

**Experiences with Medicare Part D:
Stories from Low-Income, Ethnically Diverse, and
Medically Needy Californians**

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I. Introduction

Lake Research Partners conducted in-depth interviews among 35 “vulnerable” Medicare beneficiaries in California to examine early experiences with Medicare Part D prescription drug coverage. This is the first of several interviews that will track Medicare beneficiaries through the first year of Part D. Insights from this phase of research, conducted in April 2006, focus on the process of choosing and enrolling in a Part D plan, and beneficiaries’ early experiences using their Part D coverage. This report provides a summary of key findings, followed by a brief methodology, detailed findings, insights into experiences with Part D in the future, and profiles of participants in the study, including snapshots of their experiences with Part D so far. At the end of the report is a more detailed description of the project.

Summary of Findings

Four key insights emerge from this research:

- **Difficulties and problems encountered by beneficiaries are forcing some of the most vulnerable to make serious choices that could have harmful health consequences.** Even though these beneficiaries only had a few months of experience with Part D at the time of the interview, many already faced serious problems. In some cases, like being told they had to pay full price for a medication, the issue was resolved within a few weeks. In other cases, however, problems have not been resolved. One of the main ongoing issues for many is that Part D has resulted in an *overall increase* in out-of-pocket costs in the form of co-payments. This population has little capacity to absorb extra monthly costs, and the expenses are taking a toll. Some are paying more than \$100 monthly. A few are skipping meals or going to food banks, and others are doing without medications or splitting pills to make them last longer. One HIV positive beneficiary has already reached the “donut hole” in his plan, while another is about to reach it.
- **Although some individuals are satisfied with Part D and some who have had problems resolved are content, confusion and a lack of understanding remain. This could cause problems later on if their drug coverage or medication needs change.** A quarter of dual eligibles in the study do not even know they are in a Part D plan because they were auto-enrolled and did not choose a plan. Most beneficiaries are unclear what drugs their plan covers, and some are cognitively challenged and do not have help to find answers to questions. Additionally, for many who are currently getting their medications without problems, there is no perceived reason for them to learn about their plans. This lack of knowledge may cause problems in the future if drug needs or formularies change.
- **Almost all beneficiaries lack information about how to switch plans and what the restrictions are, even though several would be interested in another plan.** Either because of increased out-of-pocket costs or difficulties in getting drugs covered, several beneficiaries say they would be interested in another Part D plan. However, almost no one seems to know how to go about switching plans or even if they can. For some who have the least awareness about Part D, switching plans has not even occurred to them. For others – even the most knowledgeable and proactive – switching is scary because the implications are unclear. What if another plan is

worse? This fear keeps beneficiaries in their current plan. Several also worry about restrictions, such as how many times they can change plans, and whether they can return to their current plan if they face problems in another one.

- **Many of these vulnerable beneficiaries seem unable to resolve Part D problems on their own, and could benefit from one-on-one help.** This population is vulnerable, lacks resources, and has difficulty navigating the processes. Many of these beneficiaries have cognitive challenges, mental health issues, and physical disabilities which can make back and forth with insurance plans and sifting through complex information difficult or even impossible. Throughout the enrollment and transition process, most beneficiaries were on their own to choose a plan and resolve issues. Added to this, many are alone in the decision-making process, except for a pharmacist or an existing insurance company. As a result, a majority of duals relied on auto-enrollment, and others depended on one or two resources to tell them what to do. Most did not turn to family and friends for help nor did they use Medicare-sponsored resources like the toll-free number or website (www.medicare.gov); and they are still not going to those resources to help solve issues. Those who are “connected” to community resources working on health issues, such as the HIV beneficiaries, tend to be more educated about Part D processes and thus may be in better shape in terms of future needs and getting information to help them through issues. Even these beneficiaries, however, are facing ongoing, unresolved issues with Part D and could use some one-on-one help.

Research Methods in Brief

Lake Research Partners conducted qualitative interviews with 35 diverse Californians who receive Medicare benefits. One distinct feature of this research is its focus on *vulnerable* Medicare beneficiaries. Specifically, all beneficiaries in this study have incomes under 200% of the federal poverty level; most are heavy users of medications; and many face chronic health conditions such as diabetes, heart problems, blindness, transplant issues, mental health needs, various physical disabilities, and HIV/AIDS. Twenty of the participants are dual eligibles (they receive both Medi-Cal and Medicare). The beneficiaries reflect a mix of gender, age, race and ethnicity. In addition, some interviews were conducted in Spanish and Cantonese, for those who have limited English proficiency or prefer to speak in their native language.

The interviews took place April 3-7, 2006, a little more than a month before the May 15th enrollment deadline for Medicare Part D. Participants were recruited from Los Angeles, the Bay Area, and Bakersfield and surrounding towns. Fourteen interviews occurred in Los Angeles, 12 in Oakland, and 9 in Bakersfield. For more details about the participants and the project overall, please refer to the methodology at end of this paper.

