Self-Reported Experiences of Individuals with Disabilities Involved in the Utah Medicaid Work Incentive Program

April 14, 2003

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Introduction

In Utah, as in the rest of the nation, there is a public value that individuals with disabilities should have opportunities to enter or return to the workforce. This value has been formalized in legislation and regulations, including the Americans with Disabilities Act, the Workforce Investment Act, Section 1619 of the Social Security Act, the Ticket to Work and Work Incentives Improvement Act, and, of particular concern with this report, the Medicaid Buy-In option contained in Section 4733 of the Balanced Budget Act of 1997. Despite these many acts and other programs to support the work effort of individuals with disabilities, few SSDI and SSI recipients have left the disability rolls to return to work.

Medicaid Buy-In Option. The Medicaid Buy-In option of the Balanced Budget Act is important as health care needs are on average quite high in this population, making access to affordable health care coverage a critical issue. Indeed this coverage is so critical that loss of Medicaid, or even the fear of losing coverage, is a substantial barrier to having individuals with disabilities take advantage of employment opportunities.

The availability of the Medicaid Buy-In option is intended to remove this barrier by allowing individuals to enter the workforce and retain their Medicaid coverage. Such coverage, however, is expensive, and officials in the Utah state government are debating the degree to which public funds should subsidize this program and the degree to which the recipients should cover the cost of this available health care solution. Much of this debate is being informed and coordinated by the efforts of the Utah Work Incentive Initiative.

Utah Work Incentive Initiative. The Utah Work Incentive Initiative (UWIN) represents an effort to promote comprehensive change in public policies aimed at supporting the work effort of persons with disabilities in Utah. Unlike many efforts at policy reform, this initiative is to be consumer-responsive by involving a wide range of stakeholders–individuals with disabilities, employers, professionals who work with persons with disabilities, and administrators of relevant state agencies. The purpose of this initiative is to identify, through dialogue among the stakeholders, the barriers and supports that are relevant to helping persons with disabilities in Utah. This identification of barriers and supports is itself supported with evaluative inquiry activities that make use of administrative and survey data. This input is important both in the initial assessments of problems and in providing feedback on the effectiveness of the policy changes developed.

As background for the UWIN efforts, previously if a person with a disability had an income over 100% of poverty, according to the Medicaid formula, but desired to participate in Medicaid, he or she had to pay the difference between the qualifying level and his or her income in order to receive a Medicaid Card each month. This was called a Spend-Down, and the lower the income of the individual or family, the lower the cost of Medicaid. Thus, there was little or no incentive to work.

The Medicaid Buy-In program developed by the Utah Work Incentive Initiative is referred to as the Medicaid Work Incentive (MWI) program. This program provides an alternative in which working individuals with disabilities became eligible to purchase Medicaid coverage for, in some cases, less than half that of the Spend-Down, making it very attractive to those with limited incomes. The Utah MWI program began in the summer of 2001, with a budget of $500,000. A budgetary shortfall in 2002 resulted in the budget being cut by 80%, to $100,000. In turn, the premiums were revised and in some cases quadrupled.

Need for More Information to Guide Policy. Administrative data are available to document use of this option by individuals with disabilities, but informed policy would benefit also from a better understanding of how this program is experienced by those who are eligible for it. Such an understanding requires interviewing individuals who have applied for the Utah MWI program. This report describes the methods and general findings of a telephone survey and a focus group conducted to provide insights about the experiences of those involved with the Utah Medicaid Work Incentive program. The telephone survey sought to inform our understanding of how individuals with disabilities have been affected by the MWI program; the focus group sought to provide more details on the experiences of those involved with this program, including why they have used the program as they have.

In addition to providing an overview of the experiences of MWI program participants, five questions are addressed in this report: (1) To what extent do individuals with disabilities know about the MWI program, and how did they get their information? (2) Does the program encourage individuals to get a job, or increase their earnings?; (3) How are participants dealing with the premium increase instituted in July 2002?; (4) Are there unmet health needs of individuals with disabilities in the context of current policies?; and (5) What barriers might limit the ability of qualified individuals to participate in the program?

Study Methodology

Telephone Survey Methodology. The telephone survey was conducted in mid-December of 2002, with follow-up attempts to contact respondents continuing through January 2003. The evaluation team (with George Julnes, Renee Nolan, and Jeff Sheen from Utah State University and Hank Liese and Lynne MacLeod from the University of Utah), in collaboration

with employees of the Utah State Department of Health designed a survey through which the five questions noted above could be addressed.

Because of the desire to understand why some people used the program regularly and others did not, three groups were distinguished based on their patterns of participation in the MWI program: a group of those who were continuously enrolled in the MWI program through August of 2002; a group of people who applied and were approved for the MWI but never enrolled; and a small group of those who were intermittently enrolled (they went off and returned to the program at least twice). The survey for those who were continuously enrolled in the MWI program is provided as an example in Appendix A.

Table 1 includes the number of individuals, by program use, identified for inclusion in the survey. It also indicates the number of surveys completed, the number of individuals that declined to participate, the people whose telephones were not answered despite numerous attempts (potential contact), and those who were unavailable based on unknown telephone numbers or, in one case, having died.

