

Experiences and Outcomes of the Utah Medicaid Work  
Incentive Program:

Summary of Findings of the Telephone Survey and In-Person  
Interviews with UMWI Participants Conducted Between  
December 2004 and February 2005



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May 19, 2006



## **Introduction**

The past two decades have witnessed what has been called a paradigm shift in expectations and public policies with regard to individuals with disabilities. For example, the major support programs, such as Social Security Disability Insurance (SSDI), had been developed with the view that most individuals who were certified as having a disability that limited or precluded employment would remain on disability status with minimal work expectations. The medical and work reviews conducted to check whether disability status should be continued generally did not result in the loss of benefits. Indeed, an often cited, though often contested, historic statistic from the U. S. Government Accountability Office (GAO, 1998, p. 1) is that “not more than 1 of every 500 DI [SSDI] beneficiaries has left the rolls by returning to work.”

The more recent view of disabilities, sometimes referred to as the new paradigm, assumes that given the right circumstances and assistance, many people currently receiving SSI or SSDI could, and should, be employed and contributing to society. This view represents a convergence of two otherwise separate value stances: (1) it is inefficient for society to support people who could otherwise be working and (2) as a matter of equality, individuals have the right to work and to have reasonable accommodations that allow them to be full members of society. In other words, work is good for both society and the individual; being a contributing member of society is both an obligation and a right.

In accordance with this new paradigm, numerous federal and state policy initiatives have sought to support the work effort of individuals with disabilities by reducing the barriers to increased work effort. One identified barrier is the loss of Medicaid health coverage when earnings rise above 100% of the federal poverty level. To address this barrier, states are allowed to implement Medicaid Buy-In (MBI) programs that allow SSDI recipients to retain Medicaid coverage even after their earnings rise above the federal poverty threshold. As of the end of

2004, 32 states have instituted MBI programs, with substantial variations in the program details across states (Black & Ireys, 2006, p. 8).

One of the major differences across states is how much people have to pay to maintain their Medicaid coverage. There are two major elements defining the premiums that states charge for MBI coverage: the threshold above which a premium is required and the percentage of income assessed above that threshold. A Mathematica report (Black & Ireys, 2006) provides data on 28 states with both MBI programs and Medicaid Infrastructure Grants. In 2004, five of the 28 states described by Mathematica had a threshold of \$0, meaning that all participants had to pay a premium, four states established the threshold at 100% of the federal poverty level (FPL), 10 at 150% of the FPL, and three at 200% of the FPL (one state set the threshold at 8% of the FPL, one at 250% of the FPL, and four with the information not available). Factoring in the cost of the monthly premium for those above the threshold, the average premium calculated across all MBI participants in a given state (including those with a \$0 premium because they are below the threshold) ranged from \$0 to \$142, with a mean of \$22 for the 28 states. In addition to obvious differences in the sizes of state populations, this variation in fees is one factor responsible for large differences in the number of participants in the 28 state MBI programs described by Mathematica, ranging, in December 2004, from 48 (3 participants per 100,000 people of those between 18 and 64 in Arkansas) to 18,610 (516 of 100,000 of those between 18 and 64 in Missouri).

The Utah MBI program is called the Utah Medicaid Work Incentive (UMWI) program. This program began in July 2001, and enrollment was 260 in December 2004 (this represents a rate of 18 participants per 100,000 people in Utah between 18 and 64). A 2002 survey of recipients found that participants were overall quite satisfied with the program. In addition, there

was broad support for the program among Utah legislators and agency officials. The only major complaint of the program found in the 2002 survey was the high cost of the premium required for Medicaid coverage. The premium was particularly high at this point as state funding for the UMWI program had been cut from \$500,000 to \$100,000 shortly before. The funding was restored and the premium decreased in 2003, but in 2004 Utah still had the highest average monthly premium of all the Medicaid Buy-in programs. When averaged across all UMWI recipients, the premium was \$142. To put this in perspective, only one of the other 27 states had an average premium above \$60 (Black & Ireys, 2006).

Consistent with a program name emphasizing work incentive, the preeminent question that many advocates and policymakers have about the Utah MWI program is the degree to which this program is effective in supporting the work effort of program participants. Analyses of administrative data in Utah have highlighted the substantial variation in changes of quarterly wages for UMWI participants, with some experiencing large declines in earnings around the time of enrolling in the UMWI program and some experiencing large increases around the time of enrollment. Further, while some leave the UMWI program and become financially self-sufficient, others work up to but remain under the limit for other public assistance benefits (e.g., under the Substantial Gainful Activity, SGA, threshold to retain SSDI assistance), a pattern known as “parking.”

While it is difficult to make firm causal claims about whether the UMWI program has led to an increase of work effort among participants, it is important to increase our understanding of the characteristics that differentiate those with differing employment outcomes. This report focuses on two issues: understanding what is happening when people first enroll in the UMWI program and understanding the differences between those who move towards financial self-

sufficiency and those who do not. We approach this issue in four ways: (1) disaggregating survey responses of UMWI recipients according to the changes in their wages around the time of their enrollment in the UMWI program, (2) disaggregating the changes in their wages around the time of their enrollment in the UMWI program by major demographic variables, (3) conducting multiple regression analyses that identify demographic, employment-related, and barrier factors associated with higher self-reported monthly earnings, and (4) reporting the results of in-person interviews with UMWI recipients identified as having substantial earnings. The first three of these four components are based largely on a survey of UMWI recipients that was conducted in December 2004 and January 2005. The in-person interviews were conducted a month later. Cathy Chambless was the Utah Department of Health project director (Work Ability Project) when this study was commissioned, designed, and completed.

## **Methodology**

The methodology for the results presented in this report is described in three sections that address the subjects for the studies, the data collection procedures, and the analyses involved.

Where relevant these are discussed separately for the three sources of information: a telephone survey, administrative data, and in-person interviews.

### **Subjects**

#### **Telephone surveys**

The 281 people who had been on the Medicaid Work Incentive Program from July 2003 to June 2004 for three or more months constituted the population of interest for this study. Because the study was concerned with understanding the different employment outcomes experienced by people on this program, certain groups were oversampled in the sampling frame.

This oversampling was based on prior research in Utah on the different patterns of changes in quarterly wages around the time of initial enrollment in the UMWI program. Three groups were of particular concern. First, to understand whether enrollment in the UMWI program might support increased work effort for some, all who experienced large gains in income around the time of initial UMWI enrollment were included in the sampling frame. Second, to understand the degree to which some people might be reducing their work effort in order to qualify for the UMWI program and other public services, all who had experienced substantial drops in income around the time of UMWI enrollment were included. A third group, those who experienced small gains in wages around the time of UMWI enrollment, was also oversampled because of the view that these small gains might support larger gains at later times.

For the purposes of this report, we distinguished participants by comparing their quarterly wages from Unemployment Income (UI) data in the quarter after enrolling to an average of the fourth, third, and second quarters before enrolling (during the first quarter before enrollment, average wages are already decreasing and so this quarter was not included). Participants with wages that increased by at least \$1,000 per quarter were labeled as the ‘Large Gain’ group (see Table 1). Those whose wages increased from \$200 to \$999 per quarter were labeled as the ‘Small Gain’ group. Those whose wage earnings decreased by at least \$500 per quarter were assigned to the ‘Large Loss’ group. While these definitions can result in individuals in the Small Gain group having a larger change in earnings (e.g., a gain of \$900 per quarter) than some in the Large Loss group (e.g., a loss of \$600), restricting the Large Loss group to only those with decreases of at least \$1,000 per quarter would have resulted in too small a group for analysis.

Table 1: Definitions of Groups Defined by Change in Wages	
Income Definitions based on subtracting the quarterly wage average of the fourth, third, & second quarters prior to UMWI enrollment from the wages in the first quarter after UMWI enrollment	
Large Loss	Loss in wages in quarter after enrollment of \$500 or more
Small Gain	Gain in wages in quarter after enrollment is \$200 or more but less than \$1,000
Large Gain	Gain in wages in quarter after enrollment is \$1,000 or more (which translates to at least about \$333 more per month)
Stable	All other respondents; specifically, those not classified as experiencing a large loss, a small gain, or a large gain in recorded quarterly earnings

All others, a large, heterogeneous group those whose quarterly wages remained relatively stable from a loss of \$499 to a gain of \$199, were labeled as ‘stable,’ even though some in this group had greater wage changes (e.g., loss of \$400 per quarter) than some in the Small Gain

group (e.g., a gain of \$300). As noted, the decision to have both a Small Gain and a Large Gain group, in contrast to only one loss group, was predicated on importance of attending to all who might benefit from the MWI program, including those with small gains that might lead to larger gains later.

With regard to response rates, of the 195 participants selected for the survey sample, 115 interviews were completed, for a response rate of 59 percent. When examined by group, the response rate was fairly consistent across groups, with the largest difference being a somewhat higher response rate for the Large Gain group (65%).

	Aggregate	Large Loss	Stable	Small Gain	Large Gain
<b>Total Population</b>	281	22	181	41	37
% of Total		8%	62%	15%	13%
<b>Sample Selected</b>	195	22	95	41	37
<b>Respondents</b>	115	13	55	23	24
% of Respondents		11%	48%	20%	21%
<b>Response Rates</b>	59%	59%	58%	56%	65%

**In-person interviews**

Subjects for in-person interviews were drawn from the 115 respondents to the UMWI survey. At the conclusion of the survey each participant was asked, “If selected, would you be interested in participating in a follow-up interview?” If the individual answered yes, and met the following criteria, they were included in the sample:

- 1) Between the ages of 18 and 55;
- 2) Currently working at the same place of employment for at least three months;

- 3) Earning over \$600 a month, based on self-report survey data; and
- 4) Residing within 250 miles of Utah State University (due to travel expenses), which includes most metropolitan areas of the state.

Fourteen individuals met most of these criteria, but one was eliminated due to confidentiality concerns because she lived in the same community as the interviewer. One additional individual was included from a pilot interview because the interview, though a pilot, was deemed successful and yielded information appropriate for this study. This individual was selected for a pilot interview because she was not in the group randomly selected for the initial UMWI telephone survey but would have been eligible for inclusion. One other individual had heard about the study and contacted the Utah Department of Health to be interviewed. While this individual did not meet the study criteria, she was interviewed and did provide insights.

