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The MaineCare Option for Workers with Disabilities: A Survey of Past and Present Enrollees

August 2002

MUSKIE SCHOOL

The MaineCare Option for Workers with Disabilities: A Survey of Past and Present Enrollees

Report on a 2001 Survey by the Maine CHOICES Project

(Continuing Health Options and Incentives via Coordinated Employment Supports)

August 2002

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The MaineCare Option for Workers with Disabilities: A Survey of Past and Present Enrollees

Background

This report describes the results of a telephone survey of enrollees in the MaineCare[1] Option for Workers with Disabilities.[2] The Workers with Disabilities (WWD) Option is a MaineCare eligibility category that provides full MaineCare coverage for working people with disabilities who have countable income up to 250% of the Federal Poverty Level (FPL) and who do not have unearned income above 100% FPL.[3] The purpose of the WWD Option is to encourage people with disabilities to increase their job earnings without fear of losing health coverage.

The Bureau of Elder and Adult Services (BEAS), Maine Department of Human Services, commissioned the survey to find out more about the people who were or ever had been enrolled in the WWD Option. BEAS wanted to know about their work experience, their support services needs (particularly their use of personal assistant services), and their opinions and concerns about receiving health coverage under the WWD Option.

Methodology

The survey population included everyone who ever had MaineCare coverage under the Workers with Disabilities Option from the program's implementation in August 1999 through May 2001. A total of 906 people fit this description. The table below shows how many people were contacted and how many participated in the survey.

Number with Workers with Disabilities Option coverage at any time from August 1999 - May 2001	906
Number not contacted because known or suspected to be under legal guardianship	-66
Number with invalid telephone information	-197
Number with valid telephone information and permission to contact	643
Number not reachable after 10 telephone attempts and 1 follow-up mailing	-104
Number who refused to complete the survey	-55
Number of completed surveys	482

[1] Effective July 1, 2002, the name of Maine Medicaid was changed to MaineCare.
[2] The Workers with Disabilities Option is Maine's "Medicaid Buy-in" for people with disabilities who have job earnings, which began August 1999. It was enacted under authority of the Balanced Budget Act (BBA) of 1997.
[3] In determining eligibility, a portion of earnings is not considered "countable" income, so enrollees' actual income may be higher than 250% of FPL.

In all, there were 643 people in the survey group who were not under legal guardianship (or we had a guardian's permission to contact them) and had valid telephone numbers. There were 482 completed surveys, for a response rate of 75%.

Before being contacted by phone, members of the survey population received a letter from the Bureau of Elder and Adult Services explaining the survey and offering accommodation to any person not able to use the telephone. The survey was conducted by trained interviewers of the Muskie School's Survey Research Center using computer-assisted telephone interviewing (CATI) technology (one person participated in the survey using a TTY relay). Interviewing began in August 2001 and was completed in January 2002.

The survey consisted of approximately 65 to 90 questions, depending on whether the respondent was working at the time of the survey.[4] On average, the survey took 15 to 20 minutes to administer, but the time varied considerably from one respondent to another due to skip patterns based on work status and the respondent's willingness to talk.

Of the 906 people in the total survey population, 548 people (60%) were still enrolled in MaineCare under the Workers with Disabilities Option at the time of the survey, and 358 (40%) were former Workers with Disabilities Option enrollees. Of the former enrollees, 247 were enrolled in MaineCare under some other eligibility category and 111 were no longer enrolled in MaineCare at all.[5]

Not surprisingly, the survey completion rate was somewhat higher among current MaineCare enrollees, whether Workers with Disabilities Option or some other category, than among people no longer enrolled in any MaineCare category. This could be because the telephone information for current enrollees is more likely to be up-to-date or because non-enrollees may be less motivated to participate in a survey about a program from which they no longer benefit.

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[4] A copy of the survey instrument is available from the authors.

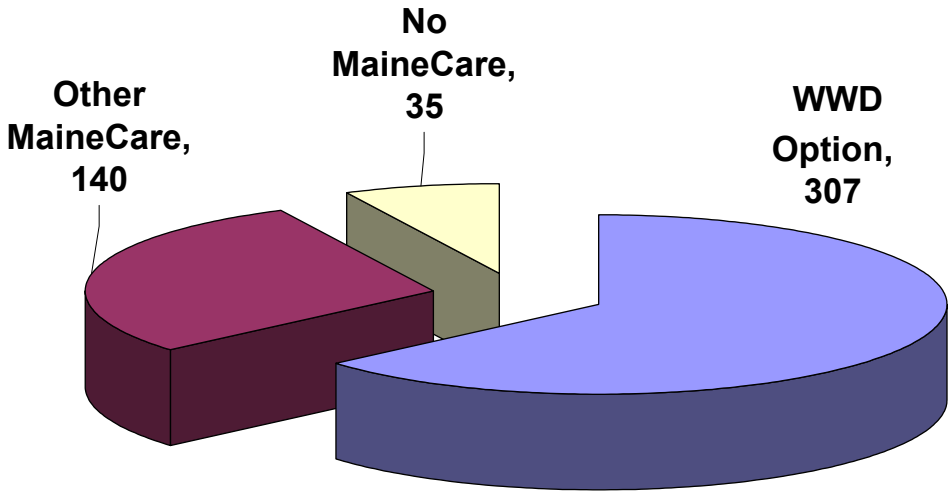
[5] For purposes of this survey, "other MaineCare" only includes enrollment categories providing full benefits. For example, enrollment categories which provide only partial benefits, such as Healthy Maine Prescriptions, were not included.

Survey Results

1. MaineCare enrollment status

Of the 482 completed surveys, 307 (64%) were with people currently enrolled in the Workers with Disabilities (WWD) Option, 140 (29%) with those no longer enrolled in the WWD Option but enrolled through some other category of MaineCare, and 35 (7%) with those no longer enrolled in any MaineCare category.

Figure 1. MaineCare (Medicaid) status at time of survey

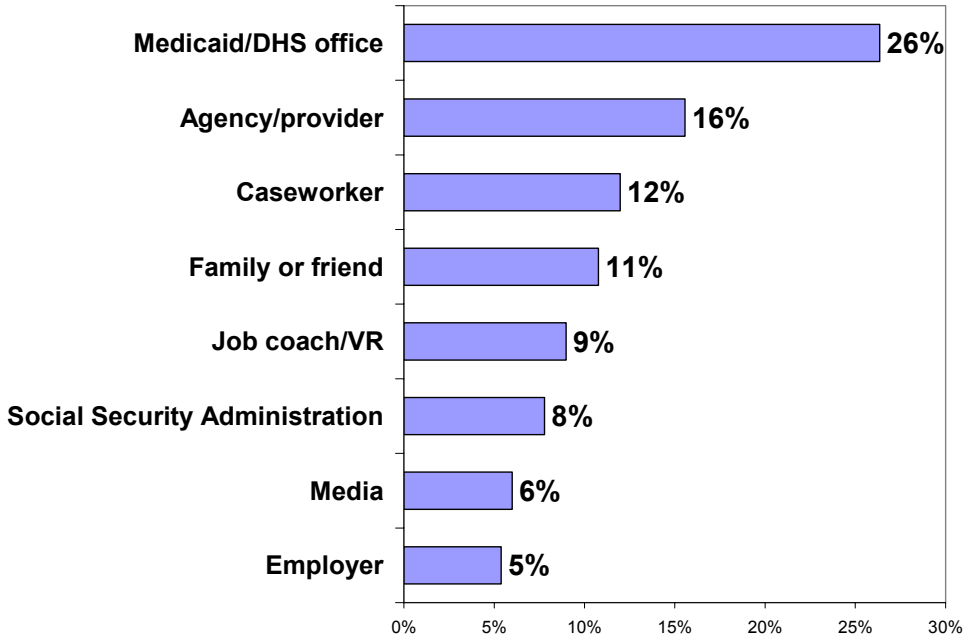


Most survey respondents – about 64% - had never heard about the Workers with Disabilities Option. Even most of those currently enrolled in MaineCare under the Option were not aware that their MaineCare coverage was through the Option: Only about one-third knew their coverage was under the Option.

Lack of knowledge about the Workers with Disabilities Option may indicate that the Option is successful in providing "seamless" coverage. As a MaineCare enrollee's earnings increase, their eligibility category may change from one based on low income to one based on increased earnings. Because enrollees not required to re-apply to take advantage of the different eligibility category, it is not surprising for enrollees to be unaware of the change. On the other hand, lack of information about the higher earnings limits allowed under the Workers with Disabilities Option may be preventing some people from taking advantage of the opportunity to increase their earnings without fear of losing MaineCare benefits.

Among those who knew about the Workers with Disabilities Option, most respondents had first heard about it from the Medicaid office, agency or provider, a caseworker, the Social Security Administration, a friend, Vocational Rehabilitation (VR), or the media. The relatively low numbers of people hearing about the WWD Option through the media or employers may suggest opportunities to improve outreach through those avenues.

Figure 2. Source of information about the Workers with Disabilities Option



2. Demographic information

Of those surveyed, most people covered under the Workers with Disabilities (WWD) Option were age 45-64, with only about 7% age 65 or older (Figure 3 below). The age distribution for those no longer covered under the Workers with Disabilities Option but now covered under another MaineCare category was similar, although there are slightly higher proportions in the older age group and the younger age group.

Most people surveyed were not married, although those with MaineCare coverage under the WWD Option were most likely to be unmarried, compared to those no longer covered under the WWD Option (Figure 4 below). The somewhat smaller proportion of married people on MaineCare may be related to the fact that a spouse's earnings count toward determining an enrollee's eligibility. Comments from survey respondents suggested that a spouse's earnings were sometimes the cause for enrollees losing MaineCare eligibility.

Figure 3. Age

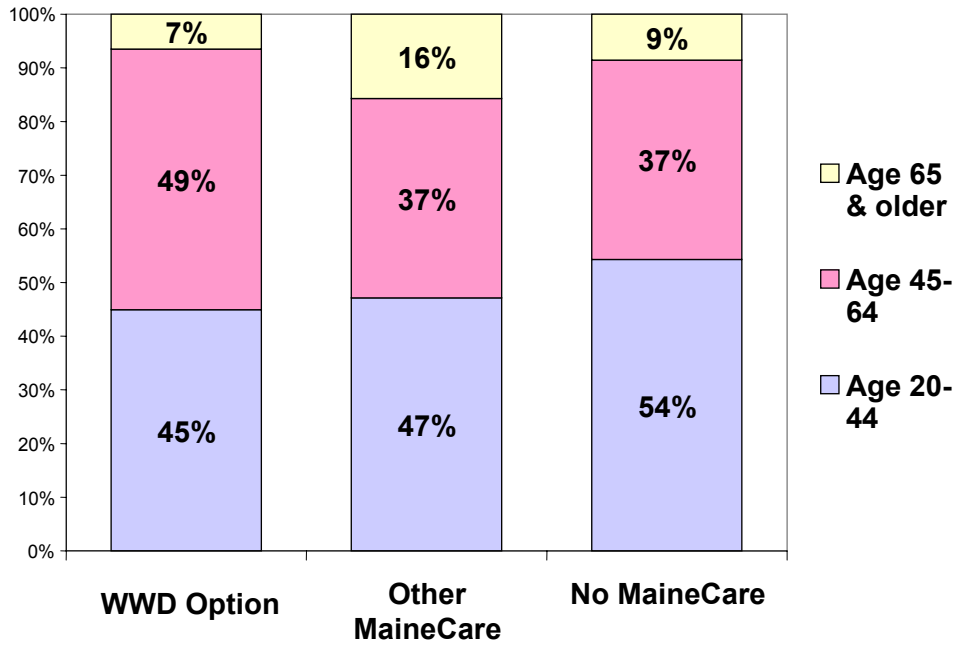
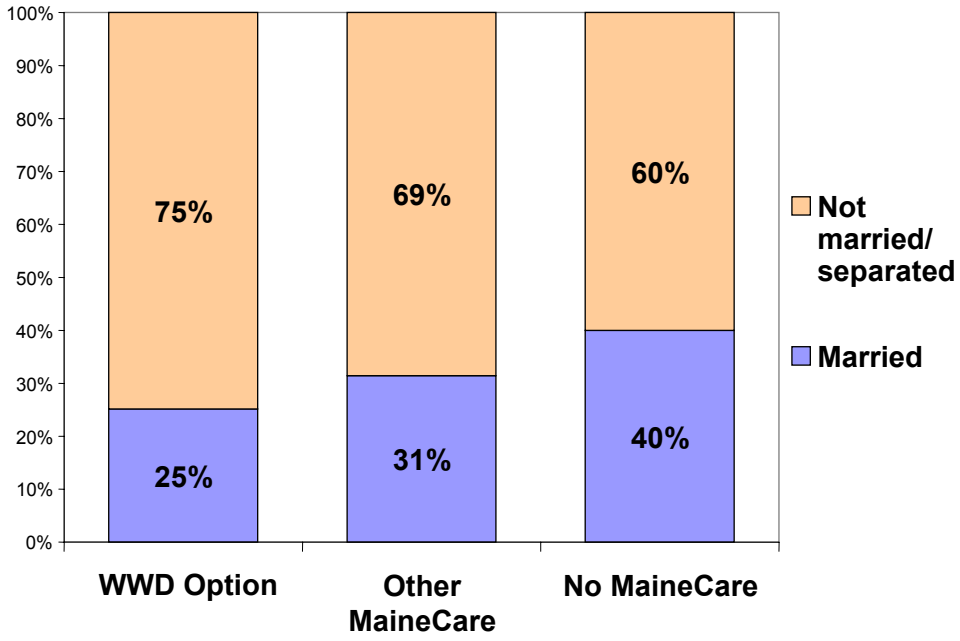


