kaiser commission on medicaid and the uninsured

The Impact of Medicaid Reductions in Oregon: Focus Group Insights

Prepared by

Gene LeCouteur and Michael Perry
Lake, Snell, Perry, & Associates, Inc.

and

Samantha Artiga and David Rousseau
Kaiser Commission on Medicaid and the Uninsured

December 2004

THE HENRY J. KAISER FAMILY FOUNDATION

kaiser commission medicaid and the uninsured

The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bi-partisan group of national leaders and experts in health care and public policy.

kaiser commission on medicaid and the uninsured

The Impact of Medicaid Reductions in Oregon: Focus Group Insights

Prepared by

Gene LeCouteur and Michael Perry
Lake, Snell, Perry, & Associates, Inc.

and

Samantha Artiga and David Rousseau
Kaiser Commission on Medicaid and the Uninsured

December 2004

THE HENRY J. KAISER FAMILY FOUNDATION

EXECUTIVE SUMMARY

In response to significant declines in state tax revenue during the recent economic downturn, all states have turned to their Medicaid programs to reduce spending growth. Oregon is one state that has significantly restructured its Medicaid program, known as the Oregon Health Plan (OHP), in response to budget pressures. As part of these changes, it implemented significant benefit reductions and increased premiums and cost sharing in OHP Standard, Oregon's program for poor parents and other adults; it eliminated its Medically Needy program; and it refinanced a previously fully state-funded premium assistance program, known as the Family Health Insurance Assistance Program (FHIAP). Since the state implemented the OHP Standard premium and cost sharing increases and benefit reductions, enrollment in the program has dropped by over half, or about 55,000 enrollees.[1]

To gain insight into how people affected by these reductions were faring, the Kaiser Commission on Medicaid and the Uninsured conducted five focus groups in Portland, Oregon in February 2004. Focus groups included current enrollees in OHP Standard and FHIAP, as well as those who were previously enrolled in OHP Standard or the Medically Needy program.

Impact of OHP Standard Changes

In February 2003, Oregon used new waiver authority to reduce coverage for previously eligible poor parents and other adults who are not receiving Temporary Assistance for Needy Families (TANF) or general assistance. The focus groups explored the impact of increased premiums and copayments and eliminated benefits, including mental health services, durable medical equipment, and dental and vision services on OHP Standard enrollees and disenrollees.

Most OHP Standard respondents had significant health care needs and had greatly valued OHP coverage, but the increased premiums and stricter premium payment policies made it difficult for them to maintain coverage. All OHP Standard enrollees live in poverty; they are required to pay premiums ranging from $6 to $20 a month either by mail or in person at locations open only during the work day. Many respondents said they had difficulty coming up with the money to pay premiums. Some reported delaying rent payments or skipping meals to afford premiums; others relied on relatives or organizations to pay their premiums. As noted by one respondent, "It doesn't hurt to miss a meal, but still to have to make that decision is kind of degrading. But there's no other alternative."

Respondents noted that stricter premium payment policies can be harsh, because if they miss or are late with one month's payment they must wait six months before attempting to reenroll; there is no grace period. Most disenrolled OHP respondents reported chronic health problems, including high blood pressure, mild schizophrenia, diabetes, and asthma. Despite the great value they placed on OHP coverage to care for these conditions, they had become uninsured largely due to the strict payment policies and difficulty coming up with the money for their premiums. They described problems making in-person payments due to inconvenient office locations and lack of weekend or evening hours. As one man recounted, "On the day payment was due, I called the office and told them that I couldn't get down there. I was going to be there

[1] OHP Standard enrollment declined from roughly 102,000 in January 2003 to 46,520 by October 2004, communication with state official, November 1, 2004. For more information on these changes, see C. Mann and S. Artiga, "The Impact of Recent Changes in Health Care Coverage for Low-Income People: A First Look at the Research Following Changes in Oregon's Medicaid Program," *Kaiser Commission on Medicaid and the Uninsured*, June 2004. http://www.kff.org/medicaid/7100a.cfm

maybe five minutes after they were supposed to close, and they said nope. If it's not in by 5:00, we can't accept it. And, even though I told them I had the cash…they just wouldn't do it."

All OHP Standard disenrollee respondents were uninsured, and many reported significant problems obtaining care. Disenrollees reported that they have no regular doctor or regular source of care and they shared the view that since losing OHP coverage their health has worsened. Some cited increased blood pressure or need for glasses that they cannot afford; others skipped preventative care and worried about exacerbating health conditions. Respondents reported living day-to-day and "praying" they do not become seriously ill.

The loss of coverage for certain benefits had significant consequences for many respondents who were still enrolled in OHP Standard. In particular, they lamented the loss of coverage for mental health. Some noted that their health and well-being had deteriorated due to the loss of counseling services and that even though psychiatric drugs are still covered, they can no longer access a psychiatrist to maintain the prescription. One respondent described difficulty getting her primary care doctor to prescribe psychiatric drugs; she noted that her doctor said, "this is out of my field." The loss of coverage for durable medical equipment, dental, and vision services also created difficulties for some respondents who reported forgoing them because they could not afford the out-of-pocket payments. Many resorted to the least-costly options—for example, having teeth pulled instead of treated.

Increased copayments under OHP Standard have led some respondents to forgo or delay necessary care. Depending on the service, copayments range from $3 to $250 per service, and physicians and pharmacists are now permitted to deny services if copayments are not made. Respondents highlighted difficulties meeting these expenses, particularly in acute situations. Respondents noted that even small copayments add up quickly when ongoing care or multiple medications are required. As one woman remarked, "Being able to afford $2 is a lot of money when you have absolutely nothing." Several described instances when they were denied prescription drugs because they did not have the copayment.

Reflecting the population targeted by the program changes, OHP Standard enrollee and disenrollee respondents were very low income, often unemployed and unable to access employer-sponsored or individual health coverage. Many faced significant challenges finding employment in the current economy. Some were in good health, but others had chronic conditions, including diabetes, mental illness, high blood pressure and asthma, that required regular medical care and multiple prescription medications to manage. Respondents were "grateful" for the program but felt the recent changes resulted in the program being "watered down" or "chopped up."