This selection procedure resulted in eight women and seven men being interviewed. Four lived in more rural areas of the state while eleven lived in larger cities or towns. Eight of the interviewees had children while seven did not. Of the eight that had children, four still had children living at home. Not all of the fifteen were found to have incomes above \$600, but those that did not provided useful contrasts for distinguishing factors responsible for financial success.

## **Data Collection Procedures**

The data for this report came from three sources: a telephone survey, administrative data, and in-person interviews.

### **Telephone surveys**

The telephone interviews were conducted in December 2004 and January 2005. Those selected for the study received letters a week prior to the interview phase that explained the purpose of

the study and provided a number that they could call with questions or to request that they not be called for this study. The interviewers were research assistants and staff members of Utah State University and the University of Utah. Individuals in the selected sample were called at least four times if they could not be reached in initial attempts.

The survey required an average of 20 minutes to complete. As part of the informed consent process by telephone, respondents were assured that their answers would not be shared with others and that they need not answer any question that they preferred not to answer. In appreciation of their time, respondents were sent a \$20 gift certificate for a local grocery store.

### **Administrative Data**

Information from administrative data fields were merged with the survey data. The variables used, age and gender, were selected because they were not seen as an intrusion on privacy and were not in need of being updated in the survey.

### **In-person interviews**

The in-person interviews were held during January and February of 2005 and were conducted by a research assistant. Interviews lasted between a half hour and one and a half hours, depending on the preferences and willingness to talk of the individuals being interviewed. Each of the 15 individuals was allowed to choose the date, time, and location of the interview.

The interviews were guided by an interview guide, but over time the questions changed somewhat to address the hypotheses that emerged from prior interviews. Even with this flexibility, however, the interview protocol remained within the parameters approved by the Utah State University IRB. For example; the interviewees were not asked questions regarding

religion, political persuasion, or gender roles; neither were they assessed on psychological dimensions, such as depression or cognitive capacity. As with the telephone survey respondents, each of the 15 interviewees received a \$20 gift card for a grocery store as appreciation for participation.

## **Analyses**

### **Quantitative analyses**

There were two approaches to conducting quantitative analyses. First, cross-tabulations were conducted to disaggregate results based on the wage change groups described above (Large Loss, Stable, Small Gain, and Large Gain). As noted above, these groups were created using administrative quarterly wage data from the SSA Unemployment Insurance file maintained by the Utah Department of Workforce Services. The second approach involved using regression analysis to predict self-reported monthly earnings, with the predictor variables being primarily from the survey but including also gender and age from administrative data.

One issue to note in the cross-tabulation tables relates to the columns labeled population percentages and means. Because of the oversampling noted above and presented in Table 2, simply reporting overall percentages and averages can be misleading. To appreciate this, recall that all who were identified as having experienced a large loss, small gain, or large gain in earnings around the time of UMWI application and enrollment were included in the target sample. Of the 181 others in the total population, only 95, or a little more than half, were included in the target sample. This means that the views of those in the Stable group are underrepresented in this survey with respect to the views expected in the population as a whole.

To compensate for this when making population estimates, the responses of the four groups are weighted in the column labeled “Population Estimate.” The weighting serves to recreate from available responses the distribution of the population among the four groups. For example, if 55 of the 115 responses were from the Stable group (or, the Stable constituted 48% of all respondents), their responses would be weighted to equal what would be expected if they had constituted 62 percent of the respondents (what they are in the population of interest, or around 71 of the 115 respondents). This weighting only applies to the column labeled Population Estimates and is commented on only when this weighting yields a population estimate that differs from the sample percentages in important ways.

This use of weighting to estimate population parameters raises several other issues. First, because of the under-representation of those in the Stable group, the population estimate differs most from sample statistics for those questions in which the percentages and averages of the Stable group are substantially higher or lower than for the other groups combined. Second, while this logic could be applied to follow-up questions asked only of a subgroup of respondents (e.g., only those who have increased their work hours are asked if the UMWI program helped them decide to work more hours), population estimates are less reliable with the smaller number of respondents in these subgroups and so were not calculated. Third, consistent with the last point, disaggregation into the four subgroups results in some small sample sizes that should caution us from over-interpreting the group differences that are found.

### **Qualitative analysis**

The qualitative analysis was based primarily on transcriptions of tape recorded in-person interviews. The goal was to build upon previous work in this area to develop ‘stories’ that

captured common experiences of subgroups of those interviewed. To this end, initial interviews provided tentative themes that served as hypotheses to be assessed in later interviews. As these themes, or integrated concepts, emerged in the interviews, they took priority in subsequent coding. Because the analysis was an ongoing process, some early transcripts were reviewed and re-coded, while later interviews and transcripts were subjected to only limited re-coding. This process yielded three distinct stories for those who had achieved some level of financial self-sufficiency, which is defined here as being employed and not receiving SSDI or SSI assistance at the time of the interviews.

## **RESULTS**

The results are presented in four sections. First, the frequencies from the telephone survey are presented in cross-tabulation tables, disaggregated by change in earnings around the time of first UMWI enrollment. Then the changes in earnings are related to demographic variables in an effort to highlight the personal characteristics associated with earnings changes. The next section continues this focus on characteristics associated with earnings but does so by using multiple regression analysis to account for self-reported monthly earnings at the time of the survey. The final section reports the results of the in-person interviews.

### **Survey Responses Disaggregated by Change in Earnings at UMWI Enrollment**

#### **Awareness of UMWI Program and Program Features**

The first awareness issue is whether participants were aware that they were in the UMWI program in the previous year. As presented in Table 3, all in the delineated groups of Large

Loss, Small Gain, and Large Gain were aware of being enrolled. Only in the Stable group were some (14.5%) not aware of being enrolled. This is likely due to their being in the Utah Medicaid Spend Down program and being transferred by a Utah agency administrator to the UMWI program when doing so would reduce the costs to enrollees. This happens when enrollee income is slightly above the federal poverty level but not high enough for the Spend Down premiums to be lower than the Utah Medicaid Buy In premiums. Because only those in the Stable group were unaware of their enrollment in the UMWI program, this is the first example of the sample statistic and the population estimate differing. As such, if one is interested in the percentage of people in the Utah MWI program who are unaware of being enrolled, the sample statistic of 7.0 percent could be misleading because those most likely to be unaware were under-represented. A better population estimate would instead be 9.4 percent, as calculated with weighting.

Table 3: Awareness of being enrolled in the Utah MWI Program						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Aware	100% (13)	85.5% (47)	100% (23)	100% (24)	93.0% (107)	90.6%
Unaware	0.0% (0)	14.5% (8)	0.0% (0)	0.0% (0)	7.0% (8)	9.4%

A second awareness issue is the level of awareness participants have about the features of the UMWI program, specifically the opportunity to increase earnings and to have greater assets and still qualify for medical coverage. As presented in Table 4, while the majority of participants know about the opportunity to earn more money (73.8%), a sizable group was unaware of this feature (26.2%). Further, this lack of awareness was more pronounced in the groups not showing large gains in earnings after enrollment (34.0%, 30.4%, and 23.1% of the

Stable, Small Gain, and Large Loss groups were unaware, as compared with only 8.3% of the Large Gain group).

Far fewer were aware of the potential for increased assets in the UMWI program (only 23.4% aware and 76.6% unaware). Significantly, awareness was highest for those experiencing wage gains after the initial UMWI enrollment (26.1% and 29.2% awareness for the Small Gain and Large Gain groups).

Table 4: Awareness of UMWI Program Features						
	Higher Limit on Earned Income					
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Aware	76.9% (10)	66.0% (31)	69.6% (16)	91.7% (22)	73.8% (79)	70.7%
Unaware	23.1% (3)	34.0% (16)	30.4% (7)	8.3% (2)	26.2% (28)	29.3%
	Higher Limit on Assets					
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Aware	15.4% (2)	21.3% (10)	26.1% (6)	29.2% (7)	23.4% (25)	22.6%
Unaware	84.6% (11)	78.7% (47)	73.9% (17)	70.8% (17)	76.6% (92)	77.4%

### **Reported UMWI Importance and Impact on Work Effort**

Survey participants who were aware of the increased limits on earnings (79 participants) and assets allowed (25 participants) under the UMWI program were asked how important these program features were to them. Keeping in mind the smaller subsets of recipients answering these questions, Table 5 shows that almost all who expressed a judgment (86.7% of 75; 4

respondents chose not to answer this question) felt that the higher limit on earnings was very important. Only those in the Stable group indicated this at below 90%, suggesting that some participants in this group may have had different goals in being covered by the program. Among those aware of the higher asset limit (25), all (100% in each group) judged it very important.

	Large Loss	Stable	Small Gain	Large Gain	Sample
Very Important	100% (8)	73.3% (22)	100% (16)	90.5% (19)	86.7% (65)
Somewhat Important	0.0%	20.0% (6)	0.0%	4.8% (1)	9.3% (7)
Not Very Important	0.0%	6.7% (2)	0.0%	4.8% (1)	4.0% (3)
Not at all Important	0.0%	0.0%	0.0%	0.0%	0.0%

In terms of the overall impact of the UMWI program in helping participants to keep working, a large majority of respondents reported that the UMWI program had been very important. As shown in Table 6, 76.6% overall rated the program as being very important, with the percentages for the different group ranging from 66.0% for Stable group to 87.5% for the Large Gain group. The lower percentage for the Stable group is consistent with the lower importance given to the increased earnings limit by this group and again highlights the degree to which some in the Stable group may be different from those experiencing larger losses or gains.

