

WHAT PARENTS SAY

Why eligible children lose SCHIP

*Findings from the focus groups for the SCHIP
Retention and Disenrollment SWOT Team Study*

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*Prepared with support from The Henry J. Kaiser Family Foundation
and The David and Lucile Packard Foundation*

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TABLE OF CONTENTS

| | |
|--------------------------------------------------------------------------------|----|
| Foreword | 2 |
| Acknowledgments | 4 |
| Executive Summary | 5 |
| Introduction | 7 |
| Findings | 9 |
| Context: Parents Praise SCHIP | 9 |
| Parents are very satisfied with many aspects of SCHIP | 9 |
| SCHIP compares favorably to other forms of insurance | 10 |
| Dental coverage is inadequate | 10 |
| Reasons for Disenrollment | 11 |
| Misinformation and mistakes in process and program | 11 |
| Discrepancies about SCHIP Status | 12 |
| Communication failures frustrate parents & affect coverage .. | 13 |
| A perceived lack of follow-up disappoints parents | 14 |
| Stiff penalties and a lack of flexibility add insult to injury | 15 |
| Third parties add to communications confusion | 15 |
| SCHIP does not account for unusual circumstances | 16 |
| Though most find forms easy to complete, a few find them overwhelming | 16 |
| Latinos face language problems | 17 |
| Caseworkers are crucial | 17 |
| Life Situations and Personal Attitudes | 18 |
| Instability & fluidity can make sustaining enrollment difficult | 18 |
| Where money is tight, there are competing priorities | 18 |
| Parents with healthy children question the need for coverage ... | 19 |
| Feeling guilty about accepting help | 19 |
| Pride and stigma may deter some parents | 20 |
| Implications for SCHIP | 22 |
| Next Steps | 25 |

FOREWORD

In the fall of 2000, the National Academy for State Health Policy (NASHP)—with support from the David and Lucile Packard Foundation and additional funding from the Henry J. Kaiser Family Foundation—launched *The SCHIP Retention and Disenrollment SWOT Team Study* to examine Strengths, Weaknesses, Opportunities and Threats related to common implementation problems affecting SCHIP. NASHP solicited state participation in these teams, and seven states (Alabama, Arizona, California, Georgia, Iowa, New Jersey, and Utah) identified retention and disenrollment as an area for program improvement. These states then formed a SWOT team whose mission was to:

1. Map current state and local policies and how they are actually being implemented;
2. Identify barriers in current policies and practices that may impede retention;
3. Understand which children are not re-enrolling and why;
4. Understand which children do re-enroll and why;
5. Develop strategies to improve retention rates based on the information gathered; and
6. Measure whether retention improves based on quality improvement strategies developed and implemented.

With technical assistance from James Schlosser, M.D., Ph.D., then of the Institute for Healthcare Improvement, SWOT team states engaged in a detailed analysis of their current program administration for enrollment and re-enrollment. By mapping those processes and by agreeing on a method to calculate comparable disenrollment rates at the start of the project, states established a baseline against which to measure the effectiveness of program and policy changes they may take as a result of the SWOT Team work. A forthcoming paper from NASHP will describe this mapping process for other states that may wish to engage in a similar review of their programs.

After examining current policies and procedures, states participating in the SWOT Team wanted to explore the reasons some parents leave their states' State Children's Health Insurance (SCHIP) program—even though their children are still eligible and will consequently be uninsured—and why other parents maintain enrollment.

NASHP enlisted Lake Snell Perry & Associates (LSPA) to conduct a public opinion study with the parents of currently enrolled and recently disenrolled children. During the early winter of 2001, LSPA completed the first part of this study: six focus groups with parents of enrolled and recently disenrolled children.

LSPA worked closely with NASHP and the SWOT Team states to develop the focus group protocols. The individual states in which groups were held were

encouraged to add state-specific areas of inquiry where necessary. In most cases, state staff observed the focus groups.

This paper describes the findings from those focus groups.

The focus groups have also informed the development of a parent survey that will be conducted this summer in each of the 7 SWOT Team states. The survey will provide states with more information to illuminate the problems and strengths related to SCHIP retention activities that are identified here and will help them make appropriate program and policy changes to improve retention.

This paper, then, reflects some of the early findings from an extensive examination of SCHIP retention and disenrollment undertaken by seven states. The states participating in this effort recognize that the information they are uncovering may have value for other state SCHIP programs, even before the study is completed and policy and program changes are undertaken. NASHP and the SWOT Team are pleased to be able to present the findings from the LSPA focus groups as preliminary data from this state initiative.

Findings should be understood as part of a study in progress; additional reports will be forthcoming following this summer's extensive survey of SCHIP parents and of the program reforms undertaken by the states participating in the SWOT Team on Retention and Disenrollment.

Trish Riley
Executive Director
National Academy for State Health Policy

ACKNOWLEDGMENTS

The National Academy for State Health Policy would like to extend its gratitude to the following: Michael Perry and Susan Kannel of Lake Snell Perry & Associates for their enthusiasm for this project and their perseverance; James Schlosser, previously with the Institute for Healthcare Improvement, for helping to frame the project using the Quality Improvement Model; and the seven states that make up the Retention and Disenrollment SWOT Team, whose members include:

- Alabama – Cathy Caldwell and Gayle Lees Sandlin
- Arizona – Roxanne Robles
- California – Sandra Shewry
- Georgia – Jana Leigh Key
- Iowa – Anita Smith
- New Jersey – Michelle Walsky and Heidi Smith
- Utah – Chad Westover

We would also like to express our appreciation to The David and Lucile Packard Foundation for its continued support of NASHP's State Children's Health Insurance Program (SCHIP) Implementation Center and to The Henry J. Kaiser Family Foundation for its support of the focus groups upon which this report is based.