Impact of the Elimination of the Medically Needy Program

In February 2003, the state eliminated its Medically Needy Medicaid program. This program provided coverage to people who did not qualify for OHP, but had significant health care expenses. Nearly 9,000 people lost coverage, primarily low-income Medicare beneficiaries who relied on the Medicaid for coverage of prescription drugs and other services not covered by Medicare, such as mental health care and durable medical equipment.

Respondents who lost Medically Needy coverage all had serious medical conditions, including multiple sclerosis, severe diabetes, and Crohn's disease, in some cases, compounded by mental health needs. While most reported that they had previously been employed, they said their medical conditions make it difficult for them to hold a steady job.

Suffering from chronic and debilitating diseases, many viewed health coverage as a life or death concern.

Since the program ended, many respondents faced hardships securing prescription drugs, as well as mental health services and durable medical equipment. Many respondents said that the loss of Medically Needy coverage forced them to make difficult choices, for example, between buying their medications or paying a heating bill, or buying test strips for their diabetes monitor or buying food. Relying on emergency rooms, clinics, physician samples, and prescription drug donation programs, some reported that they are not getting needed medications or that they are taking less than the prescribed amount in order to stretch out the prescription. One woman stated, "My medicines cost me almost $1,500 a month. My social security check is $700 a month. I am not getting my medicines and I am getting very sick because of it." Another woman described that she could no longer afford the counseling or medicines that enabled her to work. Respondents said that since their coverage ended they have often had to rely on their wits and perseverance to obtain the things that they needed or they have happened upon assistance by chance. For example, one received a free walker, another handicapped bathroom fixtures, and another exercise equipment to help with multiple sclerosis.

The elimination of the Medically Needy program increased financial pressures for respondents who often appeared ill-equipped to handle additional anxiety. Several respondents believed that the stress of living without Medically Needy coverage has contributed to the deterioration of their health. The lack of coverage pushed some into depression that they had difficulty rebounding from, especially since they could no longer access mental health care. Further, some noted that the anxiety and fear engendered by their medical conditions was exacerbated by cuts in the programs upon which they depend.

Impact of the Family Health Insurance Assistance Program (FHIAP)

FHIAP subsidizes individuals' health insurance premiums for private individual or group coverage. Insurance must meet a benchmark established by the state but can have significantly more limited benefits and higher cost sharing than allowed under Medicaid. Under its recent waiver, Oregon refinanced the previously state-funded FHIAP and began drawing down federal Medicaid and SCHIP matching funds. The state also expanded FHIAP eligibility from an upper income limit of 170% of poverty to 185% of poverty.

FHIAP respondents generally were employed, had higher incomes than OHP Standard enrollees and disenrollees, and tended to be in better health. Because more respondents had jobs and higher incomes, they were more likely to have access to employer-sponsored insurance and more resources to devote to premiums. A few said they have health conditions, such as diabetes or high blood pressure.

Without the FHIAP subsidy most respondents would not be able to afford health insurance. Without exception, FHIAP enrollees regarded health insurance as very important. Before enrolling in FHIAP some reported being uninsured, a few said they were insured but struggling to afford their coverage, and a few were enrolled in OHP. They reported that FHIAP is currently paying 50% to 95% of their premium cost depending on their income. As one respondent said, "FHIAP is really helping with this reimbursement, because without it I think I would be struggling a lot." A number of respondents commented that they liked the fact that the FHIAP assistance is largely transparent; only FHIAP and the enrollee may know that they are receiving assistance.

FHIAP respondents liked the provider choice available under their private coverage, but some reported problems with cost sharing and/or limited benefits. Some respondents found that over the course of the year out-of-pocket payments add up and become difficult to manage. Further, some commented that private coverage subsidized by FHIAP generally does not provide comprehensive benefits, such as coverage for dental and vision services. According to respondents, those with large families are especially hard hit by cost sharing and coverage limitations, particularly if they try to take several children in for check-ups at one time or if several family members get ill at the same time. Some respondents reported going without necessary health care or delaying care until they could afford the cost sharing or out-of-pocket payments.

Conclusion

These findings reveal that the reduction in benefits and increased premiums and cost sharing for poor adults in OHP Standard and the elimination of the Medically Needy program have had significant consequences for many individuals. Those affected by the changes have few resources to fall back on and getting needed health care has often devolved to "catch as catch can." This situation is particularly worrisome for those who lost Medically Needy coverage whose situations appear fragile due to ongoing physical and mental health conditions. OHP Standard reductions have also taken a toll. For this group, living on income below the poverty line, financial issues are tantamount. Coming up with the money to pay premiums or cost-sharing amounts resulted in some difficult trade-offs or was simply beyond their reach.

INTRODUCTION

Over the past several years, states have been facing increasing fiscal pressures stemming from the fall of in state revenues and increasing costs, including health care costs. One area all states have turned to in order to address their fiscal situations is their Medicaid programs. States have utilized a wide variety of methods to reduce spending in their Medicaid programs, including reducing eligibility, reinstating enrollment barriers, reducing benefits, and increasing costs imposed on beneficiaries. In some cases, states have made these changes under options available under federal Medicaid law. In other cases, states have used Section 1115 waivers to make changes that would not otherwise be allowed under current law.

Oregon is one state that recently made a variety of changes to its Medicaid program, known as the Oregon Health Plan (OHP). Some key changes included:[2]

- Reducing benefits, increasing premiums and cost sharing, and capping enrollment for some existing poor adult beneficiaries—this reduced coverage is referred to as OHP Standard,
- Eliminating its Medically Needy Medicaid program, and
- Refinancing a previously fully state-funded premium assistance program, known as the Family Health Insurance Assistance Program (FHIAP), with federal matching funds and opening enrollment to additional people.