Table 1: Survey Response Statistics

Survey group	n=	Completed		Declined		Potential contact		Unavailable*	
Never Enrolled	68	41	60.2%	3	4.4%	9	13.2%	15	22.1%
Intermittent Enrollment	37	20	54.0%	3	8.1%	6	16.2%	8	21.6%
Continuous Enrollment	54	43	79.6%	4	7.4%	3	5.6%	4	7.4%
Total	159	104	65.4%	10	6.3%	18	11.3%	27	17.0%

* Unavailable includes: Deceased (1), No telephone number (5), wrong numbers (10), disconnected service (11)

All contact information was provided to the university-based evaluators from the Utah State Department of Health. A letter explaining the survey and indicating a personal telephone call would be coming was sent to each identified individual by the State Health Department. Initial contacts were made in December of 2002. Unless reached on one of the prior attempts, each individual was called at least three times, at different times and on different days. For those who could not be found, the State was asked for updated information and a letter was sent to their last known address. Telephone book and internet searches were also used in an attempt to locate as many people as possible.

Survey interviews were completed by a team of university interviewers and data entered as it became available. Completing this telephone survey required approximately 15 minutes of the respondents' time. Each individual who participated in the survey was sent a $20 gift

certificate for a grocery story convenient to their residence. In the case of proxy respondents answering the survey, the gift certificates were sent to the disabled individuals being targeted by the survey. Only 10 of the 159 individuals (6.3%) in the sample declined to participate and most of those contacted felt that their participation was important.

Focus Group Methodology. To better understand the motivations and behaviors of consumers who utilized the Medicaid Buy-In option, a consumer focus group was conducted with individuals who had enrolled in the Medicaid Work Incentive program. As noted, the focus group was to provide a deeper understanding of the experiences of consumers of the Buy-In program.

Five consumers, representing both urban and rural Utah, participated in a focus group on November 4, 2002. The focus group was conducted by two University of Utah researchers who serve as members of the UWIN evaluation team. Two consumers who could not attend the focus group but wanted to provide input were interviewed by telephone, on November 15 and November 19, 2002. A third individual requested a personal interview and was visited in his home by a member of the UWIN evaluation team on December 6, 2002. For the focus group, the two telephone interviews, and the in-person interview, evaluators followed the same question format (see Appendix B).

Overview of Study Findings

Prior to the premium increase on July 1, 2002, most study participants were positive about the program. Said one focus group interviewee: 'It was working the way it should have worked [prior to the premium increase]." Another indicated the Buy-In had "most definitely" helped her. "I think that the money that it saved us allowed us to, for a time, put a couple of hundred dollars away in a savings account, which we had not been able to do." Similarly, one focus group participant called the Medicaid Work Incentive a "wonderful program" which "lets you own a little bit more." Several themes were noted consistently by survey and focus group respondents:

1. Most study participants felt that the Buy-In had helped them and were positive about the program and the work opportunities they were afforded. Most survey respondents indicated that the program had helped them become employed or increase their hours of work.
2. When their Buy-In premiums increased on July 1, 2002, attitudes toward the program changed. The increased premiums created financial hardship for most participants. Several were forced to discontinue their participation in the program. For others, staying in the program, though considerably more expensive, was still the better option, given

their monthly health care costs. Some remained enrolled in the Buy-In on a continuous basis; others became intermittent users, only "buying in" to the program when they could anticipate higher than usual monthly health care costs.

3. For many study participants, prescription medications represented their largest single health care cost.
4. Lack of accurate information about the MWI program was a potential barrier to participation for some respondents. Related, several study participants had negative experiences with Medicaid workers, whom they felt knew little about the Buy-In program. On the other hand, some participants had good experiences with their workers, primarily because these workers knew about the program and helped them access the Buy-In option.
5. When asked for their recommendations on how the Medicaid Work Incentive program could be improved, the most common response was to fund the program at an adequate level.

Beyond this overview, more detail is provided below in terms of the following five issues: knowledge of the Medicaid Work Incentive program; impact of MWI on employment; impact of the increase in the MWI premium; health coverage and unmet health needs; and barriers to participation in the MWI program.

Knowledge of the Medicaid Work Incentive Program

The first question asked of each person contacted in the telephone survey was, "Do you know about the Utah Medicaid Work Incentive program, or as it is sometimes called, the Medicaid Buy-In program, or just the Buy-In?" Of those who applied for and were approved but never enrolled in the MWI program, about 20 percent claimed to have no knowledge at all about the program. Among those who were intermittently or continuously enrolled, approximately 10 percent also claimed to have no knowledge of the program (see Table 2).

Table 2: Do you know about MWI? (Medicaid Buy-In program)

	Never enrolled	Intermittently enrolled	Continuously enrolled
No	8 19.5%	2 10.0%	4 9.3%
Yes	33 80.5%	18 90.0%	39 90.7%
Total	41 100%	20 100%	43 100%

While it may seem surprising that so many respondents have no knowledge of a program

to which they have applied or in which they have participated, there are several contributing factors. First, case workers were found to refer to the program in different ways. The terms "Buy-In" and "Spend-Down" have been confused by recipients and eligibility workers alike. For example, the cost of the card in the Buy-In program is characterized as a smaller spend-down, but still a spend-down. In addition, across all surveys a cross tabulation between those who "had no knowledge" and the type of disability (the final question on each survey) revealed that 45.5% of those with no knowledge had an emotional or cognitive disability. The disability itself may have contributed to the individual's inability to understand or retain a knowledge of the program. Experiences of the telephone interviewers, as recorded on the survey notes, indicate there were a number of respondents who were not able to understand or respond appropriately to the interview questions. In a few cases the interviewers were able to speak with proxy individuals, such as case managers. In these cases, the proxy respondents were able to confirm the limited ability of their clients to retain knowledge of the program and provide insight into those particular situations. Also, across all surveys, of those claiming to have no knowledge of the program, 81.8% had some other type of insurance, reducing the likelihood that they had a clear understanding of how their health care needs were covered.