II. Detailed Findings

Early Experiences with Part D

Many beneficiaries faced immediate problems when they first tried to use their Part D plan, including their medications not being covered. Eleven beneficiaries said they went to the pharmacy to fill a prescription and found out the medication was not covered by their new plan. At the cash register, they were charged the full price, which most could not afford. Some had more luck than others resolving these problems. For a handful, like Norma from Bakersfield, the problem was solved within a week or two. After many phone calls between two pharmacies and her doctor prescribing two other medications (which also were not covered), the pharmacies got the insurance company to cover the original medication. Nevertheless, Norma went two weeks without her anxiety medication while this was happening. Others who experienced these problems either had the pharmacy resolve the issue with the insurance company, asked their doctor to file an appeal to the insurance company to cover the drug, got a prescription for an alternative medication that was covered by their plan, or just did without the medication.

“It was January when I got my first prescriptions [and] the pharmacist says, ‘Oh no, you don’t have coverage.’ I said, ‘No, no, no something is wrong.’ And I didn’t get to go home with my medication that day. He just gave me what would get me through the next two nights and that was taken out of what I would owe him.” –Robert, Los Angeles

“It does not seem much, \$1 dollar to \$5 dollars a prescription, but when you are getting like 25 things a month, it adds up.” –Sue, Los Angeles

A major issue for many beneficiaries – and most dual eligibles – is new out-of-pocket costs. Seventeen beneficiaries in this study have experienced an overall increase in out-of-pocket costs since their switch to Part D. Six say they are paying less with their new coverage, and four are paying the same amount. The remaining have either not filled a prescription yet, or are not enrolled in Part D currently.

Because of their low incomes, these new costs are difficult to pay. Several dual eligibles went from paying nothing or very little in co-pays to as much as \$100 per month with their Part D plan. For example, Sue from Los Angeles used to pay nothing for her medications but now pays between \$60 and \$100 per month on a \$800 monthly disability income.

Beneficiaries are dealing with these new costs in a variety of ways, including using a credit card to pay for medications, giving up tithes at church, sacrificing on food, and even taking cost-saving measures that could compromise their health. For example, Elsie from Bakersfield ate only beans and potatoes in the later half of March when money ran out. She finds it particularly difficult to pay \$16 for her diabetic syringes and has considered re-using them. Eileen from the Bay Area pays between \$40 and \$50 per month in co-pays, whereas she paid nothing prior to Part D. She has asked her pharmacist not to cash her check for a few days when she gets her medications. Her strategy is to fill prescriptions at the beginning of the month and to split pills in order to make them last longer. Martha from Los Angeles explained, “Sometimes it ends up at the end of the month, if you have medication that you

weren't expecting to buy, and if it's not budgeted out...then you don't buy food the rest of the month. You go visiting children, friends and neighbors because there is no food you can buy. When you're going to spend \$40 for food or \$40 for the medicine, which one are you going to take? You take the medicine." Based on these stories, the new costs from Part D are having real and serious effects on these low-income Medicare beneficiaries.

"Last month I had to go to [a food bank] because I didn't have money. I couldn't buy groceries. There was nothing in my refrigerator, literally. They've got rolls there today, bread rolls, so at least I have something." –
Eileen, Bay Area

Two HIV positive beneficiaries are facing the “donut hole.” Bryan from Los Angeles already reached the “donut hole” by March. AIDS Drug Assistance Program (ADAP) is currently covering his HIV medications. For non-HIV drugs, Bryan pays about \$70 out-of-pocket for half of them and relies on doctors' samples for the other half. Leonard is also worried about the donut hole, which he expects to hit in one or two months after he starts using his Part D plan. To afford his medications once he meets the donut hole, he plans on using doctor samples to get by.

A few beneficiaries are also encountering dosage and quantity changes. There were two issues around dosage – one related to the daily dose of medication covered by their new plan and another around the quantity that could be filled by the pharmacy. Sue in Los Angeles learned that her new Part D plan would cover only half the normal dose of her acid reflux medication and is concerned because she has serious throat damage. She hopes to get samples from her doctor who is filing an appeal to the insurance company. Two other beneficiaries found that their new plan only covered a one-month supply instead of a three-month supply of their medications. In addition, their co-pay amounts changed and so now they are paying more, and more often, for these monthly refills than they use to pay.

For several beneficiaries, multiple problems have emerged. About five beneficiaries have experienced a mix of problems in the first months of Medicare Part D. Leonard, an HIV positive beneficiary from Los Angeles, signed up for a Part D plan in December, which was not processed until January 17, 2006. ADAP cancelled its assistance (without which Leonard cannot afford his drugs) in February because records showed he was not enrolled in a Part D plan – a requirement to continue assistance. Additionally, ADAP requires that he apply for Medi-Cal, even though he knows he is ineligible for assistance. He has been told that the state is running seven months behind in processing applications for Medi-Cal. Leonard is currently working with a benefits counselor to expedite the process of getting a rejection letter from Medi-Cal to give to ADAP so he can get assistance again. At the time of the interview, he had not yet used his Part D plan because of computer errors with the pharmacy. During these few months, Leonard has been getting his HIV medications through doctor samples, and is splitting his non-HIV pills because he is not sure how soon things will be resolved.