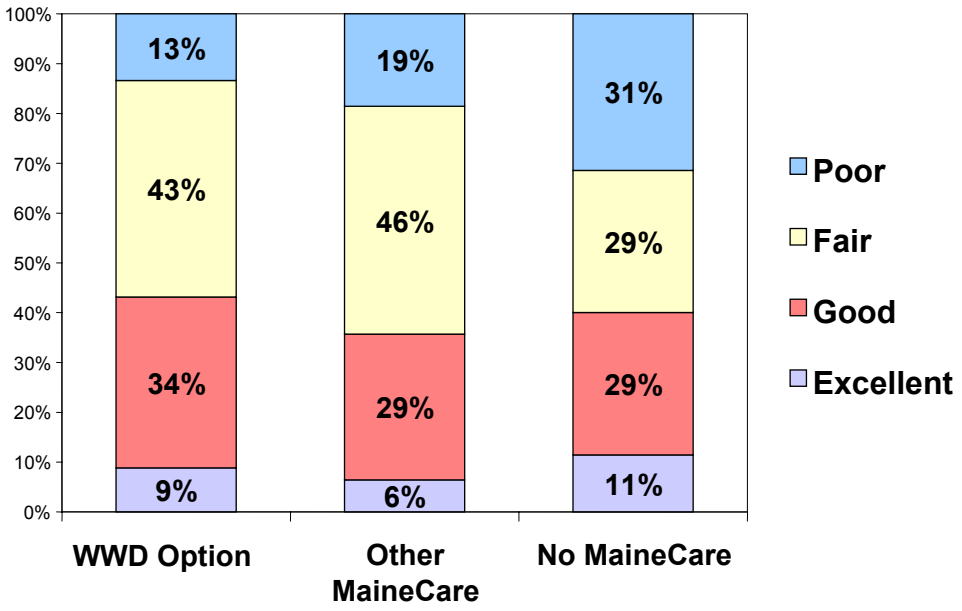
Figure 4. Marital status



3. Health and disability

Only about 41% of survey respondents overall reported that their health was "excellent" or "good"; 43% reported "fair" health and 16% reported "poor" health. People covered under the Workers with Disabilities (WWD) Option were less likely to report poor health status than the other groups, particularly compared to those who no longer have any MaineCare coverage. But when those reporting either good or excellent health are grouped together, the proportions are similar across the three groups.

Figure 5. General health



The survey asked respondents to identify their primary disability; respondents could also identify up to 6 additional disabilities, conditions or impairments. Responses were recorded as text and were categorized at the analysis stage (respondents were not asked to categorize their disability, condition or impairment). About 10% of respondents did not report any disability. More than 60% reported two or more disabilities. Figure 6 (below) shows the 10 most frequently mentioned disabilities, conditions and impairments that respondents identified as their primary disability. Figure 7 (below) shows all types of disabilities, conditions and impairments reported by respondents, whether primary or not (respondents could identify up to seven altogether).

The high frequency of mental illness, back problems and heart problems is generally consistent with disability prevalence information from other sources, including those based on providers' medical diagnoses. The predominance of mental health-related disabilities and conditions is clear and suggests the need to pay particular attention to issues related to those types of disabilities. In addition, further analysis is needed to identify co-occurring disabilities and

possible differences in employment patterns and support needs for people with different types of disabilities.

Figure 6. Most frequently mentioned primary disability, condition or impairment

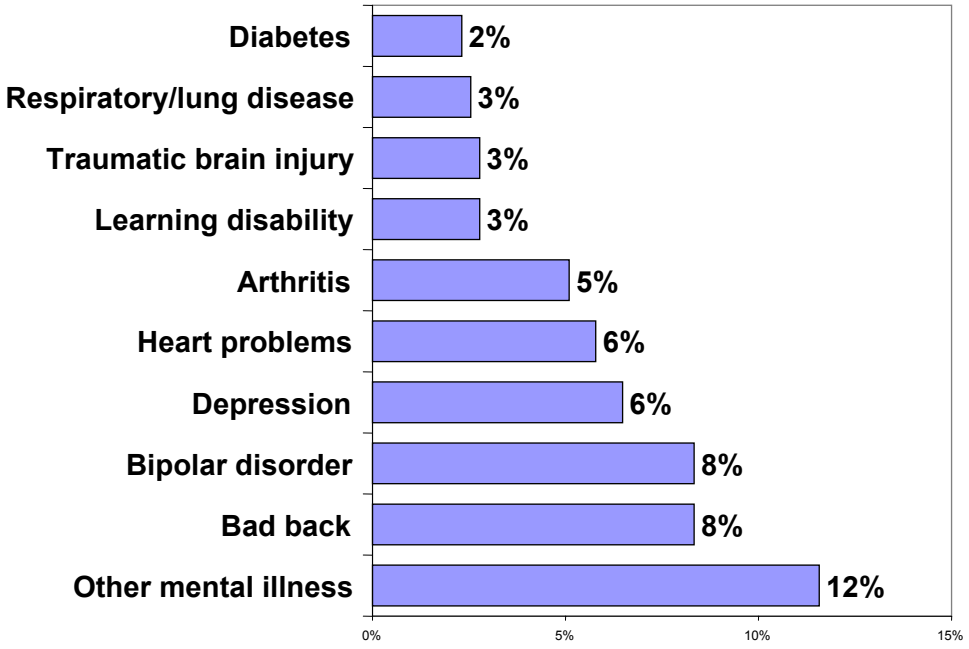
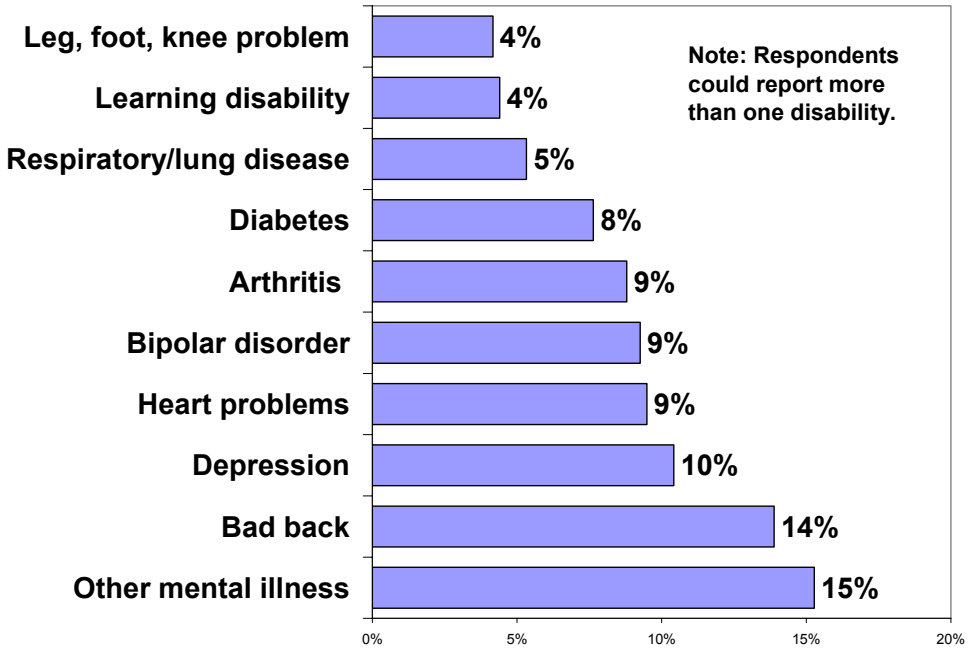


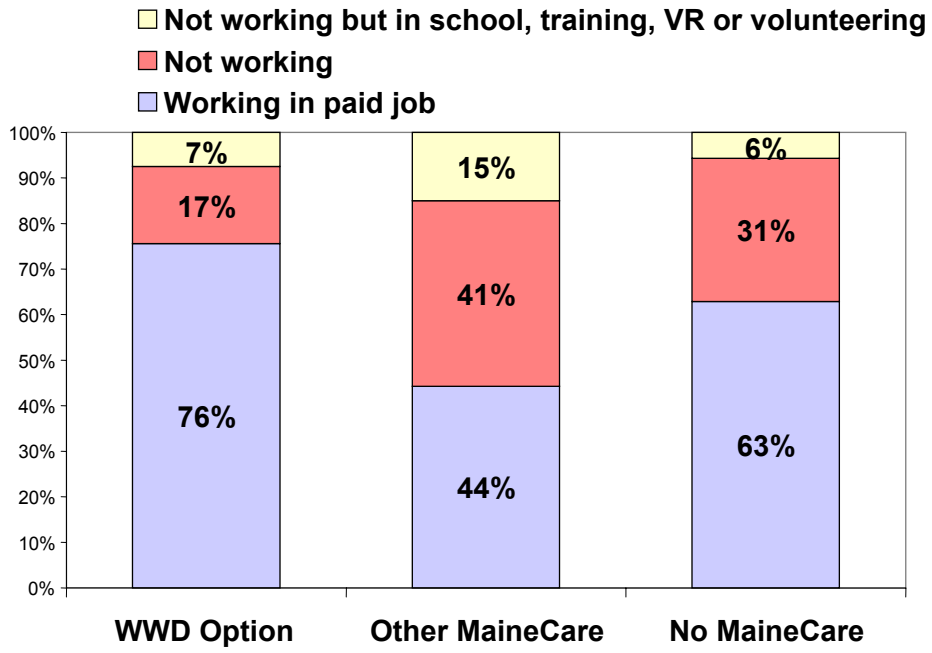
Figure 7. Most frequently mentioned disabilities, conditions or impairments



4. Employment

About 76% of survey respondents who were on the Workers with Disabilities (WWD) Option at the time they were surveyed said they were working in a paid job. For those in other MaineCare eligibility categories at the time, about half of them were working in paid jobs; for those no longer covered under any MaineCare category, about 63% were working in a paid job. Many survey respondents not in paid jobs were doing volunteer or unpaid work, going to school, getting job training, participating in Vocational Rehabilitation, actively looking for work, or engaged in a combination of these activities.

