



## Combating Isolation and Loneliness with an Online Personal Network Called Tyze

Developing and implementing Web-based personal support networks for people with disabilities, elder adults and others who are vulnerable and isolated

### SUMMARY

To combat isolation and loneliness among vulnerable individuals, including frail elders and people with disabilities, the [PLAN Institute for Caring Citizenship](#) and [Tyze Personal Networks](#), both based in Vancouver, British Columbia, promoted the use of a Web-based social support service. The service helps people create secure, online personal networks called Tyze.

Each Tyze network provides unlimited online storage and a range of features—including e-mail, a calendar, stories, photos, and goals and tasks—to support relationships among an individual and his or her friends, family, and health care and other service providers. The project gave organizations the tools to build networks for people in their care.

Examples of people with such networks include:

*Mary Ann, who had an obscure disease with no dedicated support group.* She used Tyze to create a small network of family, friends and specialists who have treated people with the disease, all of whom who posted new information regularly. Mary Ann felt that her children became more involved in her care, and that she was more in control of her life and her condition.

*Tricia, who had cerebral palsy and related complications.* Her Tyze network let her friends keep up with her repeated hospitalizations, so they knew when and where to reach her. Tyze also met a wide range of other needs, from helping her friends plan a birthday party to facilitating suggestions for second medical opinions. "Tyze has opened up many doors I thought were closed," she said. "The support I've received has been wonderful, remarkable and truly unbelievable."

## Key Results

In reports to the Robert Wood Johnson Foundation (RWJF), the PLAN Institute and Tyze Personal Networks cited these key results. Project staff:

- Worked with health care and social service organizations in San Francisco; Port Angeles, Wash.; and Vancouver, British Columbia, to launch the Tyze network model.
- Refined the network model to encourage communication among an individual's informal caregivers (family, friends and neighbors) and formal caregivers (clinicians and other service providers), and worked with 14 organizations in northern California to implement it.
- Created the Tyze Personal Networks [Web site](#) to inform providers and individuals about the service, and trained 106 people to work as network facilitators.

## Key Findings

An unpublished report from the [Center for Technology and Aging](#) in Oakland, Calif., which evaluated the project, cited these key findings:

- In an online survey completed by 70 network participants, 86 percent said they were satisfied with the Tyze experience. Some 78 percent said the network helped them better connect with the individual at the center of the network, and more than half (58%) said it helped them better support that person.
- "Early anecdotal evidence suggests that both organizations and end-users find the service valuable due to its ability to improve the emotional well-being and independence of older adults," according to the report.

## Funding

RWJF provided two grants totaling \$797,173 for the project to the Tides Canada Foundation, which acted as fiscal agent. The first grant ran from December 2007 to February 2009, and the second from November 2009 to April 2011.<sup>1</sup>

## CONTEXT

By reducing isolation and loneliness, social support networks significantly improve people's health. Yet individuals with disabilities, chronic illnesses or dementia often lack such networks, which are also essential to sustaining a high quality of life.

Many seniors, in particular, find aging in their homes and communities challenging, given far-flung families and limited access to social services. At the same time, the

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<sup>1</sup> The first grant ID# was 062707 and the second was ID# 066681.

fastest-growing group using online social networking tools is adults ages 65 and older, followed by those ages 50 to 64.<sup>2</sup>

Meanwhile health care and social service agencies are facing a growing demand for services amid declining budgets. Finding ways to collaborate with individuals' personal support networks is critical to meeting these needs at low cost.

### **RWJF's Interest in This Area**

The project fit with the Vulnerable Populations Portfolio's goal of identifying and testing new approaches to address the health and social factors that impact the health status of the most vulnerable. The team saw the Tyze network Web service as having the potential to increase the efficiency, cost effectiveness and reach of social networks, and to reduce the isolation experienced by an increasing number of vulnerable people.

### **THE PROJECT**

To combat isolation and loneliness among vulnerable individuals, including frail elders and people with disabilities, the [PLAN Institute for Caring Citizenship](#) and [Tyze Personal Networks](#) promoted the use of a Web-based social support service. The service creates and coordinates secure, online personal networks known as Tyze, which typically include three to 25 participants.

Each network provides unlimited online storage and a range of features—including e-mail, an online calendar, stories and photos, and goals and tasks—to support relationships among an individual and his or her friends, family, and health care and other service providers. The project gave social service organizations the tools to launch and maintain online networks for people in their care.

Organizations buy annual subscriptions to Tyze, which include online training and mentoring on how to create networks for the people they serve. The price varies with the number of networks they create. Individuals may also build their own networks by buying an annual subscription to Tyze (\$129 for an unlimited number of participants in 2011).

The PLAN Institute piloted the use of Tyze networks from 2007 to 2009 in three West Coast cities. After incorporating as a separate organization in January 2009, Tyze Personal Networks pursued the second phase of the project: promoting the use of Tyze among community-based organizations in northern California.

Under a \$63,000 subcontract, Mary Jobling of the [Community Living Campaign](#) helped train staff at participating organizations in building Tyze networks for their clients.

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<sup>2</sup> Lloyd J. "Seniors Surge on Social Networks," *USA Today*, Dec. 15, 2010.

## Advisers and Communications

The project's advisory committee included:

- David Lindeman, executive director of the Center for Technology and Aging, Oakland, Calif.
- Anne Hinton, executive director of the Department of Aging and Adult Services, San Francisco
- Kathy Kelly, executive director of the Family Caregiver Alliance, San Francisco

During the project, staff made presentations on Tyze at conferences in California, and at the annual conferences of the American Society on Aging in 2010 and 2011.