EXECUTIVE SUMMARY

Parents, both enrollees and disenrollees, have overwhelmingly positive opinions about the SCHIP program. They appreciate that SCHIP provides comprehensive healthcare coverage for their children, and provides it at a very low cost. Moreover, most agree that their children have received excellent health care in the SCHIP program, and receive this care from first-rate, caring healthcare providers. Many parents even say that SCHIP compares favorably to private insurance coverage. In short, this study challenges any suggestion that parents leave SCHIP because of poor quality care or inadequate coverage.

Despite these commendably high levels of satisfaction, some parents do leave the program even though their children are still eligible and even though these children will consequently be uninsured. The focus groups provided a great deal of insight into how and why some parents do leave the program.

Perhaps the most basic finding is that sometimes what seems like a decision on the part of parents to let their children's enrollment lapse is often much more complicated and ambiguous.

The circumstances leading to disenrollment often seem to be beyond parents' control and, some parents would argue, the blame lies more with the program than the parent. Some parents who are trying to keep their children enrolled are stymied by complicated, confusing processes, poor communication or unaccommodating caseworkers. Sometimes problems with programs' record-keeping and follow-up result in children being inadvertently, prematurely, and even incorrectly, terminated. Indeed, in some cases children are removed from the program despite their parents' efforts to keep them enrolled because of actions—or lack thereof—on the part of the program.

Not all problems rest mainly with the program. There are many causes of disenrollment that have more to do with the parents' life circumstances and attitudes than with the program. Volatility in these families' economic lives makes it difficult for some parents to sustain their child's enrollment. Parents say that while the price of sustaining their children's enrollment—e.g., the monthly premiums—are generally manageable, some months they are unable to pay. If money is tight, paying for immediate needs like rent or food trumps paying for health insurance. Likewise, while renewal paperwork is generally considered manageable, in some circumstances it might seem overwhelming.

Some parents whose children are very healthy question whether having their child enrolled in the program is worth the cost or is even necessary at all. Likewise, some parents feel that SCHIP is really only there for emergency situations. Some parents, especially those with healthy children, leave the

program because they feel guilty about accepting help. Lastly, some are ashamed or embarrassed about needing assistance and would rather pay their own way for their children's health care.

INTRODUCTION

In the fall of 2000, the National Academy for State Health Policy (NASHP), funded by The David and Lucile Packard Foundation, with additional funding from The Henry J. Kaiser Family Foundation, launched *The SCHIP Retention and Disenrollment SWOT Team Study*. This extensive project is exploring the reasons some parents leave their states' State Children's Health Insurance (SCHIP) program—even though their children are still eligible and will consequently be uninsured—and why other parents maintain enrollment. Seven states¹ are participating in this project.

NASHP enlisted Lake Snell Perry & Associates (LSPA) to conduct one component of this effort, a public opinion study with the parents of currently enrolled and recently disenrolled children. This past winter LSPA completed the first part of this study, six focus groups with parents of enrolled and recently disenrolled children.²

As Table One illustrates, groups were conducted in three of the seven study states: California, New Jersey, and Utah. In each state two groups were conducted: one with parents of children who are currently enrolled in the program and who have been enrolled for at least a year (enrollees).

The other group in each state was composed of disenrollees, parents of children who were enrolled in the program until recently but are no longer enrolled. The disenrollee groups were designed to include parents who left SCHIP for “preventable” reasons. Their children were still eligible for SCHIP and likely became uninsured when they left the program. We excluded parents whose children were no longer enrolled for appropriate reasons. Specifically, we excluded those who were no longer eligible because of their age or a change in family income, and those who left because they obtained other insurance.

¹ Alabama, Arizona, California, Georgia, Iowa, New Jersey, and Utah.

² This summer LSPA will be conducting a survey of over 4,000 enrolled and recently disenrolled families in the seven participating states.

Table One: Schedule of Focus Groups

| | Site and State | Date | Language | Group Description |
|---|--------------------|------|----------|-------------------------------------------------------------------------------|
| 1 | Newark, NJ | 1/16 | English | Parents of Disenrolled Children Non-payment and Non-renewal Disenrollees |
| 2 | Newark, NJ | 1/16 | English | Parents of Currently Enrolled Children |
| 3 | Salt Lake City, UT | 1/17 | English | Parents of Disenrolled Children Non-renewal Disenrollees Only ³ |
| 4 | Brigham City, UT | 1/18 | English | Parents of Currently Enrolled Children |
| 5 | Los Angeles, CA | 2/06 | English | Parents of Disenrolled Children Non-payment and Non-renewal Disenrollees |
| 6 | Fresno, CA | 2/07 | Spanish | Parents of Currently Enrolled Children (Latinos) |

Two types of disenrollees were included in the focus groups. The first was non-payment disenrollees. These are parents whose children were terminated because, according to state records, they fell behind on their child's premium payments. The second group included those who were terminated for non-renewal. This includes parents who never returned their renewal forms and those who did not complete the renewal process because of incorrect information or a lack of background documentation with their renewal form.

In reviewing these results, it is necessary to keep in mind that this study's purpose is to explore disenrollment of eligible families. The focus groups were used to ferret out attributes of the various SCHIP programs that might contribute to disenrollment or might fall short in facilitating retention. Therefore, this report focuses on the negative aspects of these SCHIP programs; programs which are in fact very popular with both enrollees and disenrollees.

³ Utah does not have a monthly premium, so there are no non-payment disenrollees.

