Assistive technology, computers and Internet may decrease sense of isolation for homebound elderly and disabled persons

Natalie Bradley* and William Poppen

University of Tennessee, Department of Education, Psychology and Counseling, A-525 Claxton, Knoxville, TN 37996-3452, USA

Abstract. In an interesting twist to the initial fear that the access to internet would result in a more isolative community, the CHIPs program (Computers for Homebound and Isolated Persons) inspired an online community for individuals who were homebound. The subjects began to get to know one another through the Internet, thereby making virtual friends with others in similar circumstances. Elderly citizens, disabled individuals and caregivers found themselves with a new sense of camaraderie and friendship. A one-year follow up to a questionnaire indicates that the subjects' level of satisfaction in the amount of contact with others increased significantly. These results suggest that the intervention may cause significant changes in the lives of isolated individuals, a change worthy of more formalized research.

1. Introduction

Beginning as a grassroots program managed by the Office on Aging, volunteers from the community installed donated computers and provided training to elderly citizens who were homebound in an effort to decrease their isolation. This contact with others and technology seemed to bring about a significant change in the lives of the recipients, leading to the desire to expand CHIPs to serve individuals who were homebound due to disability. This successful project CHIPs (Computers for Homebound and Isolated Individuals) then developed a partnership with KORRnet (Knoxville, Oak Ridge Regional Network) to acquire free Internet access and subsequently became funded by the United States Department of Commerce, Technology Opportunities Program (TOP). The \$500,000.00 award allowed for the purchase of Assistive Technology (AT) and new computers, an important element allowing for equal access to the technology by individuals with dis-

Initially, evaluation of the project was measured by feedback on a bimonthly basis from the participants via email and regular mail for those who were not yet proficient in emailing skills. Their stories described incredible life-changing experiences and were therefore summarized and submitted as a part of the application to the Stockholm Challenge Award. Subsequently, in June of 2000, CHIPs became the only US recipient in the "Equal Access" category of the Stockholm Challenge 2000 Award. This award is sponsored by the European Commission and the City of Stockholm for Internet projects that "through inspirational approaches benefit people, society and the environment in their local context." 1

The quality of life of the elderly, living alone or in residential care, is well documented. Lyons de-

abilities. As a result of this support the "East Tennessee Technology Access Center" provided AT training and evaluations by practitioners certified by RESNA, the Rehabilitation Engineering Society of North America.

^{*}Address for correspondence: Natalie Bradley, M.S., CRC, ATP, Life's Calling, 4987-A Shafter Avenue, Oakland, CA 94609, USA. Tel.: +1 510 658 1213; E-mail: lifescalling@hotmail.com.

¹The Stockholm Challenge(http://www.challenge.stockholm.se/index.html).

scribes elderly persons living in residential settings as "more socially isolated" leading to "a less satisfying sense of community than other people" [1]. Similarly, Hays and George state that "elders who live alone are more entrenched in poverty: report more depression, loneliness..." [2]. Studies have also shown "a significant negative correlation was found between loneliness and the measure of physical independence" [3].

It was our aspiration that access to computers and the Internet would effect a positive change on these life conditions. In a previous study, Internet access allowed elderly individuals to "feel as if they were out of the house even when they were housebound" and to "regain some aspects of their earlier lifestyles." Additionally, for those who were able to access the computer, the benefits also eased the impact of some of their physical limitations; "typing on their computer helped clarify their communication because it overcame their age-related illegible handwriting" [4]. It was further noted that email served as a way of documenting communications, an important aspect for those users with memory problems [5].

The CHIPs project expanded to provide computer access via assistive technology, for those individuals who could not have had access otherwise. Appropriate evaluation and procurement of necessary AT hardware and software became an essential element of the project. When reports, like those from US Census Bureau indicate that "a substantial proportion of US seniors will never go online due to disability" [5], the potential impact of AT becomes clear. Still, however, there is a lack of scientific studies on the potential correlation between disabled individuals and level of loneliness [6], and certainly fewer studies, if any, on how AT might have an effect on level of isolation. With this in mind, it became clear that additional data documenting the progress of the CHIPs project could be important.