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Very Important	84.6% (11)	66.0% (31)	82.6% (19)	87.5% (21)	76.6% (82)	72.7%
Somewhat Important	0.0%	8.5% (4)	17.4% (4)	4.2% (1)	8.4% (9)	8.6%
Not Very Important	0.0%	10.6% (5)	0.0%	0.0%	4.7% (5)	6.9%
Not at all Important	0.0%	8.5% (4)	0.0%	4.2% (1)	4.7% (5)	6.0%
Not Sure/Not Reported	15.4% (2)	6.4% (3)	0.0%	4.2% (1)	5.6% (6)	5.8%

**Employment History**

Tables 7 and 8 provide information about current and recent employment. Most (67.8%) are working for someone else, with only 7.8% working for themselves. The smallest percentages for self-employment are among those in the Small Gain and Large Gain groups. Significantly, however, large percentages of the Small Gain, Large Gain, and Stable groups were not currently employed at the time of the survey, a finding that might be due to the instability of employment for individuals in this population. Consistent with what is presented in previous tables, the Stable group was noteworthy in its difference from the other groups, in this case having a much higher current unemployment rate. Some of those unemployed may have unearned income that places them above the Federal Poverty Level and so need the UMWI program to qualify for Medicaid.

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Work for someone else	84.6% (11)	56.4% (31)	78.3% (18)	75.0% (18)	67.8% (78)	64.2%
Self-employed	7.7% (1)	10.9% (6)	4.3% (1)	4.2% (1)	7.8% (9)	8.8%
Not currently working	7.7% (1)	32.7% (18)	17.4% (4)	20.8% (5)	24.3% (28)	27.0%

As presented in Table 8, members of the Large Gain group are employed for the most hours per week (average of 23.4 hours per week) and earn the most per month (average of \$710 per month). For these two rows that report average values, the numbers in the parentheses represent the number of responses from which the averages are calculated. Approximately 15 percent (14.8% of the 115 respondents) of the sample is working as a manager or supervisor, the highest percentage working in this capacity is among those in the Large Gain group (20.8%).

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Hours/week worked in current/last job	13.0 (13)	20.5 (47)	20.3 (22)	23.4 (24)	20.2 (106)	20.3
Estimated Monthly Earnings	\$565 (13)	\$612 (43)	\$644 (22)	\$719 (22)	\$636 (100)	\$627
Manager/supervisor in current/last job	0.0%	16.4% (9)	13.0% (3)	20.8% (5)	14.8% (17)	15.4%

In trying to understand the changes in employment experienced by UMWI participants, respondents were asked if they had started a new job recently, increased the number of hours that they work, increased their weekly earnings, or taken on more job responsibilities. Table 9 shows

that those in the Stable group were most likely to have started a new job (25.5%), while those in the Large Gain group were much more likely to have increased their hours worked (37.5%) and increased weekly earnings (37.5%). At the same time, however, those in the Large Gain group were most likely to have been fired, laid off, or retired (33.3%). Those in the Small Gain group were most likely to have taken on more job responsibilities (47.8%).

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
New job in past year	15.4% (2)	25.5% (14)	17.4% (4)	20.8% (5)	21.7% (25)	22.9%
Increased hours worked	7.7% (1)	21.8% (12)	17.4% (4)	37.5% (9)	22.6% (26)	22.1%
Increased weekly earning	0.0%	25.5% (14)	34.8% (8)	37.5% (9)	27.0% (31)	26.4%
Taken on more job responsibilities	15.4% (2)	20.0% (11)	47.8% (11)	37.5% (9)	28.7% (33)	26.0%
Quit, laid off, fired, or retired	15.4% (2)	25.5% (14)	26.1% (6)	33.3% (8)	26.1% (30)	25.8%

### **Barriers to Increasing Work Hours**

In considering why UMWI participants are not working more hours, their disability is reported as the primary reason (79.1%, as reported in Table 10). Interestingly, those in the Large Loss group are the most likely to report being concerned with losing Social Security or cash benefits (53.8%). For those in the Small Gain and Large Gain groups, ‘no other job options’ is the most reported (39.1% and 37.5%; about the same as the 38.5% for the Large Loss) non-disability reason for not working more hours.

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Disability	100% (13)	74.5% (41)	73.9% (17)	83.3% (20)	79.1% (91)	77.6%
Worried about losing SS or cash benefits	53.8% (7)	38.2% (21)	26.1% (6)	33.3% (8)	36.5% (42)	37.0%
Pay more for Medicaid	23.1% (3)	27.3% (15)	30.4% (7)	29.2% (7)	27.8% (32)	27.7%
No other job options	38.5% (5)	30.9% (17)	39.1% (9)	37.5% (9)	34.8% (40)	33.6%

**Health Care Coverage**

Health care coverage is traditionally of concern in the disability arena and the main focus of the Utah MWI program. Table 11 indicates that, overall, just over 80 percent (81.7%) were covered by Medicaid when surveyed and a little under 80 percent (77.4%) were covered by Medicare. Those in the Small Gain group stand out as having the highest coverage by Medicaid and the highest coverage rate for having other health insurance. Also noteworthy is that the Large Loss group has the lowest coverage levels for Medicaid. In contrast, it is the Stable group that has the lowest coverage by Medicare, with the Large Loss, Small Gain, and Large Gain groups each having coverage rates about 12 to 14 percentage points higher than the Stable group.

Despite the lowest level of other health insurance, the Large Gain group has the highest percentage (66.7%) reporting that their current insurance covers all of their health needs (see table 12). Relatively few people (15 out of 115 surveyed) reported that their current insurance does not cover their medical needs, but even with the resulting small sample sizes it may still be worth noting that the Stable and Large Loss groups had the highest percentages (16.4% and 15.4%) reporting medical needs not covered.

Table 11: Health Care Coverage						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Currently have Medicaid	69.2% (9)	80.0% (44)	95.7% (22)	79.2% (19)	81.7% (94)	81.3%
Currently have Medicare	84.6% (11)	70.9% (39)	82.6% (19)	83.3% (20)	77.4% (89)	75.3%
Currently have other health insurance	15.4% (2)	18.2% (10)	26.1% (6)	8.3% (2)	17.4% (20)	17.8%

Table 12: Adequacy of Current Health Care Coverage						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Current insurance covers all needs	46.2% (6)	52.7% (29)	47.8% (11)	66.7% (16)	53.9% (62)	53.3%
Current insurance covers most needs	38.5% (5)	29.1% (16)	43.5% (10)	20.8% (5)	31.3% (36)	30.8%
Current insurance does not cover needs	15.4% (2)	16.4% (9)	8.7% (2)	8.3% (2)	13.0% (15)	14.1%
Don't know/Not Reported	0.0%	1.8% (1)	0.0%	4.2% (1)	1.7% (2)	1.7%

**Awareness of Utah Employment Support Programs**

The final programmatic issue addressed by the survey was the perceived usefulness and awareness of two important work support programs, BPAO and EPAS. Consistent with other surveys (e.g., the BPAO survey), participants in this program were largely unaware of these other programs (see Table 13). Whereas around 81 percent of respondents (80.9%) indicated that benefits planning would be useful for them, less than 17 percent (16.5%) of these people (those indicating that it would be useful for them) were aware that such services already existed in the BPAO program. This awareness ranged from under 5 percent (4.8% for the Small Gain

group) to almost 40 percent (38.9% for the Large Gain group). Fewer respondents (21.7%) indicated that EPAS services would be useful for themselves, and those seeing a benefit were slightly more likely to know of the available services (22.7%).

Table 13: Usefulness and Awareness of Utah Support Services (Percentages and Number Answering Yes)						
	<b>Benefits Planning</b>					
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
If available, would you use this	92.3% (12)	72.7% (40)	91.3% (21)	83.3% (20)	80.9% (93)	78.4%
Are you aware of BPAO	16.7% (2)	11.4% (5)	4.8% (1)	38.9% (7)	16.5% (15)	
	<b>Personal Assistance to get ready for and help with work</b>					
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
If available, would you use this	23.1% (3)	21.8% (12)	21.7% (5)	20.8% (5)	21.7% (25)	21.8%
Are you aware of EPAS	0.0%	27.3% (3)	50% (2)	0.0%	22.7% (5)	

## Satisfaction with Life

A final outcome measured was general life satisfaction of respondents. As presented in Table 14, around three-fourths of respondents indicated being either very satisfied or somewhat satisfied with life (37.4% and 35.7%, or a total of 73.1%). It is interesting that the lowest levels of satisfaction were found in the groups with wage gains, with 65.2% either very satisfied or somewhat satisfied for the Small Gain group and 66.7% for the Large Gain group. In contrast, the Large Loss and Stable groups reported somewhat higher levels of satisfaction (77.0% and 72.7%). While these percentages are based on small sample sizes and need to be interpreted with

some caution, they raise the possibility that those with wage gains around the time of UMWI enrollment are experiencing different difficulties or have different expectations that are not being met.

**Table 14: Satisfaction with life in general**

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Very Satisfied	46.2% (6)	32.7% (18)	34.8% (8)	33.3% (8)	37.4% (40)	37.5%
Somewhat Satisfied	30.8% (4)	40.0% (22)	30.4% (7)	33.3% (8)	35.7% (41)	37.0%
Neither Satisfied nor Dissatisfied	7.7% (1)	7.3% (4)	17.4% (4)	8.3% (2)	9.6% (11)	8.9%
Somewhat Dissatisfied	0.0%	9.1% (5)	17.4% (4)	12.5% (3)	10.4% (12)	10.0%
Very Dissatisfied	7.7% (1)	10.9% (6)	0.0%	12.5% (3)	8.7% (10)	9.3%
Don't Know/Not Reported	7.7% (1)	0.0%	0.0%	0.0%	0.9% (1)	

**Demographic Characteristics Associated with Changes in Earnings at Enrollment**

To understand further the different patterns of wage change around the time of initial UMWI enrollment, it is useful to report the demographic characteristics of the different groups. Table 15 summarizes the marital status of those in the different wage change groups. Those in the Small Gain group were most likely to be married when surveyed (43.5%), while those in the Large Gain group were least likely to be married (16.7%) and most likely to have never been married (62.5%). Those in the Large Loss group were most likely to have been married at some point (only 15.4% have never been married) but also most likely to have been divorced (30.8%).