Sue from Los Angeles also faced a multitude of issues in addition to paying up to \$100 per month in co-pays. She was auto-enrolled in a plan in December, and in January, she found out the plan did not cover half of her 20 or so medications (her health problems include diabetes, a transplant, three strokes, and renal failure). She had heard from Medi-Cal that if she ordered 100 days worth of prescriptions in December, they would pay while any issues got sorted out in January. However, her company only sent a 30-day supply. After back and

forth, they agreed not to charge her for January and February (which came to \$2,500). Sue immediately switched to a new Part D plan, which she says covers more, but she is still having issues. The new plan does not cover one of her medications, and it covers only half the dosage for another. Her doctor is appealing to the insurance company. Sue has also found that the insurance does not cover enough diabetic supplies.

Robert, an HIV positive beneficiary from Los Angeles, has also encountered problems. He was told initially that one of his prescriptions was not covered, so the pharmacist charged him for a few pills to cover him for a few days while things got resolved. On a different medication, his doctor knew a specific cholesterol drug would not be covered, so the doctor had to appeal to the insurance company. Robert also faced increases in co-pays, which are difficult for him to afford. To avoid a \$3 co-pay for Lexapro, the pharmacist gave him a cheaper generic. However, that was too potent for him and thus has gone back to paying for the brand name.

A handful of beneficiaries had a seamless transition to Part D. Of the 27 beneficiaries who have tried to use their new Part D coverage, eight had a seamless experience. That is, these beneficiaries had no delays or problems getting their drugs with Part D, and the costs either did not change or actually decreased. Five of the twenty dual eligibles had a seamless experience, although three are still unclear whether or not they are enrolled in a Part D plan.

Current Understanding of Part D Plans

Because most beneficiaries were auto-enrolled in a Part D plan (including some non-dual beneficiaries), many did not learn about the details of their plan. While a few beneficiaries sought out information from specific insurance companies, got answers to their questions, and compared the out-of-pocket costs and drugs covered among different plans – most did not. Fifteen of the 20 dual eligibles ended up being auto-enrolled and not choosing a plan. Their reasons for not choosing include being confused about the process, having little awareness their drug coverage would change, and they could not get the necessary information or assistance to choose a plan on their own. Wilma from Bakersfield had a typical experience. She received information in the mail about enrolling in Part D, but “the more I read, the more confused I got.” Her only resource appears to have been her pharmacist, who advised her to simply stick with the plan in which she would be auto-enrolled.

Even some non-dual beneficiaries describe the process of enrollment as automatic, and still lack details. This happened to those who receive coverage through a managed care plan. Senortha, from the Bay Area, had a typical experience. She called her managed care plan when she heard about Part D and had a question. They simply told her they took care of everything already. All seem content with this process because it lifted the burden from them having to research various plans and make a choice.

The result of being auto-enrolled, however, is that the enrollment process was not informative or educational. Many headed into January with little or no awareness about the costs and formularies in their plan.

Many still have unanswered questions and little to no understanding of their Part D plan. A quarter of dual eligible beneficiaries in the study do not even know they are in a Part D plan. One or two simply said a prescription card appeared in the mail and so they used it at the pharmacy. They do not know why they received the card or who pays for their prescription coverage. Even beyond these cases, beneficiaries on the whole lack details about which drugs are covered and what happens if drug needs change. For those who have had problems resolved or had a seamless experience, there is no sense of pressure to learn more about their plans. Carl from Bakersfield has not yet filled a prescription with his Part D plan and says, “I got a book [from the insurance company], a half-inch thick, and read nothing. I can’t understand all of that stuff anyway, so why read it?”

Almost no one is clear about what is involved in switching plans. This includes a lack of knowledge and information about whether beneficiaries *can* change plans or how to do it. Several dual eligibles say they would like to switch to another plan that has a lower co-pay but they lack help or knowledge about how to do this. This may stem from the lack of help and information they had to choose a Part D plan to begin with. Additionally, several say they are scared to switch because the implications are unknown: Could they switch back if a new plan turns out to be worse or if they need a medication suddenly not covered? Can they switch plans more than once?

Language barriers are an issue for some. For the Cantonese-speaking beneficiaries in the study, language is a barrier to understanding Part D processes, enrolling in a plan, and learning any details about their new plan. Both Xiao and Shu Ping from Los Angeles have limited English-proficiency and received all of the enrollment materials from Medicare and specific drug plans in English through the mail. Xiao took all of the English materials she received to the Chinese Service Center, which chose a plan for her. Shu Ping sought help from several resources because of language barriers, including his doctor and a social worker at an adult day care center, both of whom knew little about the enrollment process and could not help him. He heard a Chinese radio ad about a seminar on Part D but could not attend because of the inconvenience caused by his disability (he is in a wheelchair). Eventually Shu Ping was auto-enrolled in a plan, without clear explanation why and still lacks details about the plan.