For those who did indicate knowing about the MWI program, a follow-up question asked how they learned or heard about the program (see Table 3).

Table 3: Sources of information by enrollment group

Source	**Never enrolled**	**Intermittently enrolled**	**Continuously enrolled**
Government Brochure	6 /31 19.4%	3 /18 16.7%	3/ 39 7.7%
Clientele Newsletter	1/31 3.2%	0 /18 0.0%	4 /39 10.3%
Eligibility Worker	17/31 54.8%	10 /18 55.6%	24 /39 61.5%
Someone they know	7/31 22.6%	1 /18 5.6%	10 /39 25.6%
Some other way	8/31 25.8%	8 /18 44.4%	14 /39 35.9%

The most often cited source of information by all three groups was the state eligibility worker. This highlights the importance of the eligibility worker possessing accurate knowledge of all the programs and qualifying factors or being able to direct clients to others with this accurate knowledge. On the other hand, these numbers indicate that over 40% of all individuals in the three survey groups were not hearing about the MWI program from an eligibility worker, highlighting the importance of other sources, but also pointing to the need to increase the awareness of eligibility workers of this benefit.

The second most often cited source of information came in the form of qualitative answers found in the "other" category. Of those who never enrolled, 71.4% heard about the MWI program from another state agency. Sixty-one percent of the responses from those who have been continuously enrolled indicated they heard about MWI from their case manager at a mental health service provider.

When those who never enrolled were asked why they chose not to pay the premium, 19.5% gave a response that indicated a lack of understanding or communications problem with their eligibility worker. For example, one woman, from the Intermittently Enrolled Group told the story of having heard about the Buy-In from someone else's eligibility worker who was assisting them in the enrollment process.

Impact of MWI on Employment

Question three of the Intermittent and Continuously Enrolled surveys asked, "How did paying for a Medicaid Card help you at work?" The frequencies for the yes/no responses are shown in Table 4. Those in the Never Enrolled group did not pay for the Medicaid Card and so were asked whether knowing about the existence of the program encouraged them to get a job.

Table 4: How did paying for a Medicaid Card help you at work?

	Intermittently Enrolled	Continuously Enrolled
Go to work	9 50.0%	19 46.3%
Work more hours	5 27.8%	3 7.3%
Take another job	0 0.0%	2 4.9%
Take on more responsibilities	3 16.7%	5 12.2%
Other	12 66.7%	25 61.0%

Across all three survey groups, respondents reported that the program, or just knowing about the program, encouraged them to find a job or better their position. For example, 17.1% of those who were Never Enrolled claimed that knowing about the program encouraged them to get a job. Qualitative comments from those Never Enrolled included general references about how it provided motivation as well as added to the individuals' enlightenment about how they can contribute to society. One individual expressed appreciation for the opportunity to feel like she was supporting herself and not just always taking handouts. Significantly, of the individuals in the Never Enrolled group, 70.7% were working. Of those working, 82.1% did not have a Medicaid Card, yet they were at one time qualified and approved to enroll in Medicaid through MWI.

Of those who were Continuously Enrolled and said the Buy-In program had encouraged them to seek employment, 84.2% were employed. Almost 10 percent (9.3%) were no longer on Medicaid at all. In the Intermittently Enrolled group, 75% were working, and of that group 64.2% claimed the Buy-In program also encouraged them to find a job. While many of these individuals did not work even half-time, Table 5 indicates that at least 40 percent in each survey group were working at least 10 hours per week.

Table 5: Number of hours worked by members of three survey groups*

Hours	not currently working	0.5-9 hours	10-19 hours	20-29 hours	30-40+ hours
Continuously Enrolled	8 18.6%	18 41.8%	7 16.8%	9 20.9%	1 2.3%
Intermittently Enrolled	6 30.0%	6 30.0%	4 20.0%	2 10.0%	2 10.0%
Never Enrolled	12 29.3%	0 0.0%	9 21.9%	10 24.4%	9 21.9%

*percentages are based on those in each group who answered the question

In the Intermittently Enrolled group, 75% of those not working and 62.5% not working more hours indicated the cause was the disability itself. In the Continuously Enrolled group, the

Table 6: Reasons for not working, or not working more hours*

Survey Group	Never Enrolled		Intermittently Enrolled		Continuously Enrolled	
Reason given	Not Working	Not working more hours	Not Working	Not working more hours	Not Working	Not working more hours
Disability	66.7% (6/9)	85.7% (12/14)	75.0% (3/4)	62.5% (5/8)	71.4% (5/7)	81.5% (22/27)
Worried about losing Social Security	44.4% (4/9)	78.6% (11/14)	50.0% (2/4)	37.5% (3/8)	42.9% (3/7)	29.6% (8/27)
Pay more for Medicaid	22.2% (2/9)	21.4% (3/14)	0.0% (0/0)	25.0% (2/8)	14.3% (1/7)	29.6% (8/27)
No other job options	22.2% (2/9)	28.6% (4/14)	50.0% (2/4)	25.0% (2/8)	42.9% (3/7)	25.9% (7/27)

*percentages are based on those in each group who answered the question

percentages were similar, 71% of those not currently working and 82% of those that would like to work more hours also indicated the reason was the disability itself. However, other reasons were also indicated (see Table 6).