Table 15: Marital Status						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Married	30.8% (4)	36.4% (20)	43.5% (10)	16.7% (4)	33.0% (38)	34.1%
Never Married	15.4% (2)	27.3% (15)	34.8% (8)	62.5% (15)	34.8% (40)	31.8%
Divorced	30.8% (4)	27.3% (15)	21.7% (5)	16.7% (4)	24.3% (28)	25.1%
Widowed	7.7% (1)	3.6% (2)	0.0%	0.0%	2.6% (3)	2.9%
Separated	0.0%	3.6% (2)	0.0%	4.2% (1)	2.6% (3)	2.9%
Not Reported	15.4% (2)	1.8% (1)	0.0%	0.0%	2.6% (3)	

Table 16 presents information on ethnicity and race, indicating that around 90 percent of the sample and population estimate was white (87.8%) and non-Hispanic (90.4%). The small numbers of non-white and Hispanic/Latino respondents preclude much interpretation of inter-group differences.

Table 16: Ethnicity and Race						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Hispanic/Latino	7.7% (1)	5.5% (3)	13.0% (3)	16.7% (4)	9.6% (11)	8.2%
White	92.3% (12)	92.7% (51)	78.3% (18)	83.3% (20)	87.8% (101)	89.3%
African-American	0.0%	0.0%	4.3% (1)	0.0%	0.9% (1)	0.6%
Asian	0.0%	0.0%	4.3% (1)	0.0%	0.9% (1)	0.6%
Native American	0.0%	1.8% (1)	0.0%	0.0%	0.9% (1)	1.2%
Multicultural	0.0%	0.0%	8.7% (2)	0.0%	1.7% (2)	1.3%
Other	7.7% (1)	1.8% (1)	4.3% (1)	16.7% (4)	6.1% (7)	4.6%
Not Reported	0.0%	3.6% (2)	0.0%	0.0%	1.7% (2)	

The main pattern to emerge from examination of the education levels in the four groups (Table 17) is the somewhat mixed education levels for those in the Large Loss group. While they had the highest percentage of those with a college degree (23.1%), the Large Loss Group also had the highest percentage of those who did not report ever having attended college (38.5% reported having attended at least some college or received a degree, and so, including one non-respondent, 61.5% did not report ever having attended college). In contrast, two-thirds of the sample had attended some college or more (46.1%, 16.5%, and 3.5%). The Stable group had the highest percentage (76.3%) of respondents with some college experience or more.

Table 17: Education						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
8 <sup>th</sup> Grade or Less	0.0%	1.8% (1)	0.0%	4.2% (1)	1.7% (2)	1.7%
Some High School	23.1% (3)	3.6% (2)	8.7% (2)	4.2% (1)	7.0% (8)	6.0%
High School Diploma	30.8% (4)	18.2% (10)	30.4% (7)	29.2% (7)	24.3% (28)	22.4%
Some College	15.4% (2)	54.5% (30)	47.8% (11)	41.7% (10)	46.1% (53)	48.8%
College Degree	23.1% (3)	14.5% (8)	13.0% (3)	20.8% (5)	16.5% (19)	15.8%
Post-College	0.0%	7.3% (4)	0.0%	0.0%	3.5% (4)	4.7%
Not Reported	7.7% (1)	0.0%	0.0%	0.0%	0.0%	0.9% (1)

The issues of age and gender are of particular interest with regard to employment of persons with disabilities. As shown in Table 18, the pattern is fairly clear for age—as wage change becomes more positive, from Large Loss to Stable to Small Gain to Large Gain, the average age decreases (numbers in parentheses are the sample sizes from which the averages

were calculated). This is consistent with prior research findings on the greater propensity for younger workers to increase their work effort.

The pattern for gender is not as straightforward, but the two groups with small and large wage gains were the two groups with above average percentages of males; the Large Loss group was comprised of only 23 percent males. The reasons why women are three times as likely as men to have a large loss in earnings after UMWI enrollment need further study, as does this pattern of men being more likely to be in the Small and Large Gain groups. One possibility is that men feel greater pressure to work by family, peers, and counselors, but, again, this needs to be investigated.

Table 18 Age and Gender						
	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Average Age (yrs)	50.5 (13)	48.8 (55)	48.2 (23)	42.6 (24)	47.6 (115)	48.0
% Male	23.1% (3)	45.5% (25)	73.9% (17)	58.3% (14)	51.3% (69)	49.6%

The relationship between self-reported disability type and wage change was also noteworthy. As illustrated in Table 19, around 60 percent of respondents reported having physical disabilities and around 36 percent reported mental health disabilities. Furthermore, both the Small Gain and Large Gain groups had substantial representation of people from both main groups, those reporting physical disabilities as primary and those reporting mental health disabilities as primary. Nonetheless, moving across groups from Large Loss to Stable to Small Gain and to Large Gain is associated with a consistent decrease in the percentage of those with physical disabilities (from 69.2% to 37.5%) and a consistent increase of those reporting mental health

disabilities (from 23.1% to 54.2%). Table 19 also reveals the failure of the survey effort to reach those in Utah with sensory disabilities. Not having any respondents with sensory disabilities, it is not useful to estimate a population percentage from the sample and more caution is needed in interpreting the population estimates for the other disability type categories.

Examining the different patterns of those with physical versus mental health disabilities suggests different uses of the UMWI program. Those with physical disabilities may be more likely to enroll in the UMWI program when the onset or worsening of their disabilities leads to an abrupt drop in earnings and the need for public assistance. Those with mental health disabilities, however, seem less likely to experience this abrupt loss in earnings around enrollment and instead enroll in the UMWI program when they are beginning to increase their work effort. The results presented in the next section show a different dynamic when accounting for differing levels of earnings at the time of the survey.

	Large Loss	Stable	Small Gain	Large Gain	Sample	Population Estimate
Physical	69.2% (9)	63.6% (35)	52.2% (12)	37.5% (9)	56.5% (65)	59.0%
Mental Health	23.1% (3)	32.7% (18)	39.1% (9)	54.2% (13)	37.4% (43)	35.7%
Sensory	0.0%	0.0%	0.0%	0.0%	0.0%	
Cognitive	0.0%	3.6% (2)	4.3% (1)	4.2% (1)	3.5% (4)	3.5%
Other/Not Reported	7.7% (1)	0.0%	4.3% (1)	4.2% (1)	2.6% (3)	1.8%

## **Predictors of Monthly Earnings at Time of Survey**

As noted in the Methodology section, a second approach to understanding the earned income of MWI participants involved using multiple regression analysis to identify factors associated with higher self-reported earned income at the time of the survey. Two separate regression analyses were conducted, one with only demographic variables and the other with employment and ‘barriers to work’ variables added to the demographic variables. To the extent that the coefficients for the demographic variables move closer to zero in this second analysis, those reductions represent the indirect impacts by which the demographic variables affect monthly earnings through the other variables.

Table 20 shows that the demographic variables account for 22.5 percent of the variance in self-reported monthly earnings (with an overall F value of 5.41,  $p=0.0002$ ). This also means that 77.5 percent of the variability in monthly income cannot be explained with just the available demographic variables. All of the predictor variables beside ‘never married’ are statistically significant at the 0.10 level. The coefficients indicate that, controlling for the other variables, for every additional year in age for the respondent the predicted monthly income decreased by \$8.20 (or, by \$82 more per month for every additional 10 years of age). Similarly, controlling for the other variables in the equation, the unique impact of being a male was an increase of monthly earnings by \$316 over those predicted for females. This is a large gap in earnings (almost \$1,000 more per quarter for men), and it is important to remember that this is the unique effect of gender and not simply the result of men having more education or different disabilities, as these characteristics were also included in the analysis.

Table 20: Regression Prediction of Self-Reported Monthly Earnings with Demographic Predictor Variables

Source	DF	Sum of Squares	Mean Square	F Value	Probability
Model	5	6779921	1355984	5.41	0.0002
Error	93	23324173	250798		
Corrected Total	98	30104094			
			R-Square	0.225	
	Mean Income	\$641.5	Adjusted R-Square	0.184	
Variable	DF	Parameter Estimate	Standard Error	t value	Probability
Intercept	1	752.0	311.5	2.41	0.018
Age	1	-8.2	4.8	-1.70	0.092
Gender	1	316.5	108.4	-2.92	0.004
Education	1	171.0	54.9	3.12	0.002
Never married	1	-167.3	112.4	-1.49	0.140
Physical Disability	1	302.6	108.1	2.80	0.006

The coefficient for education indicates that every one-unit increase in the education variable was associated with a \$171 increase in monthly income. For example, as currently coded, moving from having a high school diploma to having attended some college represents a one-unit change; so does the increase from having attended some college to having a college degree. It is almost certain that the lack of equal intervals in this coding reduces the magnitude and statistical significance of the education variable. As such, that the education variable is nonetheless statistically significant ( $p=.002$ ) is a testament to its importance.

While not statistically significant, those who were never married were predicted to have monthly earnings \$167 (167.3; coefficients reported are rounded to the nearest dollar) below those who were married or had been previously. This may reflect a general effect of the severity of disabilities, wherein, while controlling for things like education and type of disability, those with more severe disabilities may find it both more difficult to enter into and maintain a

relationship that leads to marriage and also more difficult to obtain high paying employment. To test this possible general effect would require a direct measure of the severity of disability, something not in the current data.

The current data do include self-reported primary type of disability (sample percentages are physical, 56.5%; mental health, 37.4%; cognitive, 3.5%; and not reported/other, 2.6%). Those with physical disabilities were predicted to have monthly earnings \$303 above other respondents, primarily those with mental health disabilities. These higher average earnings for those with physical disabilities are somewhat at odds with the findings reported above in which most people in the Large Loss group reported having physical disabilities whereas most in the Small and Large Gain groups reported having mental health disabilities. Recall, however, that the prior analysis was with changes in UI-reported wages after UMWI enrollment while this regression analysis is with self-reported earnings at the time of the survey. It is also the case that the multiple regression results provide an estimate of the direct effect of disability type, controlling for the other four factors in the equation.

Table 21 shows the results of regression analysis when five employment characteristics and two job barriers variables are added to demographic variables used in the regression analysis presented in Table 20. All of the coefficients for the demographic variables are closer to zero, with the exception of the never married variable, which became somewhat closer to statistical significance. For example, the coefficient for education dropped from 171.0 to 133.3. This indicates that part of the impact of additional education operates through the added variables, such as type of job or having supervisory responsibilities.