For Spanish speakers in the study, language barriers were less of an issue, particularly for the beneficiaries who have been in the U.S. for many years and have some English proficiency. Nevertheless, advertisements on Spanish television were key for one or two in learning about the changes to their prescription drug coverage.

Where Beneficiaries Have Turned for Help with Part D

“Connected” beneficiaries sought help from agencies and community-based organizations in choosing a plan. The HIV positive beneficiaries were the most connected in the study and sought help in understanding Part D and choosing a plan from several health-related resources, such as ADAP, the AIDS Project Los Angeles (APLA), and the AIDS Healthcare Foundation (AHF). While some of these sources were

helpful, others were not and were confused themselves about Part D. Leonard from Los Angeles went to seminars and said the speakers apologized because so many questions could not be answered. He also spoke with counselors through HIV/AIDS organizations and found they lacked knowledge about Part D as well.

“I was desperate. In October and November, I called all of these different [HIV/AIDS] benefits counselors [and] they didn’t know anything.” –Leonard, Los Angeles

Most beneficiaries are not “connected” to local agencies, and many rely on pharmacists. Some local pharmacies notified beneficiaries of the changes in their drug coverage, and in some cases, advised on various plans or offered valued reassurance about the plans beneficiaries chose. Eileen from the Bay Area took a list of plans that had free premiums to her pharmacist of 20 years, who then ranked them for her. After unsuccessful attempts at contacting the insurance companies, she went back to her pharmacist who told her: “It doesn’t matter, they’re all horrible.” He advised her to stick with the plan she would be auto-enrolled in, so she did.

“[I called insurance companies] probably 30 [times]. I spent on the average, a half an hour each time. I tried several times a day. I tried several different combinations [of the phone number] just to talk to a real person.... I got sent to several different places, then I was promised several different times that I’d be called up by a certain day at a certain hour and that never happened.” –Eileen, Bay Area

Several beneficiaries contacted insurance companies directly for information, with mixed results. A few, like George from Bakersfield, had all of his questions about Part D answered. He called his existing supplemental insurance company, which was instrumental in helping him choose one of their plans. A few dual eligibles, however, called insurance companies and despite persistence, could not get answers to questions or help signing up. These duals tell stories very similar to Eileen from the Bay Area, who tried many times to sign up with two companies. Not getting through to insurance companies was the main reason that some dual eligibles were auto-enrolled in a plan.

Family members, Medicare-sponsored resources, and community events have been least tapped by beneficiaries. Only three beneficiaries in the study received help from a family member in choosing a plan. Most say they were more informed than family members, or family simply was not around to help. They felt similarly about seeking advice from friends; many said they were either more informed than or just as confused as their friends.

In addition, most beneficiaries say they did not seek help through 1-800-Medicare or www.medicare.gov, because they did not know about it. Four or five used the phone number or website, with mixed results. A couple of beneficiaries, like Leonard from Los Angeles, felt the website was too overwhelming and excluded cost information. On the other hand, a few like Bryan from Los Angeles, said the phone number or website was a good resource. He called the 800 number, reached a helpful person who gave him an ID number to go online for information on selecting a plan. Through the website, he was reassured that the plan he was leaning toward could be a good fit.

Additionally, most beneficiaries did not hear about or attend a community event. The three beneficiaries who went found them discouraging. Frances, a dual eligible from the Bay Area, said the event was too loud and confusing. She ended up being auto-enrolled in a plan. The other two beneficiaries who attended events were “connected” HIV positive beneficiaries who found other resources much more helpful.

III. Looking Ahead

Costs are a primary concern now and in the future. Beneficiaries have little ability to deal with increased costs in their lives. Already some are going to food banks or skipping meals, splitting pills in half to stretch out their prescriptions, considering re-using medical supplies that are not meant to be re-used, and even doing without some medications. These actions could have a negative effect on beneficiaries' health and finances over time. It will be important to track the effects of these additional costs on this vulnerable population over time.

As they look to the future, another primary worry is drug formularies. Some beneficiaries who are more knowledgeable about Part D say they have heard insurance companies can change formularies "at any moment." Others wonder whether drugs they will need in the future will be covered by their new plans. They see no clear answers to their questions and that contributes significantly to their anxiety. Robert, an HIV positive beneficiary from Los Angeles, contacted his insurance company to ask about future changes in formularies and changing medication needs, and the representative simply told him not to project into the future and not to worry until something happens.

These vulnerable, low-income, and medically needy beneficiaries cannot tolerate a lot of problems. Most of the beneficiaries in this study have serious health needs for which their medications are vitally important – either life-saving or allowing them to maintain their quality of life. Missing a medication is not an option for many. Resolving problems with their Medicare Part D plans is also burdensome for these individuals, some of whom have cognitive challenges or physical disabilities that make the back-and-forth with insurance companies, pharmacists, and doctors difficult. They also have low incomes which means they lack the financial resources to deal with new costs. In the future, they will need help navigating changes. This may be difficult, as many could not find the help they needed last fall to choose a plan.