Research conducted soon after these changes found that enrollment in OHP Standard dropped by about 50,000 people, largely due to difficulty paying premiums; care appears to have been compromised both for people who have lost coverage as well for many who remained enrolled; and pressures have increased on clinics and at least one emergency room within the state.[3]

The Kaiser Commission on Medicaid and the Uninsured sponsored this focus group study of Oregonians to gain greater insight into how their coverage and care has been affected by these recent changes. The experiences of these individuals in Oregon may be instructive for other states that have implemented or are considering similar changes to their Medicaid programs, as they provide a window into understanding how such policy changes affect individuals. This study is based on five focus groups that were conducted in Portland, Oregon during February 8-9, 2004. Study participants were drawn from the metropolitan Portland area. Two focus groups were conducted with current enrollees in OHP Standard, one group with those disenrolled from OHP Standard, one group with former enrollees in the eliminated Medically Needy program, and one group with current enrollees in the FHIAP premium assistance program. Demographic profiles of participants in this study can be found in the Appendix at the end of this report along with more detail about the project methodology.

Overview of Recent Changes to the Oregon Health Plan (OHP)

Beginning in 2003, Oregon significantly restructured its Medicaid program, OHP, through a Section 1115 waiver and other program changes, largely in response to the state's growing fiscal problems.

---

[2] In addition the state implemented a small expansion in eligibility for children and pregnant women from 170% to 185% of the federal poverty level (FPL); this change is not address by this report. Further, the state obtained authority to increase eligibility for parents and other adults from 100% to 185% (FPL), but this expansion has not been implemented due to budget constraints.

[3] Mann, C. and S. Artiga, "The Impact of Recent Changes in Health Care Coverage for Low-Income People: A First Look at the Research Following Changes in Oregon's Medicaid Program," *Kaiser Commission on Medicaid and the Uninsured*, June 2004. http://www.kff.org/medicaid/7100a.cfm

Waiver Changes. The state's approved waiver changes included a number of reductions as well as expansions in coverage. While the original intent of the waiver was not to reduce coverage, as the state's fiscal problems increased, it moved forward with the waiver-approved reductions, but only implemented a small piece of the approved expansions (Figure 1). In February 2003, the state reduced benefits, increased premiums, and increased cost sharing for previously eligible poor parents and other adults who were not receiving TANF or general assistance. This reduced coverage is called OHP Standard. However, as a result of a recent court ruling, the state stopped charging these adults copayments beginning June 19, 2004, after these focus groups were conducted. The state made several other changes in coverage for these adults after the focus groups were conducted, including closing enrollment into OHP Standard in July 2004 and placing significant new limits on hospital coverage in August 2004.

Figure 1

Waiver Changes in Oregon: Reductions Outweigh Expansions

	Changes Allowed Under Waiver:	Number Affected:
Implemented Reductions	**OHP Standard**: Changes for some parents and other adults <100% FPL : • Enrollment cap • Increased premiums and cost sharing • Reduced benefits	Over 100,000 adults affected in February 2003 (Enrollment dropped to 46,520 as of October 2004, largely due to reductions)
Implemented Expansions	Children & pregnant women 170-185% FPL Premium assistance program 170-185% FPL	3,748 enrollees as of October 2004
Expansions that Have Not Been Implemented	Parents 100-185% FPL Other adults 100-185% FPL Subsequent expansion for children and premium assistance program 185-200% FPL	N/A

Note: Oregon has not yet implemented its approved expansion for parents and other adults due to state funding constraints. Copayments for poor parents and other adults were eliminated in June 2004, following a court ruling.

KAISER COMMISSION ON Medicaid and the Uninsured

Also, in February 2003, the state folded an existing state-funded premium assistance program, FHIAP, into its Medicaid program, enabling the state to receive federal matching funds for FHIAP enrollees and to open FHIAP to more people. Finally, the state implemented a small expansion for pregnant women and children (from 170% to 185% of poverty). The state has not implemented its larger approved expansion for parents and other adults (from 100% to 185% of poverty). Because only a small piece of the approved expansion has been implemented, less than 4,000 people had gained new coverage as of October 2004, while enrollment had dropped by over 55,000, largely due to the implemented reductions.

Elimination of Medically Needy Program. Outside of the waiver, the state made other program changes, including eliminating its Medically Needy program, which assisted people with high medical expenses relative to their incomes. The Medically Needy Program provided partial Medicaid coverage to people with incomes somewhat above the OHP eligibility standards who had significant health care expenses. The overwhelming majority of individuals assisted by the Medically Needy program were low-income Medicare beneficiaries who relied on the Medically Needy coverage for services not covered by Medicare, most notably, prescription drug coverage, and, in some cases, mental health services and durable medical equipment. Nearly 9,000 people lost coverage as a result of this program ending in February 2003.

This focus group study focused on learning more about the experiences of individuals affected by the OHP Standard waiver reductions, those who lost Medically Needy coverage, and those enrolled in the FHIAP premium assistance program. Findings from focus groups with these individuals are discussed below.

FINDINGS: OHP STANDARD ENROLLEES AND DISENROLLEES

Overview of OHP Standard Changes

In February 2003, Oregon used new waiver authority to reduce coverage for previously eligible poor parents and other adults who are not receiving TANF or general assistance. This reduced coverage is called "OHP Standard." Specifically, these adults:

- *Lost coverage for certain benefits.* Eliminated benefits include mental health services, durable medical equipment, and dental and vision services. Coverage for prescription drugs was also eliminated in March 2003 but then later restored. Additionally, significant new limits were placed on hospital coverage in August 2004, after these focus groups were conducted.
- *Had premiums increased and faced stricter premium payment policies.* All OHP Standard enrollees are subject to premiums, including those with no incomes. Premiums range from $6-$20 per person per month, based on income. People are disenrolled if they miss or are late with one premium payment and are "locked out" for six months before they can reenroll. There is no grace period for late payments. (Since enrollment was closed in July 2004, those who miss or are late with one premium payment can no longer reenroll.)
- *Faced increased copayments for covered services.* These copays range from $3 to $250, based on service. Providers and pharmacies can now deny services or drugs to OHP Standard enrollees if they are unable to pay copays. Previously, services could not be denied based on inability to pay. In June 2004, after these focus groups were conducted, the state eliminated these copays per a court ruling.
- *Became subject to a new enrollment cap.* This cap was first implemented in July 2004, after the focus groups were conducted. The cap closed new enrollment in OHP Standard, preventing eligible people from enrolling in the program. Also, as noted, individuals who are disenrolled for nonpayment or late payment of premiums can no longer reenroll.