2. CHIPs project description

2.1. Methods of evaluation

Objectively evaluating the project's success was a complex issue. The primary aim of management was to avoid any infraction of the applicant's privacy through potentially invasive questionnaires. Similar concerns have been documented in other studies, and the result was the use of questions relating to amount of contact with others, as opposed to direct questions concerning loneliness [5]. We proceeded along a similar approach

utilizing questions that arose out of the content of the project itself, and adding a 1–5 scale to better objectify the responses. The intent was to then follow up with the same questions, one year after the computer and Internet was installed, to evaluate whether or not there was a statistically significant difference in the responses.

2.2. Eligibility criteria

Applicants considered eligible for the project were required to provide information verifying that they were unable to leave their homes and were isolated from the community as a result. Caregivers for elderly and disabled homebound individuals could also apply. Personal income was not a factor considered in the eligibility criteria.

Local agencies such as the Office on Aging, home health agencies and dialysis clinics were the main source of referrals. Many self-referred individuals had learned of the program through newspaper or television stories on the CHIPs project.

Applicants were required to submit an application that provided demographic data, a questionnaire consisting of a 1–5 scale, and subjective statements from the applicants. Applicants who were unable to complete the necessary materials were given personal assistance via telephone or home interview. A home visit and interview was also completed on all applicants appearing to be homebound and isolated. Upon completion of the interview, the information was then presented to the CHIPs/TOP Review Committee for a final determination of eligibility.

2.3. Mentors

Prior to installing the computer, a volunteer mentor was assigned to teach email, Internet and basic computer skills. Volunteers from the community often participated, but many volunteers originated from the participant's family or circle of friends. Mentors signed an agreement consisting of a commitment to make weekly visits to the participant's homes. Mentors worked with the participants approximately 3 months to one year, depending upon level of need.

In order to assess progress, the participant's only requirement in the CHIPs program was to email a progress report to the Program Coordinator once every two weeks, describing the skills learned. Often the participants also described various achievements or stories that clearly indicated positive effects on the lives of these individuals.

2.4. CHIPs online community

The CHIPs Website was the first stage of the online community that eventually developed. The website contained a section called "Chipper's Corner," aptly named by the participants. It was composed primarily of the participants' contributions such as photos of the members, their pets, hobbies and some poems and short stories written by the participants.

Upon receiving a computer and acquiring adequate email skills, the participants could also choose to subscribe to the CHIPs Discussion Group, a Listserv for the CHIPs members. It became an essential part of the CHIPs online community, providing a method of contact with others living under similar circumstances. And the CHIPs Listserv was not limited to persons who were clients of the program. Requests to join the Listserv sometimes arose from others in the community who were homebound and isolated, but already had their own computers and who were in need of community with others. Pertinent issues such as health insurance and accessibility were brought to the attention of the Participants via the Listserv. This awareness has resulted in political action taken through emails, letters and phone calls to legislators. The potential for social change is limitless, as persons who were initially invisible in the community became agents of social change.

The last feature to develop was a chat feature, accessible to the participants from the CHIPs website. "CHIP chat" sessions first occurred on a regular basis at a specific time during the week. From that point, it evolved to the point that members were chatting with one another into the early morning hours. This was especially useful for those individuals unable to sleep due to pain or other reasons. Chat has been an especially important communication tool for one individual who has a severe speech impediment. He writes "... since I have been a member of CHIPs, it has been better for me to communicate with all of my friends!"

2.5. Education and employment opportunities

Access to a computer and the Internet has also led to home-based employment opportunities, allowing the participants to supplement their incomes. Some participants from CHIPs have been selected to participate in a pilot project, involving an online distance education program where an individual can obtain credentials in the area of Internet Technology (IT). Once again, the implications for economic change here is significant for this group of individuals who are often on a fixed income and in need of supplemental income to meet their needs.

3. Design of the study

The initial questionnaire completed at the time of application was utilized as the baseline for level of communication and participant satisfaction with the amount of contact they had with others. In order to assess the impact of computer use and Internet connectivity, the same questionnaire was then resubmitted to and completed by all participants who had utilized the computer for approximately one year. The questionnaires were completed by mail, personal interview, phone interview, or via the Internet. Pre and post-test scores were then computed to determine any significant changes in the levels reported on each of the questions.

