PEOPLE WITH DISABILITIES SHARE THEIR EARLY EXPERIENCES

Working Healthy is now in its seventh month of operation. In this issue, we share findings from discussions with eight early enrollees. They offered their opinions, talked about changes in their lives since enrolling, and also touched on other issues that affect their employment efforts. The participants in the interviews represent a variety of disability types, educational levels, race, age, geographic locations, and gender. The group also included both enrollees who pay a premium and those who do not.

HOW’S WORKING HEALTHY WORKING?

All of the participants feel that Working Healthy is a worthwhile addition to their lives:

“I can’t say enough about it… For people with disabilities who choose to work it’s just a great program.”

They also expressed their deep convictions about the value of work and the responsibility to be productive:

“We are trying to better our life. We don’t want to be labeled as living

on SRS or things like that. We don’t want to be a sponge and soak on other people. We want to provide for ourselves. We want to be a regular person in society. We don’t want to be on AFDC and things like that. We want to be a working member of society and living our normal life and living the American dream.”

Two participants expressed concern about the “marriage penalty” inherent to the Working Healthy program. In one instance, the spouse of a Working Healthy participant lost his medical card due to his wife’s earnings. In the other instance, a current Working Healthy participant who is in a long-term relationship expressed concern about getting married because doing so might make her ineligible for the program.
HOW PARTICIPANTS’ LIVES HAVE CHANGED

According to one Working Healthy enrollee, employers oftentimes “see the disability first” and do not consider a person’s ability to do the job.

Only one person in the interview group had increased her earnings subsequent to enrolling in Working Healthy. One person had been laid off in October, but was very pleased that Working Healthy allows for a six-month extension of eligibility in such situations. All of the interviewees were glad to have more disposable income due to the loss of their spenddowns. Many reported being able to pay off outstanding pharmacy bills or make purchases that increased their ability to work, such as fixing a car or buying a used one. Most of the participants with mental illness also reported they were better able to get the medications they need because they had often gone without their medications due to their spenddowns:

“I really thought the spend down process was just ridiculous. I had this huge amount and actually, if I didn’t work in a pharmacy where my boss would let me charge all the medicines and everything until I came up with the spenddown amount, there was no way I could make this work, because it was just a ridiculous situation and having it just kind of balloon on me every six months seemed really crazy. But … when you said you could just make a [premium] payment … it seemed so logical.”

HOW DID PARTICIPANTS FIND THEIR JOBS?

Working Healthy was established under the Ticket to Work/Work Incentives Improvement Act. Part of that legislation provides “tickets” or vouchers to people with disabilities to use in obtaining employment services. When asked how they had found their current jobs, five of the interviewees indicated they had responded to newspaper ads or to word of mouth information. Of the remaining three, two received assistance finding their jobs through their community mental health centers and one had found his job through the local community developmental disability organization.

BARRIERS TO EMPLOYMENT

Many of the people interviewed had jobs that are not commensurate with their educational level or experience. One, with a Master’s degree and teaching experience, is currently working from home typing text for cookbooks. Given her typing speed, she makes about $2.30 per hour. Another interviewee with a bachelor’s degree in education and many years of teaching experience is currently working in food service.

The participants cited numerous barriers to work, or to better work. Several reported having experienced overt disability-related discrimination by potential or former
employers. One had been told that she would not be hired because she would cause the employer’s health insurance premiums to increase and one had been fired when she had to be hospitalized. Another stated that employers “see the disability first” and do not consider a person’s ability to do the job.

Although many interviewees expressed the belief that their disabilities were the biggest barrier to work, further discussion indicated that other factors were equally, if not more, important. Foremost among these was advice from various professionals including physicians and case managers. These service providers had often discouraged the interview participants from getting jobs or increasing employment levels due to the often misguided belief that doing so would cause a loss of benefits or automatically result in a worsening of their patient’s or client’s condition.

Some of the implications from this research are that doctors and other professionals need to learn more about work incentive programs for people with disabilities and also about the availability of job accommodations that can make working a reasonable and even healthy goal for most people with disabilities. In addition, people with disabilities want to work and Working Healthy is one way to support that endeavor.

**IN A NUTSHELL:**
*Overall impressions about Working Healthy from early enrollees*

- Working Healthy is a good idea and is appreciated
- The apparent marriage penalty is a real concern to some
- Many enrollees are now better able to get the medications they need
- Participants have more disposable income to put back into the state’s economy
- Most of the interviewees found their jobs independently, usually by responding to a newspaper advertisement
- At least some of the participants are working in jobs well below their educational level or abilities.
- Several had experienced overt disability-related discrimination by potential or former employers
- In many cases, medical or other service providers had discouraged participants from increasing their work efforts, seemingly based on outdated perceptions about work incentive programs and job accommodations
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