As the transition to Part D evolves, this project will explore several questions. We will probe how Part D plans are working for beneficiaries over the next year. Several questions will be explored, including: Have issues been resolved for those who are still dealing with medications not covered? Have health and medication needs changed? If so, were new drugs covered? How have beneficiaries dealt with new out-of-pocket costs? Have any drug formularies changed? Are there any other unforeseen changes? How are those facing the "donut hole" getting by? Have beneficiaries become more comfortable and knowledgeable about their plans? Did those planning to enroll indeed do so, and by the deadline? Are those who decided not to enroll still content with their decision?

IV. Beneficiary Profiles

Following are brief profiles of twenty of the beneficiaries who are participating in this study to give more detail about their situations and challenges. They are organized by geographic location.

Walter, 70, from the Bakersfield Area, dual eligible

Current Status: Enrolled in Part D plan, takes about nine medications

Walter's medications are vital to keeping him alive. He suffers from asthma and emphysema, and cannot perform daily living activities like washing dishes, without taking breaks to rest. Walter first learned about Part D from his pharmacist who told him he could choose a plan. At the doctor's office, Walter noticed brochures from various companies, and selected the one advertised plan that did not require co-pays. In January, Walter's card came a few weeks late so he said he was down to one or two pills before he could get them filled, but never ran out, unlike his wife who went without medications because her card was late. In his new plan, Walter pays \$1 for aspirin whereas prior, it was free. However, he says the new cost is manageable, and feels lucky because his wife's new plan now requires co-pays for all of her medications. Overall, he is content right now because he is getting his medications and has had no other problems.

Elsie, 71, from the Bakersfield Area, dual eligible

Current Status: Enrolled in Part D plan, takes about 12 medications

Elsie describes her own health as poor and relies heavily on medications to manage her diabetes. She also has some health needs related to her years of work as a foreman in the field, including a knee replacement surgery. Elsie was and continues to be very confused about the Part D process and plans. Her pharmacist informed her that she could choose a plan and offered to help if she had trouble. After several phone calls to insurance companies and having no luck, Elsie returned to her pharmacist who told her she was already (auto-) enrolled in a plan. So far, all of Elsie's medications have been covered, but she went from paying no co-pays to a total of about \$35 per month in co-pays. On her monthly income of \$924, she worries about these costs. Elsie ate only beans and potatoes in the later half of March when money ran out. She finds it particularly difficult to pay \$16 for her diabetic syringes and has considered re-using them. Elsie hopes her caseworker can help her get a plan that has no co-pays. She is still not sure what pays for her medications, nor the roles that Medicare, Medi-Cal, and her Part D plan play in her health coverage.

Wilma, 81, from the Bakersfield Area, dual eligible

Current Status: Enrolled in Part D plan, takes about four medications

Wilma says her health right now is good, but her medications are critical to managing her diabetes; she forgot to take them in December and ended up in the hospital. Wilma has been in a managed care plan for the past five years. Last fall, she received a few things in the mail about Part D, including something from her current plan, but said that the more she read, the more confused she became. She asked her pharmacist for advice, who told her to stay with the managed care plan she has. Wilma was content with that answer, and was auto-enrolled into a Part D plan through her existing insurance company. However, Wilma does not realize she was auto-enrolled in a Part D plan (she does not think she has one), nor does she realize she receives assistance from Medi-Cal. Wilma is one of the few dual eligible beneficiaries for whom the transition was seamless, without glitches in drug coverage, delays, or changes in costs.

Norma, 73, from the Bakersfield Area, non-dual

Current Status: Enrolled in Part D plan, takes about seven medications

Norma, a savvy web user, decided last fall she would not enroll in a Part D plan after seeking information from many sources. She feared becoming locked into one plan, without knowing how well it would work. As a former county employee, she went through open enrollment last year and chose a plan she thought did not include Part D. When she received a form in the mail to “enroll in Part D” through the insurance company, she called them to make sure it was *not* a Part D plan. The representative assured her that the form was only needed in case she decided to enroll later. She returned the form and was upset when she received the plan’s “Medicare Rx” card in the mail and found herself enrolled in Part D. When Norma first tried to use her new coverage, she was told one medication was not covered. After two weeks of going without her anxiety medication and having her doctor prescribe two substitute drugs that were also not covered, the issue was finally resolved with the insurance company. Her former employer contributes to the premium under this plan – through which she is saving about \$150 a month. However, her co-pays have gone up to \$50. Norma is content now that issues have been resolved and feels safest sticking with a plan that is now working for her.