The disability itself appears to affect the job options of a large percentage of the persons who were Intermittently and Continuously Enrolled far more than those who were Never Enrolled. Because we do not know the level of the disabilities of individuals in each category, we cannot comment on the reason for this discrepancy. We can only report that, from the qualitative comments recorded, persons with emotional problems seem to have a harder time finding a job that respects their need to be absent more often. Recent surgery was also listed fairly frequently by all survey groups as a reason for not working or not working more hours. Other reasons given for not working at all or not working more hours included those one would expect to see in the general population, e.g., injuries, layoffs, seasonal needs of employers and returning to school for more training.

Survey results could also provide insight into how different groups of individuals as defined by the disability might have benefitted differently from their participation in the Buy-In program, thus answering the question, "Was the program more or less beneficial to people with certain disabilities than others?" This issue was not addressed in the same manner by the members of the Never Enrolled group as it was by the others. Thus, only the responses from members of the Continuously Enrolled and Intermittently Enrolled groups were analyzed. Table 7 below indicates the number of individuals by disability who claim to have benefitted from the program in the employment arena. Since only affirmative answers were recorded it is impossible to differentiate between those who did not answer the question at all and those who said "no, the program did not help me in these ways."

Table 7: Employment assisted through the MWI program by disability category

Disability	**Percentage helped**
Physical disability	48.8% (20 of 41)
Emotional/Cognitive disability	65.0% (26 of 40)
Hearing disability	55.6% (5 of 9)
Visual disability	58.9% (10 of 17)

Impact of Increase in MWI Premium

The Utah MWI program initially reduced the amount of money an individual would have to pay for a Medicaid Card as an incentive to work. However, a funding cut of $400,000 resulted in a premium increase. The cost to the card holder went up dramatically in July of 2002. The purpose of this section is to explore what effect that change had on those enrolled in the program.

The individuals who were enrolled in the MWI program intermittently were asked why they paid the premium in some months but not in others. Eighty-one percent (13 of 16 responding) indicated they could not afford it. Two people reported they would get their prescriptions filled the first of the month and then again at the very end of the month so they only needed the card every other month. Twenty-five percent (4 of 16) reported having additional insurance, thus limiting their dependence on Medicaid. When directly asked about the change in premium, 72.2% (13 of 18) indicated they were aware of the increase and, of those individuals, 69.2% (9 of 13) dropped out because of it. Of those who did not drop out, 75% (3 of 4) did not even consider it as their expenses were still higher than the MWI premium.

The Continuously Enrolled group also reported concern with the increased premium. Of those who were still paying for their card in August of 2002, 82% (32 of 39) reported that paying for the card caused financial difficulties and 31.3% (10 of 32) had considered dropping out because of the cost increases. However, 95.3% (41 of 43) indicated having monthly health costs, and 97.4% (37 of 38) of those continuing to pay for their Medicaid Card, who had monthly health costs, indicated that those costs were the reason they paid each month.

There were some individuals who did not know about the increase in premium. Interviewers indicated that some of these individuals were not cognitively able to take care of their own enrollment, care, and financial responsibilities. Nearly 20% of the Continuously Enrolled group, during the initial contact, referred us to their case manager at service providers such as Wasatch and Valley Mental Health. With the permission of the consumer, the case managers explained the situation. Both organizations worked closely with their clientele, assisting them in securing Medicaid benefits in the most cost-effective way possible. For some the rise in premium was more than the individuals could financially handle. The mental health agencies were actually covering some of the costs of the Medicaid Cards in order to ensure that their consumers could continue getting the prescription medications they needed. Other organizations reported as contributing to the payments for the Medicaid Card include the National Kidney Foundation.

Members of the Intermittently Enrolled group were the most vocal about the impact of the premium change. When asked if they had any other comments about the program they

expressed several related concerns:

- I cannot afford the premium at all.
- I qualified one month and did not qualify another because of wife's job. Spend down is so high I cannot pay for it.
- Due to the premium change cannot afford card now.
- For a little while it was cheaper; now that I am on dialysis I have to be on Medicaid also for anti-rejection drugs.
- I am suffering daily with chronic pain [and] cannot afford any medical treatment or prescriptions.

Some of the proxy interviews with the case managers from mental health service providers confirmed that anti-psychotic drugs can be quite expensive. People with schizophrenia who need these drugs would not be able to afford them without the MWI program. In fact 8 of the 13 people that indicated they learned about the program "from another source" in the Continuously Enrolled group said it was a mental health services provider or National Alliance for the Mentally Ill (NAMI) that told them about it.