FINDINGS

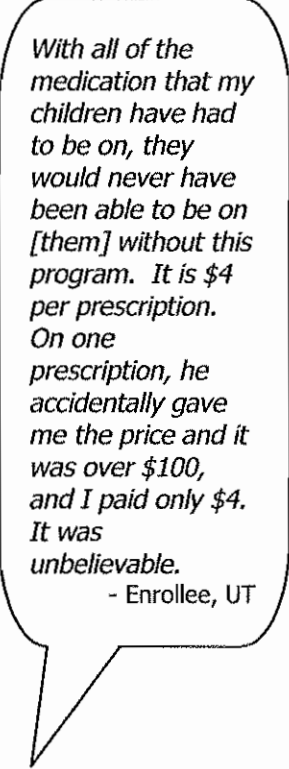
CONTEXT: Parents Praise SCHIP

SCHIP is regarded with near unanimous favorability among parents in the focus groups. Enrollees and disenrollees alike praise the program. In fact, they are so pleased that some are reluctant to criticize any aspect of the program. In the words of one Utah enrollee, “I am grateful to have it. I am not going to complain about it.” Parents facing acute medical or financial crisis are especially appreciative of and positive about the program.

Parents are very satisfied with many aspects of SCHIP

Parents applaud the program for several reasons:

- **Coverage:** Parents agree that SCHIP covers most of the health care services, treatments and medications their children need and that these benefits are easily accessible. As a Spanish-speaking enrollee from California explained, “I am 100% satisfied [with the program] because it covers everything. They take very good care of my children.” Complaints about coverage are few and far between, and generally have to do with dental coverage (see below).
- **Cost:** Parents appreciate that SCHIP offers coverage at a reasonable price. Parents who pay monthly premiums generally agree their premiums are affordable. As a Spanish-speaking California enrollee explained, “It’s a very small payment and it’s for our children’s health. Instead of buying a hamburger, we can pay [for SCHIP].”
- **Parents Contribute:** Another positive aspect of SCHIP, according to some parents, is that parents contribute to their child’s health care coverage. As one Utah disenrollee explained, “One thing I really liked about the program was that you did have a co-pay, and when people are allowed to help themselves along the way they are more accepting of help. I think it is very dignified, the way they have it set up.”
- **High Quality Doctors and Other Healthcare Providers:** Parents report that their children see excellent doctors, and receive high quality care from health care providers in general. In the words of one California disenrollee, “I think the doctor’s care more...The doctors were real good to the patients. They were patient with the patients. They weren’t like, ‘Okay well you just got Healthy Families.’ [Patients] were still treated correctly.” Many parents were especially appreciative that they could keep their regular pediatrician after having switched their children to SCHIP.



With all of the medication that my children have had to be on, they would never have been able to be on [them] without this program. It is \$4 per prescription. On one prescription, he accidentally gave me the price and it was over \$100, and I paid only \$4. It was unbelievable.
- Enrollee, UT

SCHIP compares favorably to other forms of insurance

Parents are so enthusiastic about SCHIP, that many prefer it to other types of coverage. Many disenrollees whose children are now privately insured feel SCHIP was better. Now, with their private insurance, they have deductibles, as well as higher premiums and co-payments. Moreover, despite these higher costs, most say the care their children receive is no better than the care they receive in SCHIP. Some complain that now, with their private coverage, they must see a primary care physician, choose providers from limited lists, and obtain referrals. Also, many privately insured children are now without dental and vision coverage. As one Utah disenrollee explained, “I don’t like [my private insurance] as much. I don’t have any vision [coverage]. I have dental, but it’s not real good. It costs \$180 a month. Plus, the co-pay for prescriptions is between \$10 and \$20, and we have six prescriptions that we have to get every single month....It is very, very expensive.”

Similarly, among those parents with experience in Medicaid, most prefer SCHIP. They believe that SCHIP’s coverage and services are better and that the enrollment and renewal processes are simpler and less intrusive.

Dental coverage is inadequate

The only serious problem parents say they have with coverage under SCHIP is in the area of dental care. Most believe strongly that SCHIP’s dental coverage is inadequate. They complain that it does not cover preventive care or dental procedures that need to be done for medical reasons such as x-rays and extractions. Moreover, some parents complain that there are not enough dentists in their area who participate in SCHIP, and the ones that do have too many rules about participation. Not only is it difficult to find dentists who will accept SCHIP, but many parents also say the treatment their children receive from SCHIP dentists is less than acceptable.

Parental dissatisfaction with SCHIP’s dental coverage does not appear to make participants drop out of the program; many are grateful to have any dental coverage at all. However, this flaw in the system does lead to considerable frustration with the program.

The focus groups with parents of enrolled and disenrolled children found that most hold the SCHIP program in high regard and are appreciative of and enthusiastic about the coverage and care it provides their children. Why then are some parents leaving the program even though it means that, in many cases, their children will not have any coverage at all? The focus group results suggest a number of possible answers; the remainder of this report explores these suggested explanations.

REASONS FOR DISENROLLMENT

In this research effort, we have learned a great deal about why and how families leave SCHIP. Much of this learning came from the groups themselves; some came in the process of recruiting focus group participants. Therefore, before delving into the reasons for disenrollment, it is necessary to revisit the process by which focus group participants were selected, and review what was learned during that process.

The disenrollee groups were designed to include parents who left SCHIP for “preventable” reasons, that is, parents whose children, according to state records, were terminated for premium non-payment or non-completion of the renewal process. We excluded parents whose children were no longer enrolled for appropriate reasons. Specifically, we excluded parents whose children were no longer eligible because of their age or a change in family income and those who left because they obtained other insurance for their children.

Over the course of recruiting the groups—and in the groups themselves—it became clear that these classifications are not so easily drawn; the line between preventable and non-preventable reasons for disenrollment is often hazy. It is often assumed parents who leave for preventable reasons have made a conscious decision to do so, or at the very least are responsible for the circumstances that led to their SCHIP termination. Certainly, much of the burden does lie with parents, but there are also aspects of the SCHIP programs that contribute to inadvertent disenrollment of eligible children.

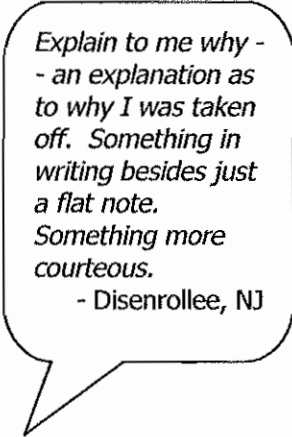
Based on this, we have divided the reasons for leaving into two categories:

- A. misinformation and mistakes in process and program, and
- B. life situations and personal attitudes.