Table 21: Regression Prediction of Self-Reported Monthly Earning with Demographic, Employment and Barrier Predictor Variables					
Source	DF	Sum of Squares	Mean Square	F Value	Probability
Model	12	10974640	914553	5.15	<0.0001
Error	78	13845574	177507		
Corrected Total	90	24820214			
			R-Square	0.442	
	Mean Income	\$603.8	Adjusted R-Square	0.356	
Variable	DF	Parameter Estimate	Standard Error	t value	Probability
Intercept	1	337.5	478.8		
<b><i>Demographic Variables</i></b>					
Age	1	-6.11	4.45	-1.37	0.174
Gender	1	177.7	97.4	-1.83	0.072
Education	1	133.3	49.9	2.67	0.009
Never married	1	-174.8	106.5	-1.64	0.105
Physical Disability	1	181.5	101.6	1.79	0.078
<b><i>Employment Variables</i></b>					
Months in Current Job	1	0.42	0.17	2.41	0.018
Supervisory Job	1	251.2	134.8	-1.86	0.066
Health/Social Services	1	-139.8	110.4	-1.27	0.209
Sales Job	1	260.8	183.6	1.42	0.159
Education Job	1	371.7	183.2	2.03	0.046
<b><i>Barriers to Working</i></b>					
Disability as Barrier	1	-230.9	124.1	1.86	0.067
Lack of Job Options	1	-231.4	93.9	2.46	0.016

For the employment variables, every additional month of employment in the current job is associated with a \$0.42 increase in wages (or \$4.20 more per month for an additional 10 months in the current job). Supervisory jobs are associated with an additional \$251 in monthly earnings. Of the three job sector variables used in the analysis, having a job in the health services or social services areas was associated \$140 less in monthly earnings (controlling for the other variables in the equation and compared to all other job categories not in the equation), sales

jobs had earnings predicted \$261 higher than for other jobs (though this coefficient was not statistically significant), and jobs in the education sector had monthly earnings predicted as \$372 higher than for other jobs.

Those who reported their disability as a barrier to working more had monthly earnings \$231 below those who did not report their disability as a barrier (controlling for the other variables in the equation). A nearly identical coefficient was found for those reporting the lack of job options as a barrier to working more, indicating that those with this barrier also earned \$231 less per month than those not reporting lack of job options as a barrier. It is important to recognize, however, that regression analysis reveals relationships but not causal order. While it may be reasonable that those confronting these barriers earn less, it is also possible that those earning less are more likely to report having barriers that limit their work effort.

## **Results of In-person interviews**

The results of the in-person interviews are reported as three storylines for six of the 15 people interviewed who had achieved some level of financial self-sufficiency, defined as employed and not receiving SSDI. These results are compared to what was found for the other nine interviewees, those who were still receiving SSDI cash assistance. Note that the names used are not the actual names of the interviewee but rather are pseudonyms.

### **Self-Sufficiency Storyline One**

The most common story among the six respondents who became self-sufficient begins with an accident. The driver is not using his seatbelt, loses control of his vehicle, and is injured in the resulting accident. As a result, he incurs a C-6 spinal cord injury and is a quadriplegic. The

stories are very similar for the three members of this storyline of individuals, none of whom now receive SSDI benefits.

After their accidents, and for the most part unable to move, each received intensive rehabilitative physical and occupational therapy. When released from the hospital, each went home to live with supportive families that encouraged the person to continue working towards recovering capacity. While none of the three men in this group expected full recovery, each felt that more was possible. Two of the young men had previously been involved in athletics. They understood the importance of training and worked at therapy with the same motivation they had employed for traditional sports. These young men recovered more ability and strength than did the third. Both of the two former athletes can today drive an automobile.

One of the men had a college education prior to the accident and two obtained it with the assistance of VR and used SSI or SSDI for living expenses. Thereafter each was able to secure employment through individuals with whom they were acquainted. Today all of these three men are employed full time and off SSDI.

**Jim.** Jim had a professional position before the accident (around 20 years ago), as well as a college degree from the University of Utah. He had the opportunity to work because he was able to return to his previous job in five months with some adjustments to his employment roles and responsibilities. Jim is enrolled in EPAS, and he needs a personal assistant to get him in and out of bed and for various self-care necessities. Personal assistance is not part of his employer's health insurance benefits.

“I am called permanent part time, I still work twenty six to thirty hours a week. I get health benefits, but it doesn't cover personal attendance care.”

“By being on EPAS you get your attendance service....It frees up . . .a lot of money I can put into savings. My spend down is \$200-250 a month.”

Jim lived with his wife immediately following his hospitalization but was divorced a few years after the accident and never remarried. His mother moved in with him and they live together in a family setting. His mother is able to cook and clean but also provides the on-going emotional support Jim needs to keep going. Regarding EPAS, Jim said, “My savings look a lot more comfortable. My mother hasn’t had to pay a bill in I don’t know how many years. She is on fixed income.”

Jim believed all along that he would return to work and never applied for SSDI. His disability designation was approved by the state for Medicaid assistance. Jim now earns too much money to qualify for SSDI. His housing is secure as he was able to buy a small home, about which he proudly proclaimed, “Yeah, I own my own home, free and clear.” The home is completely wheelchair accessible, and he can access his vehicle via an attached garage.

**Michael.** Michael was 19 and in his first year at college when, around seven years ago, he had his automobile accident and became quadriplegic. He was in the hospital for about four months, and then spent another four months at his parents’ home. Throughout that time he had the emotional and financial support of his family. He also had the additional support and encouragement of his occupational therapist.

“My physical therapist, she was great. She was really good to work with. She was more of a friend than a therapist. She told me about things outside the hospital that I could still do. She introduced me to wheelchair sports. I still play to this day.”

“I have a couple of friends, they had the same therapist. We always talk about what an impact she had on our lives.”

Michael had goals. When asked about using a personal assistant, he said:

“I haven’t had that since a year after my injury. That was one of my main goals. That is what this therapist taught too. Make goals to become completely independent. If you

do, your life will become 10 times better. It is never going to be the same it used to be. But it will be pretty dang close.”

Michael returned to college using SSI for living expenses and depending somewhat on his family for financial assistance. He felt that college was the best place for him, and VR was ready, willing, and able to assist him. They paid for the major expenses, including the computer and programs he needed and the lift for his van that enabled him to get to school.

“[VR] they helped me with my van, paid \$25,000 one-time for a lift in my van. That was really helpful being able to get to school. Being able to drive yourself to school, that was the biggest thing in being independent. Not have to rely on someone else’s promise. That was the best thing that ever happened, because I can go wherever I want, do whatever I want, whenever I want. So that was the biggest thing for me. So they did help me out there.”

Michael completed his education and graduated with a degree in a computer-related field. He found employment in the school he attended and worked his way up to full time. Michael got married a few years ago, and his housing is secure as he and his wife recently purchased a home they share with their two-year old son.

Michael also became involved in wheelchair sports and has traveled out of the state with his team. He claims this has been very beneficial to him. Here he can ask questions and get straight answers from other individuals that have been through similar experiences.

“My biggest support group actually, was playing [wheelchair sports]. The guys I met there, we talked about things you wouldn’t normally talk about with other people. You learned how to become independent through what they did and what they had experienced. That was my biggest support group. That is something people don’t understand . . . It wasn’t made for that, but it is the largest growing support group in the world for wheelchair. I think that is why, it is two things in one.”

Michael and his family no longer receive any support from the government. They rely on the income they make and the benefits they receive from employment.

**Richard.** Richard was in his early twenties when he became quadriplegic in an automobile accident that occurred about 15 years ago. Prior to the accident, he was working in construction and never planned on going to college. Following his accident, Richard returned to live with his parents. He took one class at the local Applied Technology Center but then quit school for four or five years. He bounced around to different counselors. Eventually he said,

“I got hooked up with Sid, who is also a quadriplegic and I kind of think he understood more. We worked well together. When I had a problem or something, well, he did pretty much anything I needed for me. He was always encouraging, just keep going. Especially for me to get started, not to just take a class here and there. Just get in and take three or four hours a day.

Richard got the education he needed and then had the opportunity to work at that college. He now works full time at the college as an instructor, and he interacts with students and faculty regularly. Richard has health insurance but described his experience with personal assistance and associated costs:

“I know I couldn’t [pay for my own personal assistant] because of the bill IHC sends out. The way it works is they bill my insurance company first and they deny it. They bill Medicare, and Medicare denies it. Once it is denied, Medicaid pays for it . . . the first time I got a bill it was like \$4,000 a month. So we figured it out with the hours I get with the aides coming in, that they charge about \$75 an hour. I’m on the list for DSPD, Department of Service for People with Disabilities [receiving this benefit would allow him to do such things as hire his own aide].”

Richard went on to comment about EPAS:

“Without the EPAS, I would be homebound more than likely. It would be difficult. [Emotionally] I would be bouncing off the walls. Yeah, I was home five years after my accident and the last couple of years it was hard to find enough to do to keep me busy. It was very hard. I enjoy coming to work every day.”

Richard shared the following when asked how he got off of SSDI.

“It was worth more to work than to—either that or cut my hours back to 15 per week, which is only 3 hours a day. It wasn’t worth it. I was already working 4 hours a day so I thought I might as well see if I couldn’t just keep increasing my hours. I was 20 hours a week, and I’m now up to 36.”

“At 20 hours, I could only make \$500 over what my disability payments were. It was only about \$1100 a month that I was making [through SSDI] and I can almost make that working. So I thought I might as well quit doing that [SSDI] and increase my hours. That gives me certain goals. My hours are like a runner, you just keep increasing your endurance, increase your strength.”

### **Self-Sufficiency Storyline Two**

The second storyline applied to two of the interviewees who became financially self-sufficient.

The story begins with the onset of a potentially devastating health problem. The person does not have sufficient income to pay for the needed medical services and is approached by the hospital providing care regarding securing Medicaid to cover these expenses. With the aid of the hospital, the individual applies to the state for disability designation and then for Medicaid. When released from the hospital, the person returns to live in a family environment where health and a return to a pre-disability state is emphasized. Once the disability can be managed, the individual returns to work and possibly secures group insurance.