One woman told the story of how she desperately needed Medicaid to purchase her prescriptions, but the cost was simply out of reach. She learned that if she were to divorce her husband, they could keep the house, by making the payments, and afford to purchase Medicaid. They did get a divorce, but later remarried, choosing the company of her husband and the house over the medication that she needed.

Additional Comments about the Premium Increase from the Focus Group

For the majority of focus group participants, the positives about the MWI program turned into negatives on July 1, 2002. Interviewees indicated that their Buy-In premiums increased as follows:

- from $200 a month to $400 a month
- from $336 a month to $672 a month
- from $200 a month to $700 a month
- from $355 a month to $975 a month
- from $442 a month to $1,112 a month

"That was just kind of ridiculous," said one Buy-In enrollee about the premium change. "What do they expect you to live on for the rest of the time? That's my big heartburn with that program." Said another, "On July 1st, everything just went to hell in a handbasket." Personal

situations changed dramatically after the premium increase, as the following quotes reveal:

> "I have a disabling disease, and there are medications that would make my life better, where I would be able to live a fuller life. I'd be able to work better, would be able to live without pain. But I can't afford it, so I go without. I go without."

> "It's a quality of life issue, and what I'm finding is that I am going without. I was told I have a growth on my tongue. They said, 'Go to an oral surgeon.' I can't afford to go to an oral surgeon. So the growth sits there, and I have no idea what it is. But I don't go. I haven't had a mammogram. I haven't had a pap smear, any kind of physical exam, for I don't know how many years, because I can't afford it. So you go without, because I ask, 'Where am I going to get $1,000 a month to pay the premium.' I don't have it."

> "I cannot tell you how terrible that [the premium increase] was. I mean, we had pretty much set our whole financial situation around the $442 [monthly Buy-In premium], and we actually were lacking about $150 a month to make it, but we just kind of seemed to keep making it. We did okay. We just kind of pinched here and pinched there. But anyway, when that [the premium increase] hit us, there was no way to pay that. And they only gave us two days notice. Now, you're not supposed to have very much on hand if you're on the Medicaid program, but in two days, you're supposed to come up with $1,200 for your insurance. It was really, really shocking. We don't have any way to pay that much money. But, actually, the last two premiums, my Bishop has taken care of that. But we can't do that. We can't ask the Ward to pay our medical. There are a lot of people that need help."

> "To tell you how bad it got come July 1st, we actually...my wife and I sat down and said, 'If we had divorced, and I move out of here, how does that change [the situation]?' It came to that point. It's come to that point, I'm sure, for other people. 'If I divorce you, and I just turn all my Social Security over to you, I have zero income. Does that count?'"

> "We have too many legislators who have no concept of what it's like to really

> decide, 'Do I buy pills? Do I buy food? Or do I pay a mortgage?' They do not have that concept."

The Buy-In participant who had to seek help from her Bishop considered dropping out of the program following the premium increase, but stayed enrolled, as her monthly medical costs were in excess of $3,000. For some participants, it is literally a matter of life or death. One interviewee, who is suffering from leukemia, observed that those who remain continuously enrolled in the Buy-In often have no other choice: "I don't know what I'd do if I had to go off [the Buy-In]. I wouldn't be able to. I mean, I'd be dead, you know. I'd just be dead. That's all there is to it. So how do you say, 'Okay, somebody, you've got to go off it. You're going to die.'"

One focus group participant explained that intermittent users of the Buy-In were essentially "hedging their bets," adding that "a lot of people are doing it." She explained how it works:

> "It's just like with my neck, okay? I know if I go see a specialist, they're going to do x-rays. They're going to do all kinds of tests...on my neck. So what I would do is schedule...ahead of time, because it takes two months to get into a specialist, at least. Then I call [my Medicaid worker] and I tell her for that month I want to go on Medicaid, so that Medicaid will cover all those costs. Then I go off the next month. And if [the doctor] says, 'Well, you've got to have surgery'...then I wait, and I schedule with him, and I wait until I can dig up another $1,000, and then I schedule my surgery for that month, and all the medical things I can get done during that month. That's how you have to play this."

Some interviewees had to leave the Buy-In entirely following the premium increase. Said one woman, who had not participated in the Buy-In for four months, ever since the premium increase: "My health suffers. I don't have any money to [pay the premium]. I'm still trying to figure that out still."

Health Coverage and Unmet Health Needs

The Medicaid Card is intended to provide health care coverage to those who could not otherwise afford medical care. As indicated in Table 8, all of those in the Continuously Enrolled group had either Medicaid (90.7%) or Medicare (67.4%) coverage; there was no one in the group without any health insurance. The Intermittently Enrolled group was not asked about current

Medicaid coverage, but it had the lowest percentage of coverage by Medicare (45%) and by other insurance (0.5%). Of those on record as never enrolling in the MWI program, almost 32% reported having a current Medicaid card and the same number (31.7%) reported having other insurance, with the result that less than 10% reported having no health insurance.