The first category addresses those reasons that have to do mostly with the SCHIP programs and how they are administered, the second with parents themselves. To some extent, this is a false distinction; the circumstances in which any family leaves SCHIP are complex and not easily classified.

Misinformation and mistakes in process and program

Focus group results suggest that, in some cases, disenrollment has more to do with SCHIP’s shortcomings and errors than with decisions or actions on the part of the parents. Complexities, confusion, and poor communication around renewal, payment, and coverage cause parents’ frustration and even lead to children being terminated. Indeed, some parents make a strong case that their children were incorrectly dropped from the program, despite their best efforts to



*Explain to me why -
- an explanation as
to why I was taken
off. Something in
writing besides just
a flat note.
Something more
courteous.
- Disenrollee, NJ*

sustain enrollment. Sometimes the programs' information about families' reasons for disenrollment or even the actual status of a case differs from what the parents understand to be true. In short, as much as they appreciate SCHIP, some parents feel the program is overly bureaucratic and poorly managed, leading to unnecessary confusion and, sometimes, mistakes that affect children's coverage.

Discrepancies about SCHIP Status

Occasionally there are discrepancies between the state's records and a parent's perception of what a child's SCHIP status actually is. This first came to light during the recruitment for the disenrollee groups and was most evident in Utah. Many potential participants who, according to Utah's records, were disenrolled for non-renewal told recruiters that they left SCHIP because they were able to obtain coverage for their children from their employers. While some of these parents admitted that they had not informed the SCHIP office about this alternative insurance, quite a few insisted that they had reported this to SCHIP.

Discrepancies about children's enrollment status emerged in others states as well. For example, in New Jersey at least one parent invited to the disenrollee group did not know for sure that her son was disenrolled until she was called by a recruiter. As she explained, "I didn't know until you called and said that he wasn't [enrolled]. [I did not know] because I'm constantly receiving my paperwork. The only thing I hadn't received maybe was December's New Jersey Kid Care statement card." Some disenrollees insisted they were never told that their child had been dropped from SCHIP. Conversely, there were parents invited to the enrollee groups who were somewhat surprised to learn that their children were still enrolled in SCHIP.

Some of these parents had been trying to determine their child's status and had been unable to do so. They were frustrated and believed SCHIP was not doing an adequate job of communicating with them about their child's case.

I've only been without his insurance for maybe three months, since it expired in October. So from October until now he's been uninsured, but I'm constantly calling and wondering what happened, because I sent in my paperwork. They said they'd respond and to send in my paychecks. I sent those in and I've had no response. I'm constantly calling.
- Disenrollee, NJ

Communication failures frustrate parents and affect coverage

As the previous section illustrated, one of the most frequent—in some cases the only—complaint parents have about SCHIP is that communicating with the program and resolving problems is difficult at best.

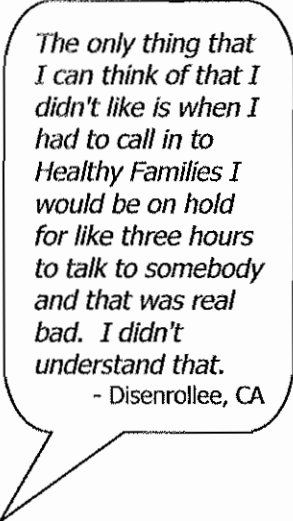
Focus group results suggest that flaws and delays in SCHIP’s communications with clients can result in children being incorrectly terminated. In California, several disenrollees said they had received termination letters from *Healthy Families* stating that they had not paid their premiums. These parents insisted that they were paid-up. A few even brought cancelled checks to the focus groups as proof. As one explained, “[The envelope] is postmarked January 8th, at the top of the paper it says your premium is due on the 20th, but in the body of the letter it says that [my son] is going to be discontinued on December 30th for nonpayment. I have the cancelled check from October that I paid.”

This parent’s story illustrates two other problems with SCHIP programs’ communications: notices about changes in status or impending terminations sometimes arrive after the fact and do not make sense to the recipients.

These communication difficulties do not always result in termination. Nevertheless, they can be frustrating for parents and affect their opinion of and comfort with the program. As one Utah disenrollee explained, “I got more mail from them saying different things. I would get a letter one day saying that I was on co-pay A, and then three days later I got one saying I was on co-pay B. Then a week later they put me back on A. That went on for three months.” A New Jersey enrollee said, “They never sent me the paperwork telling me that my co-payment has gone from \$1 to \$5. I was arguing with the pharmacist. I was saying, ‘Why are you charging me \$5? I never paid \$5 before.’ He said to call them, and when I did they said I would be getting a letter in the mail.”

Miscommunication and management problems are evident not just in eligibility and renewal issues, but also in coverage. Parents say it is often unclear what SCHIP covers, and that errors occur. Two Utah parents shared stories about being incorrectly charged for the anesthesia their children got during dental surgery covered by CHIP. In fact, the anesthesia should have been covered.⁴

Sometimes parents are uninformed about the most basic elements of SCHIP. While most parents say they knew when they enrolled their children that they would have to renew their enrollment at some point, a few were unaware. As one California disenrollee explained, “I didn’t even know that I had to renew. I thought that I would continue paying, that they would know that my son is 11 so



The only thing that I can think of that I didn't like is when I had to call in to Healthy Families I would be on hold for like three hours to talk to somebody and that was real bad. I didn't understand that.

- Disenrollee, CA

⁴ Utah CHIP staff observing this group recognized that these parents had been charged for the anesthesia erroneously. It should have been covered because both patients were under age five. Utah CHIP has since rectified this situation for both of the families.

he is going to be in it for seven more years....I didn't know that I had to send in more information."