There were two women among those who became self-sufficient who fit this storyline, Ruby and Robin. Neither of them ever received SSDI. They needed health care that exceeded their financial ability. A state certification of disability enabled them to receive Medicaid, and that was all that was needed. A third individual, Jim, fit much of this storyline, but his story was even more consistent with the first storyline and so was described above.

**Ruby.** Ruby is a registered nurse (R.N.). She moved away from home at 20, completed her education, and has been on her own since that time. When she was in her early 30’s, Ruby began having seizures that doctors assume resulted from a traumatic brain injury she suffered as

a child. Unable to work, Ruby had to sell her house and car and declare bankruptcy in order to finance the COBRA insurance from her employer.

Ruby had substantial emotional support from her parents, with whom she lived following her release from the hospital. There was a therapist in Salt Lake that also helped her through some tough times. Following an improvement in her condition, Ruby decided to return to work. Opportunity to work is abundant for registered nurses, and work was important for Ruby.

Describing what it was like for her not to work and how she feels about her current job, she said,

“I was very depressed and suicidal . . . I had worked ever since I was 16 . . . It is very rewarding emotionally. Of course, [it was also] very rewarding financially. I just can’t imagine not working. I, like my patients or residents, whatever you want to call them. I just can’t imagine sitting at home and not doing anything.”

With a range of work opportunities, she chose to work at a nursing home where her new boss understood the situation and would take the time to help her adjust. She also had interpersonal support from a counselor at the hospital where she was treated. About her, Ruby said,

“I could identify with her, she was really good and encouraging to me. She didn’t treat me like I was the bum off the street. She treated me like I was someone who was really trying to get back to work. She was going to help in any way she could.”

Ruby’s return to work involved problems with Medicaid and securing the medications that made it possible for her to work. Nevertheless, she now has secure housing and lives in an apartment attached to her parents’ home. She pays about \$500 per month for rent. She also works four or five 12-hour shifts at the nursing home each week. She commented about her life now,

“I don’t have a car right now and [family members] drive me to and from work, even though there is a bus I took for awhile in the winter. They [family members] purposely take me, I suffer from Fibromyalgia and I hurt when I get cold, and so they have been wonderful to take me back and forth to work.”

**Robin.** Robin is a mother in her early thirties. She lives with her husband and their six children who give her plenty of emotional support. They live in a modest home being purchased by the family. It was not until late in her last pregnancy, around three or four years ago, that the doctors discovered she had renal disease. Her child was born premature and required extensive medical intervention to stay alive.

As with Ruby, it was the hospital that approached her about getting on Medicaid, Medicare, and SSI. She said,

“I think I went on it after he was born, when they diagnosed me. Well, he was in the hospital for two months in the NICU. . .that was a \$127,000 bill. Plus me, that was just for him for those two months, and that was just the hospital bill, not all the other little bills you get along with everything. So, it was at that time I went in and applied. . . .I think that is when I went on it, to help pay for that.”

Robin is no longer on Medicaid. She claims that as a self-employed worker, the family must submit their income tax return and that has been just too much for her to handle. She also had difficulties paying her Medicare bills.

“Medicare costs maybe \$88 a month, so \$200-\$250 [for] three months, which isn’t huge. But I would rather have made a monthly payment instead of a three month payment and it’s not. I am not really good at paying bills. So this bill comes in and this bill, and I’ve got so many of them that they all [mount up] ...that is why they cancelled my Medicare, because of non-payment of premium. I think I can apply just for that, or apply differently. I can apply and they can take it directly out of my account and they can do that monthly that way. But if they bill me, it’s every three months.”

But she also added at the end of the interview, “I am probably just in denial about [not] needing it [Medicare].” Robin does not feel that she can afford private insurance either. She said,

“I am uninsurable, but we can get on for the kids. They will insure me at a super high premium. I looked at it once, applied for the family, and I put it down and they could send me a letter. Where there was no “pre-existing conditions” clause, I went in and they would have covered me, but they would have charged me \$5,000. But that is what I

would have paid the hospital anyway. Why should I get the insurance if I have to pay the same to the hospital?”

### **Self-Sufficiency Storyline Three**

The third and final storyline of becoming self-sufficient has elements of the previous two but has some distinguishing features for the one person represented in it. The individual receives a letter from the SSA telling him that he has made too much money and so has been over-paid with his SSDI benefits. The individual, knowing he can earn over \$500 per month, and that this is about all he had been receiving from SSA, decides to forgo the benefits and make it on his own. The person does manage to stay off public assistance, but the financial situation is precarious and future self-sufficiency not assured. The one individual with this storyline asked if he could be referred to by the pseudonym of Og. While this choice is quite different from the pseudonyms assigned to other interviewees, his choice is respected in the description that follows.

**Og.** Og and his family stopped receiving SSDI after being notified about having received one or two overpayments. He has some confusion about how much he owes and is uncertain how he will ever be able to pay it.

“The state of Utah over-calculated our benefits, and now [they] say we owe \$500 back pay. Every time we talk to them about food stamps or anything that is what we hear, ‘You owe money.’ It’s not the people there, it is what the machine tells them.”

“All of a sudden last August they received this letter saying, did you forget to pay us the \$620? I called but I got no response. Social Security, they have no reason why, they can’t tell me what it is about other than I owe that money.

Og’s wife said, “When I called on that \$600, they just told me flat out that they would just grab your tax return. So I get no information on what this is about.” When asked if he would consider getting an attorney he responded,

“Yeah, we have had that done a couple of times. I’ve talked to a couple of other lawyers, etc., the only way they go after that money is if it pays for their time. I didn’t want to appeal it, I didn’t want to hang on to it.”

Og added this about getting off of Social Security,

“Getting off social security was [serendipitous] because I had gotten used to the check, use to sitting and rotting. Feeling useless, helpless, and a waste of skin. When that check stopped, yeah, it was strange, it was rough. It was like having the umbilical cut with a butter knife. But I needed it. I did not need it that way. I did not need everything else that was cut away from it. But it was time anyway. I had the skills, I started to support myself. I can contribute.”

Og does not feel good about his life right now. He said,

“Right now, as far as I feel about life, I don’t feel like I am doing what I need to do. To be honest with you, I don’t. It is really I need to make a plan and then follow it. That is where I am hitting the wall on this. Part of this is that I realize I need to continue to get the education.”

“I’m surviving. I don’t feel that I am doing right by my daughter or my wife. They deserve or I don’t feel they should be stuck dealing with my lack of motivation, my lack of ability. I feel like I pretty much am failing, I’ve got a plan.”

### **Stories of Those Still Receiving Cash Assistance**

For the nine interviewees who were still receiving SSDI assistance, all had come up against one or more barriers that interfered with becoming financially self-sufficient.

**Joshua’s Story.** Joshua attended college and found employment selling computer programs. He was doing well until schizophrenia and alcoholism took over his life. Eventually he was hospitalized and treated for both conditions. He lived in the community and was relatively stable for a few years before a crisis pushed him into a hospital and later into subsidized housing.

Joshua was referred to a college program for individuals with disabilities by VR and began attending as he said, “With no intention of ever working.” A few months after finishing

the program the program director called him and asked him to come to work for the program. Joshua accepted and has become a valuable member of the staff.

Joshua has minimal family support. He has two brothers who are well-off financially and living with families of their own in other states. While he stays in touch with them from time to time, he does not want to call on them for assistance. Joshua limits his income in order to keep his housing assistance intact, but he feels good about his work and contributions to the community.

**Judy's Story.** Judy has a physical disability related to numerous medical problems. One surgical procedure in particular would not heal and pushed her over into a crisis involving housing which was resolved with placement and aid from the local housing authority. Judy had three children living with her at the time.

Judy's medically limited activity level resulted in VR's decision to support her through both an undergraduate and a master's degree. Judy is now employed, albeit part time, in a position that enables her to assist other individuals with disabilities. Judy is an articulate individual who has become politically active both advocating for individuals with disabilities and for programs that can assist them as well.

Judy lives alone; her children have graduated from high school and gone on to higher education and are economically self-sufficient. Judy enjoys the respect she has earned from her community and family as she has dealt with the challenges life presented to her. However, she limits her income to ensure the continuation of her SSDI benefits and HUD Section 8 housing assistance.

**Eric's Story.** Eric was self-employed when he was struck by heart problems that doctors first concluded would take his life in very short time. This crisis was created in part because his

lack of health insurance led him to avoid going to the hospital as long as he could. This delay almost cost him his life, and he now is quite limited in his physical activity.

Eric and his wife chose to sell their home, scale down, and find a house where all the functions Eric needed were on one floor. He now lives with his wife and four children in the suburbs. Eric and his wife used to own their own business but lost it while dealing with the medical trauma associated with the onset of his disability.

Eric had a neighbor that employed him on a part-time basis, doing telephone and office work. He was only a few semesters away from college graduation and felt like that education was the key to finding employment that could contribute to the financial stability of his family. With limited resources, the cost of his education was ultimately covered with the family's credit cards. Eric graduated in May of 2005 and is now looking for employment.

Eric knows his physical limitations and believes he needs to work from home. Eric wants to work for the government, doing background checks and verifications. He believes that he has all the skills he needs, and a college degree to prove it, but as of the time of the interview he had received no job offers. From Eric's perspective, the lack of the opportunity to work is the primary barrier to him earning more money.

**Carl's Story.** Carl is the only individual of all those interviewed to have had a disability from childhood. Carl has epilepsy; it is well-controlled with medications, and he knows his limitations.

Carl is married, but as of yet they have no children. Carl's wife works full-time, and they own their house and supplement their income with rent they receive from a relative who lives with them. Carl works part-time to contribute to the family income. He had the opportunity to work full time, but he would have lost his automatic Medicaid coverage, or would have had to

pay so much for Medicaid that it would not, from Carl's perspective, have been worth it financially. He could have received health benefits from his employer, after a waiting period, but, even then, the high co-payments for medications would have left him with less money than he brings in now.

Carl believes that if he could get a specific work certification he could increase his income to \$10 per hour. With that income, he claims he could get off SSDI and UMWI and make it on his own. He has not checked into available forms of educational assistance but has concluded that he cannot save enough to pay for the classes he needs until his family is finished re-paying SSA for an overpayment.