Figure 8. Employment status

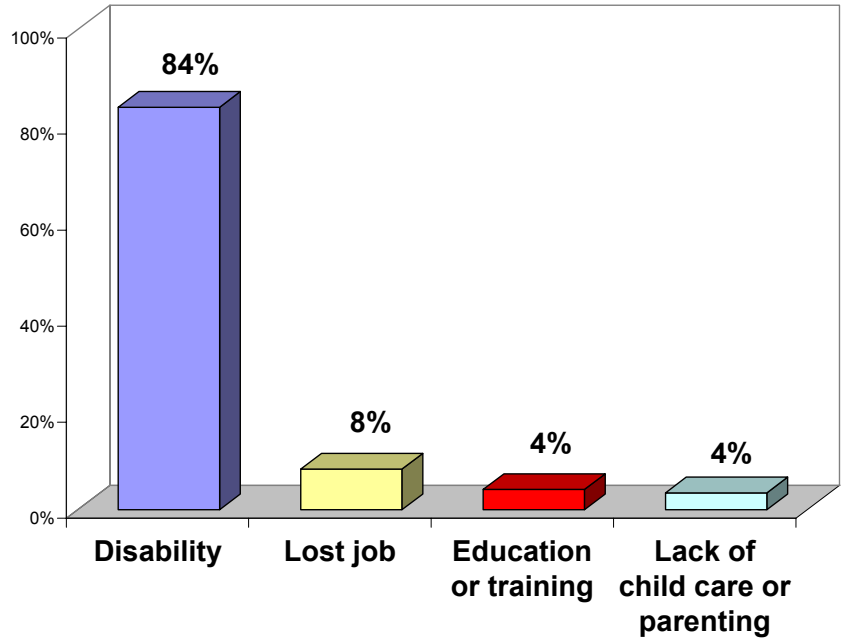


Disability was by far the reason given most often for not working in a paid job (Figure 9 below). Other reasons were the loss of a job, the need for more education or training, and the lack of childcare or full-time parenting responsibilities. Respondents did not mention transportation problems or inadequate personal assistance as reasons they were not working.

About 40% of all respondents who were not working in a paid job at the time of the survey said they expected to be working for pay in the next 12 months. Among those on the WWD Option but not working, about 45% said they expected to be working within the next year, while only about 34% of those no longer on the WWD Option expected to be working. Across all groups, about 15% did not know whether they expected to be working within the next year.

When asked why they did not expect to be working, the reason given by most people – about 75% - was their disability.

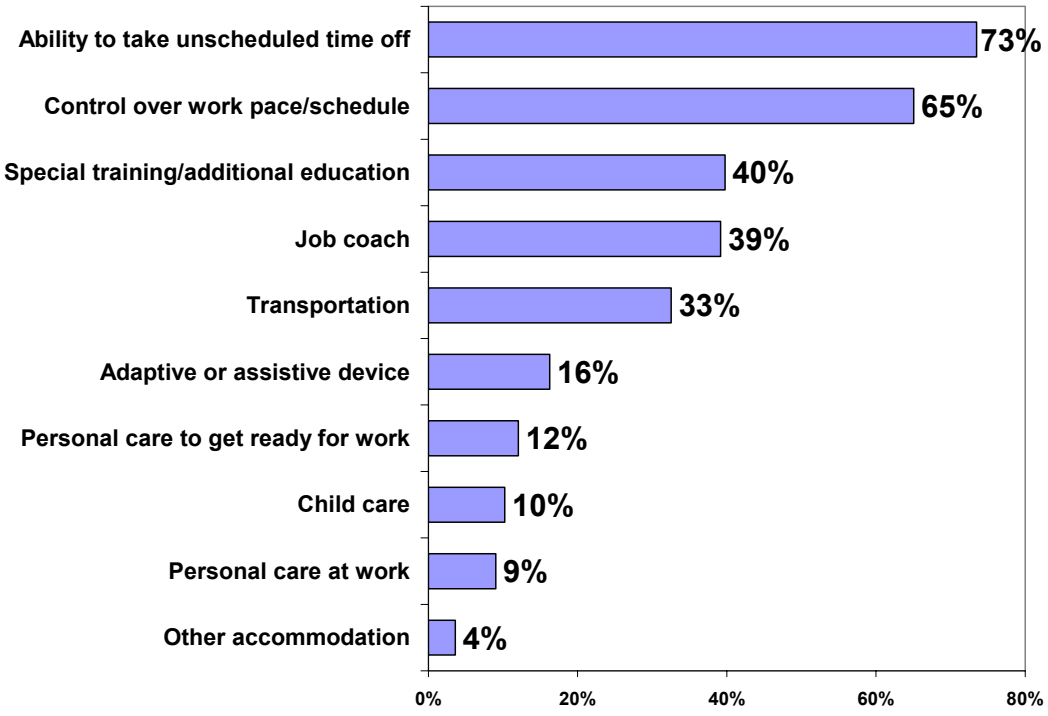
Figure 9. Reasons not working in a paid job



Whether respondents expected to work in the next 12 months or not, they were asked what work supports they would need. They were questioned specifically about nine different kinds of work supports ranging from personal assistance services to adaptive equipment to child care. Figure 10 (below) shows how many people indicated they would need particular support services. The supports identified most frequently were the ability to take unscheduled time off, control over or flexibility in work pace or schedule, and special training or additional education. About 9% of respondents (15 individuals) said they would need personal care at work and about 12% (20 individuals) said they would need personal assistance or other help at home to get ready for work.

The anticipated needs of people not working at the time of the survey are similar to the actual work-related needs of survey respondents who were working (see Figure 16).

Figure 10. Anticipated work support needs for those not currently working



As noted above, almost 70% of all respondents said they were working in a paid job, including about 76% of those on the Workers with Disabilities Option and about 48% of other respondents (see Figure 8). Working respondents were asked what kind of work they did and eight job categories were created based on an analysis of the responses, which are shown in Figure 11 (below). Of the 316 respondents who said they had paid work, about 65% worked in service jobs. Service jobs included retail sales and cashiers, custodians, personal care workers, and telemarketers, for example. Respondents could identify up to four paid jobs. Eighteen individuals said they worked more than one paid job.

Most people working at the time of the survey said they had worked at their current job for more than a year. A large proportion – 45% - said they had worked more than two years at their current job, while about 18% had worked at their current job less than six months (Figure 12 below).

Figure 11. Type of paid jobs

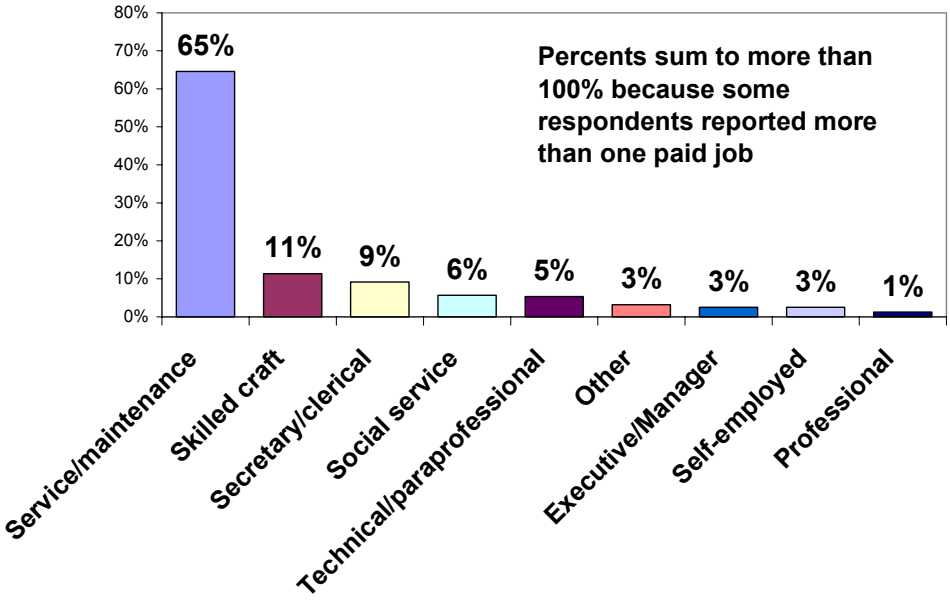
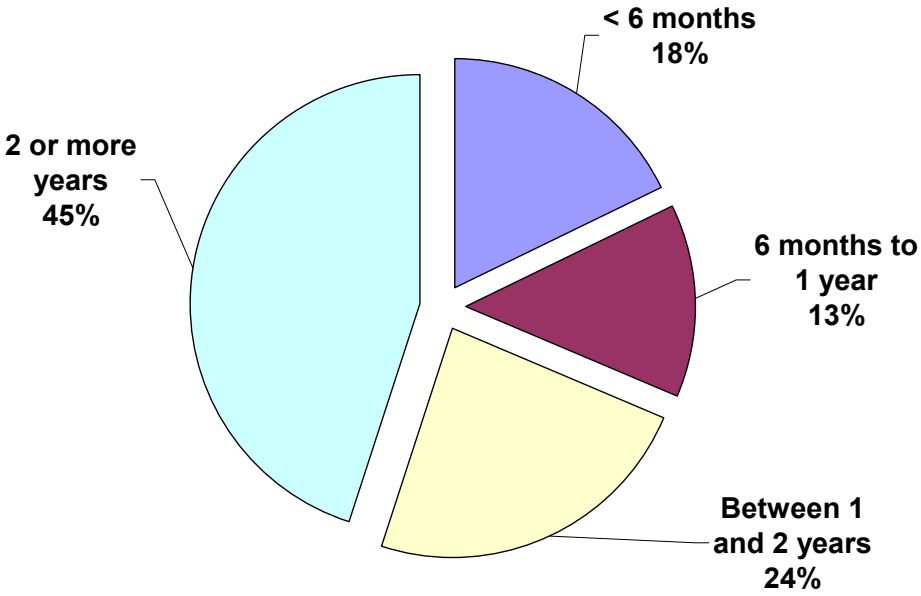
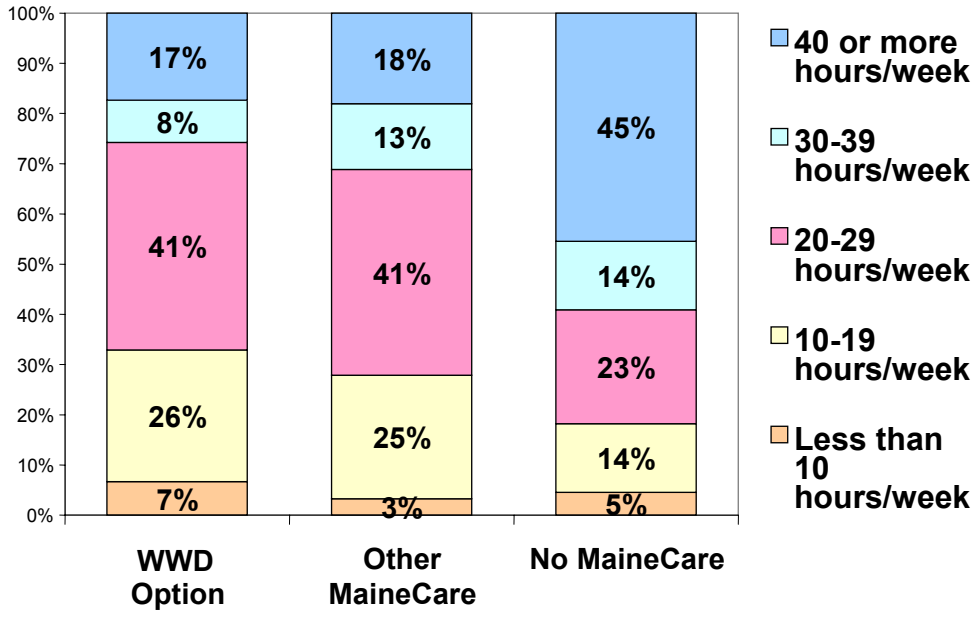


Figure 12. Length of time employed



Most people with MaineCare coverage under the WWD Option said they worked more than 20 hours per week and about 17% reported working 40 or more hours per week. The number of hours worked per week was similar for people on the WWD Option compared to people in other MaineCare categories. But workers no longer receiving any MaineCare coverage typically worked more hours per week compared to other respondents (however, the group of survey respondents with no MaineCare coverage is small, so it is difficult to draw firm conclusions).