A perceived lack of follow-up disappoints parents

Many disenrolled parents feel frustrated that more attempts are not made to straighten out misunderstandings, especially those that lead to termination. As one New Jersey disenrollee explained, "They did send me a letter saying that I need to bring in or mail in two more pay stubs, which I did. They could have responded explaining that maybe they'd never received it. They could have picked up the phone, the same way you did [to invite me to the focus group]; you picked up and called my seven digits....If they couldn't contact me from the phone, [they could] mail a letter, but they did nothing."

Likewise, some Californian disenrollees report a great deal of frustration with lack of follow-up and disorganization on the part of the program, as well as a cumbersome appeals process. As one explained:

I called them when I first got the letter [about termination] and the person I was talking to didn't seem to understand what I was talking about. They said, 'Well, you have to write a letter and here is the appeals address.' I was like, 'Well, can you tell me what happened? Did you get my check? I sent my check. I have it cancelled.' And they said, 'Oh I don't have that information you have to write an appeal.' That was all they could say. I think he didn't have access to the file. I work as a secretary in an office and we keep a record on all of your accounts. Did he not have access to that? Couldn't he just look at that and tell me something?

I think that they need to follow up with people [on the phone]... It is not enough to send something in the mail.

- Enrollee, NJ

Another explained:

They called and asked me why my children are terminated. And I was thinking - you should know.... I had to cry because it is just so frustrating trying to get through to these people and telling them that they should have that information on your system. I sent in the appeal, and I am sending out another one. They said my payment was late, and then I get a letter saying that it wasn't late, that it was their fault, not my fault. I just don't understand and it is really frustrating. Then you have to pay all this money just to get them back on the program, and then they tell me that they are terminated again.

The lack of follow-up and personal attention that parents describe seems particularly disconcerting to some because their experiences with outreach and enrollment were so easy. Many parents, particularly in New Jersey, seemed frustrated that the program seemed so eager to get them enrolled and so helpful

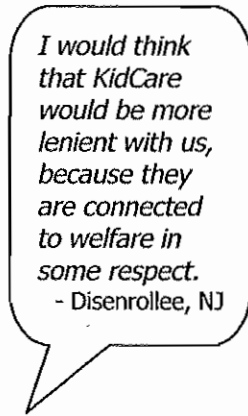
in the enrollment process, but not at all supportive of their efforts to stay enrolled.

Stiff penalties and a lack of flexibility add insult to injury

The problems parents have had trying to solve renewal problems are especially frustrating because the resulting penalties can be so harsh. In both California and New Jersey, disenrolled children are ineligible for SCHIP for six months; in Utah the period is three months. Parents would like to see more flexibility from the program on this point. As one California disenrollee lamented, “If you are paying all the time and then all of a sudden one payment is late, it is like they are crucifying you....You just make your payments, and if you don’t then you are gone...” On the other hand, some parents insisted SCHIP has been very flexible. As one New Jersey disenrollee explained, “They gave me like three months before they cut me off. They were good about that.”

Many parents assume, in some cases incorrectly, that there is no flexibility in SCHIP. For example, when a New Jersey non-payment disenrollee lost her job and was unemployed for several months, it did not occur to her contact *NJ FamilyCare* to explain her situation. This suggests that SCHIP programs need to be made clear to participants when and where there is flexibility.

On a broader scale, some feel there should be more flexibility in the income threshold for SCHIP. As one New Jersey disenrollee explained, “When I enrolled the first time, I just made that limit to be eligible. I remember saying to myself that if I just made an extra dollar or two dollars an hour, I would not be eligible.... [What if I’m caught where] there’s no way *KidCare* is going to pick me up and I still cannot afford my own healthcare.” Some single, working parents feel strongly that SCHIP programs should be more flexible and supportive of parents like themselves since they are trying to help themselves, rather than relying on welfare. As one New Jersey disenrollee explained, “If you’re not working, oh they’re just giving it to you....But once you try to do something for yourself, then they don’t want to do nothing for you.”



*I would think that KidCare would be more lenient with us, because they are connected to welfare in some respect.
- Disenrollee, NJ*

Third parties add to communications confusion

An already complicated system is often made more so by the involvement of the plans through which SCHIP services are delivered. For example, the New Jersey disenrollee mentioned above (who did not know her son had been dropped from SCHIP until she was recruited for our study) was confused in part because she continued to receive materials from Aetna even after *NJ KidCare* dropped her son.

In Utah, SCHIP services are delivered by the public employees’ health plan (PEHP). Some parents admit this confuses them; a few did not even know what

PEHP was. PEHP publishes a single benefits booklet that outlines the regular PEHP benefits with special notes where SCHIP coverage differs. For some, this is confusing. As one enrollee explained, “I have called in and asked, ‘Can this be covered? Can I do this? Can I go here?’ And they will ask me if I am through SCHIP and then tell me that’s not covered. I will say, ‘It’s in the book,’ and they will say, ‘Well, it’s not for the SCHIP program.’”

SCHIP does not account for unusual circumstances

Parents in atypical or shifting work or life situations appear to have more trouble with the SCHIP system. One New Jersey mother, for example, faced extra hurdles in signing-up her children because of how her employer pays his employees. She explained “I don’t get pay stubs, I get personal checks from my boss. They wouldn’t accept that. I had to go and get certified papers stating how much money I make per week. It was a real pain...It took approximately three months.”

Income verification is especially challenging for parents who change jobs frequently or are self-employed. Farmers in Utah explained that they have to provide a great deal of financial information about their business, as do seasonal workers in California and others whose incomes vary widely from month to month. One Utah enrollee shared her frustration: “My husband is in the National Guard. The Guard always throws them off, always, because it is different every month. That throws them off every time.”

Though most find forms easy to complete, a few find them overwhelming

In general, participants feel the forms they need to fill out for SCHIP are fairly simple and straightforward. Those with experience filling out Medicaid forms say SCHIP forms are simpler and much less intrusive. As a Spanish-speaking Californian noted, “They don’t ask how many houses you own, how many cars. You only send what you earn and that’s it.”