The Never Enrolled group was the only group to have more than one person with health coverage by secondary insurance providers (13 of 41 in the Never Enrolled group, or 31.7%). Of these, five (12.2 %) were covered by their own employer, five (12.2%) were covered by someone else's employer, two (4.9%) carried private insurance and one (2.4%) was covered by VA

Table 8: Currently have Medicaid Card, Medicare Card, and unmet health needs

	Never Enrolled	Intermittently Enrolled	Continuously Enrolled*
Medicaid Card	31.7% (13/41)	NA**	90.7% (39/43)
Medicare Card	63.4% (26/41)	45.0% (9/20)	67.4% (29/43)
Medicaid or Medicare	75.6% (31/41	NA**	100.0% (43/43)
Other Insurance	31.7% (13/41)	0.5% (1/20)	2.3% (1/43)
No Medicaid or Medicare	14.6% (6/41)***	NA**	0.0% (0/43)
No Insurance	9.8% (4/41)	55.0% (11/20)	0.0% (0/43)
Unmet Medical needs	39.0% (16/41)	55.0% (11/20)	23.3% (10/43)

* as of August 2002 ** Information not available ***Some did not answer

benefits. Of the four individuals in this group without any health insurance, all indicated they currently worked, one at forty hours a week, and said that the cost, even of the Buy-in program, was too high for them.

It appears, however, that having health insurance is not enough to ensure that medical needs are being met. Whereas no one in the Continuously Enrolled group was without health insurance, almost a quarter of them (23.3%) reported having unmet health needs. Dental care and pain management were the two most often cited medical needs by those continuously enrolled in the Buy-in program. Even more concerning, while around 10% (9.8%) of those in the Never Enrolled group reported having no health insurance, four times that number (39%) reported having unmet medical needs. Finally, while we do not know the percent of the Intermittently Enrolled group without health insurance, 55% of them reported having unmet medical needs.

Among the problems listed by this group were concerns about dental and vision no longer being covered by Medicaid; hearing aids were also mentioned as a need.

Additional Comments from the Focus Group on Health Needs

For many focus group participants, prescription medications represented their largest single health care expense. The interviewee suffering from leukemia said he took 42 different pills a day and that one pill alone cost him $250,000 a year. Remarked another focus group respondent: "That [medication] is one of our biggest expenses. My husband's on about a dozen to 15 different medications that would run us on a monthly basis over $2,000, if we had to buy them out of pocket. I suppose there are medications he [her husband, who was the Buy-In enrollee] could have gone without, but four different heart drugs, how could we have not gotten those? We couldn't keep our family together without him being able to take that medication."

Barriers to Participation

The last question is whether we can identify barriers that might unnecessarily limit participation in the MWI program. Some of these barriers were noted in the previous discussion of the telephone survey findings. However, to focus attention on these barriers we will review them again.

Knowledge. Lack of knowledge about the program's existence prevents those who might qualify from applying. While the eligibility worker was responsible for informing the most clients (41.3%), 11.5% learned about it through a government brochure, and 4.8% through the Clientele Newsletter. However, many did not learn about the MWI program from any government agency. Hearing about the program from people they knew accounted for 17.3%, and 28.8% learned some other way (the total is over 100% because the categories are not mutually exclusive). Further, individuals who claimed they knew nothing at all about the program accounted for 13.4% of the total number of individuals surveyed, even though they at one time applied or were enrolled.

Access to Knowledge. Beyond the advertising limitations listed above, the eligibility workers themselves were at times blamed for the individuals' lack of knowledge. Either communications were not good or they simply were not told about the program at all. One respondent from rural Utah described the eligibility worker as a very nice individual who knew little about regulations. Related, some of the respondents reported believing that they no longer qualified for the program because they were not working at least 10 hours per week. As the Medicaid definition of work does not require this degree of work effort, these individuals were left without services because of lack of access to accurate knowledge.

Discretionary bias. One woman in rural Utah told of bringing her mother to Utah from another state and her feelings that if she had been born and raised here it wouldn't have been nearly so difficult to get her mother on Medicaid. Her suspicions were to her confirmed when she later learned about the program from someone other than her mother's eligibility worker and was subsequently able to get her mother's Medicaid costs down to where they could afford to get her medications for her.

Transportation. Given the client dependence on the eligibility worker, transportation to and from the Medicaid office should not be overlooked as a barrier. Most of Utah does not have public transportation. For many in the rural parts of the state, it can be over an hour's drive to the county seat, where the Medicaid office often is located. While clients do not have to be physically present for their applications to be accepted and processed, having access to the Medicaid offices seemed important to clients. None of the survey respondents complained about getting into the office once he or she was there, only about getting to the office initially.

Additional Comments from the Focus Group on Program Information

A number of focus group participants were disappointed in the lack of knowledge displayed by their Medicaid Workers around the Buy-In option, although just as many indicated more positive experiences with their workers. Said one individual about the ease of gaining access to the Buy-In: "I think a lot depends on who you work with." Another interviewee remarked:

> "When it came time to make an appointment with a Medicaid worker in our area, come to find out, they didn't really know much about this program [the Buy-In]. In fact, they gave me a lot of wrong information, initially, on the phone. And I kind of went back to my sister-in-law [who was an outreach worker for the Buy-In] and said, 'What is going on?' She said, 'Well, you know, we've discovered that a lot of the Medicaid workers just aren't up on this program. I don't know if the information didn't get out or what.'"