Figure 13. Hours worked per week



Most working people in the survey – 264 people, or about 84% – were paid on an hourly basis. Of these, the largest proportion earned $8 or less an hour (Figure 14 below). Only about 3% earned $12 per hour or more. Compared to workers with MaineCare coverage, a larger proportion of workers no longer on MaineCare appeared to earn wages in the $10-$12 category, but there were too few people in this group to draw firm conclusions. These results do suggest, however, that too few workers with disabilities are holding jobs that allow them to earn what could be called a "living" wage.

Most people surveyed who were working reported that their employers offered health insurance (Figure 15 below). Former WWD Option enrollees who no longer had any MaineCare coverage were the group most likely to work for employers that offered health insurance, with 77% of them reporting that their employer offered insurance. Still, more than half (63%) of those with MaineCare coverage under the WWD Option worked for employers offering health insurance. The group least likely to work for an employer that offered insurance was those who were on MaineCare under a category other than WWD Option; 47% of them reported that their employer offered insurance.

Figure 14. Job earnings for hourly workers

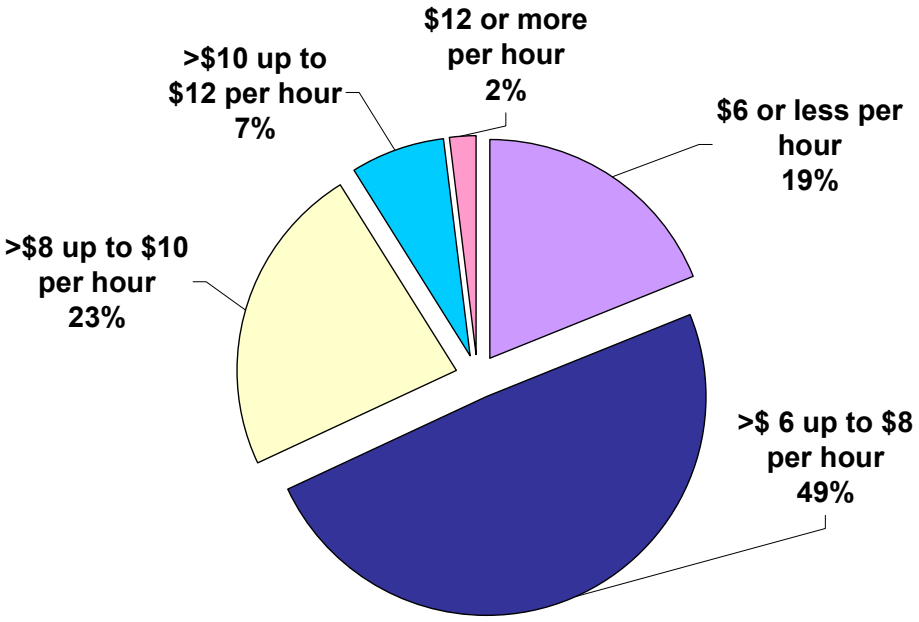
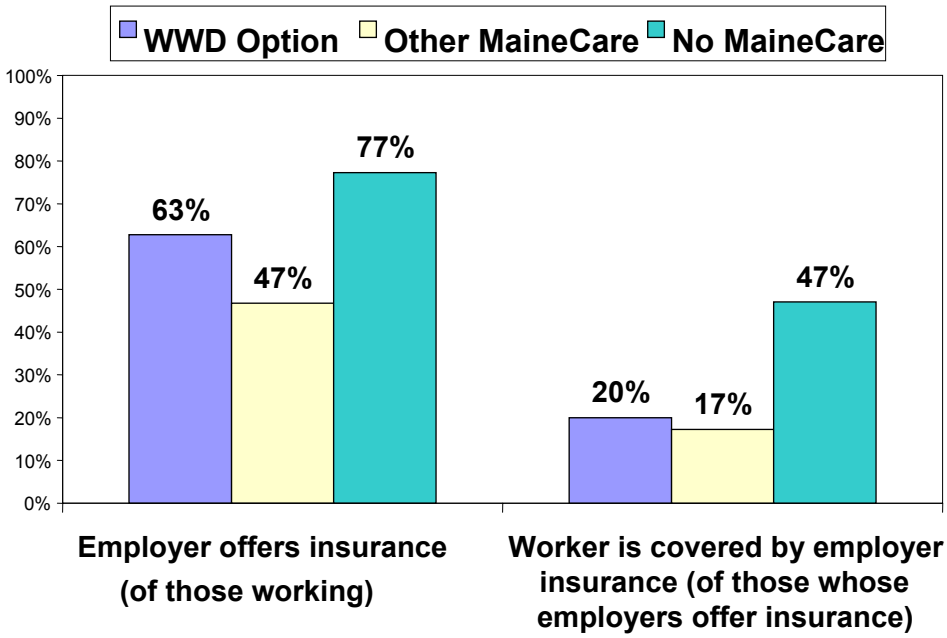


Figure 15. Employer-based insurance



Unfortunately, those who worked for employers offering insurance were not likely to be covered by that insurance, especially among people with MaineCare coverage. Only about 20% of those covered under the Workers with Disabilities Option, whose employers offered insurance, were covered under their employers' insurance. This is in contrast to those not on MaineCare; almost half of this group – 47% - were covered under their employers' health insurance.

Most of those not covered by employer-based insurance said they were not covered because they don't work enough hours. A substantial number of people said they were not covered because the employer-based insurance was too expensive. These reasons echo the health insurance access problems confronting all Americans, but the health needs of people with disabilities make access issues particularly important.

5. Work-related Supports

Each working person was asked specifically about the following supports or working conditions they used to be able to work:

- Personal care at home to get ready for work
- Transportation assistance
- Child care
- Job coach
- Personal care at work
- Special training
- Adaptive or assistive device or technology
- Control over work pace or schedule
- Ability to take unscheduled time off

Survey respondents were also asked to identify any other support services or working conditions they used in connection with work. For each support service or working condition, those surveyed were asked to say whether they used it and if they did, whether they had enough or needed more of it. If they did not use it, they were asked whether they needed it.

Of the 316 people who were working in paid jobs when surveyed, only 65 of them (about 21%) did not use any work-related supports. Figure 16 (below) shows the most commonly-used supports or working conditions.[6] The two most frequently mentioned supports or working conditions were the ability to take unscheduled time off and having control over one's work pace or schedule. Transportation, job coaches and special training were also used by many workers.

Relatively few people used personal care at work and only one person indicated he or she needed that type of support and was not getting it. Low reported use of personal care among working people could be because people with personal care needs during the work day are less likely to work outside the home. Among those *not* working, about 9% (15 individuals) indicated they would need personal care at work if they started working (see Figure 6 above).

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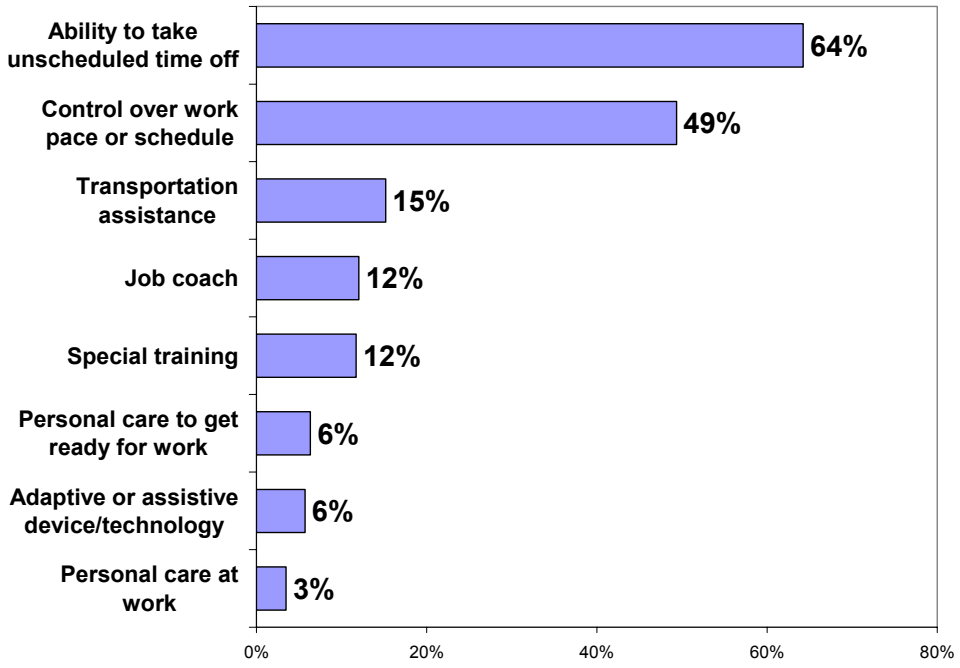
[6] The "Other" category includes supports or working conditions that were mentioned by at least 1 but not more than 10 people surveyed; the category includes vocational rehabilitation, medical/physical accommodation, child care, psychological services, stool or seat, case worker, education/training, and assistance with job tasks.

Figure 16. Use of work-related supports



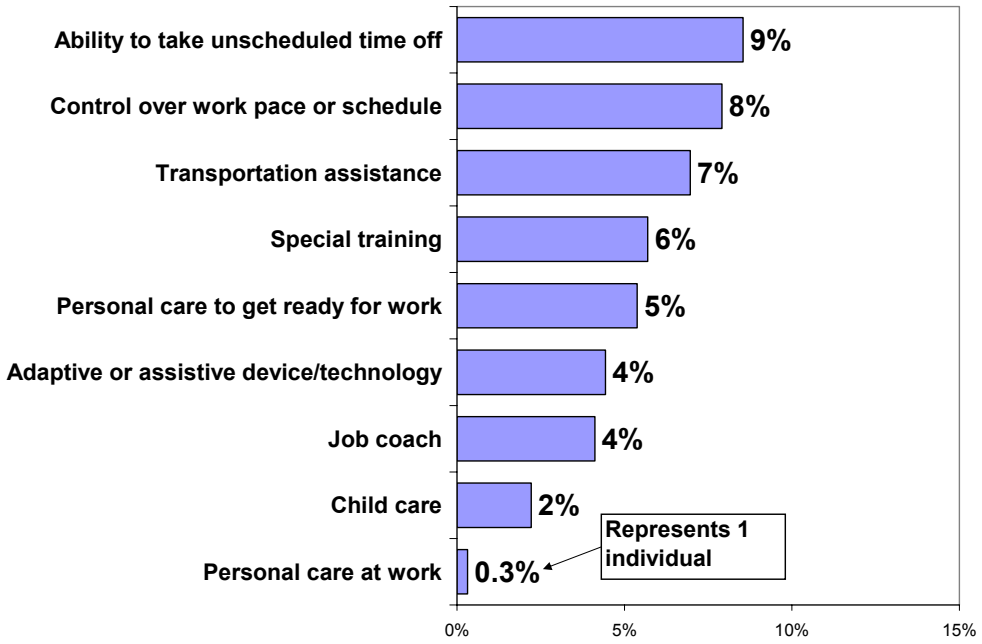
The survey identified unmet needs among the working population by asking people not using a particular service whether they thought they needed it, and by asking people using the service whether they needed more of it. Based on their answers, people were put into one of four categories with respect to each service:

1 – use the support and have enough
2 – use the support but need more
3 – do not use the support but need it
4 – do not use the support and do not need it.

Figure 17 (below) shows the proportion of people with unmet needs – categories 2 and 3 - for particular supports or working conditions. The need to control one's work pace and schedule and the need to take unscheduled time off were the top two unmet needs among people in the survey; forty-two individuals said they had unmet needs for one or the other of these, or both. Other frequently mentioned unmet needs were help with transportation and special training.