Despite the relative simplicity of the forms, parents do occasionally have trouble with their enrollment and renewal paperwork. Moreover, parents fear that one incorrect answer could mean their children do not get health care coverage, so many are anxious about filling out the forms correctly. Even simple forms can be overwhelming for some parents, especially those who have literacy issues. As one Utah enrollee explained, “I have a friend who would not fill out the renewal form. She was intimidated by the paper work part of it.”

My most recent pay stub might say that I made \$5,000 that month. So, [my child] is not eligible. But, maybe two months forward it is not going to be that, and maybe four months back it was not that. So, that is the problem. It is inconsistent when you are self-employed, it is not predictable how much you are going to make.

- Disenrollee, CA

Latinos face language problems

For the Spanish-speaking Latino participants in California, there is a very real language barrier. Many Spanish-speaking parents complained that the language in SCHIP materials and forms is difficult to follow. Although the forms are in Spanish, they take issue with *the level of Spanish*, which some say is above their education level. In the words of one Spanish-speaking enrollee in California, “It is very difficult for someone who has very little schooling to fill out a questionnaire of that kind.”

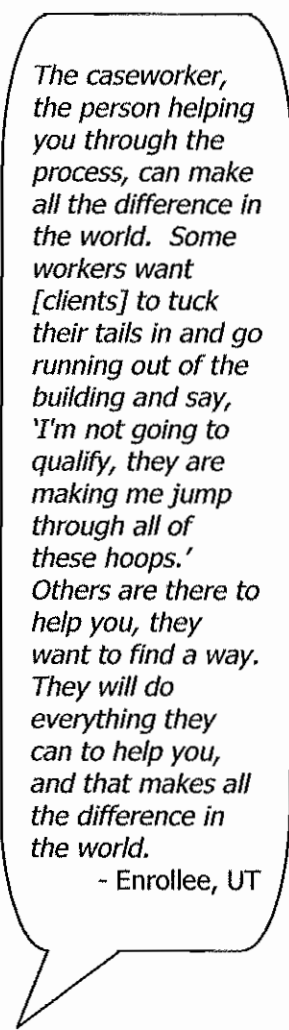
Caseworkers are crucial

Focus groups results suggest that the role of caseworkers and others who work for SCHIP is vital. Those who are helpful, polite, and knowledgeable can substantially facilitate enrolling in SCHIP and staying enrolled. Those who are insensitive, ill-informed, or disrespectful can make enrolling and remaining with the program difficult for parents. Parents’ comments about caseworkers generally fall along three dimensions: how they treat people on a personal level; how helpful they are; and how knowledgeable they are about program rules and regulations.

How caseworkers interact with parents can make a big difference. As one Utah disenrollee complained, “I never felt like a caseworker was the least bit interested in myself, my problems, in the situation at all. I didn’t feel much cooperation at all. It was a bad experience, caseworker-wise....It was just like, ‘Get the SOB out of here. Get it done, I want to go to lunch.’”

On the other hand, a compassionate caseworker can be quite encouraging. One Utah enrollee referred to her caseworker as her “angel.” This caseworker was polite and respectful. Moreover, she was proactive and helpful, even going so far as to call her clients to ask if they had received their renewal paperwork after a mistake at the state level meant some forms were delayed. Conversely, other participants complained about caseworkers who were indifferent and seemed reluctant to help their clients.

Some parents complain that the problem is not with how workers treat them or even how helpful they try to be, but with their lack of understanding about the program itself. As one California disenrollee explained, “They are polite, and they give you information, but it is not the correct information.” Some parents were more understanding about caseworkers not having all the facts because they feel the program is fairly new, and the regulations are complicated and constantly changing. Nevertheless, parents feel frustrated when they get confusing or contradictory answers from program staff, even if the program staff is compassionate and cooperative.



The caseworker, the person helping you through the process, can make all the difference in the world. Some workers want [clients] to tuck their tails in and go running out of the building and say, 'I'm not going to qualify, they are making me jump through all of these hoops.' Others are there to help you, they want to find a way. They will do everything they can to help you, and that makes all the difference in the world.

- Enrollee, UT

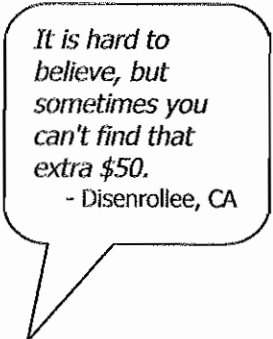
Life situations and personal attitudes

The second category of reasons for disenrollment emerging from this research has to do with the life situations and personal beliefs of the parents involved. These reasons are less about the SCHIP program per se, though there are certainly programmatic elements that contribute to these reasons and programmatic changes that could mitigate them.

Some parents who left the program had made a conscious decision to do so or, at the very least, were responsible for and cognizant of the circumstances that led to their child's SCHIP termination. Others were simply overwhelmed by circumstances. In any case, understanding the events and conditions in these families' lives that can lead to leaving SCHIP is vital to helping parents sustain their children's enrollment.

Instability and fluidity can make sustaining enrollment difficult

The parents in our focus groups come from many different backgrounds, but most share one characteristic: their families' economic lives, at least at present, are marked by instability. This explains why some parents are unable to sustain their child's enrollment. Parents in New Jersey and California explained that while paying their monthly premiums is not usually a problem, it can become overwhelming if they have unexpected expenses. As one New Jersey disenrollee explained, "I felt bad not paying but I had my rent and my car insurance hit me at the same time that month, so I had \$5 in my checking account. I had nothing."



It is hard to believe, but sometimes you can't find that extra \$50.
- Disenrollee, CA

For some families this instability goes beyond economics. For example, one New Jersey disenrollee explained that she did not renew her child's enrollment because she was expecting to get coverage through her child's father's new employer, but then his job fell through. Another New Jersey parent explained that her children's premium went unpaid because her family had a fire and just did not remember to pay the premium for a few months.