## Evaluation

Under a \$25,000 contract to the Public Health Institute, in Oakland, Calif., its [Center for Technology and Aging](#) evaluated the project. The evaluators conducted two online surveys of network participants, and interviewed staff at 10 social service organizations in September 2010, and at 14 organizations in March 2011.

## Other Funding

Saint Christopher's Foundation of Vancouver provided a \$50,000 grant to the PLAN Foundation in March 2009, to enable it to develop a business plan for disseminating the Tyze model.

## RESULTS

In reports to RWJF, the PLAN Institute and Tyze Personal Networks indicated that project staff:

- **Worked with health care and social service organizations in San Francisco, Port Angeles, Wash., and Vancouver, British Columbia, to launch the Tyze network model.** The PLAN Institute provided each organization with its own Tyze Web site, training and mentoring in building online networks for their clients. These networks drew some 700 participants.
- **Refined the network model to encourage communication among an individual's informal caregivers (family, friends and neighbors) and formal caregivers (clinicians and other service providers).** For example, project staff added a vault—a section of the network where formal caregivers can leave confidential information that other participants need specific permission to read.
- **Worked with 14 community-based organizations in northern California to implement the revised model.** These organizations, which included San Francisco

Village, the Family Caregiver Alliance and the Family Service Agency, developed networks for clients that drew some 400 participants.

About 10 percent of those participants were professionals—physicians, social workers, nurses and home health aides, according to Vickie Cammack, executive director of Tyze Personal Networks and project director.

- **Created the Tyze Personal Networks Web site to inform providers and individuals about the service, and trained 106 people at participating organizations to help clients set up Tyze networks.** Project staff also developed marketing and training materials, tutorials, sample networks and other tools to help organizations build Tyze networks for their clients.

## EVALUATION FINDINGS & RECOMMENDATIONS

### Findings

In an unpublished evaluation report, the Center for Technology and Aging cited these findings:

- **In an online survey completed by 70 network participants, 86 percent said they were satisfied with the Tyze experience.** Some 78 percent said the network helped them better connect with the individual at the center of the network, and more than half (58%) said it helped them better support that person.
- **The project had "modest success" in creating personal networks, given that 14 organizations in the second phase of the project created a total of 95 networks.** The organizations had aimed to create 10–15 networks each, but averaged 7.9.
- **Implementation challenges largely reflected organizational and end-user barriers, rather than deficiencies in the Tyze technology.** Some organizations fell short in the number of networks they hoped to build because they did not investigate their clients' access to computers and sophistication in using them. Others faced staff shortages and funding cuts, so they could not devote enough resources to helping their clients create networks.
- **"Early anecdotal evidence suggests that both organizations and end-users find the service valuable due to its ability to improve the emotional well-being and independence of older adults,"** the report stated. "Organizations have spoken highly of recommending the service to others, as well as the support and training provided by Tyze." Comments from participating organizations include:

*"Tyze is great for allowing families to stay in touch and know how elder members of the family are coming along and how they can help."*

*"Tyze provides a more secure social network, which means younger users or users with special needs are more protected in their Internet use but can still have fun connecting with others online."*

## Recommendations

The Center for Technology and Aging recommended that Tyze Personal Networks:

- **Develop an evidence-based method for showing outcomes from Tyze, to help improve the service and secure funding for it.**
- **Screen both organizations and individuals carefully, to ensure that they can use and benefit from Tyze.**
- **Make network features such as videoconferencing easier to use, and translate Tyze materials into languages other than English.**
- **Find dedicated funding for Tyze and other models designed to foster collaborative care.**
- **Develop more robust privacy guidelines for Tyze networks, particularly to enable traditional health care providers to participate.**

## LESSONS LEARNED

1. **Organizations should assess their capacity and workflow carefully before implementing Tyze.** Although small community-based organizations were eager to use technology to innovate, their limited capacity and funding hampered their efforts to do so. (Project Director/Vickie Cammack)
2. **Offering a new tool and service requires developing trusting relationships with clients and understanding their needs.** Agencies dealing with developmentally disabled individuals were the most effective in using Tyze, because they often had experience building support networks for their clients and technically savvy employees who championed the service.

Such agencies were also flexible and creative in their application of Tyze. For example, they used Tyze networks to help service providers collaborate. (Project Director/Cammack)

3. **No single implementation model works for Tyze.** Because organizational workflows, capacities and resources vary, Tyze Personal Networks is developing new tools to allow some agencies to share information and resources with clients without actively participating in their network. (Project Director/Cammack)
4. **Offering a new technology-based service requires flexibility in workflow and organizational process.** "Tyze isn't a technology, it's a technology-enabled service," Cammack commented. "It requires a cultural shift for many organizations: they have

to move from an individual model of care to a network model of care." Some organizations were unable to adapt.

## AFTERWARD

Tyze Personal Networks is partnering with the University of Indiana to implement Tyze with the family caregivers of elders. The Community Living Campaign received a 30-month grant in September 2010 from the U.S. Department of Commerce to train seniors and people with disabilities in using social media, including Tyze.

The British Columbia Ministry of Health is spending \$1.8 million to develop Tyze networks for people with chronic illnesses and early-stage dementia. One goal is to have physicians who are not part of a patient's network place medical information in his or her vault.

In June 2011, Tyze Personal Networks and two other organizations received \$3 million from the British Columbia government to implement Connect for Care, a program to help elders and individuals with disabilities remain socially connected while living at home.

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