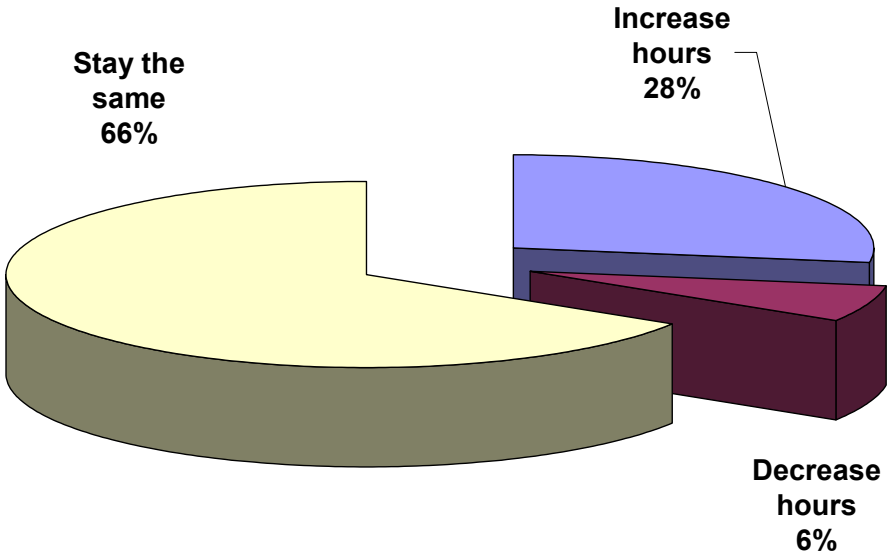
These results suggest that employers can help meet the work-support needs of many people with disabilities by simply providing greater flexibility in scheduling and work pace. Further analysis of the results will identify the type of work-related needs associated with specific types of disabilities.

Figure 17. Unmet needs for work-related supports



Persons who were working at the time of the interview were asked whether, during the next 12 months, they wanted to increase, decrease or keep the same number of hours they were working. Figure 18 illustrates that most of those surveyed wanted to keep their level of work the same, but a substantial number – about 28% - wanted to increase their hours.

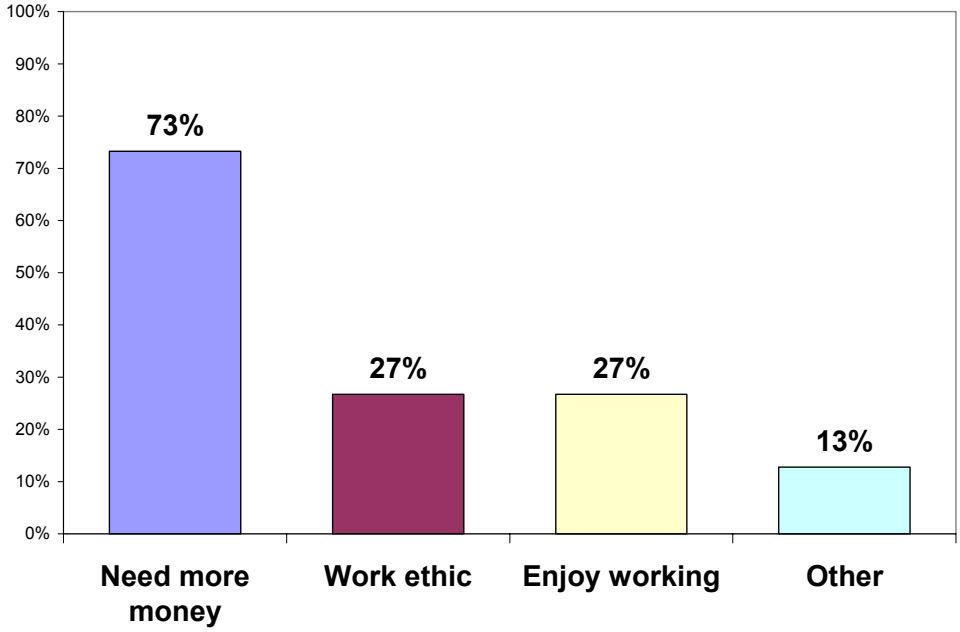
Figure 18. Interest in changing number of hours worked



When asked the reasons for their desire to work more hours, most people said they needed or wanted to earn more money and many said they enjoyed working (Figure 19). About the same number of people cited reasons related to their personal work ethic, such as wanting the independence that comes from working or feeling useful when working.

Only about 6% (19 individuals) wanted to decrease their hours. Most reasons were related to health or disability or stress.

Figure 19. Reasons for wanting to increase work hours

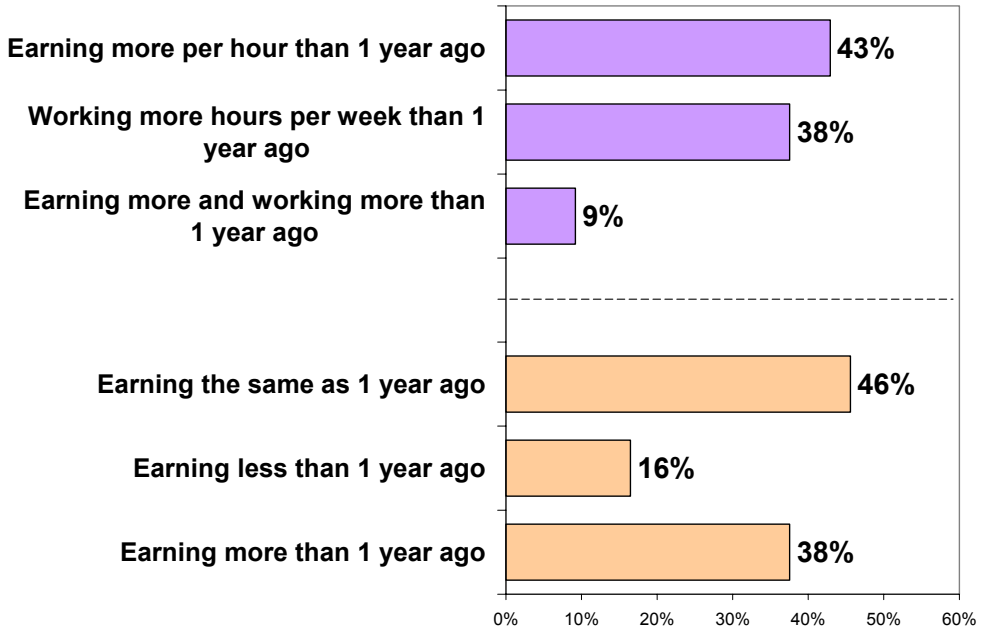


The survey asked people who were working whether they were working 12 months before and if so, whether their pay had increased, decreased or stayed the same. People were asked about the amount they earned and the number of hours worked, to distinguish between increased earnings due to higher wages and increased earnings due to working more hours.

About 83%, or 261 of the 316 individuals working at the time of the survey, were also working a year earlier (Figure 20 below). Of the 261, about 38% said they earned more than they had a year earlier, 16% reported earning less, and 46% reported earning the same.

A large proportion - about 38% of the 261 - said they were working more hours than they had a year earlier. About 43% said they were earning more per hour than a year earlier. About 9% said they were both working more hours and earning more per hour. Additional analysis will be needed to determine the Workers with Disabilities Option status was for these individuals during the year prior to the survey, to discover how changes in earnings are related to changes in WWD Option status.

Figure 20. Earnings compared to one year earlier



6. Personal Assistance Services

Survey participants were asked a series of questions about their use of paid and unpaid personal assistance services (or PAS) at home, without regard to their work-related needs. About 6% of people surveyed – 31 individuals – said they used paid PAS at home, while a much larger proportion – about 24%, or 76 people - said they used unpaid PAS at home (Figure 21 below). The proportions of people using unpaid PAS were similar for people covered under the Workers with Disabilities Option, those covered under another MaineCare category, and those no longer covered under any MaineCare. However, there were no people in the last category (no MaineCare coverage) who said they used paid PAS. Because the number of people in the survey in that category is small (35), no firm conclusions can be drawn from this finding.

For those using paid PAS at home, the most frequently mentioned type of assistance was with shopping, errands, meals and housekeeping (used by 61% of respondents using paid PAS), followed by assistance with personal care (used by 35% of respondents using paid PAS) (Figure 22 below). People who used paid PAS also said the paid assistant helped with making decisions, paying bills, and providing counseling or moral support. Just over half the people using paid PAS (55%, or 17 individuals) said they used less than five hours of paid PAS per week.

About 74% of people using paid PAS said they had enough hours of PAS and 26% (eight individuals) said they did not have enough hours of PAS. All paid PAS users were either very or somewhat satisfied with their paid PAS.

People used unpaid PAS in ways similar to paid PAS, although unpaid PAS was even more often used for shopping, errands, meals and housework, with 80% of users reporting that type of assistance.

Figure 21. Use of personal assistance services at home

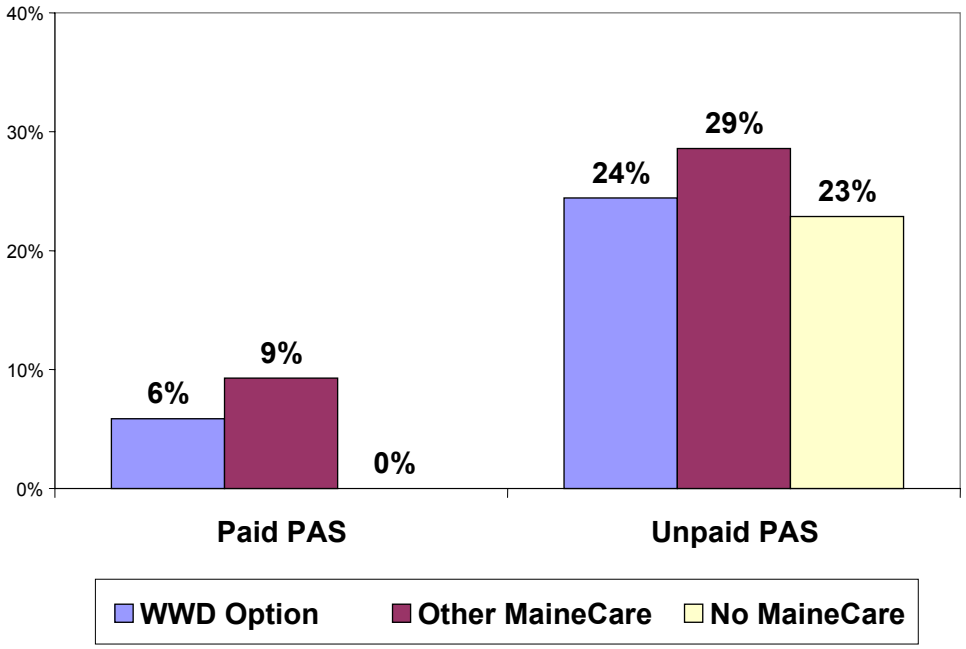
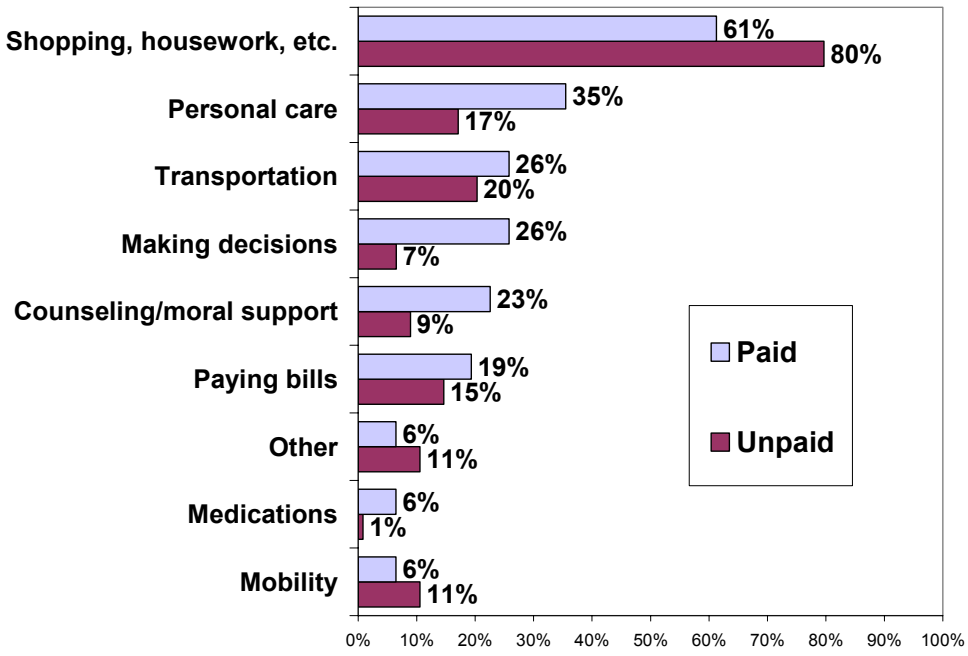