Where money is tight, there are competing priorities

Although most parents put a high priority on their child's health coverage in theory, *in reality* they cannot always follow through. Rent, food, groceries, and other bills take precedence over paying for health insurance. As a California disenrollee explained, "When you are choosing between spending \$50 a week on groceries or insurance...then you tend to put it on the back burner. It's not a necessity at the moment." A Utah enrollee added, "My top [priority] is to put a roof over their heads and to feed and clothe them....we have tons of health problems in our family, constantly, [so health care coverage] is a priority, but it

gets pushed down because I have to do all of these other things..." Simply put, immediate needs trump potential future ones.

Parents with healthy children question the need for coverage

Most parents, even those whose children are very healthy, agree that being enrolled in SCHIP is very important for the security and peace of mind it affords, as well as the access to preventive care. As one California disenrollee explained, "I didn't use [Healthy Families] that much really. Every year we would go for a [well-child] visit and then I used it once when he was sick.... But, to me it was worth having it every month and just knowing that it was there."

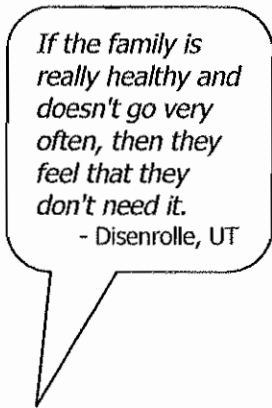
However, some parents whose children are healthy question whether having their child enrolled in the program is worth the cost, or is even necessary at all. As one enrolled Utah enrollee explained, "I almost let [my son's enrollment] lapse this time. My son was on CHIP, and I didn't even know if he was on it or not, because he never got sick in an entire year." Another added, "For me, health care coverage is down on the list of priorities. My kids are pretty healthy."

Some parents—especially in Utah—feel that SCHIP should really only be used in emergency situations. As one Utah disenrollee explained, "CHIP was there when we had a catastrophic event, it helped us out a lot. But I did not renew because I don't want to leach."

Some parents, especially those with older children, are not swayed by arguments about the importance of preventive care. As one New Jersey parent explained about her peers who don't take advantage of the preventive care SCHIP has to offer, "There's a mentality of living from day to day and dealing with situations as they come up, and the idea of preventive medicine [is not part of that]."

Feeling guilty about accepting help

Another reason parents, especially those with healthy children, say they leave the program is that they feel guilty about accepting help that others may need more. For example, the Utah enrollee quoted above who came close to not renewing her son's CHIP explained that she almost did not renew her son's enrollment, in part, because she felt guilty taking help that somebody else might need more. Another Utah parent, this one a disenrollee explained, "I wanted to get off it so maybe there would be room for someone else who needed some help."



If the family is really healthy and doesn't go very often, then they feel that they don't need it.
- Disenrollee, UT

Pride and stigma may deter some parents

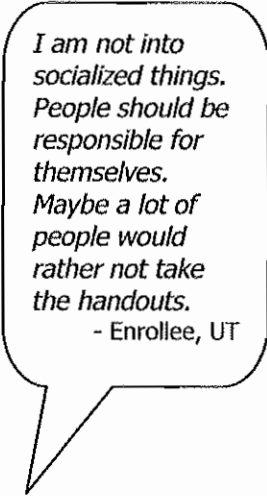
Most of the parents in our groups decry those who would put their own pride before their child's health and not get help if they needed it. However, there are indications that pride does make it difficult for some parents to accept assistance. This was most evident in Utah; perhaps Utah parents see SCHIP more as "getting help" (and thus more like Medicaid) because there is no premium payment. A Utah disenrollee, who left the program voluntarily and was one of the few focus group disenrollees who said she would not want to re-enroll her children, explained, "My husband felt this way when we were thinking about going on SCHIP. It was the first time that we'd ever had help of any kind, and I think it was a little bit humbling for him. I think when he saw that he couldn't provide everything that he wanted to for his family, it was hard on him. So by going off the CHIP program it proved to him that he was on his own."

The issue of pride—particularly in terms of SCHIP's relationship to Medicaid—is evident in other states as well. For example, in the New Jersey disenrollee group, several parents discussed whether and how *NJ FamilyCare* was related to Medicaid. One parent asked, "I was told that [FamilyCare] was a subdivision of Medicaid or Medicaid itself. Is that true? I heard that, but I never really believed it." When she was told the programs are connected, she continued, "I don't understand that. I thought Medicaid was through welfare or social security or disability and yet we're paying, you understand? I don't have a problem if it's whatever, whatever."

Feeling stigmatized or looked down upon can be especially disconcerting to parents who have never asked for help before. As one parent in New Jersey explained, "It can be intimidating, especially when you have been successful and you had these things and never had to sit in that chair and ask for help. It is not a good feeling, and it can be very intimidating. It can be very degrading."

Issues of pride are exacerbated when parents feel that they or their children are treated poorly because they are part of SCHIP. As one Utah disenrollee explained, "I did have one experience with a dentist. When I told him that we were on the program I felt like they thought poorly of me because of it. And here I was, thinking I was doing pretty good, here I am on the SCHIP program. And because it is federally or state funded, whatever it is, I think some people feel like they are thought of differently because of it."

A few parents, primarily in Utah, argued that their objection to the program had less to do with their own guilt, pride, or fear of being stigmatized and more to do with SCHIP itself and programs like it. As one Utah enrollee explained her mixed feelings about her involvement with the program, "I'm not really into socialized medicine, I don't go for it. But I am in this program, which to me is, in a sense, a social program....I wouldn't [be in the program] if there was any other way for me to manage the medical costs."