3.1. Data collection

The data collected included scores reported on a scale from 1 to 5 (See Table 1). The questionnaire was designed first to assess the applicant's level of isolation and mobility in order to determine eligibility, and secondly to assess the impact of the CHIPs program on the individual's level of isolation approximately one year after working with their computer and the Internet. The questions therefore covered variables that would not be expected to change ("I am able to leave my house") to variables that could possibly change ("I am satisfied with the amount of contact I have with other people").

3.2. Variables

On the 1–5 scale, numbers one and five had a descriptive value, whereas 2, 3 and 4 did not. Therefore, it is possible that there was some variation on the values that each participant placed on these scores.

Not all participants completed the questionnaire at exactly one year from the date their computer was installed. Although the times usually varied by 2 to 3 weeks, one individual's was completed 1 year and 3 months after the date of installation. This individual, however, did not learn computer skills during the additional time and so the results are not expected to have affected the results.

Although most participants completed the surveys by mail, some surveys were completed via email, or during a phone or home interview. We are uncertain as to whether the differing modes of completion affected the outcomes.

Although the results indicate that the improvements in communication were due to computer use after one year, participants also received assistance from men-

Table 1 Sample questionnaire

| Question | Not at all | | Very extensively | | |
|--|-------------------|---|------------------|---|---|
| 1. I am able to move around my house easily. | 1 | 2 | 3 | 4 | 5 |
| 2. I am able to leave my house. | 1 | 2 | 3 | 4 | 5 |
| 3. I communicate with a friend or family member. | 1 | 2 | 3 | 4 | 5 |
| 4. I communicate with a community service or governmental agency. | ental agency. 1 2 | | 3 | 4 | 5 |
| 5. I require assistance with activities of daily living and self care. | 1 | 2 | 3 | 4 | 5 |
| 6. My knowledge of computers is: | 1 | 2 | 3 | 4 | 5 |
| 7. I am interested in learning computer skills. | 1 | 2 | 3 | 4 | 5 |
| 8. I use a computer to communicate with a friend or family member. | 1 | 2 | 3 | 4 | 5 |
| 9. I use a computer to communicate with a community/government agency. | 1 | 2 | 3 | 4 | 5 |
| 10. I am satisfied with the amount of contact that I have with other people. | 1 | 2 | 3 | 4 | 5 |

tors for varying amounts of times, depending upon need. We are uncertain as to how much of the improvements were due to the mentor service. Feedback from the mentors and participants indicated that many of the teaching relationships of the mentors evolved into friendships, and these relationships may have affected the results.

4. Demographics

4.1. Participant profile

One of the progressively attractive elements of the CHIPs project was the outreach to persons with severe or numerous disabilities. Eight of the participants were over age 60, and some of these individuals also had disabilities. Two of the participants were caregivers, and one of the caregivers was also elderly with a significant disability.

The population of this study represented a wide range of disabilities: stroke, paralysis, diabetes, multiple sclerosis, thyroid disease, epilepsy, emphysema, osteoporosis, pancreatitis, cerebral palsy, mobility impairments, orthopedic impairments, cancer, acquired immune deficiency syndrome and depression.

Income was not a factor considered in the eligibility criteria, so 12 of the participants income was unreported. However, two of the participants reported incomes over \$1000 per month, and six reported monthly incomes of below \$900, many of whom were on some form of public assistance.

4.2. Assistive technology

Of the twenty participants five did not require any type of assistive technology. Six of the participants had visual impairments requiring 17" or 19" monitors. Thirteen trackballs were provided in lieu of a regular

mouse for participants with limited hand coordination or fine motor skills. The trackballs and larger monitors, often accompanied with larger print lettering on the keyboard were the most often needed forms of assistive technology. Some individuals, however, required more sophisticated forms of adaptive assistance such as voice recognition software.

The computers that were installed varied from older model (486 processors) to relatively new Pentium I, II and III class computers. A Pentium class computer was always utilized for individuals requiring assistive technology, due to the requirement for higher memory and processing speed to run specialized software programs. Initially, as the program began as a grassroots volunteer program, all of the computers installed had 486 processors. At the time of the study, however, 14 of the 20 participants had utilized a Pentium-class system. It is important to note that two of the participants returned their computer to CHIPs after purchasing their own personal computer, thereby allowing the computers to be utilized by other persons who were homebound.