But there were positive comments about Medicaid workers as well:

> "The Medicaid eligibility worker at the hospital actually knew about this Buy-In program, knew about all the other little programs, was able to pick and choose and help me get along so we could pay our bills and do things, and gave me advice on what to do and how to play the game. And it's almost like you hate to tell anybody

what his name is and what a good job he did for fear he'll go away. He'll get promoted."

Conclusions and Participants' Recommendations

The MWI program was described by most survey respondents as a potentially valuable program for encouraging work effort, particularly for those who described themselves as having cognitive or emotional disabilities (26 of 40, or 65% indicating that the program helped them in some way in working more). The July 2002 premium increase, however, was described as a source of financial burden by most and a reason to discontinue participation by those whose monthly health costs are not too high. As a result, many individuals participate in the program only intermittently and leave themselves without insurance in many months. This results in many potential MWI participants not having proper health coverage and, equally important, having unmet health care needs (55%, or 11 of 20 of those receiving program coverage only intermittently).

When asked how the Medicaid Work Incentive program might be improved, focus group participants were ready with a number of recommendations, many of which focused on putting more money into the Buy-In program:

> "It's got to be funded by the Legislature somehow."

> "Well, I think certainly the funding needs to increase, so that people can actually afford it, without having to go to such drastic measures. I mean, in many ways it helps us, but there's also an element of it that helps to keep you in a sort of poverty area..."

> "I still go back to the premise that you cannot make square pegs out of everyone and try to fit them into a round hole program. Just as income tax has to be figured on an individual basis, a program like this [the Buy-In] needs to be considered on an individual basis. Whether it's projected medical expense, whether it's existing medical expense, what is the existing...just cost of living? There needs to be more individuality in the program."

> "They could have a special Medicaid program just for prescriptions and less than four doctor visits a month or something, and that would be it."

“I think if I had not had the familial connections to find out about the [Buy-In] program...I don’t imagine I would ever have heard of it. Therefore, we wouldn’t have been able to take advantage of it, so I think getting the word out there is a big deal. I think making sure that the actual Medicaid workers understand how the plan works, and maybe now that more time has gone by, maybe that’s not as big an issue as it was initially for us.”

<u>Appendix A: Survey Form #2</u>: *Eligible, paid premium, continuous enrollment*

I am going to begin the survey now and ask you some questions about your experience with Medicaid since July 2001. Thank you very much for taking your time for this.

1) Do you know about the Utah Medicaid Work Incentive program, or as it is sometimes called, the Medicaid Buy-in Program, or just the Buy-in?

9 ***YES*** [If "yes"]: I'm going to read to you some choices to ask you how you learned or heard about the Utah Medicaid Work Incentive (Buy-In) program. Please say "yes" or "no" to the following. Did you learn or hear about the Buy-in program:

Through a government brochure?	9 Yes	9 No
Through *The Clientele* newsletter?	9 Yes	9 No
From your eligibility worker?	9 Yes	9 No
Did you learn or hear about the program by word-of-mouth from people you know?	9 Yes	9 No
Is there some other way that you heard about the Buy-in program?	9 Yes	9 No

[If "yes"]: Please specify: ____________________

9 ***NO***, I do not know about the Utah Medicaid Work Incentive (Buy-In) program.

[PROMPT: Provide a summary of MWI features; if respondent now remembers program, cycle back to the "yes" questions]

<u>Summary of MWI features</u>:

Person meets disability definition of Social Security.

Person has earned income.

Countable income must be less than 250% federal poverty level for household (includes spouse, dependent children).

Countable income is all unearned income (such as disability benefits) and about one-half of earned income (such as wages) for entire household.

Must pay premium if countable income above 100% poverty.

Premium ranges from between 30%-55% of countable income of person with disability.

Asset/resource limit is $15,000, compared to $2,000 for other Medicaid program.

Intent of MWI is to encourage people to return to work or increase their work effort.

2) For Medicaid purposes, people are considered to be working if they are earning any amount of money for any work performed. Are you currently working, according to this "definition"?

9 ***YES*** [If "yes"]: How many hours per week do you work? ____________

Would you like to work more hours per week?

9 <u>Yes</u> [If "yes"]: What is keeping you from working more hours per week? Please say "yes" or "no" to the following:

Is your disability itself keeping you from working more?
9 Yes 9 No
Are you worried about losing Social Security or other cash benefits?
9 Yes 9 No
Are you not working more hours per week because you would have to pay more money for Medicaid?
9 Yes 9 No
Are you not working more because you don't have any job options?
9 Yes 9 No
Is there any other reason that is keeping you from working more hours?

9 Yes 9 No
[If "yes"]: Please specify: ____________________

9 No, I would not like to work more hours per week.

9 ***NO***, I am not currently working.
[If "no"]: Would you like to work at all?
9 Yes [If "yes"]: What is keeping you from working? Please say "yes" or "no" to the following:
Is your disability itself keeping you from working?
9 Yes 9 No
Are you worried about losing Social Security or other cash benefits?
9 Yes 9 No
Are you not working because you would have to pay more money for Medicaid?
9 Yes 9 No
Are you not working because you don't have any job options?
9 Yes 9 No
Is there any other reason that is keeping you from working hours?
9 Yes 9 No
[If "yes"]: Please specify: ____________________

9 No, I would not like to work at all.

3) Since July 2001, people on Medicaid who are working have been able to pay a monthly premium for their Medicaid card. This premium costs less than the Medicaid "spend-down," which is the monthly charge people whose income is above 100% of poverty must pay for their Medicaid card.