Los Angeles

Martha, 71, from Los Angeles, dual eligible

Current Status: Enrolled in Part D, takes two medications

Martha's main health issues are acid reflux and hypertension, for which she takes two medications. Sometimes she takes additional medications for occasional "flare-ups" of other health needs. Martha has been in a managed care plan, which auto-enrolled her into Part D. Like other beneficiaries, Martha is confused and did not find out about any changes until she went to the pharmacy and the clerk said her co-pays were \$20, instead of the usual \$10. She lacks details about why things changed, but assumes "it has something to do with the national prescription coverage." These costs are very worrisome for Martha, who says with occasional flare-ups she spends about \$75 to \$125 a month on medications. Martha's only income is her deceased husband's Social Security. She is at risk for going without her medication, which she did three or four times in the past year when she could not make ends meet. Martha feels she needs to look into other plans, like one that she received in the mail advertising no co-pays. However, she is afraid of switching because she says she might lose her doctor and is worried about the "fine print" in the advertisements. She planned to make a decision about switching plans by May 15th.

Robert, 47, from Los Angeles, dual eligible

Current Status: Enrolled in Part D, takes eight medications

Robert has been HIV positive since 1987, and suffers from manic depression, neuropathy, and lipodystrophy. Robert knew about auto-enrollment and was in the process of picking a plan when he learned he had already been auto-enrolled, which he says happened prior to the deadline he was given. After learning he would pay a lot more out-of-pocket for the new Part D plan, he signed up for assistance through ADAP. As of April, however, he had neither his new Part D nor ADAP card, which caused an initial delay in getting his prescriptions filled. Robert also encountered a glitch when his doctor prescribed a cholesterol medication not covered by the plan, who then successfully appealed to the insurance company. Looking into the future, Robert worries a great deal about plans changing formularies monthly and costs rising. His share of costs have increased with his new Part D plan, and he struggles to make ends meet.

Shirley, 67, from Los Angeles, dual eligible

Current Status: Enrolled in Part D, takes three medications

Shirley says she feels lucky for her good health, facing only knee problems and high blood pressure. Last fall, she learned about the Medicare drug coverage changes from her pharmacy, where she got a pamphlet from a specific insurance plan that outlined various levels and options. It is unclear whether Shirley was auto-enrolled in a plan, or whether it simply felt automatic because she made a phone call to the company advertised on the brochure from her pharmacy. Shirley remembers calling the insurance company and they said she should choose the plan that corresponds with her earnings. At one point in the interview she says she never pursued enrollment, but got a letter in the mail saying she was auto-enrolled in one of their plans. Later in the interview, however, Shirley says she called the specific insurance company and they had asked for her income level and then enrolled her in the appropriate plan. Shirley lacks details about her plan: “I got a booklet from [her Part D insurance company, but] I didn’t even read much of it. I guess I should. Thank God I really don’t have a lot of problems...there was nothing I really wanted to know.” Shirley is one of the few duals for whom the transition to Part D – getting medications and costs of prescriptions – was seamless.

Cecilia, 76, from Los Angeles, non-dual

Current Status: Enrolled in Part D, takes three medications

Cecilia has a private managed care plan from her former employer, which helps her with her prescription costs. She remembers receiving a letter from her insurance company indicating if she chose an outside Part D plan, she could no longer participate in their managed care plan. Cecilia wanted to stay with her existing insurance, and was auto-enrolled in a Part D plan through them. She says her co-pays are about the same since the change, although she finds it difficult to pay what totals about \$40 per month. Currently, her Social Security and small pension supports Cecilia, her grandson and her daughter, whose health issues limit full time work. Cecilia has had no problems getting her prescriptions filled with her Part D coverage.

Bryan, 50, from Los Angeles, non dual

Current Status: Enrolled in Part D, takes 20+ medications

Bryan is HIV positive and relies heavily on his medications for treatment and HIV-related issues such as cardiomyopathy and neuropathy, as well as drugs for arthritis, osteoporosis, and allergies. Bryan enrolled in a Part D program solely because ADAP required it in order to continue receiving its assistance. When he chose his Part D plan, he used a number of resources including Social Security seminars, workshops sponsored by an HIV/AIDS organization, and www.medicare.gov. However, he says he feels deceived because he never had information about the high cost sharing involved with his new plan. Immediately, Bryan had delays with getting his prescriptions and faced higher out-of-pocket costs. Additionally, within the first month or two, he hit the “donut hole.” Bryan says ADAP will not cover prescriptions during the donut hole, so he is getting by with paying out-of-pocket for some medications, and doctor’s samples for the rest. He worries a great deal about affording his prescriptions and says, “[it is] constantly on my mind.” In April, he was looking into another plan that has a higher premium and deductible, but no donut hole. However, he says he is scared to switch because he does not know the restrictions around how many times beneficiaries can switch plans.