Who are OHP Standard enrollees and disenrollees?

The focus group respondents provide a window into the kinds of individuals enrolled or previously enrolled in OHP Standard. Of course the thirty individuals participating in the OHP focus groups cannot represent the diversity in this program, but they do shed light on the type of problems and challenges these individuals can face.

OHP Standard enrollee and disenrollee respondents were very low income and were generally uninsured prior to enrolling in (and after disenrolling from) OHP. Because OHP Standard eligibility is limited to adults with incomes below the federal poverty level, all enrollees and disenrollees were poor. Most reported that they were unemployed and lacked access to employer sponsored health coverage. Additionally, several reported that they could not afford individual coverage on the private market. Prior to enrolling in OHP Standard, most respondents had been uninsured. Several described the significant challenges they face finding employment in the current economy and the difficulties getting by on such limited incomes, which often requires juggling different bills and needs.

Respondents represented a range of health statuses, with some reporting chronic illnesses. Some were in good health while others reported suffering from chronic illnesses. Many had health conditions that require them to take multiple prescription medications. Some examples of reported health conditions include, diabetes, asthma, high blood pressure, and mental illness.

How do they value health insurance coverage?

Health insurance coverage is a top priority for OHP Standard enrollee and disenrollee respondents. Respondents described health insurance as "vital" or "extremely important." Both current enrollees and disenrollees recognized the importance of coverage. Some said health insurance is particularly important because of the high cost of health care and because they often have many health care needs, including treatment for chronic conditions and regular medications.

Generally, respondents recognized that without health coverage, medical expenses are unaffordable. As such, they saw health insurance as important for providing financial security. As one man noted, "If something happens to you, you want to be able to go to the hospital...without having to worry about them charging you thousands of dollars…"

Some current OHP Standard enrollees remarked that, because of their health problems, they could not survive without health insurance. They said that they have a number of illnesses to deal with that they cannot manage without regular care and a range of costly medications. In particular, respondents commented that coverage for physician visits and prescription drugs is vitally important. Others recognized the increasing importance of health coverage associated with increasing age. A few said that, as they have gotten older, there health needs have increased, and, as such, the need for health coverage is greater.

Respondents highly valued the OHP program, but felt the program cuts made the program significantly less valuable. Most respondents noted that they did not have access to employer-sponsored health insurance, and, because of their low incomes, they could not afford private coverage on the individual market. As such, respondents were generally uninsured prior to enrolling in OHP Standard. Further, all disenrollee respondents had become uninsured following their disenrollment from OHP Standard.

In light of the limited availability of private coverage options for this population, respondents highly valued the OHP Program. Both enrollees and disenrollees were "grateful" for the program and felt "fortunate" to have such a coverage option. They remarked that, prior to the program cutbacks, the program had covered a broad range of services that met their needs and that it had been affordable. However, they generally felt that the program had become significantly less valuable since the cutbacks. Some described the plan as "watered down" and "chopped up." However, despite the reductions, respondents still recognized the importance of OHP, commenting that, without it, they would have no other coverage options and that it is "better than nothing."

Respondents viewed health insurance as a top priority…

"Most people in this country cannot afford to pay for their medical expenses straight–up without insurance. So it's really important."
-OHP Standard Enrollee

"If something happens to you, you want to be able to go to the hospital…without having to worry about them charging you thousands of dollars…"
-OHP Standard Disenrollee

"The older you get, and then sometimes like in my case, I've become less insured as I've gotten older, as actually my health has gone south of me a little bit, I haven't had anything to back it up, either income or insurance."
-OHP Standard Disenrollee

Respondents highly valued OHP…

"…when I started on the program, it was, I think a great program; it really covered a lot of bases. And now, the plan's really watered down and doesn't cover many bases at all. But again, I've got to make the point that it's better than nothing. Which is, if we didn't have it, we wouldn't have anything."
-OHP Standard Disenrollee

"It was the only thing affordable!"
-OHP Standard Disenrollee

"…it once was a good program; now it's barely a program."
-OHP Standard Disenrollee

How were they affected by the premium changes?

Many respondents had difficulty affording the increased premiums. Although OHP Standard premiums, which range from $6 to $20, may appear relatively low, many respondents had difficulty paying them. As previously noted, all OHP Standard enrollees have incomes below poverty and even those with no income have to pay a premium of $6. Given these low incomes, a number of respondents described difficulties affording the premiums.

Many commented that it was difficult to come up with the money each month, and several said they rely on assistance from family or organizations. Some found themselves having to make difficult financial trade-offs to afford their premiums, such as getting behind on the rent or skipping meals to save the money needed to cover the premium. Some disenrollees said they simply could not come up with the money to pay their premiums, and, as such, they lost their OHP Standard coverage and became uninsured.

Respondents also cited difficulties meeting the stricter premium payment requirements. Under the new premium payment requirements, individuals are disenrolled if they miss one payment; there is no grace period for late payments. They must then wait six months before they can attempt to reenroll in coverage. (Since enrollment closed in July 2004, individuals can no longer reenroll.) Most respondents who were disenrolled from OHP lost their coverage because they missed one premium payment and then became uninsured. As one man described, "On the day payment was due, I called the office and told them that I couldn't get down there. I was going to be there maybe five minutes after they were supposed to close, and they said nope. If it's not in by 5:00, we can't accept it. And, even though I told them I had the cash…they just wouldn't do it."