Figure 22. Types of personal assistant services

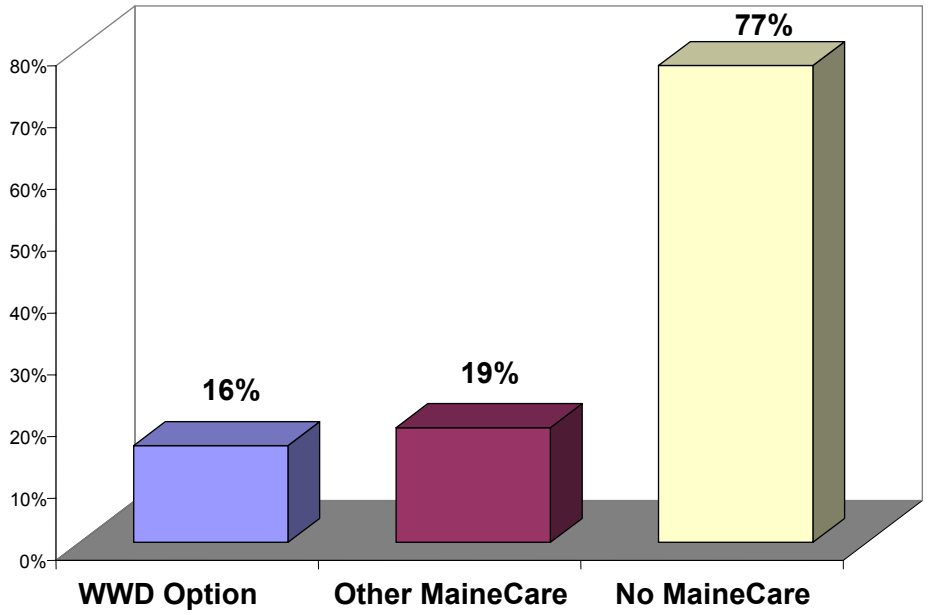


7. MaineCare experience

To learn more about workers' concerns about health care coverage, survey respondents were asked about their past loss of MaineCare coverage and about their expectations for the future. About 16% of those on the Workers with Disabilities Option at the time of the survey said they had lost MaineCare coverage at some time during the previous 12 months; about 19% of those covered under some other MaineCare category had lost coverage the previous 12 months (Figure 23). These results suggest that MaineCare coverage is unstable for many individuals. Future analyses of eligibility data may help explain patterns in enrollees' periodic loss of coverage.

For those not covered under MaineCare at the time of the survey, the results reveal that most people in that group lost coverage fairly recently. About 77% said they had lost MaineCare coverage within the previous 12 months.

Figure 23. Lost MaineCare during previous 12 months



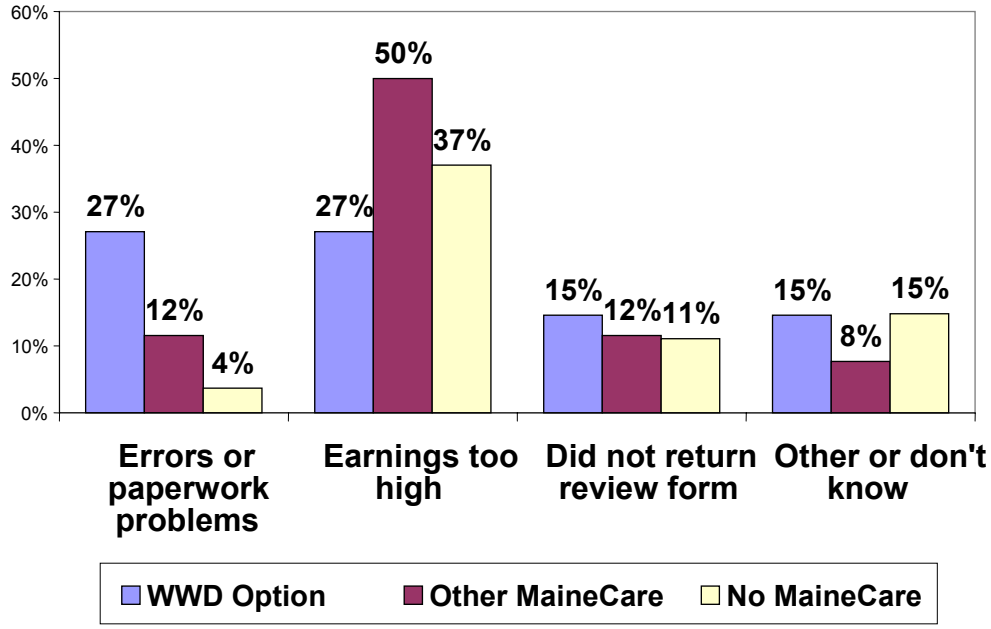
Reasons given for the loss of coverage varied depending on MaineCare status. For people covered under the WWD Option, the most commonly reported reasons were earnings being too high and administrative errors or paperwork problems (Figure 24 below).

For people covered under other MaineCare categories, higher earnings was the reason reported by about half of the people who said they had lost MaineCare coverage in the previous year. This raises the question whether people on various categories of MaineCare, whose earnings increase, are being offered MaineCare coverage under the higher earnings limits for the WWD Option. It may be that people do not have clear information about why they lost MaineCare coverage or that WWD Option eligibility criteria other than earnings

prevented some people from moving from another MaineCare category to the WWD Option. Further analysis of the survey results and other data is needed to explore these issues.

Higher earnings was also the most commonly mentioned reason why people with no MaineCare coverage at the time of the survey said they had lost coverage during the previous year.

Figure 24. Reasons for loss of MaineCare coverage in previous 12 months



Regardless of whether they were covered under the Workers with Disabilities Option or another MaineCare category, many people with MaineCare coverage were concerned about the possibility of losing coverage in the future. About 48% of people covered under the Workers with Disabilities Option and about 43% with other MaineCare coverage said they were concerned about losing coverage in the next 12 months (Figure 25 below).

When asked why they were concerned, many people mentioned their income becoming too high, anxiety about how program requirements change frequently, the uncertain political climate, or how important health coverage was to their well-being (Figure 26 below). A large proportion of those who mentioned the importance of health coverage said insurance was critical for them to be able to afford their medications. These results highlight the instability of health care coverage for workers with disabilities and the resulting health and emotional consequences. They also suggest that access to medication coverage is especially important.

Figure 25. Concerned about losing MaineCare in the next 12 months

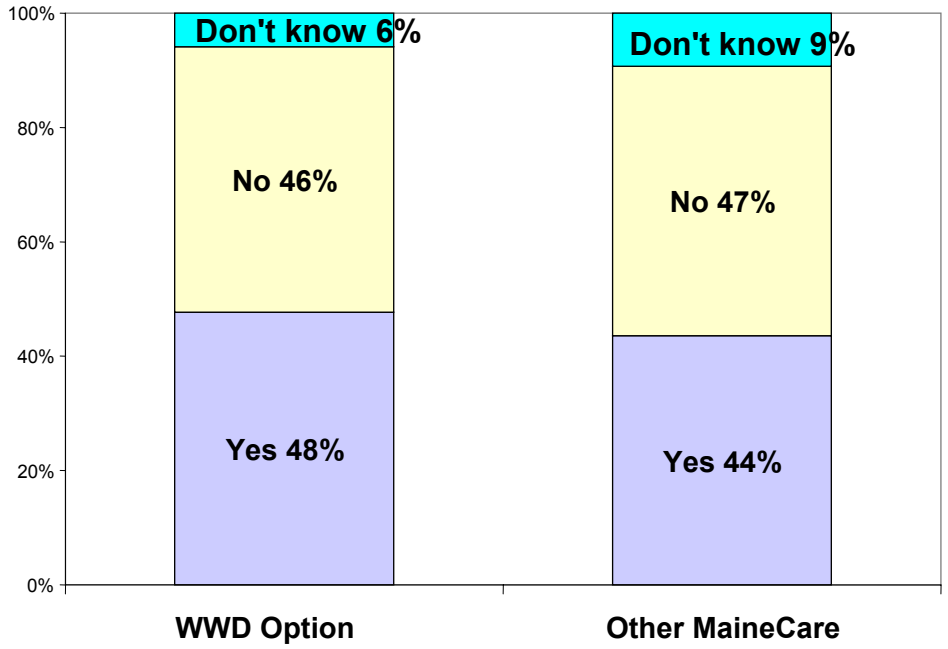
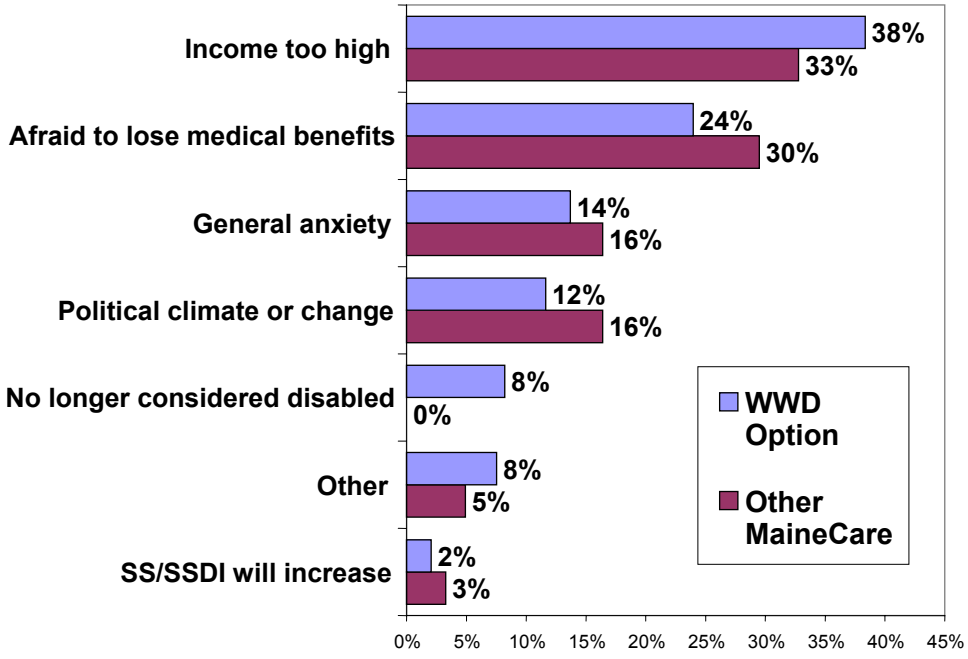
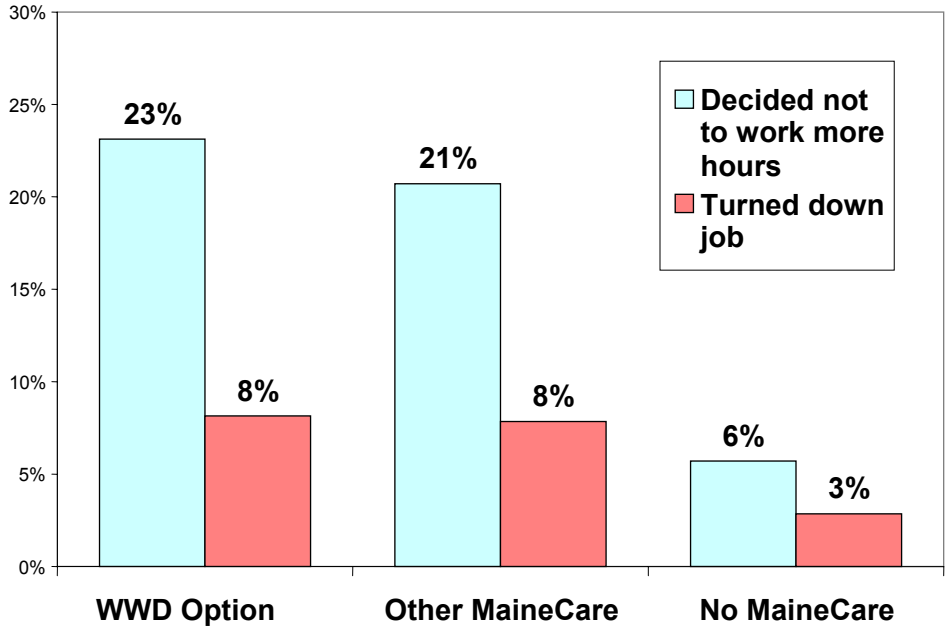