Larry, 65, from Los Angeles, dual

Current Status: Not certain whether enrolled in Part D, takes about eight medications

Larry says his health is not what it used to be, particularly since having a liver transplant three years ago and dealing with diabetes and high blood pressure. Larry takes about eight medications a day, and says they are life-saving. He receives Medicare and Medi-Cal, but does not know what each pays for; he always presents both cards at pharmacy. Larry says he does not have anything called a Medicare prescription drug plan or Part D coverage. He lacks any knowledge of Part D – his only exposure was hearing something on TV. Larry’s wife has heard more about Part D than he. She called 1-800-Medicare in February to get more information through the mail, but has not yet received it. She is worried about the deadline and has many questions about what drugs are covered and how much they cost. Right now, Larry pays about \$120 out-of-pocket in co-pays per month, which he says is difficult. He has not noticed any changes in cost or coverage over the past year. Thus, at this point, it is unclear whether Larry was auto-enrolled in a Part D plan. Larry’s wife is researching Part D as if he is not enrolled and they need to choose a plan by the May deadline.

Sue, 61, from Los Angeles, dual

Current Status: Enrolled in Part D, takes about 18 medications

Sue relies heavily on medications for a host of medical issues, including diabetes, renal failure, having had three strokes, a kidney transplant, and losing her eyesight. She has faced a multitude of issues around Part D coverage, some of which are still unresolved. After several unsuccessful attempts last fall at trying to get information from insurance companies, Sue was auto-enrolled in a plan in December. In January, she found out the plan chosen for her did not cover half of her medications. She heard from Medi-Cal that if she ordered 100 days worth of prescriptions in December, they would pay while any issues got sorted out in January. However, her company only sent a 30-day supply. After back and forth, they agreed not to charge her for January and February (which came to \$2,500). Sue immediately switched to a new Part D plan, which she says covers more, but she is still having issues. The plan does not cover one medication, and it covers only half the dosage for another. She is going without both drugs while her doctor appeals to the insurance company. Sue has also found that the insurance does not cover enough diabetic supplies. The co-pays for her medications range from \$1 to \$5, yet total between \$60 and \$100 per month. This is difficult, she says, when she lives on a fixed income of \$800 from Social Security disability, and since prior to Part D she did not have any co-pays. Sue has done all of the work and research around Part D herself. She has no family and no other source of help. Sue worries about future illnesses and needs, and her ability in the future to afford her medications.

Guillermina, 65, from the Bay Area, non dual

Current Status: No drug coverage, takes no medications

Guillermina considers her health stable currently and does not take any medications. She turned 65 last year, and has not yet used Medicare. She relies on a local clinic that provides low cost health care and medicines for multilingual and multicultural low-income populations. Guillermina lives on an income of \$532. While she lacks very little knowledge of Part D, a woman at her local Senior Citizen Center told her she needed to choose a plan by May or face a penalty. She has not felt a sense of urgency to enroll because she is happy with the services she receives at the clinic, currently does not take any medications, and lacks information about Part D. She seems unclear whether Part D is a mandate or a choice. Guillermina says she plans to enroll, and will talk to a social worker at the clinic for help in answering questions about enrollment.

Frances, 72, from the Bay Area, dual

Current Status: Enrolled in Part D, takes four medications

Frances says her health is poor, after having a pacemaker and other heart issues, as well as cholesterol and gas problems. Frances lacks knowledge about Part D. She attended a community event last fall describing Part D, but had trouble hearing and understanding the information. In December she received a letter saying she was (auto-) enrolled in a prescription drug plan. She went to her pharmacy and found out they did not take her new coverage, so she got help from her doctor's office in finding a pharmacy that did accept the insurance. Frances worries about affording medications in the future because she now has a \$3 co-pay, which she says is difficult for her to pay. Prior to Part D, she did not have a co-pay. When asked if she wanted to switch plans, she said she would like to if a new one did not have co-pays, but she lacks details about other plans and whether or not she can switch. She has received materials about different plans in the mail, but because of her heart issues, she says she has trouble understanding and retaining the information.

Rosalio, 28, from the Bay Area, dual

Current Status: Enrolled in Part D, takes four medications

Rosalio suffers from muscular dystrophy and has a host of related health issues. He has an enlarged heart due to being in a wheelchair, leg braces, and stool issues that could cause a stroke if not managed with medication. Rosalio was auto-enrolled in a Part D plan, but had checked on www.medicare.gov to make sure the plan he would be auto-enrolled in would cover his drugs, and found the website helpful. Still, he would like to know more about his current plan, such as what drugs are not covered and whether he could reduce his co-pays. His main concern is affordability; Rosalio went from no co-pays prior to Part D to anywhere between a \$1 and \$13 co-pay per prescription. He worries about these costs and has thought about skipping a medication to pay for a bills.

Octavio, 37, from the Bay Area, dual

Current Status: Enrolled in Part D, takes three medications

Octavio is HIV positive and found out last fall through material in the mail that his prescription drug coverage would be changing. His doctor informed him of the plan he would be auto-enrolled in and that he could switch later if he wanted to, so he opted for auto-enrollment. With his new coverage, Octavio now has co-pays, which he did not have before Part D. However, ADAP helps with all of the co-pays except one, which is \$1. The only other change Octavio experienced is that his new plan does not cover one of his brand name HIV drugs. In April, he was trying a generic prescribed by his doctor to test out for a month. Octavio says Medi-Cal covered all of his HIV drugs prior to Part D, and he worries about the future coverage and medications he may need for treating his disease.

