apply or go in for a re-determination meeting.

Receiving a letter from Medicaid appears to be the primary way of finding out about being dropped. Individuals who first found out when they took their child to the doctor usually reported that soon after they also received a letter. For many, the letter came a month or more after the effective date of disenrollment meaning they were unprepared to deal with the sudden lack of insurance. Similarly, parents who found out at the doctor's office that their child had been disenrolled were typically left with no way to deal with the immediate situation.

Missing a re-determination meeting, either purposefully or not, was also cited by parents/caretakers as a possible reason for their child's disenrollment. Those who felt they would be denied even if they did update their information appeared to opt to not go for a meeting. Others indicated that they were either never notified they needed to come in for re-determination or worse, were foiled from doing so by the unavailability and seeming lack of cooperation of Children and Families Medicaid eligibility caseworkers.

From difficulties getting questions answered by phone, to inaccessible caseworkers, to poor treatment at the Department of Children and Families offices, parents/caretakers expressed frustration at the way they and their children were treated by Children and Families Medicaid eligibility staff. In addition, limited anecdotal evidence from some of the interviews suggests that WAGES participants were not being adequately informed of the likely continued Medicaid eligibility of their children.

Recommendations and Conclusion

Despite the reason for disenrollment, it is imperative that the Department of Children and Families and the Agency for Health Care Administration explore ways to be more timely in informing families about a child's pending disenrollment. One way to address the delay in informing parents of disenrollment would be to produce letters before the effective date of disenrollment. From the raw data, it appears that all disenrollments were made effective at the end of the month. Producing the letters on a regular basis would avoid the pile-up of letters to be printed and mailed at the end of each month. With the availability of Florida KidCare, it would be helpful to include an application for that program in disenrollment letters. In addition to providing information on KidCare to such parents, the Agency for Health Care Administration should consider extending one-appointment coverage for children who present for care but whose coverage has been unknowingly terminated within the last few months.

In addition, these interviews reveal some dispute about the level of information provided in the disenrollment letters. Some respondents said they were explicitly told the reason the child was being dropped (chiefly for income reasons), but some recalled that no reason was provided. At a minimum this confusion suggests disenrollment letters be reviewed for clarity and literacy level.

Fulfilling the obligation of attending re-determination meetings was a hardship for some study participants, and is a problem that defies an easy remedy. The issue of how best to handle re-determination procedures has received national attention by the Health Care Financing Administration (HCFA), further confirming it as a problem in disenrollment from Medicaid. In a letter to all state Medicaid directors, HCFA listed some strategies for dealing with re-determination, including reinstating those dropped while reviewing current eligibility and limiting information required at re-determination meetings to only that necessary to determine ongoing eligibility. In addition, HCFA encouraged conducting ex parte reviews which entails using information available through other state agencies to assess Medicaid eligibility (Health Care Financing Administration, 2000). The adoption of ex parte reviews would be a useful strategy not only for keeping down the administrative costs of Medicaid, but for dealing with families who likely have an even more difficult time attending such meetings due to employment.

The poor treatment of some of the study respondents suggests the need to explore service procedures at the Department of Children and Families Medicaid eligibility (and WAGES) offices. Implementing support staff training for dealing with clients in an affirmative, non-judgmental way would be one step toward addressing this issue. Additionally, efforts to streamline procedures and to address employee morale might help in the provision of timely, friendly service. This is particularly crucial in the long run for sustaining positive relationships with families so that preventive and well-child care continues.

The results of this study also affirm findings from another study (Weissman, Witzburg, Linov, and Campbell 1999) that shows termination from Medicaid leads to problems getting prescriptions, obtaining treatment, and ultimately accessing needed care. Steps to address the unwarranted disenrollment of children and families from Medicaid can hopefully prevent the needless interruption of primary preventive health care, and the attendant administrative and personal difficulties it causes.

References

Families USA Foundation. 1999. *Losing Health Insurance: The Unintended Consequences of Welfare Reform*. Families USA Publication No. 99-103. Families USA: Washington, DC.

Health Care Financing Administration. 1999. *Supporting Families in Transition: A Guide to Expanding Health Coverage in the Post-Welfare Reform World*. Available at <http://www.hcfa.gov/medicaid/welfare.htm>

Health Care Financing Administration. 2000. Letter to State Medicaid Directors: Efforts to Improve Eligible Families Ability to Enroll in Medicaid [April 7, 2000]. Available at <http://www.hcfa.gov/medicaid/smd40700.htm>

Rosenbach, Margo L., Carol Irvin, and Robert F. Coulam. 1999. "Access for Low-Income Children: Is Health Insurance Enough?" *Pediatrics*. 103 (6): 1167-1174.

United States General Accounting Office. 1999. *Medicaid Enrollment: Amid Declines, State Efforts to Ensure Coverage After Welfare Reform Vary*. GAO Publication No. 99-163. Available at <http://www.gao.gov/new.items/he99163.pdf>

Weissman, Joel S., Robert Witzburg, Pamela Linov, and Eric G. Campbell. 1999. "Termination from Medicaid: How Does it Affect Access, Continuity of Care, and Willingness to Purchase Insurance?" *Journal of Health Care for the Poor and Underserved*. 10 (1): 122-137.