Figure 26. Reasons for concern about losing MaineCare



The concern about losing MaineCare coverage was considerable enough to cause a substantial number of people to decide not to work more hours or to turn down a job. More than 20% of those with WWD Option or other MaineCare coverage said they had at least once decided not to work more hours because they were concerned about losing MaineCare coverage; this represents 100 individuals (Figure 27). An additional 8% of each group surveyed, or 36 people, said they had turned down a job for the same reason. A much smaller proportion – 6% - of the people formerly covered under the Workers with Disabilities Option but with no MaineCare coverage at the time of the survey had made the decision not to work more hours due to concerns about MaineCare coverage.

Figure 27. Decided not to work more hours or turned down a job because concerned about losing MaineCare



8. Opinions about the MaineCare Workers with Disabilities Option

As mentioned above, many current and former Workers with Disabilities (WWD) Option enrollees were not aware that their MaineCare coverage was based on the WWD Option. As a result, when asked about their satisfaction with the WWD Option, many of those surveyed – about 40% - could not express an opinion about the Workers Option per se. Of those who could answer the satisfaction question, more than 90% said they were very or somewhat satisfied with the WWD Option (Figure 28 below).

Some people surveyed had experienced problems with the WWD Option, however. Forty-seven people surveyed (14% of those who knew their coverage was based on the WWD Option) said they had had some kind of problem with

the WWD Option; about 13% of those covered by MaineCare at the time of the survey (Workers Option or other MaineCare), and about 24% of those no longer covered by MaineCare, said they had experienced a problem (Figure 29).

Three types of problems were mentioned by more than five individuals: Problems communicating with the MaineCare office, administrative problems and delays, and problems with coverage for specific prescription drugs.

Figure 28. Satisfaction with Workers with Disabilities Option

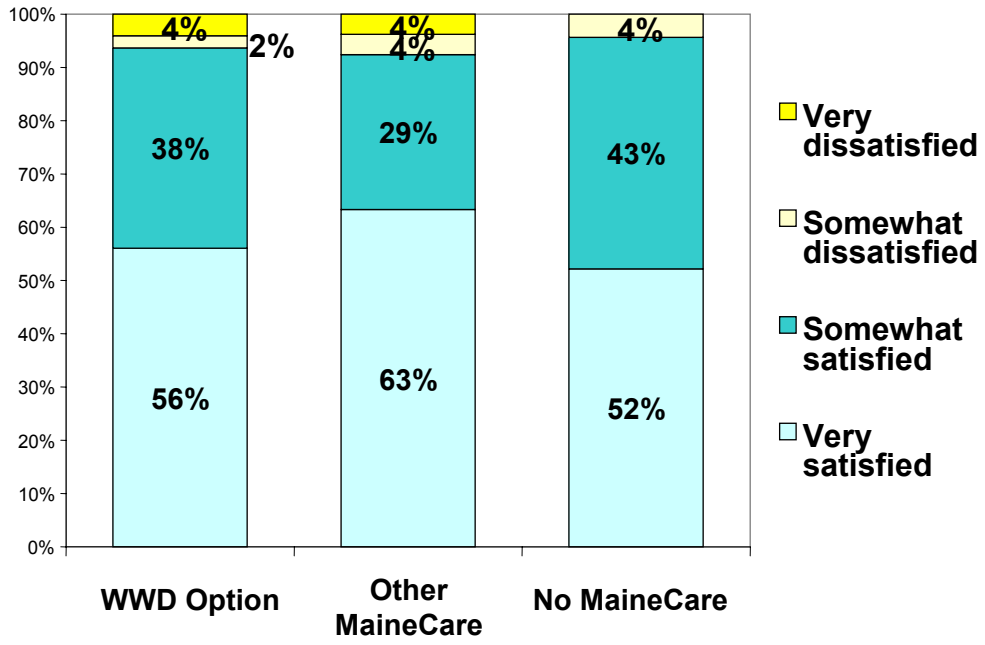
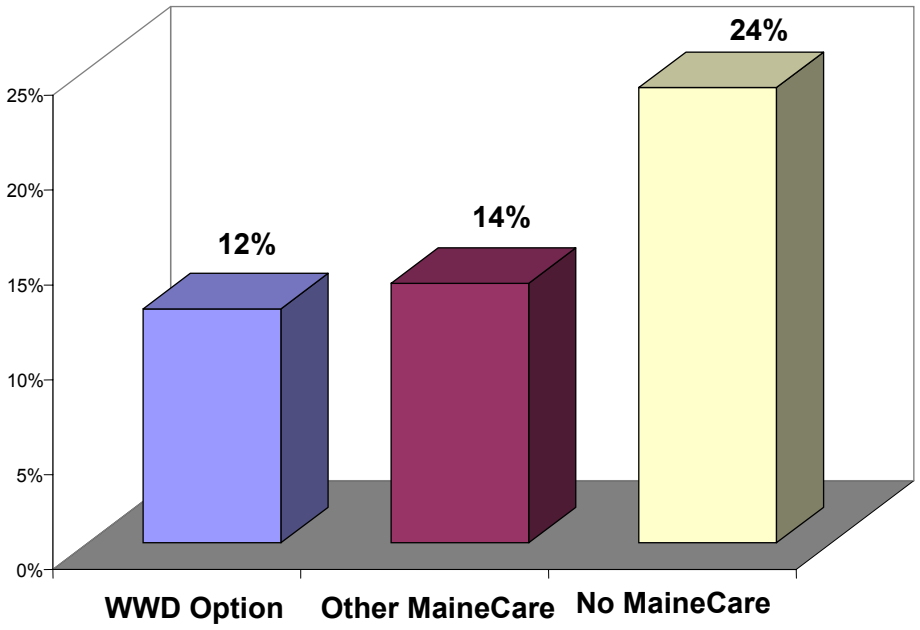


Figure 29. Had problems with the Workers Option



When invited to do so, survey respondents offered a wealth of general comments about the Workers with Disabilities Option specifically and health coverage for workers with disabilities in general. About 27% of respondents provided comments when asked "Is there anything else you'd like to tell us about your experience with the Medicaid [MaineCare] buy-in option for workers with disabilities?" Categorizing the comments was challenging, but 16% of those commenting (20 people) mentioned how important insurance coverage was to them; about 23% (29 people) described a bad experience with DHS, administrative problems, or unclear program guidelines; about 9% (11 people) suggested raising income or asset limits; and about 30% (38 people) offered gratitude, praise or other positive comments about the program.

These comments, both positive and negative, provide rich and valuable information about respondents' feelings and attitudes about work and the important role that health care coverage plays in their lives. The full text of the comments are attached as Appendix A, which starts of page 26.

Next Steps for Further Analysis

Analysis of the results of this survey is continuing. The initial results reported in this document will be enhanced by more detailed examination of the data, including comparisons of issues such as age differences in expectations to work more and differences in support needs among different disability types. In addition, results of this survey will be compared with related data from MaineCare eligibility and claims records.

Other research related to the Workers with Disabilities Option and work incentives for people with disabilities include a telephone survey of MaineCare enrollees who have never been covered under the WWD Option to identify the barriers that may prevent people with disabilities from working or increasing their earnings. Case studies are also being conducted to explore in greater depth a variety of work-related issues among people with disabilities. Results of these research initiatives are expected in late 2002.

For more information on these efforts, or to provide feedback on this report, please contact Larry Glantz, CHOICES Project Director, at (207) 228-8345, or glantz@usm.maine.edu.

Appendix A

Full text of responses to the survey question, "Why are you concerned about the possibility of losing Medicaid (MaineCare) benefits during the next 12 months?"

1. Working too many hours
2. $1000 per month for meds
3. They will make their judgment on whether you have a just cause
4. Medicaid is unpredictable. Never know what may happen
5. Any reason
6. You never know what s going tom happen with the big guys on the hill
7. Would really be in trouble financially if lost them
8. I'm a worrier
9. George W Bush
10. Because I'm not working now
11. She just worries about it
12. Provided insurance through employer
13. Extremely behind in his bills, and doesn't know how to pay for them
14. Just thinks about it, anything can change
15. Depends on the guys in Washington
16. Afraid government will take away benefits
17. If I tried to increase my hours
18. Hearing about program losing funding
19. The number of hours that I would put in and the rate of pay might reflect on it.
20. Holding a 20% of business for my son but he is the one that collects the profits, not me
21. Don't know what will happen when I turn 65 (retire)
22. Expenses for medication so high that I worry about paying for them
23. Working worried about how long it extends
24. Husband s soc sec benefits will decrease and daughter turns 18 and his income will be too much
25. 401k from other employment , I used for bills and didn't keep receipts, now they want a record of everything
26. Just can't afford to lose any bit of help they receive
27. Because of my being forgetful
28. If I lose the benefits I lose the medications if I lose the medications I lose my life
29. I've just got off of disability and I'm not sure how it works
30. Because both of us are diabetics and we have to buy pills.
31. If the laws changed
32. Hears so much about the state being so far in debt
33. If the rules change he d be in deep doo doo
34. Up a creek if she lost it
35. Just scared because no way she could afford medical bills and prescriptions
36. Because out of work and has no insurance

37. I know that the programs are constantly changing and I'm not aware of where I stand.
38. Because of my daughter needing health care.
39. It s difficult to find out accurately what the ceiling of income would be, based on different circumstances. I need to know how much our family could make.
40. Because I'm a small business owner and I will no longer be qualified for disability.
41. I have to go for blood work five times a week and I have no way to pay for the bills.
42. My wife pays medical insurance and it takes her entire check.
43. Way things are going in the government-
44. Government might cut off the disabled
45. Because she lost Medicare
46. My medication is quite expensive.
47. I'm still going to counseling and for doctors visits.
48. I'm concerned about losing my medication.
49. Due to changing of the laws, what you qualify for and what you don t.
50. Never know what the state of Maine is going to do. They may change guidelines.
51. I can only handle working so many hours, and if I lost health insurance I couldn't afford medications, psychiatrists, etc.
52. Afraid the government might change the rules
53. Concerned that Medicaid will change the rules/qualifications
54. We can't afford health insurance and it s the only coverage I have.
55. I can't afford doctor Visits.
56. I couldn't afford the services that I'm getting without it. I can't afford it.
57. Afraid the rules will change
58. Government might change
59. Just all the troubles with the country at the moment
60. The cost of medication. The co-pay is 30 per prescription.
61. Don't know what is happening in Washington
62. Because I've gone back to work
63. Don't know what is going to happen- there are changes in program all the time
64. The last time wasn't my fault, it was the doctor's office who neglected the paperwork.
65. Poor work history afraid of losing job, and then will lose disability ins.
66. I'm concerned about everything, that's part of my nervous problems. I'm worried about how to afford oil for the oil burner.
67. Everybody needs insurance. I could end up in the hospital tomorrow.
68. Government
69. Government changes/ completely eliminated some of my medications
70. Trying to make the transition from a part time to a full time schedule.
71. My medication is so high so extremely costly
72. Don't actually have it currently
73. Hours will increase and make you ineligible