Marjorie, 68, from the Bay Area, non-dual

Current Status: No drug coverage, takes no medications

Margery says she is in excellent health and takes no medications currently. She is very knowledgeable about Part D because she has enrolled her husband in a plan, who lives in an Alzheimer's facility. She pays \$143 per day out-of-pocket for her husband's care there, and prior to Part D, had been paying about \$600 per month out-of-pocket for his prescription drugs. She researched several plans and found two that covered all of his medications and could be filled at the pharmacy his care facility uses. While shopping one day, she saw a booth and representative from one of these companies and she got all of her questions answered, so she enrolled her husband in that plan. She now pays \$60 per month for his medications – a savings of \$540 a month. She plans to enroll in a Part D plan by May, and may choose a plan recommended by her friends.

Jonathan, 67, from the Bay Area, dual

Current Status: Enrolled in Part D, takes six medications

Jonathan was born with a chronic heart condition that has led to four heart attacks, and he relies heavily on his heart medications. He had heard about Part D on TV and the “cut-off date” in January. He contacted his managed care plan in January, and they said he was already enrolled in Part D. Jonathan's main concern about Part D is affordability. He says being low-income in Northern California is a struggle, and his medications used to be free. With his Part D plan, he now has \$1 co-pays which he says is a burden. Jonathan also has a prescription for aspirin, but was told he has to pay full price because it is over-the-counter. He has not found resolution yet, despite trying to talk to his insurance company.

Tony, 66, from the Bay Area, non-dual

Current Status: Enrolled in Part D, takes three medications

Tony has a difficult time making ends meet, yet says he makes just enough to be ineligible for Medi-Cal assistance and food stamps. When he started hearing about the new Medicare Part D coverage, Tony was confused and went to his existing managed care plan for information. He recalls, “The guy sat me down and said, ‘Don't change. A lot of people make those terrible mistakes and then they find out they have to pay higher prices.’” So Tony stuck with what he had and was enrolled through his existing plan. With his new plan, however, he found his co-pays went from \$10 to \$30, which is difficult. Tony struggles to pay a total of about \$100 a month on prescriptions, which he sometimes charges to his credit card and gives up other things, like tithes to his church. He says the change is very worrisome and wonders how soon before co-pays will go up again.

Senortha, 70, from the Bay Area, non-dual

Current Status: Enrolled in Part D, takes 12 medications

Senortha suffers with a host of health conditions, including diabetes, lupus, coronary artery disease, and high blood pressure. She has had two bouts of breast cancer, but because of stress from all of her current health problems, has not seen her cancer doctor for almost a year. Senortha was automatically enrolled in her managed care plan's Part D coverage, and since, has seen a decrease in prescription costs. She pays about \$20 per month, and says that has not been a problem. She worries a little about the future as other bills are going up.

John, 76, from the Bay Area, dual

Current Status: Enrolled in Part D, takes nine medications

John's health is fair. He has early signs of Alzheimer's, diabetes, and hypertension. A social worker at the John's hospital signed him up for a Part D plan. His wife consulted a number of different sources in making sure the plan was a good choice, and so far, it has worked out well. However, she is confused because they received a letter saying John was not eligible for Part D, yet he had already received a card in the mail from the plan in which the social worker enrolled him. Nevertheless, the coverage is working. John now pays a lower co-pay with his Part D plan – from \$0 to \$3 – whereas previously it ranged from \$3 to \$6. When he first tried to fill a prescription for diabetic testing supplies, however, the pharmacy wanted to charge full price. The matter was resolved with help from the hospital, and within a week, he received the supplies with a \$3 co-pay. John's wife says the plan has “worked just like clockwork” and they do not worry about the future. She will be turning 65 shortly and plans to enroll in the same insurance plan as her husband.

V. More About the Project

Lake Research Partners conducted a series of structured interviews with a diverse group of low-income Medicare beneficiaries. Participants with different drug coverage sources are included in this project, including twenty dually eligible individuals (*i.e.*, enrolled in both Medicaid and Medicare). The interviews capture a range of experiences that individuals face as they initially learn about, make enrollment decisions about, and experience Medicare's new drug benefit. The 35 men and women participating in this project range in age from 28 to 81 years old, have varying health conditions, and have incomes below 200% of the federal poverty level.

The first round of interviews was conducted in-person in the first week of April 2006. Phone interviews will be conducted periodically over the next several months, followed by a final in-person interview next year.

The project is sponsored by The California Endowment. This California-specific project complements a project sponsored by the Kaiser Family Foundation called the "Voices of Beneficiaries," which tracks Medicare beneficiaries' experiences with Part D from a national perspective. For more information on the Kaiser Family Foundation's project, please visit: <http://kff.org/medicare/7504.cfm>.