**Darla's Story.** Darla is a hostess at a local café; she cannot take the stress related to being a waitress. Prior to her mental health disability, Darla trained at a police academy and was employed by the sheriff's office. Darla has had depression for over 15 years, and two years ago was diagnosed with multiple sclerosis (MS).

Darla lives alone and has little or no family support. She went through a divorce a few years ago. Her husband did not believe she was truly physically or mentally ill. She said, "He told me it was nothing but me trying to get attention. He thought I could control it." Darla has adult children, though none live near her. She also has a brother who is well-off but lives out of state and does not understand her situation. She gave the following example. "And when my mom called my brother and told him I had been diagnosed with multiple sclerosis, his reaction was, 'Where did she get that from?' You know, like I had been out with somebody with AIDS or something." Darla's mother is still alive but over 80 years old and lives in a nursing home.

Darla had been depressed recently and had been judged suicidal. Talking about her depression and her future, she explained that Medicaid required a large co-payment for mental

health counseling and for the drugs that had been prescribed for her as well. Her therapist had been supplying her with free samples, but she indicated that these drugs, or level of medication she received, provided only limited relief.

**Beth's Story.** Beth has multiple sclerosis (MS) and is losing the use of her arms. What started out as a part-time job and hobby of making jewelry has become her only source of earned income. Her MS now is compromising her ability to do even that. To find a way to increase her earnings, Beth is looking at using the internet to market her jewelry. Believing that she lacks the skills she needs to do this, she has been attending seminars at the community college to learn and to network with other, more computer savvy, individuals who might be able to help her. In her view, she could become financially independent if she could find the right computer-related work opportunity.

Beth lives alone, but her parents live near by and she has a sister in Salt Lake. She owns her car, but would not have the money necessary should she need to replace it. She says when people ask her why she is so positive, she answers, "What do you want me to do? Make myself miserable." She explained, "I wish the circumstances weren't the way they are. But there is not anything I can do about that. You have to accept the changes and yea, it gets, I don't know. As far as I am concerned, some depression is a normal part of life." Beth needs shots that are over \$400 each once a month and other shots that are weekly. She has made arrangements with three different organizations to help her pay for the shots, including IHC Charity Care.

**Marge's Story.** Marge works part-time developing pictures at a local drug store. She suffers from depression and cannot deal with stress. She lives at home with her mother and an adult daughter. Marge feels that it is the lack of education that is limiting her work effort. She

had started a training program with the aid of VR but dropped out because she felt it was too difficult.

Marge talked at length about her struggles with the SSA regarding an overpayment. The overpayment put her into a difficult financial situation. She called attorneys and looked for help to fight SSA but was unable to find anyone who would take the job if it was worth less than \$50,000. The overpayment was “only” \$10,000, so she agreed to repay it. Marge recently had to refinance the home in order to pay off this overpayment by SSA.

**Shirley’s Story.** Shirley is a registered nurse who worked for a home health program. When asked if she was currently receiving SSDI she answered no. That information along with the income she reported indicated she was doing well. This is in a process of change, however. Shirley is not listed as receiving SSDI because she was in the process of appealing the denial of her claim for disability with SSA. Her list of physical ailments is growing, and so she is not sure which will be recognized. When asked about her conditions she read the following from a note book.,

“I started it on my fibro. Then after the fibro came numerous other things. I didn’t reapply but my lawyers sent in the other things that did come up. Because now, gosh, I’ve got a list here. I’ve got the fibro, then I have got osteoarthritis, and I’ve got a really significant hearing loss, in my right ear, and my left ear unto the point where well the doctor wants me to have hearing aids. But I won’t do that right now and he says just from the one year to the next year my hearing has decreased significantly. And I have got really bad tinnitus and it is really loud, sometimes it gets so loud I can’t even hardly hear what people say to me. I have to listen really hard. Chronic fatigue syndrome, I’ve got diabetes, type 2. Chronic leucopenia, I had a lymphoma in my scapula that I finally had removed. I’ve got bi-polar with severe depression, I had white matter lesions on my brain, I have a patent ferainimal valley in my heart, I have a diabetic nueropathy, IBF, myochronic jerks.”

Shirley was the only individual interviewed who was participating in a formal support group. She was also doing research on-line to learn more about her problems. Her children were

supporting her appeals for SSDI benefits. Shirley's husband, she says, does not really believe anything is wrong with her. They were talking about divorce for a while, but that has been put on hold for the time being. The couple had to file for bankruptcy when she went down to part time work, and SSDI is the only way she can see holding onto what little they have left.

**Jessica's Story.** Jessica was included in the interviews at the request of the Utah Health Department. She had heard of the study and had volunteered to participate even though she did not meet the inclusion criteria as she had changed jobs only a week before the interview and did not make over \$600 a month.

Jessica suffers from narcolepsy that can be ameliorated but not totally controlled by medication. She is married to a man who also has a disability and receives SSDI. He is a convicted felon and although he has a Department of Transportation certification for flagging, he finds it difficult to find regular employment. Jessica's husband encourages her and supports her working.

Jessica went to college for one semester and later found out about available VR services. VR provided her with the opportunity for training, but she found the training too difficult and quit. Because she quit, she feels like she cannot go back and try again. Jessica's new job is in the dietary department of a nursing home. She, however, needs glasses and struggles to read the dietary menus and instructions that differ from tray to tray. Eyeglasses are not covered in Disability Medicaid in Utah and so they are an expense she and her husband cannot afford.

### **Summary of Qualitative Analysis**

To pull together the themes that emerged from the qualitative analysis of the in-person interviews, we begin with an overview presented in Tables 22 and 23. Table 22 provides a

summary of the three financial self-sufficient storylines. The first three columns provide the storyline number, the types of disabilities, and the self-reported reason for not receiving SSDI cash assistance. The next column describes the health insurance coverage for the interviewees, and the current status listed in the final column indicates that all six people in these three storylines were financially self-sufficient at the time of the interview. Table 23 provides an overview of all interviewees, the six within the three storylines and the nine others who were still receiving SSDI assistance at the time of the interview.

Table 22 Storyline Comparisons for Financial Self-Sufficient Group				
Storyline	Disability	Reason for leaving SSDI	Health Insurance	Current Status
1	Physical. permanent	Could make more money; Values	Continues with EPAS or Group Insurance or Both	Stable self-sufficient
2	Physical, need assistance for shorter times	Never on SSDI	Group Insurance	Stable self-sufficient
			No insurance-will use Medicaid for emergency	Self-sufficient
3	Mental Health	Overpayment; He assumed he made too much	No insurance (CHIPS for children)	Self-sufficient

Table 23: Interview Participants (Pseudonyms) Summary

	SSDI	Employment & Education	Medicaid/ Health Insurance	Disability	Housing / Living arrangements (alone unless stated)
<b>Group 1: Financially Self-Sufficient</b>					
Jim	Never on	Scheduling for a governmental agency	EPAS only State certification Ins. through job	Quadriplegic Car accident	Lives with his mother, owns home
Michael	No	Computer graphics	EPAS only Ins. through job	Quadriplegic Car accident	Lives with wife and child (2 yr.). Just bought a home.
Richard	No	Teachers Aide in a computer lab	EPAS Only Ins. through job	Quadriplegic Car accident	Lives with his mother who owns home
Ruby	Never on	Nurse	No Ins. through job	Seizures Bi-Polar	Apartment attached to parents home
Robin	Never on	Bookkeeper for Husband's company	Not currently	End stage renal disease	Her husband provides for the family
Og	No	Computer trouble shooter	No	Mental Health	Lives with wife and child (14) in home owned by his mother
<b>Group 2: Still Receiving SSDI</b>					
Eric	Yes	Construction Crew manager. finishing college	Yes	Heart failure	Lives with wife and children (4,6,11) purchasing home.
Carl	Yes	Program assistant, wants more education	Yes	Epilepsy	Lives with wife in home being purchased
Joshua	Yes	Counselor (has a 4 year degree)	Yes	Schizophrenia	Apartment (Sec 8)
Judy (practice)	Yes	Advocate (has BS and MA)	Yes	Physical	Duplex (Sec 8)
Darla	Yes	Hostess at a café	Yes	Mental Illness	Buying home recently divorced
Beth	Yes	Makes jewelry self employed	Yes	Multiple Sclerosis	Rented home (Sec 8)
Marge	Yes	Photo shop assistant	Yes	Mental Health	Refinanced home (to pay SSA overpayment)
Shirley	No/ in appeal	Nurse	Yes State certification	Multiple problems	Lives with husband (divorce is possible), just refinanced home
Jessica (not eligible)	Yes	Food service	Yes	Mental health	Lives with husband who also has a disability & SSDI

With this overview in mind, the subsections that follow address five key factors that appear to affect the likelihood of UMWI participants achieving financial self-sufficiency. The first two of the factors, education and interpersonal support, can be thought of as enabling factors; the remaining three, disability, concern with losing benefits and limited opportunity for work, are constraining factors. These factors have been identified in previous research on increasing the work efforts of people receiving government assistance and so are not novel, but it is important to highlight them in this context, nonetheless.

**Education.** Education was the most evident common support for helping people with disabilities return to gainful employment. Four of the six people in the self-sufficient group reported benefiting from their education.

On the other hand, Og acknowledges that he needs education. Even though he has left SSDI and Medicaid and been successful in staying off for over a year, his self-sufficiency is tenuous. Computer certifications would increase the likelihood of his remaining self-sufficient. Similarly, Eric, not yet in the financially self-sufficient group, also recognized that education is important. He lacked three semesters required for graduating from a university and went back to college. He did not believe that he could get assistance from VR because he had a small part-time job, and so he paid for it himself using credit card debt. At the time of the interview, he was taking the last class he needed to graduate.

In sum, education is an important factor for financial self-sufficiency. Most of those classified as financially self-sufficient had adequate education, and several people still receiving benefits reported that they would have been better-off with more education.