4.3. Community resources

The mentoring service was an integral part of the CHIPs project, as most participants had no previous exposure to computer use. Four of the mentors were friends and seven were family members of the participant. Although many of the mentors for the overall project were volunteers from the community, only two volunteers worked with subjects in this study. Finally, the entire existence of the CHIPs project was due entirely to a cooperative partnership between local and federal governments, private and non-profit agencies.

5. Results

As a follow-up, the same survey was completed by each participant after having utilized the computer for

Table 2
Paired t-tes

| Paired t-test | | | | | | | | |
|---------------|------------|----------|---------|-------------|--|--|--|--|
| Question | Degrees of | Mean X-Y | Paired | Probability | | | | |
| | freedom | | t-Value | 2-Tailed | | | | |
| 1 | 19 | -0.25 | -0.815 | 0.4251 | | | | |
| 2 | 19 | -0.5 | -2.127 | 0.0467 | | | | |
| 3 | 18 | -1.158 | -4.925 | 0.0001 | | | | |
| 4 | 19 | -0.85 | -2.602 | 0.0175 | | | | |
| 5 | 19 | -0.5 | -1.486 | 0.1536 | | | | |
| 6 | *15 | -1.562 | -6.484 | 0.0001 | | | | |
| 7 | 19 | -0.45 | -1.229 | 0.2341 | | | | |
| 8 | 19 | -3.3 | -13.653 | 0.0001 | | | | |
| 9 | 19 | -1.4 | -3.5 | 0.0024 | | | | |
| 10 | 19 | -2.316 | -6.6 | 0.0001 | | | | |

^{*15} degrees of freedom due to incomplete data.

approximately one year. In a paired t-test on each of the 10 questions, a significant difference was noted in 7 out of 10 of the questions. A significant increase was seen in all questions relating to the use of a computer to communicate, level of communication and level of satisfaction in the amount of contact with others.

5.1. Discussion of results

The results from question #1 are not significant, but no change in mobility was expected. Question #2 is significant at the 0.05 level. Although physical mobility was not affected, it does appear that better communication via the computer led to the participant's ability or willingness to leave their house more often. This finding further supports reports by participants that their desire to meet others was increased. For example, one participant, who had not left her house in 6 months, felt compelled to attend the CHIPs gathering so that she could physically meet the participants with whom she had formed friendships.

Question #3 shows a significance in increased communication with friends or family. Similarly, question #4 shows significantly better communication reported with community service and governmental agencies. This finding may be of particular interest to the Department of Commerce, Technology Opportunities Program (TOP). In addition to their goal of decreasing the digital divide, TOP funded the CHIPs also to provide better access to governmental and community services for individuals who could not leave their homes. These preliminary results support the idea that the project did help participants to more easily access those governmental and community resources.

No significant change in answers to question 5 is consistent with our expectation that the participants still require assistance for activities of daily living. This includes visits from home health workers and caregivers. Some of the participants failed to answer question #6, possibly due to lack of clarity of the question, which was intended to measure their ability to use computers. For this question, the total number of subjects was decreased in the statistical analysis (see degrees of freedom for Question #6 under Results). Despite fewer subjects in the analysis, the results were significant, suggesting that the participants increased their knowledge of computers. This is a change that would be expected, especially with the assistance of mentors.

No significance was found in changes in answers to Question #7 regarding the client's interest in learning computer skills. This may indicate the participant's are satisfied with their level of computer skills after one year. This question was intended to measure level of motivation, an important factor that was considered by the CHIPs/TOP Review Committee when determining applicant eligibility. However, some individuals have consistently continued to build upon their computer skills and are motivated to continue to learn. We would have expected that more of the participants felt this way. Perhaps many of them have reached their level of competency and/or are satisfied with being able to email and surf the internet and do not see the need for additional uses of the internet.