I'd like to ask you how paying a Buy-in premium for your Medicaid card may have helped you at work. Please say "yes" or "no" to the following:
Did your Medicaid card help you decide to go to work?
9 Yes 9 No
Did your Medicaid card help you to work more hours per week in your current job?
9 Yes 9 No
Did your Medicaid card help you take another job with more pay?
9 Yes 9 No

Did your Medicaid card help you take on more job responsibilities?

9 Yes 9 No

Are there other ways that having the Medicaid card helps you?

9 Yes 9 No

[If "yes"]: Please specify: ____________________

4) As of August 2002, you were paying for your Medicaid card every month. Are you still paying for your card every month?

9 ***YES***

9 ***NO***

5) Do you have monthly health costs because of ongoing health needs?

9 ***YES*** [If "yes"]: Are these monthly health costs the reason why you are or were paying for your Medicaid card every month?

9 Yes

9 No

9 ***NO***, I do not have monthly health costs because of ongoing health needs.

5) Does paying for your Medicaid card each month cause financial difficulties for you?

9 ***YES***

9 ***NO***

6) On July 1, 2002, there was an increase in the monthly premium you have to pay for your Medicaid card. Were you aware of this premium change?

9 ***YES*** [If "yes"]: Did you drop out of the program because it got more expensive?

9 Yes [GO TO #7]

9 No [If "no"]: Did you *consider* dropping out of the program because it got more expensive?

9 *Yes*, but I didn't drop out.

9 *No*, I didn't consider dropping out.

9 ***NO***, I was not aware of the premium change.

9 ***NO***, I was not enrolled in the Buy-in program at the time.

9 ***OTHER***. Please explain: ____________________

7) In addition to Medicaid, do you currently have any other health insurance?

9 ***YES*** [If "yes"]: Who provides this health insurance? Please say "yes" or "no" to the following:

Do you have a current employer who provides health insurance?

9 Yes 9 No

Does another employer, for example, your spouse's, partner's, or another family member's employer provide you with health insurance?

9 Yes 9 No

Do you have Medicare insurance coverage?

9 Yes 9 No

Do receive health insurance from some other source that I haven't mentioned?

9 Yes 9 No
[If "yes"]: Please specify:________________________________

9 ***NO***, I do not currently have any other health insurance.

8) Are you having any health or medical problems right now that are not being treated because you don't have enough health insurance?
9 ***YES***
9 ***NO***

9) Is there anything else you'd like to share with us about your participation in the Utah Medicaid Work Incentive (Buy-In) program?
____

10) In order to help us understand who is being helped by the Medicaid Work Incentive program and who needs more assistance, we'd like to know the nature of your disability. Would you be willing to share that information with me now?
9 ***YES*** [If "yes"]: Do you have:

a physical disability?	9 Yes	9 No
an emotional or cognitive disability?	9 Yes	9 No
a hearing disability?	9 Yes	9 No
a visual disability?	9 Yes	9 No
any other type of disability?	9 Yes	9 No
	[If "yes"]: Please specify: ____________________________	

9 ***NO*** [If "no"]: I understand, we do respect your wishes on this.

This is the end of the survey. Thank you very much for your time in going through these questions. As I mentioned before, we would like to send you a $20 gift certificate for Smith's Food Centers. If you would like to receive this certificate, what address should we send it to?

If you have any questions about this survey or if you would like to receive a copy of the report when it is released, please call Cathy Chambless at 801-887-9529. [Repeat name and phone number as necessary.]

Appendix B: Medicaid Work Incentive Focus Group Questions

Intro: Probe how they refer to the program, e.g., Medicaid Work Incentive program, Buy-in. Use that terminology throughout.

6. What made you decide to enroll in the Medicaid Work Incentive program?
   Probe: For example, were you able to go back to work because you knew about the program?
7. Did you experience any difficulties enrolling in the program?
   Probe: What were the problems you encountered?

We're trying to understand how people use the Medicaid Work Incentive program. We've found there are generally two types of users: (1) those who go on the Buy-in then stay on it in a continuous fashion and (2) those who go on the program briefly, go off it, then come back on, in more of an intermittent fashion. How have you been using the program, continuously or intermittently?

8. For those of you who have used the program continuously, why have you stayed enrolled?
   Probe: For example, does it help you meet your health costs every month?
9. For those of you who have come on to the program, gone off, then come back on, what drives your decision to use or not use the program at any given time?
   Probe: For example, do you have health costs in some months but not other months? Do you have other health insurance you can use? Can you not afford the program every month?
10. Were you affected by the increase in premium that went into effect on July 1, 2002? How?
    Probe: For example, did you consider dropping out of the program because it got more expensive?
11. Has the Medicaid Work Incentive program helped you?
    Probe: How has the program helped you?
12. Has your participation in the program *hurt* you in any way?
    Probe: For example, have you lost any benefits, or have other benefits been decreased as a result of your participation in the program? Are you experiencing any financial hardship?
13. Do you feel anything could be done to improve the Medicaid Work Incentive program?
    Probe: What?
14. Is there anything else you'd like to share with us about your participation in the Medicaid Work Incentive program?