Respondents reported either mailing their monthly premiums or paying them in person. They highlighted a number of problems associated with getting their premium payments in on time. Some received the notice that their payment was due late and then did not have enough time to make their payment before the due date. Further, respondents remarked that there is only one office in Portland that will accept payment in person. While the office is centrally located in Portland, they said that it is not easy to reach by bus, which is how many of them travel, nor is it in a convenient walking distance from where they live. As one woman described, "…then you've got to go downtown, and then try and find this other bus, and get up there…You know, it's like a big, major hassle." Respondents also noted that the office is not open during evenings or on weekends and had conflicting information regarding whether the office accepts cash or only money orders or checks. Finally, several respondents described significant difficulties getting assistance from agency staff over the phone.

Premiums were unaffordable for many respondents…

"It doesn't hurt to miss a meal, but still to have to make that decision is kind of degrading. But there's no other alternative. And what coverage I do have I don't want to lose… If you are not getting any general assistance or working, getting money, it's just difficult."
-OHP Standard Enrollee

"I didn't have the money, to tell you the truth. I could not do it. I couldn't afford it…Even though it's not that much, I didn't have it.
-OHP Standard Disenrollee

The strict premium payment policy created difficulties …

"On the day payment was due, I called the office and told them that I couldn't get down there. I was going to be there maybe five minutes after they were supposed to close, and they said nope. If it's not in by 5:00, we can't accept it. And, even though I told them I had the cash…they just wouldn't do it."
-OHP Standard Disenrollee

"I mailed my payment in and I was late and I was kicked off. My doctor and the hospital wrote letters trying to get them to budge and they wouldn't budge and so I lost."
-OHP Standard Disenrollee

How have the reduced benefits and increased cost sharing requirements impacted individuals' access to care?

A number of respondents faced substantial difficulties accessing care due to the elimination of benefits. As noted, OHP Standard enrollees lost coverage for several benefits, including mental health services, durable medical equipment, and dental and vision services. Respondents described significant problems accessing necessary care due to the loss of coverage for these benefits.

Problems stemming from the loss of mental health coverage were particularly pronounced. Respondents noted that, while they are still able to get their psychiatric medications (with a copayment), their counseling is no longer covered by OHP. Some said that their health and quality of life were deteriorating due to the loss of counseling services. One described her difficulty trying to get her psychiatric drugs prescribed by her primary care doctor, who responded, "this is out of my field."

Some respondents also described problems from the loss of coverage for medical equipment. It is difficult for them to afford diabetic test strips and other supplies because they are very expensive. Further, the loss of coverage for dental and vision services were highlighted as problematic. Because they cannot afford to pay out-of-pocket for dental and vision care, many are foregoing treatment. This means they have to make do with outdated prescription glasses or that they do not seek care for problems with their teeth. One respondent had a tooth pulled because it was the only treatment she could afford.

The increased copayments were unaffordable for some respondents, causing them to forgo or delay necessary care. In addition to reduced benefits, individuals also faced increased copayments for covered services, ranging from $3 to $250, based on service. Also, physicians and pharmacists can now deny care or drugs based on inability to pay copayments. (Previously services could not be denied based on inability to pay.) According to respondents, this has created barriers to accessing necessary care and increased their financial burden, sometimes forcing them to make difficult financial choices.

While the dollar amount of the copayments may seem small, for these individuals, they are often too much to afford. As one woman remarked, "Being able to afford $2 is a lot of money when you have absolutely nothing." Some said they relied on help from family, friends, charities, or churches to cover copayments. Respondents noted that it is particularly difficult to come up with money for copayments in acute situations, when they cannot plan ahead for the expense. However, respondents said that even when they can plan for the expense it usually means financial

The loss of benefits led to problems accessing care…

"My health has really deteriorated because they've cut off some of my care, some psychiatric care. And, so I have been unable to go to a psychiatrist, and…my primary care physician they said is supposed to prescribe me these drugs, and she's like, this is out of my field"
-OHP Standard Enrollee

"The only thing that they say they will do, for $40 I think, is they'll yank the tooth out. Well, I finally, one got so bad that it was just agony, and so I finally found a place that would give me a voucher so I didn't have to pay the $40 to get my tooth yanked out. I could get the tooth yanked out free. So, I have a big hole in my mouth. I'm only in my forties, and they said every time I get a toothache, they'll just take another tooth until OHP covers it again."
-OHP Standard Enrollee

Many had problems affording copayments…

"Sometimes $2 is like a million dollars to me."
-OHP Standard Enrollee

"I went down to have my prescriptions filled, and he'd changed me to two other drugs, and those copays were $15 each, and I had enough if they'd all been $2, but I couldn't take those two medications…I don't know what, how they choose to work with it, but he [the pharmacist] just took those two out of my bag and I got the ones that I could afford."
-OHP Standard Enrollee

"…a couple of times I couldn't get my prescription and the girl behind the counter actually paid the $3 right out of her purse, the girl behind the counter, and paid it for me."
-OHP Standard Enrollee

trade-offs, such as choosing whether to pay rent, utility bills, or medical bills. Further, several commented that they already have significant medical debt and are concerned about accumulating more.

In particular, many reported difficulty affording their medications since copayments were implemented. Several described instances in which they had been denied prescription drugs because they were unable to pay the required copay. In one case, a respondent noted that the woman behind the counter paid her copayment for her. Some reported obtaining samples from their physician. Others said they have had to do without food or some other necessity in order to obtain their medications. These copayments proved most problematic for those who take several medications because the copays add up per drug.

How have those who have lost coverage fared?

All OHP Standard disenrollee respondents were uninsured, and many reported significant problems obtaining necessary care. Disenrollee respondents had no regular doctor or regular source of care. Instead, they described relying on clinics, the emergency room, prescription drug donation programs, and drug samples for their care. Although these resources provide help, they are not substitutes for coverage. For example, a few respondents were able to obtain some of their medications through pharmaceutical assistance programs, but, in most cases, they were not able to obtain all of their needed medications. As one woman described, "I was on seven prescriptions when I came off of the plan. My pharmacist at my clinic has been working with me and kept me on three of them."