I am not into socialized things. People should be responsible for themselves. Maybe a lot of people would rather not take the handouts.
- Enrollee, UT

Other parents disdain this notion, arguing that they, as taxpayers, are entitled to get help during tough times. As one Utah disenrollee explained, “That’s what it is there for, for when you are having a hard time.” Another explained, “If I am in a situation where I need help I don’t feel bad about using it to get me through a rough spot.... I pay my taxes, that’s how I feel.”

Parents argue that stressing that SCHIP is a program that they, as taxpayers, pay for may make some parents more comfortable accepting help. Similarly, stressing that, under the program, you pay for part of your child’s health care may help take some of the guilt or shame away from some parents. As one New Jersey enrollee explained, “We’re paying [for our children’s coverage in SCHIP]. We may be paying a little, but we’re still paying.”

IMPLICATIONS FOR SCHIP

The focus groups shed a great deal of light on the circumstances and situations that lead to the termination of eligible children from SCHIP. The findings to date, however, suggest several ideas for programmatic and policy changes that may improve retention. Some of these are the actual suggestions of parents, and others are inferred from their experiences and opinions.

The first several have to do with changes in program, policy, and administration:

- **Improve efforts to keep families enrolled through increased follow-up.** Many parents feel SCHIP does not put enough effort into helping families stay enrolled. Some even believe the program hinders continued enrollment, either inadvertently or even purposefully. Some note that this is especially frustrating given that the program made such efforts to enroll them initially. Following up with parents who have not paid their premium or completed the renewal process is an important way to support continued enrollment. Parents stress that following up by phone, instead of or in addition to mail, is important.
- **Be more timely and clear in communications with families.** Parents also express frustration with the program's communications. For example, they complain about letters warning of impending termination or changes in premium or co-pay being sent out after the fact. Others complain about confusion as to what is covered and what is not. Likewise, they complain that when they have called to ask questions or sort out problems the person on the phone did not have the details of their case or was unable to answer their queries. In short, better communications and coordination would go a long way toward facilitating continuous enrollment.
- **Try to accommodate families' fluid economic and personal lives.** Parents feel it is very important that the program be more flexible. First, it is important for SCHIP to be more accommodating of people's various lifestyles and the instability inherent in their lives. This might mean allowing for more leniency in late payments, allowing people to change their premium amounts, or loosening restrictions on requirements for income verification. Some parents feel that the "penalty period," the period a child must be uninsured before being eligible for SCHIP, is too long for those whose children had been on SCHIP before their current period of being uninsured. It is also vital to let parents know this flexibility is built into the system.

- **Provide additional training and support for program representatives.** Focus group results suggest that worker training, on a number of different fronts, could facilitate retention. Encouraging workers to be compassionate and respectful would make working through enrollment and renewal—and dealing with any problems that arise—much more palatable for parents. Parents also feel that workers are sometimes not familiar enough with SCHIP’s rules and regulations and should be trained and kept abreast of changes in program rules and regulations.
- **Make improvements to dental coverage.** The focus groups findings do not suggest that unhappiness with SCHIP’s dental coverage leads to disenrollment. Nevertheless, concerns about a lack of dentists willing to see SCHIP patients, and the apparent lack of cooperation and responsiveness from some of those who do, clearly frustrates parents. This frustration could sour what is otherwise an overwhelmingly positive opinion about the program’s coverage.

Focus group results also suggest specific aspects of the program that should be emphasized, or ways it can be presented, to encourage parents to sustain their children’s enrollment. These approaches may be especially important in addressing parents who may be uncomfortable accepting help or who may feel sustaining their children’s enrollment is not a high priority.

- **SCHIP is for working families, you pay your own way.** It is important to continue to stress that SCHIP is a program that provides affordable health insurance for children in working families. In this program, parents pay for their children’s healthcare; it is a hand up, not a handout. For those who are uncomfortable with SCHIP’s connections with or similarity to Medicaid and public assistance programs, stressing how SCHIP differs is vital.
- **SCHIP is your tax dollars at work.** Some parents—again most often those who are somewhat uncomfortable accepting help or who have never been in any government program before—might be comforted by the notion that they have paid for this program. As taxpayers, they are entitled to avail themselves of this help during a time when they are unable to access or afford private insurance for their children.
- **Health coverage is a priority.** It is also crucial to continue to stress the importance and benefits of having continuous health insurance coverage for your children. Not only does SCHIP provide for free preventive care, it is also there if a child has an accident or develops an illness that requires long-term or expensive care. Stressing that even the healthiest child should have health coverage “just in case” will resonate with some parents. This

approach must be used with caution; parents resent being scared or made to feel guilty.

- **Children need preventive care to thrive.** Educating parents about the importance and benefits of preventive care, even for older and healthy children, will encourage parents to sustain enrollment. It is also important to emphasize that preventive care is free under SCHIP.
- **SCHIP provides comprehensive, high-quality care.** Stressing that those in the program are pleased with their coverage and the health care their child receives may encourage parents to stay enrolled.

NEXT STEPS

Based on these focus group findings, NASHP'S SWOT Team has worked with LSPA to craft the questionnaire for a comprehensive telephone survey of SCHIP parents. This survey will explore further the issues raised here. The survey, which will be fielded this summer, will include the voices of over 4,000 SCHIP enrollees and disenrollees in the seven participating states. Though much work has been done around SCHIP enrollment, this will be the first national survey about SCHIP retention and disenrollment issues specifically.

In addition, with technical guidance from James Schlosser M.D., Ph.D., formerly of the Institute for Healthcare Improvement, SWOT team states have engaged in a detailed analysis of their current program administration for enrollment and reenrollment. By mapping those processes and by agreeing on a method to calculate a comparable disenrollment rate at the start of the project, states established a baseline against which to measure the effectiveness of program changes introduced in response to the focus groups and the survey findings. The SWOT team continues to work together—learning from LSPA's studies, the process mapping, and each other's expertise—and advancing program improvements aimed at maximizing the rate of retention of SCHIP eligible children.