**Interpersonal Support.** Interpersonal support is a broad construct which relates to emotional, social, and financial needs that could be met in a number of ways. This construct is

intended to capture situations where the person with a disability lives with, or interacts with, another person that is able to support the movement towards self-sufficiency. The most important source of interpersonal support for these interviewees was their families, but some also reported the positive influence of counselors and peers. Part of the support from family is likely to be emotional support and encouragement, but family members are also able to offer financial help in crisis situations.

All but two of the individuals in the group still needing SSDI, group 2, were single and living alone. On the other hand, all of the members in group one, the financially self-sufficient group, shared living space with another person, or others, to whom they were related. For example, immediately following his injury Jim went home to his wife. She knew Jim as an athlete and supported his rehabilitation. He never intended to file for SSDI; he only needed assistance with his medical and personal assistant costs. Jim is now divorced but lives with his mother, who also provides emotional support and is available to help in other ways. Similarly, Ruby lives in an apartment attached to her parent's home. She credits her mother with helping her sort through things and both of her parents for instilling a good work ethic in her. These two types of support helped her get back to work as soon as possible.

**Concerns with Losing Benefits.** Education and family support are presented above as important but insufficient in themselves. Joshua and Judy, for example, have all the education they need, but restrict their incomes to maintain benefits. Joshua is a counselor in a school system. He has a college degree and contributes extensively to the activities of the office, including writing grants. Joshua thinks he probably could be self-sufficient. Judy also received assistance from VR, not only to complete her undergraduate degree but to secure a Masters

degree as well. Yet, she makes sure her income does not exceed SGA in order to maintain her benefits.

Similarly, Carl believes that if he can just get a Certified Nurses Assistant (CNA) certification he could make nine or ten dollars an hour and could get off of SSI. He has epilepsy that is very well controlled by medications, making access to the medications critical. If Carl worked full time at the job he now has, he could get health insurance, but even then the co-payments on his medications would cost more than the additional amount he could earn. “We have actually looked at getting off benefits and getting on the work’s insurance. The spend down for the medication would be \$300 for the medication alone!”

**Opportunity to work.** Often overriding the fear of losing benefits is the difficulty in finding meaningful employment. Two issues stand out in this regard: (1) the degree to which available jobs appear secure and (2) the degree to which people are open to a wide range of job opportunities. With regard to job security, Joshua reports having the opportunity to work—right now—if he were more confident that he had an offer of secure employment.

“The reason I am not totally off SSDI right now, if I knew the future of [where I work], if the grant was going to be there year after year that kind of thing, I could go in right now and say put me down for full time, and I’ll just bag social security. Something that I could control right now and they would do it. Got to wait to see if [the]grant is funded.”

With regard to openness to various opportunities, Eric is finishing college and reports being ready to risk leaving his SSDI benefits behind, but he has not found the employment opportunities that he wants. As is illustrated in the following quote, he has a specific job in mind that may or may not be realistic given the competition for this type of job.

“Now if I went to work for the Federal Government, all it requires is a Bachelor’s degree to do background checks. I have been pursuing that. That is an area where I could score, but so far I have not been able to get into it. I find that every retired police officer in

America is trying to get into that job. So far it has been a dead end. I wish I could find the key to get into that.”

With the proper skills, a narrow focus on only certain kinds of jobs can be successful.

For example, Ruby was able to secure employment in her chosen field via a newspaper advertisement because she is a nurse and there is a current need for nurses in Utah. Accordingly, she was able to choose where she works from among many alternatives. On the other hand, employment in family-owned or family-operated businesses would likely require a willingness to work in whatever way is needed by the family business. For example, Robin works for her husband, who owns the business. She contributes because she is willing to manage the office tasks that her husband does not have time to do. Benefits of such a family employment opportunity can include a willingness to hire someone with a disability and greater flexibility in accommodating the special needs that some persons with disabilities can bring into the workplace.

**Nature of Disability Limitations.** Finally, all of the individuals interviewed were dealing with serious physical or mental health problems. For some, such as those in the first storyline as well as Carl, the associated disabilities can be managed with the right support. For others, however, such as Eric, Darla, and Beth, the limitations imposed by their disabilities will likely get worse and will continue to complicate efforts to attain financial self-sufficiency. Highlighting the nature of the disability as a constraining factor may seem sufficiently obvious to warrant little attention, particularly given the absence of policy solutions for this source of work constraint. Nonetheless, it is important to recognize that confidence that the disability was manageable and stable was essential to having the confidence to forgo SSDI assistance. Further,

this confidence seemed easier for some with physical disabilities than for those with mental health disabilities.

## **Discussion**

Among the goals of the survey and the interviews were to understand better the impact of the Utah MWI program on participants and to differentiate who used the program to move towards financial self-sufficiency and who instead restricted their earnings in order to remain eligible for various disability benefits. Without attempting to review all of the findings presented above, three issues warrant conclusions.

### **Programmatic Issues**

**Awareness of UMWI Program.** First, awareness by participants of the basic features of the UMWI program (higher limits on income and assets) is too low, even among those who are or have been enrolled in the program. This may matter even more because of the higher levels of awareness among those who have experienced a large gain in quarterly wages. If more individuals were aware of the UMWI features, potentially more would be willing to increase their income. Part of the lack of awareness can be explained by caseworkers who have moved clients from the Spend Down program to the UMWI program when the UMWI program would cost them less. The lack of awareness of the UMWI features, however, is broader than this one explanation.

Awareness of other Utah employment support programs is also too low. While it might be expected that the EPAS program, which makes personal assistants available for supporting employment, would not be needed or known about by the majority of the UMWI recipients,

benefits planning was rated as useful by around 80 percent of the recipients. Yet, of those who judged it useful, only a few (around 15%) were aware that a program like BPAO existed in Utah. Significantly, those in the Large Gain group were much more likely to be aware of the BPAO program.

**Perceived Importance of UMWI Program.** Around three-fourths of all recipients view the UMWI program as being important in supporting their work effort. More important, this view is even more common among those in the Small Gains and the Large Gains groups. Furthermore, among those who are aware of the two UMWI program features, increased limits on income and assets, almost all view them as very important.

### Level of Work Effort

Three-fourths (75.6%) of the telephone survey respondents were working at the time of the interview, with around 10 percent of those working being self-employed (9 of 87) and the rest working for someone else. The highest percent unemployed was for the Stable group (32.7%); this finding, along with those reported in other tables, suggests that many in the Stable group are using the UMWI program more as a way of managing health care costs than as a work support.

The average number of hours worked per week was just over 20 hours (20.2 hours per week). The average monthly earnings at the time of the telephone interview was \$636, well under the limit for Substantial Gainful Activity limit that would result in loss of SSDI cash assistance. This is consistent with the findings of the in-person interviews, with respondents reporting that they were limiting their work efforts to remain under SGA. Nonetheless, those in the Small and Large Gain groups show evidence of increasing their number of hours worked, their monthly earnings, and their work responsibilities.

## **Factors Affecting Work Effort**

**Education.** Education emerged as a key factor in the in-person interviews as well as being a notable factor in the cross-tabulation tables and in the regression analysis. Most of those who were financially self-sufficient had gone to college, and the lack of relevant education was a reported barrier by several who were not financially self-sufficient.

**Age and Gender.** Age and gender were related to the level of wage change. As expected, the Large Gain group had the lowest average age, and the Large Loss group had the highest average age. Similarly, the multiple regression analyses showed increasing age to be associated with lower monthly earnings at the time of the interview. This consistent finding of wages being related to age is often used to argue for greater efforts to intervene earlier with work support programs, both earlier with regard to age and with regard to the time after a disability occurs. The in-person interviews also suggested the importance of returning to work relatively soon after a disability occurs, or at least after major complications are managed.

Gender was important in that less than a quarter of the Large Loss group was male, whereas a majority was male in the Small Gain (73.9%) and the Large Gain (58.3%) groups. This finding is supported by the similar findings in the multiple regression analyses that showed higher monthly earnings for males (\$316 higher monthly earnings for males in the analysis with only demographic variables). Some gender effect was expected, but the magnitude was quite large and warrants additional attention to understand if women face other job barriers or instead are more likely to choose not to work. The in-person interviews found too much variation in outcomes and barriers to support any particular explanation for this wage gap, such as lower hourly wages available for women or lower work motivation.

**Interpersonal Support.** Interpersonal support, often from family members, was noted as an important factor in the in-person interviews. Indeed, all of those in the Financial Self-Sufficient group reported some form of family support. On the other hand, the survey data revealed an interesting pattern regarding marriage, which is often viewed as an important source of interpersonal support. Whereas those who had never been married were by far the most likely to be in the Large Gain group, the multiple regression analyses showed being never married to be associated with lower earnings at interview (\$167 per month less than those who were or had been married). One possibility is that those who were never married had more severe disabilities but that the UMWI program was particularly effective in drawing in these people who went from earning very little to somewhat higher earnings.

**Type of Disability.** Finally, whereas a majority of those in the Large Loss group had physical disabilities, a majority of the Large Gain group had mental health disabilities. This warrants more attention in that it would suggest that people with physical disabilities are experiencing a disruption to earnings shortly before enrolling in the UMWI program. In contrast, those with mental health disabilities were more likely to have long-term problems and to experience an increase in employment around the time of UMWI initial enrollment.

Interestingly, however, is that the multiple regression analyses revealed that those with physical disabilities tended to have higher monthly earnings at interview time than mental health respondents. This indicates a greater gain in earnings after enrollment for those in the mental health group but higher overall earnings for those in the physical disabilities group. This suggests that people with physical and mental health disabilities are using the UMWI program in different ways to address their differing needs.

## **Conclusions**

In conclusion, this study found that the Utah Medicaid Buy-In program (UMWI) is valued by participants but not fully understood; participants are also largely unaware of other employment support services offered by the State of Utah. Program participants tend to restrict their earnings so that they do not lose medical, housing, or cash assistance benefits. Earnings tended to be highest for those who had earned an undergraduate degree, were younger, were male, and had a physical disability (as opposed to a mental health disability). Where the UMWI program is effective in increasing the work efforts of program participants, it seems to be the result of a confluence of supportive influences—interpersonal support, secure housing, appropriate education and/or training, and a stable health condition. When these supportive factors are present, the participants are more likely to accept job offers for more pay and/or more hours that result in their transitioning off SSDI cash assistance.

## **References**

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