Respondents said that the stress and pressure they feel without health coverage often exacerbated their health problems. Without any coverage most are without the means to pay for their health care needs, so they have to rely on their wits and the random selection of free services that they can find. Disenrollees shared the view that since losing OHP coverage their health has worsened. Some cited specific problems such as increased blood pressure or the need for glasses that they cannot afford. Others said that they cannot afford preventative care and that they worry about new health conditions going undiagnosed.

Most disenrolled OHP respondents reported significant chronic health problems, ranging from high blood pressure to mild schizophrenia, diabetes, and asthma. Despite the great value they placed on OHP coverage to care for these conditions, they had become uninsured largely due to strict payment policies and an inability to come up with the money for their premiums. Overall, this group of disenrollees was fearful of becoming seriously ill and concerned about the future. Some said they are living day-to-day and "praying" they do not become seriously ill. One man commented, "I've been trying to eat really healthy and I'm just taking like double extra care of myself so I don't put myself at risk."

Of note, most of those who were disenrolled planned to reapply for OHP. However, some did not plan to reapply because they cannot afford the premiums and/or do not believe that it is worth paying the premiums because of the reduced benefits and increased copayments associated with the coverage. Some hoped to find a job that offers employer-sponsored insurance. One was hoping to purchase an individual plan, although it was not clear how she could afford it. Until then, these individuals live in the situation where health care is "catch as catch can."

FINDINGS: FORMER MEDICALLY NEEDY ENROLLEES

Elimination of Medically Needy Program

In February 2003, the state eliminated its Medically Needy Medicaid program. This program provided partial Medicaid coverage to people with incomes somewhat above OHP eligibility limits who have significant health care expenses. Nearly 9,000 people lost coverage as a result of the elimination of the program. These people were primarily low-income Medicare beneficiaries who relied on Medicaid for prescription drugs and other services not covered by Medicare, such as some mental health care and durable medical equipment.

Who are former Medically Needy enrollees?

Former Medically Needy enrollee respondents had serious medical conditions with extensive medical needs that prevented them from working. All respondents reported suffering from medical conditions that preclude them from working. Some examples of these conditions include: multiple sclerosis, severe diabetes, Post Traumatic Stress Disorder, and Crohn's Disease. Respondents said that they are taking multiple medications to treat their medical conditions. Several had need of regular mental health care, either because of the nature of their condition or because of the difficulties they have dealing with their physical health. While most were employed in the past, they said their medical conditions make it difficult to hold down a steady job. When they have tried to find work more recently, they say prospective employers have been unwilling to take a chance on people in such dire physical straits.

Most respondents had Medicare coverage and had relied on the Medically Needy program for coverage of prescription drugs and other services not covered by Medicare. As such, although they did not become completely uninsured as a result of the elimination of the Medically Needy program, they lost coverage for critical services. Given the serious health conditions of these individuals, the loss of coverage for prescription drugs and other services had a significant impact.

Who are Former Medically Needy Enrollees?
Mary's Story

Mary* is a 48-year-old, divorced Caucasian woman. She was diagnosed with multiple sclerosis (MS) in 1996. Her MS has progressed over the last eight years to the point that she can no longer work. She suffers from double vision, difficulty concentrating, and problems with muscle coordination and strength. In order to walk she needs to use a walker for support. "I have fallen and laid on the sidewalk and had people yelling out their cars, 'Drunk!' 'Look at that person! Look at that lady! What's wrong with you?' Sometimes I would have to lie there for the longest time until somebody would stop and help me up, because I couldn't get up…When I wake up in the morning my muscles are stiff. I've got spasms. I can barely move. I've got a living rigor mortis every freaking morning."

She takes many medications. She receives most of her medications through pharmaceutical assistance programs. However, she reports that she has to make co-payments of $5-$25 for her medications. She also takes one medication where she has to pay a $75 shipping fee. She also gets a few medications as samples from her physician. She says she spends much of her time filling out forms for health care assistance programs when she can concentrate and her eyesight is not bothering her. She states, "My life has been a living hell since I no longer have the Medically Needy program."

*Real names have been changed to protect privacy of focus group participants.

How do they value health insurance coverage?

Former Medically Needy respondents placed an extremely high value on health insurance coverage and were dependent on the Medically Needy program. Members of this group are highly dependent on the health care system. They all suffer from chronic and debilitating illnesses. Many viewed having health insurance as a life or death concern. Access to physicians, medications, therapists, and durable medical equipment was described as an absolute necessity. Without this access, many are not able to get out of bed or leave their homes.

Respondents highly valued the Medically Needy program and felt that it made a significant difference in their lives. That is, the program helped them afford their medications and obtain mental health services and durable medical equipment that Medicare does not cover and that they would not have been able to afford otherwise. While their prescription drug coverage required them to pay a copayment for their medications, most found the copayments manageable. Typically they felt that this was a small price to pay in order to receive what are otherwise very expensive medications. However, those who were taking many medications could find the copayments difficult to manage because they can add up over a month's time.

How have individuals been affected by the elimination of the Medically Needy program?

Respondents faced significant hardships due to the elimination of the Medically Needy program, particularly due to loss of prescription drug coverage. Several respondents believed that the stress of living without Medically Needy coverage has contributed to the deterioration of their health. In particular, many noted that the loss of prescription drug coverage has led to significant problems because prescription drugs are not currently covered by Medicare and because they are taking multiple medications.

The loss of prescription drug coverage has had a severe effect on their ability to afford medications. Some said that since they have lost their Medically Needy coverage they are no longer getting all their needed medications or that they sometimes ration their medications, taking less than the prescribed amount in order to stretch out the prescription.

A few had been able to qualify for patient assistance programs through pharmaceutical companies, which supply medications for free to low-income people. However, respondents described several drawbacks of these programs. Some said these programs often do not cover all medications and if a medication has gone from brand name to generic it is not covered at all. Also, they said the programs are difficult to qualify for and enrollees are required to reapply frequently. One man pointed out, "I scrambled and I got help from people that know what they were doing and put me in a position where I could get these pharmaceuticals for free. That is the answer to my quandary but it still, like I said, doesn't leave you with a real secure point of view because you don't know how long these people are going to allow you to take these." Some participants rely on physician samples to obtain their medications, but they point out that physicians are receiving fewer samples from manufacturers.

