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Research Report

Tele-Health Promotion for Rural People with Disabilities: Toward a Technology Assisted Peer Support Model

There are relatively few health promotion programs for people with disabilities who live in rural areas. An exception is Living Well with a Disability, a health promotion program for people with disabilities developed by researchers at the RTC: Rural (Ravesloot & Seekins et al., 1994). The Living Well program was originally designed to be delivered in-person by peer-support staff of Centers for Independent Living (CILs) to groups of participants with disabilities. For many rural people with disabilities, however, the distances and travel difficulties inherent in their environment make onsite group programs impractical or inaccessible. Limited funding for programs such as Living Well with a Disability is an additional barrier to health promotion dissemination.

To overcome these rural barriers, we are exploring ways to use the Internet to deliver the Living Well program. Based on a series of national surveys, Enders & Bridges (2006) estimate that more than a quarter of people with disabilities living in non-metropolitan areas use the Internet. As Internet access grows, a greater proportion of rural people with disabilities will have access. Developing effective Internet delivery of the Living Well program would increase access to health promotion materials for individuals who currently use the technology and for the large proportion of non-metropolitan people with disabilities who do not yet use the Internet, but will in the future.

Our study asked, "Will people with disabilities naturally adopt an Internet health promotion program?" We hypothesized that after an initial introduction to the program, word-of-mouth among participants would gradually increase participation.

Participatory Action Research (PAR) Methods

During the program's development, people with disabilities collaborated with us to ensure that it would be acceptable and useful. The first step was deciding which methods to use to deliver Living Well Online. This decision balanced various concerns and

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constraints, such as the fact that rural areas often lack band-width, which limits the speed of rural Internet transmissions. Compared to urban areas, methods such as streaming video might be slower and more impractical in rural areas. In technical terms, the most efficient way to deliver Living Well with a Disability Online materials to rural participants would have been a simple website with text for participants to read. We doubted, however, that most participants would sit down and read the materials. Based on these considerations, we decided to deliver the program curriculum via audio-supported slide shows.

We presented pilot versions of these materials at an open session of the Association of Programs for Rural Independent Living (APRIL) annual meeting. Incorporating feedback from this session, we converted the Living Well with a Disability curriculum to Living Well Online audio-supported slide shows. The Board of Directors of a rural CIL also reviewed the online program and we made additional adjustments to the program based on their feedback.

Finally, a specialist in computer access for blind and visually impaired individuals reviewed the program and identified navigation problems in the standard Internet version. To circumvent these problems, we programmed a separate website with links to audio files. The final versions of both versions (standard and for users of screen readers) are at www.livingwellweb.com/2005/. The web site's initial pages introduce the Living Well Online program and demonstrate the audio-supported slide show format.

Study Methods

In June, 2006, we recruited participants by emailing a brief message to all CILs on the APRIL distribution list (N=240). APRIL's Executive Director co-signed this message and endorsed the program. In order to receive additional information about the program, recipients were instructed to reply to the email. This additional information included the Internet address for the program and a flyer which centers could use to advertise the program. In July, we distributed the announcement again.

Prospective participants were required to view informed consent pages on the web site, agree to the informed consent, and create a login account. After this procedure, they completed online study measures on a secure server, then were free to complete the Living Well Online program at leisure.

We collected two different process measures to evaluate distribution and response to the program announcement. First, one month after the second email distribution, we sent a brief questionnaire to all CILs which had requested additional information about the program. This questionnaire asked about the disposition of program information sent to them in the previous month. The other process measure used eight months (June, 2006 - February, 2007) of statistical data collected by the internet service provider regarding the number of visitors to each of the web site's pages. We tracked the number of individuals who investigated the website (visited its home page, viewed the demonstration, viewed the informed consent) and compared it to the number of individuals who actually created login accounts.

Finally, we used the web site to collect outcome data. Participants who created login accounts were asked to complete outcome measures for the research project. Although we do not report those results in this report, the requirement to complete outcome measures may have affected the participation rates reported here.

Findings

As a result of both e-mail distributions, twelve centers requested additional information. Five centers returned completed surveys about the disposition of program information. Two of these reported reviewing the program information and choosing not to disseminate it. The other three centers promoted the program in various ways, including announcing it at staff meetings, forwarding the informational email to all staff, printing the flyer and distributing it to consumers, and describing the program in their newsletters. One CIL also announced the program on a list-serve used by 29 other CILs; another center mailed the flyer to other agencies serving people

with disabilities in the community.

Figure 1.