Changes measured in Questions 8, 9, and 10, are all significant. We were expecting significant results in these areas that reflect the participants' use of computers for communication with friends, family, community and governmental service agencies. Here again, question #9 may be of particular interest to governmental or community service agencies desiring better contact with this population. Specifically relating to communication via computer, participants reported better contact with their home health agencies, increased self-sufficiency due to ordering prescriptions online, and better access to information on disability benefits and other government-based programs.

Question 10 was perhaps the most important with respect to the intrinsic value. The participants interpreted the question to be related to their amount of social contact. The question was intentionally worded in a manner that would not seem invasive to the participants, many of whom suffer from depression. We are assuming that a significant increase in personal satisfaction in the amount of contact with others results in a better overall sense of well-being.

In sum, these results seem to verify that the participants utilized their computer skills to communicate more with others, that this communication led to increased social contact and that they are more satisfied

with the amount of contact that they have with others. These results are certainly more than what would be expected randomly, and provide a good basis for a more formalized study.

5.2. Recommendations for future research

In evaluating a program similar to CHIPs, we would recommend a larger number of subjects. Although the CHIPs project served approximately 85 clients, our study was limited to the 20 members that had computer access for a year, and a more comprehensive study was not possible at the time. More specifically, this study would have also benefited from a control group that receiving the same weekly visits from mentors as the test subjects, but without computer installation and training. In such a study, it would be useful also to measure longer-term improvements in outcome, such as a follow-up questionnaire six months or more following discontinuation of the mentoring service. If, as seems likely, positive changes were maintained longer by the computer group than the mentor-only group, this would lend greater strength to the conclusion that access to and knowledge of computers and the internet was the primary cause of many of the improvements reported by subjects of the study.

We would also recommend an established valid and reliable measurement tool such as the UCLA (University of California Los Angeles) Loneliness Scale [3]. Making efforts to focus on subcultures could also bring to surface much needed information on minorities and other groups previous overlooked [2]. Within the scope of the CHIPs program itself, it was obvious that many applicants who were ineligible (individuals in nursing homes, group homes, and housing projects) could have benefited from access to computers and the Internet. Further studies on these subcultures, utilizing a larger number of subjects and isolated interventions could produce results clarifying the therapeutic factors and their effects.

6. Conclusion

The numbers of elderly and disabled individuals living alone are increasing on a global basis [2,7]. Furthermore there is the neglected issue of minorities living alone. And the advancement of technology and environmental control systems, is potentially increasing the amount of time that elderly persons can live at home [8]. It seems imperative that social policy must

be developed to meet the increasing need for Assistive Technology access for these individuals. Although there is some evidence that notice has been taken [5], it has still not met the demands of the day [2,4,7]. In addition to social policy changing at a much slower pace than technology, there is another problem inherent in the advancement of technology: "By the time a particular access problem has been addressed, technology has advanced to a point where the same or a similar problem re-occurs." The suggestion offered is a more progressive approach by designing "access features into a product, as early as possible" [9]. By now a larger population of persons who are elderly and disabled have had some access to computers and some experience with Assistive Technology. We could benefit in knowledge from their direct experiences, perhaps in focus groups designed for this specific purpose [10]. Any of these actions could be one step closer to narrowing the gap of the digital divide in traditionally underserved populations, and thereby positively affecting their quality of life and health by simply improving their access to technology.

We'd like to conclude by quoting a progress report received by one of our original participants, a man who experienced several severe disabilities in the prime of his life. He suffered from a neck injury, heart problems, and depression, all three factors leading to isolation within his home. After receiving his computer from CHIPs, he described his story as follows:

"I started sinking into my small dark room, no ambitions, depression as my best friend. I am living on 20 or so medications. I am not able to do any type of physical activities. I was rarely aware of what world I was in. I had made up my mind I was going down hill with no way to recover. Then, I was introduced to a program. CHIPS and KORRnet . . . As I was introduced into the world of computers and cyberspace my life has changed. I began a revelation. . . I have access to the outside that would never have been possible without CHIPS, the staff, KORRnet and my connections to the Internet. This computer is my friend. It saved me from sinking down to the abyss of no return. Though still disabled, still gravely ill, I am here and I want to help others. I am sure there are people worse off than myself... The best thing I can say about the computer and KORRnet, let me say it has literally saved my life ... "

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