The loss of prescription drug coverage has caused significant hardships…

"I don't take my medications as prescribed, because I can't afford them and there aren't any generics."
-former Medically Needy Enrollee

"I also find that I am stockpiling my medication and not taking as much because I am so afraid …that it is going to run out."
-former Medically Needy Enrollee

"I am not getting my medications and I am getting very sick because of it."
-former Medically Needy Enrollee

The loss of coverage for mental health services and durable medical equipment through the Medically Needy program also had significant consequences for respondents. The elimination of the Medically Needy program also led to the loss of coverage for some mental health services and durable medical equipment. Respondents felt that this also has been particularly difficult. These are individuals with disabilities or serious chronic illnesses who are unable to work and reliant on their assistance. One woman described her challenges due to the loss of mental health coverage:

> "When the Medically Needy Program ended, I couldn't see a counselor any longer and I couldn't take any medicine any longer. When I quit working, I reapplied for social security. I was denied on the fact that the people that they talked to were the counselors that I saw while I was working because that year it looked like I was not seeing a counselor, I was not taking my meds because I had gotten better, where, in fact, I wasn't doing any of that because I couldn't afford it."

Respondents said they often had to rely on their wits and perseverance to obtain the things that they needed. It is important to realize that these were services that they had to seek out or that they happened upon by chance. For example, one received free medical equipment such as a walker, another handicapped bathroom fixtures, and another exercise equipment to help with multiple sclerosis. They named a number of organizations that helped them, including the MS Society, Diabetes Association, and the Blanche Fischer Foundation (a charitable foundation that assists disabled Oregonians).

Overall, the elimination of the Medically Needy program increased respondents' financial pressures and anxieties. When the program ended, many said they were faced with the choice of buying their medications or paying a heating bill, or buying test strips for their diabetes monitor or buying food. Not surprisingly, these are hard choices that are compounded by the fragile condition of the physical and mental health of these individuals. As one woman stated, "My total income is $740 a month. That's all I get. My total medical bill is $912 a month. You do the math." Respondents struggled with juggling bills and the fear that they might lose their housing or their heating, because they could not afford those and their medical expenses, too. One woman stated, "I have my Medicare and I pay almost $200 a month for Medicare supplement because I am ineligible for an HMO. My medicines cost me almost $1,500 a month. My social security check is $700 a month. I am not getting my medicines and I am getting very sick because of it."

The lack of coverage pushed some into a depression that they had difficulty rebounding from, especially since they could no longer access mental health care. Further, some commented that the anxiety and fear engendered by their medical conditions were exacerbated by cuts in the programs upon which they depend. These anxieties were further heightened by stories circulating about people suffering dire consequences, such as comas and suicides, due to the loss of their Medically Needy coverage.

Loss of Medically Needy coverage increased overall financial pressures…

"Oh, God! You are talking about getting shut off notices for the phone. Shut off notices for the electric. It's bad. It's really bad! Who do you pay?"
-former Medically Needy Enrollee

"My total income is $740 a month. That's all I get. My total medical bill is $912 a month. You do the math."
-former Medically Needy Enrollee

FINDINGS: FAMILY HEALTH INSURANCE ASSISTANCE PROGRAM (FHIAP) ENROLLES

Overview of Changes

FHIAP was created in 1997 to help low-income Oregonians afford private health insurance. The program subsidizes individuals' health insurance premiums for private individual or group coverage. Subsidized private coverage must meet a benchmark established by the state, but can have significantly more limited benefits and higher cost sharing than allowed under Medicaid. For example, it can include up to a six-month pre-existing condition waiting period and up to a $500 deductible. FHIAP does not provide individuals assistance paying for cost sharing or obtaining benefits not covered by their private plan.

Under its recent waiver, Oregon refinanced the previously state-funded FHIAP and began drawing down federal Medicaid and SCHIP match funds. The state also expanded FHIAP eligibility from an upper income limit of 170% of poverty to 185% of poverty. Enrollment in FHIAP remains relatively limited—about 7,000 people were enrolled as of September 2004.[4]

Who are FHIAP enrollees?

FHIAP respondents generally were employed, had higher incomes than OHP Standard respondents, and tended to be in better health. Because more respondents had jobs and higher incomes, they were more likely to have access to employer-sponsored insurance and more resources to devote to premiums. A few said they have health conditions, such as diabetes or high blood pressure. [5]

How has FHIAP impacted enrollees ability to access coverage and care?

Without the FHIAP subsidy most respondents would not be able to afford health insurance. Without exception, FHIAP respondents regarded health insurance as very important. Before enrolling in FHIAP some reported being uninsured, a few said they were insured but struggling to afford their coverage, and a few were enrolled in OHP. FHIAP is paying 50% to 95% of respondents' premium costs, depending on their income. With these premium subsidies, they report being able to pay their share of premium costs. Respondents said that without the FHIAP subsidy they would not be able to afford health insurance. As one remarked, "FHIAP is really helping with this reimbursement, because without it I think I would be struggling a lot." Thus, FHIAP is making health coverage affordable for many of these respondents**.**

Without the FHIAP subsidy coverage would be unaffordable…

"FHIAP is really helping with this reimbursement, because without it I think I would be struggling a lot."
-FHIAP Enrollee

"I don't think I'd be able to afford insurance without FHIAP."
-FHIAP Enrollee

[4] FHIAP Snapshot of Program Activity, September 27, 2004, http://www.ipgb.state.or.us/fhiap/snap/9_27_04.pdf
[5] Most focus group respondents were enrolled in group employer-sponsored coverage. Follow-up telephone interviews were conducted with FHIAP enrollees who have individual private coverage. These respondents had many more health problems including insulin-dependent diabetes, asthma, high blood pressure, heart valve replacement, chronic fatigue, sleep apnea, and gastric bypass.