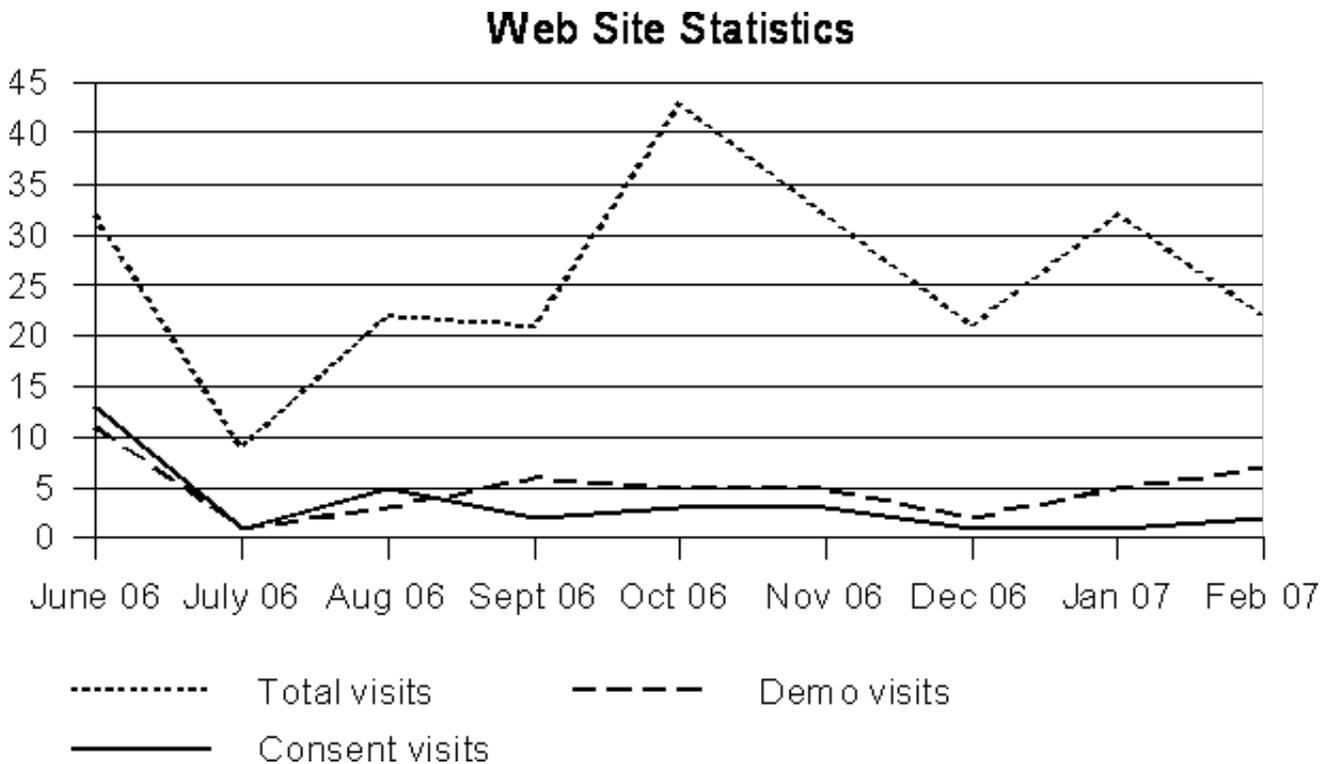


Figure 1 tracks 234 web site visits from June 2006 through February 2007. The demonstration page had 45 visits (19.2%). The informed consent page had 31 visits (13.2%). Six individuals registered for the program. Of those six, three completed the program's online questionnaire. One individual completed the entire program, and the other two did not complete any program component.

Observations

Despite our rigorous use of PAR procedures in developing the intervention, very few CIL consumers explored and later accessed the online program. To effectively recruit CIL consumers, an Internet-based strategy first requires an adequate response from the centers. After two email distributions, fewer than five percent of CILs requested information about the program. This response rate markedly differs from that observed ten years ago when we announced the in-person, group-oriented Living Well with a Disability research program (Ravesloot, Seekins & White, 2005). That outreach effort resulted in 30 percent of all U.S. CILs submitting applications to collaborate as program trial sites. Based on that response rate, we expected CILs in the present study to be very interested in learning about an online program.

We identified three main differences between the 2006 online program outreach and the 1997 onsite program outreach. First, in 1997 we mailed information; in 2006 we emailed the information. Second, the 1997 outreach offered participants a small stipend. Third, the 1997 outreach involved all U.S. CILs; in 2006, we contacted only APRIL members.

It is possible that mailing outreach materials and providing a stipend would have increased this study's response rate. However, the intent of this study was to examine the utility of a program that demanded less effort from CIL staff. The hope was that CILs would not need incentives or contracts to disseminate information about Living Well Online to their consumers. In the 2006 study, only three CILs disseminated the information to their consumers.

Several factors potentially affected consumer participation in the project. We know from other RTC: Rural research that only 26% of non-metro individuals with disabilities use the Internet. Even so, if these individuals were inherently interested in an online health promotion program, we would expect a greater participation rate than we observed. Perhaps little of the information disseminated by the CILs actually reached end consumers. The outreach method may have been ineffective – Raveslout (in press) has reported that passive efforts may be less effective in recruiting people with disabilities into health promotion programs. Finally, consumers may not have found the audio-supported slide shows appealing. As it stands, the Living Well Online program web site is not a useful health promotion intervention. Neither the CIL nor the consumer interest appears to be sufficient to support our hypothesis regarding word-of-mouth leading to increased participation.

Next Steps

Based on these observations, our advisors suggested that we combine peer support with the online program. Therefore, we are piloting procedures and materials for peers to use in their outreach with consumers. We have written a start-up guide that peers can use to help others access and use the online program. This guide provides instructions on using a computer, as well as information for accessing the Living Well Online program. Along with the start-up guide, we have developed activities, procedures and training to support peers' outreach activities. Since peer support is a core CIL service, center staff appreciate the availability of structured programs that focus peer activities. Living Well with a Disability is such a program. It encourages consumers to set quality-of-life goals that increase their participation in life activities and it is very consistent with the purpose of peer counseling. This may provide the additional incentive necessary to engage consumers in Living Well Online.

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