74. Just on my mind; no real reason
75. The way the laws change
76. Just generally worried about it
77. Cost of medications and what her responsibility is for her portion, none of the other choices apply
78. Because they told him very recently that he did lose them
79. Because already lost it once
80. Not sure about cuts that they might have
81. Never know what will happen
82. Government
83. In case I ever need anything because of disability
84. Had saved retirement money
85. Worried about changes that might happen that would affect coverage
86. Worried medications that I need won't be covered (because other medications are cheaper and this medication was not approved by the program).
87. Wouldn't be able to afford my meds; wouldn't be able to stay in the home; would fall back sick again
88. The way the systems works
89. The way the system is going, we don't know what changes will be made or if the guidelines will change.
90. Wants to work
91. Couldn't live without it
92. Don't trust state
93. If I end up sick again, I'll need to go to the doctor's and have medicine paid for.
94. Everything that is happening (bombing at world trade center) and cutbacks
95. Without Medicaid couldn't afford doctors or prescriptions
96. Things are changing constantly so you never know
97. Concerned because wife has no insurance / he needs it
98. I don't know what the cut off amount is going to be with my income
99. Afraid of not being able to work and getting the insurance
100. Just worried in general that he might be cut off
101. Government
102. I'm looking for more hours at my next job. I'm concerned if there is a 30 day waiting period for coverage or if I take another job and am unable to continue working the hours--losing coverage.
103. Because I've had health problems, whenever you go to see a doctor You won't be seen.
104. Medications are very expensive
105. They only pay for my medicine one time and I didn't know that. This might be something they changed. I end up on the short end of the stick sometimes.
106. Economy and changing formula
107. In case this program doesn't stay or in case I have to change jobs

108. Helps me pay for medical bills and would not be able to afford surgery if I needed it. Also couldn't pay for medication that allows me to work.
109. Insurance costs a lot of money.
110. Just a general concern
111. Rules might change around it
112. I'm not stable with my job right now.
113. Because everything with cancer treatment is very expensive
114. Medications are very expensive
115. With everything going on relating to terrorism and all of the money bush is using from social security worries me.
116. Just worries
117. Is on very expensive medication
118. When you get 68 years old, you start worrying and you never know what will happen
119. Receiving money from SSDI and so won't be eligible in a month for Medicaid. Won't be able to pay for my medications which costs over 1000 dollars.
120. President is not supporting the poor
121. Injections each week are very expensive
122. Just always fears it because can't afford medication
123. Because really needs it and sees doctors often
124. I won't have any insurance. I have to see a psychologist or buy my meds.
125. Don't know how I would pay for my bills
126. Because the difference between Medicaid and Medicare, because Medicare doesn't pay for your prescriptions. They only pay 20% of hospitalization bills.
127. They re getting awfully fussy. My medications need prior authorization, it makes it very awkward for a re-fill. Faxing back & forth between different parties.
128. Social security is her only means of money for the most part
129. Not confident about his ability to keep his job and is just very nervous about it
130. I don't understand the guidelines.
131. So insecure program
132. Really can't afford to loose it too much medication
133. Doesn't want to lose benefits if goes back to work full time
134. Have no other way to pay for hospital bill and something like that
135. Just generally concerned

Full text of response to the survey question, "Is there anything else you would like to tell us about your experience with the Medicaid buy-in option for workers with disabilities?"

1. Rules and regulations are very unclear. Aren't even expressed to people until after the fact; typical gov't bureaucracy; he'd be better off not working, but he wants to work and it's humiliating to not work; someone at DHS flat out told him he'd be . . .
2. I'm glad that it's available.
3. They shouldn't look at the money you make but instead look at the conditions you have and how much you half to spend to stay healthy.
4. DHS did not give clear information about the Medicaid program
5. Went to DHS and had to get approved; took too long
6. A problem keeping up with my bills even with this program
7. Lost benefits for working 38 hours at K Mart....K Mart won't let anyone work more than 38 hours so they won't have to give health benefits…so she just didn't go to any doctor during that whole time...until she got sick, and then had to quit working
8. I take 9 pills a day and...I have to go to the drugstore all the time...have to wait for each one to expire before getting a refill
9. Medicaid and Medicare and SSI all fall into the same bureaucratic bowl of soup. The rules are impossible to understand. I think they give the rules to lawyers to pass the bar exam. I was very disturbed that we were not told about these benefits
10. If we weren't worried about losing our medical coverage, there would be a lot more people working. My medications would be $1,000 a month if I had to pay for them myself. Even the co-pay is $50.
11. If you lose your job or stop working for some reason, they cut you off too soon. There ought to be a 3-month grace period. If they could provide more information--an information sheet or booklet--it would be helpful. Otherwise the information varies
12. Just that a person on disability can't afford dental, but Medicaid doesn't pay for it and he really needs it and can't afford it. But he thinks it would really help his over-all health if he could have his teeth worked on
13. I've been grateful to have it it's taken care of everything that I've needed except glasses I fear letting go of that security and going back to regular insurance
14. I wish they had that a long time ago.
15. I d like them to lift the cap and just let disabled people make whatever they can earn.
16. More pressure because review is every 3 months, very frustrating, because for me nothing chances
17. Respondent was told that he could only make $700 and keep Medicaid.
18. A lot of people are unaware of it and are afraid to work because they think they won't get benefits.

19. I wasn't aware of the program before it was offered to me. Fear of losing health coverage is only thing holding me back (from working), more so than losing money. Program has been very helpful. I can get the meds I need to work and see my health provider
20. Income limit should be higher
21. I wish there was a tiny bit more leeway as far as hours
22. Income requirements count husbands too even though they don't share money, it makes it hard
23. I don't feel impressed with the medical care
24. The problem we had with Medicaid is that they decided that I had too much money in the bank. We had to pay for my pills directly.
25. Able to work and this is a big boost to my self esteem
26. I've had a problem with the co-payment and I've had problems a couple of times meeting them and also I don't always know what medications are covered
27. Was very thankful to have it...and it covered my kids too
28. Happy with co-pay program but is worried about her renewal
29. Wishes child could be part of the program as well
30. Just that it was extremely handy to have
31. Medicaid should help those that are trying to better themselves instead of cutting them off
32. I'm thankful that we re able to have it.
33. I'm just glad there is something to help people who want to work, especially the older folks.
34. I think it needs to be understood more. The recipients need help understanding it.
35. It helped out a lot when I had it.
36. I d like to keep this Medicaid option.
37. It's helped to get along with myself.
38. It sounds wonderful. It sounds like I could gradually go back to work.
39. Not every program is explained, they only tell you what they think you need at the time and don't let you know all the programs that are offered. A reminder or a list of all programs offered would be good.
40. If I start making a little more money, I'll no longer be eligible. I'm grateful that it's there, we re a family of five and we don't make a whole lot of money.
41. They count any 401k plan against you, thus you can't set up any retirement plan for yourself
42. Finding physicians who would take program was a little bit of a problem
43. Happy to hear about it - allowing him to hold down a job. More dignity in working job.
44. It's not fair to a lot of people. When you get a little more income you end up losing everything. Hard to communicate or get accurate/consistent information from DHS. People at DHS are impersonal. Medicaid doesn't cover a lot of services or level of . . .

45. It would be better to make it clearly. That's why I waited a year. Never told me about the buy-in option. Took a year and a half to finally get the Medicaid.
46. Just that it was very helpful
47. It's helped me a lot, it helps me get what I need. It lets me work so that I have self worth.
48. I would have to get divorced to get anything.
49. I'm concerned that someday someone will make a mistake and I won't get my check.
50. Appreciate the help paying for her prescription glasses
51. I would like it to cover dentists.
52. Its a good programs, has always had good people helping her at DHS
53. Can't work because will lose benefits
54. It takes your stress away knowing that I can't work 40 hours a week.
55. Always afraid of working because might loose medication
56. The rumor that President Bush might take out the outpatient benefits is concerning me a great deal.
57. They were great when I needed them
58. I think it's great. I don't know what I'd do without it.
59. Can't find dentist who will take Medicaid
60. I don't like paperwork. All of the renewal stuff--I have a hard time with it.
61. Didn't have adequate information
62. No real complaints...quality seems to be as good as anywhere
63. Disability coverage doesn't give her enough money to live on
64. It is rather vague.
65. They need to communicate with the people who have it
66. Its very transparent, you hardly know it exists. Its done in a seamless way.
67. Just don't trust them; never sent anything in the mail; don't know what programs are available
68. Feels it is an excellent program and assists with payments toward her medications
69. Just that it helped a great deal, because it is so hard to get along without, no one wants to bother with u when u don't have any plan
70. It gives a little bit more leeway for hours to work.
71. It would be great if you started a chat room so that we could communicate via the computer.
72. Could work more if Medicaid would cover more alternative work help, such as massages, acupuncture, and herbs
73. Have fungus of the nails and Medicaid won't approve the meds for it
74. It's been a great help to me because I'm on a limited income
75. I think when you are going for disability, as soon as Social Security denies you they immediately cut Medicaid. Should keep you on program at least while you are waiting for findings for appeal.
76. I find it very helpful because I really need the health insurance for my medical condition.

77. Couldn't get food stamps because we earned a dollar too much
78. One procedure wasn't covered and you didn't know it in advance...being billed for it right now and it's $7000.
79. It should be broader coverage....income cap should be lifted
80. Wish they wouldn't change workers every time I turn around- every time I go into the office there is some new who doesn't know about my case
81. Medicaid wouldn't take the doctor's prescriptions, so doctor had to change it
82. They stopped paying for the medication that he was taking unless you had a written statement from your doctor.
83. It has helped me a lot
84. Glad he had it when he did
85. I am extremely happy with the way I've been treated in the past 3 years that I've needed it.
86. The system doesn't allow me to survive. I earned 6.50 and hour and made too much to get food stamps and didn't qualify for TANF
87. I don't think they are fair. My prescriptions are very high and they told me my income was too high for Medicaid.
88. Getting prescriptions for every 90 days instead of 30 days. It's hard for people to get to the drug store when they live in rural areas.
89. A few times it still seems hard to pay the amounts but overall it wasn't
90. I think workers with disabilities should be able to work a lot more and not have to worry about losing benefits
91. Maine med pharmacy won't take Medicaid- have to go to drugstore
92. God bless it
93. I'm confused about some of the rules.
94. A lot of meds they don't approve
95. I think eligibility should depend on your own income and not that of your spouse if you get married
96. There needs to be more support when you get hurt on a job.
97. I thought it was wonderful when I had it. I had it for four-six months.
98. Very sorry she lost it
99. No dental coverage
100. It was very helpful. I was afraid I would lose Medicaid benefits when I got a job, but I was offered this program and I could afford it.
101. It's wonderful, and can finally get medications that were previously too expensive
102. I am thankful for this program and that I've opportunity to be able to work without losing health benefits.
103. Degrading experience to get Medicaid, DHS makes you feel like you are lying to get the benefits
104. It's a good program for people that can utilize it. Insurance is a big issue for people with disabilities.
105. It's very confusing for people- it is a vulnerable feeling leaving it up to case workers. The DHS Medicaid workers give conflicting information.

It would be good to educate clients about all the programs that the department offers- maybe offer a work

106. Would like to get wife back on it on Medicaid. Sent in check to pay premium for myself and DHS wrote back saying we hadn't sent it. Are still on it but don't know for how long.
107. I don't understand why more people aren't in the system.
108. Really irritates me when I had to pay the co-pay; couldn't come up with that much money; prescriptions are very costly

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