FHIAP respondents liked the provider choice available under their coverage, but some had problems with cost sharing and/or limited benefits. Respondents consistently reported that they liked the provider choice available through their private coverage. As one woman stated, "I think I'm better off with FHIAP because I have my private insurance. Like I said, I can pick which doctor I want to go to." Many perceived that they would have less provider choice with OHP coverage. Additionally, a number liked that the FHIAP assistance is largely transparent. They said that once they are enrolled in FHIAP, only FHIAP and the enrollee may know that they are receiving assistance. Their employer may not even know they are enrolled in FHIAP. Respondents also felt that health care providers see them as any other individual with private insurance.

Some respondents described difficulties affording the cost sharing associated with their private coverage, such as deductibles and copayments. They said that over the course of the year these payments add up and become difficult to manage and remarked that those with large families are especially hard hit, particularly if they try to take several children in for check-ups at one time or if several family members get ill at the same time. Some respondents reported going without necessary health care or delaying care until they could afford the cost sharing.

Private coverage subsidized by FHIAP generally does not provide comprehensive benefits, such as coverage for dental and vision services. Because these services are not covered, individuals have to pay out-of-pocket for them. A few respondents put off obtaining vision and dental care until they could save the money to afford services. One noted, "I'm having a problem with a tooth right now, and I've had to wait nine months before I can save up enough money…" Another respondent had to go to the clinic and have a tooth pulled because that was the only affordable treatment. Even though respondents recognized these problems stemming from the higher cost sharing and reduced benefits of their private coverage, most commented that they thought these difficulties were worth their increased choice in providers.

Some had difficulties due to cost sharing and limited benefits…

"Putting out three hundred bucks and then twenty percent a year is quite a bit of money. My prescriptions were over $1,000 this year."
-FHIAP Enrollee

"I just hope I don't have to go to any emergency, or any hospital, because I will be liable for all the deductible besides the copay."
-FHIAP Enrollee

"I'm having a problem with a tooth right now, and I've had to wait nine months before I can save up enough money…"
-FHIAP Enrollee

CONCLUSION

Oregon recently made significant changes to its Medicaid program, largely in an effort to address growing state fiscal problems. Earlier research found that these changes led to significant coverage losses, problems accessing care, and increased strains on safety net providers.[6] This focus group study provides greater insight into how individuals were affected by the changes. These findings reveal that the reduction in benefits and increased premiums

[6] See research summarized in C. Mann and S. Artiga, "The Impact of Recent Changes in Health Care Coverage for Low-Income People: A First Look at the Research Following Changes in Oregon's Medicaid Program," *Kaiser Commission on Medicaid and the Uninsured*, June 2004. http://www.kff.org/medicaid/7100a.cfm

and cost sharing for poor adults in OHP Standard and the elimination of the Medically Needy program have had significant consequences for individuals. Consistent with earlier research findings, these focus groups found that these reductions led to coverage losses and problems accessing care. Additionally, they found that these reductions have increased individuals' financial burden, leading them to make difficult financial trade-offs. Further, they have increased individuals' anxiety about their ability to obtain care and their overall futures.

The focus group with FHIAP enrollees found that, overall, the program is serving them well. They liked the provider choice that accompanies private coverage, although some expressed difficulties with the higher cost sharing and limited benefits of their private plans. However, it seems that FHIAP enrollees generally are higher income than those served by OHP and, thus, better able to deal with these coverage limitations. As such, it is not clear that such a program would work well for those at lower incomes.

In sum, these findings illustrate the significant consequences faced by individuals due to Medicaid program reductions. Most of these individuals are unable to access health care coverage or medical services without this coverage. As such, those who lose coverage or have coverage reduced are left with very limited options and face increased strains on their already limited financial situations.

APPENDIX

Research Methodology

To learn about the experiences of Oregonians currently enrolled or previously enrolled in one of the three programs (OHP Standard, FHIAP, or Medically Needy Program), Lake Snell Perry & Associates conducted five focus groups on February 8 and 9, 2004 in Portland, Oregon. For the OHP Standard and Medically Needy Program groups, potential participants were pre-recruited by the Oregon Health Access Project, an advocacy group for the uninsured in Oregon. Potential participants for the FHIAP focus group were pre-recruited by caseworkers in the FHIAP program. Potential participants were told about this study – i.e., that we wanted to learn about their experiences in the program but that their participation in this study had no bearing on their enrollment status – and they were paid $75 for their time. A profile of research participants follows.

As a supplement to the FHIAP focus group, two telephone interviews were conducted with FHIAP enrollees who were covered by individual private coverage rather than group coverage.

Trained professional focus group moderators conducted all focus groups and interviews.

TABLE 1: PROFILE OF FOCUS GROUP RESPONDENTS

	OHP Enrollees	OHP Disenrollees	Former Medically Needy	FHIAP Enrollees
Health Coverage				
OHP or FHIAP	20	0	0	9
Medicare	0	0	4	0
Other	0	0	2	1
Uninsured	0	10	1	0
Health Status				
Excellent	2	0	0	1
Good	6	6	1	6
Fair	6	4	4	3
Poor	5	0	2	0
Don't Know	1	0	0	0
Current Employment				
Employed	4	4	1	8
Not employed	16	6	6	2
Age				
20-29	3	0	0	2
30-39	3	1	1	3
40-49	8	4	3	2
50-64	5	5	3	3
No response	1	0	0	0
Education				
High school or less	7	4	0	4
Technical school	2	0	1	2
Some college	5	2	5	2
College graduate	4	2	0	2
Post graduate	2	1	1	0
No response	0	1	0	0
Marital status				
Married/Domestic partner	4	0	0	5
Single	8	5	3	3
Separated/Divorced	8	5	4	1
Race/Ethnicity				
White	14	7	5	6
African American	1	3	1	0
Hispanic	0	0	0	1
Other	5	0	1	3
Total Respondents	20	10	7	10

1330 G Street NW, Washington, DC 20005
Phone: (202) 347-5270, *Fax:* (202) 347-5274
Website: www.kff.org/KCMU

Additional copies of this report (#7233) are available
on the Kaiser Family Foundation's website at www.kff.org.