

Unique and Successful Methods for Designing Products for Stroke Survivors

Design4Stroke team project 2006–2007

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Sponsorship of the project: Archeworks, an alternative design school based in Chicago, in partnership with The Rehabilitation Institute of Chicago's Rehabilitation Research and Training Center (RRTC), Northwestern University's Institute for Design Engineering Application (IDEA) with support from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR H133B031127) explored design applications for improving the work and home life of stroke survivors. This project is the first design application in a medical research project to be funded by the NIDRR.

Introduction

Stroke is the third leading cause of death in America and the number-one cause of adult disability. Each year, 700,000 Americans suffer a stroke. In this design case, the team's objective was to design objects for stroke survivors, paying special attention to survivors suffering from aphasia. Aphasia is an impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury. Someone with aphasia may have trouble finding the right word, may find it impossible to express distinct ideas, or may only be able to repeat one syllable. The mission of the design team was to enable stroke survivors to reengage in dignified lives and begin their new lives through well-designed products. This paper discusses two aspects of the design effort: first, the unique and effective details of the process and secondly, the designing-for-aphasia effort as an effective model for reintegrating stroke survivors.

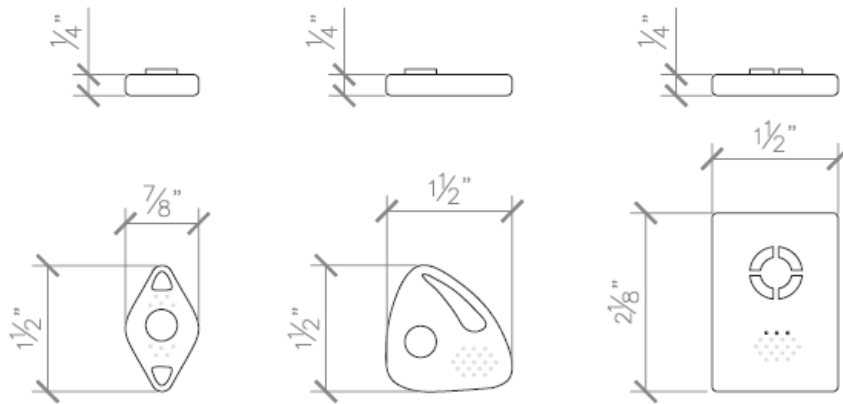
Unique and Effective Details of the Process

Shortly before the conclusion of the eight-month design effort, the team met to review what worked well within the process. Six factors contributed to the effort including: a team that had users as part of the design team, creative approaches to feedback, aggressive work delegation, intentional role reversal, frequent public critiques, and extraordinary resources for further testing of products.

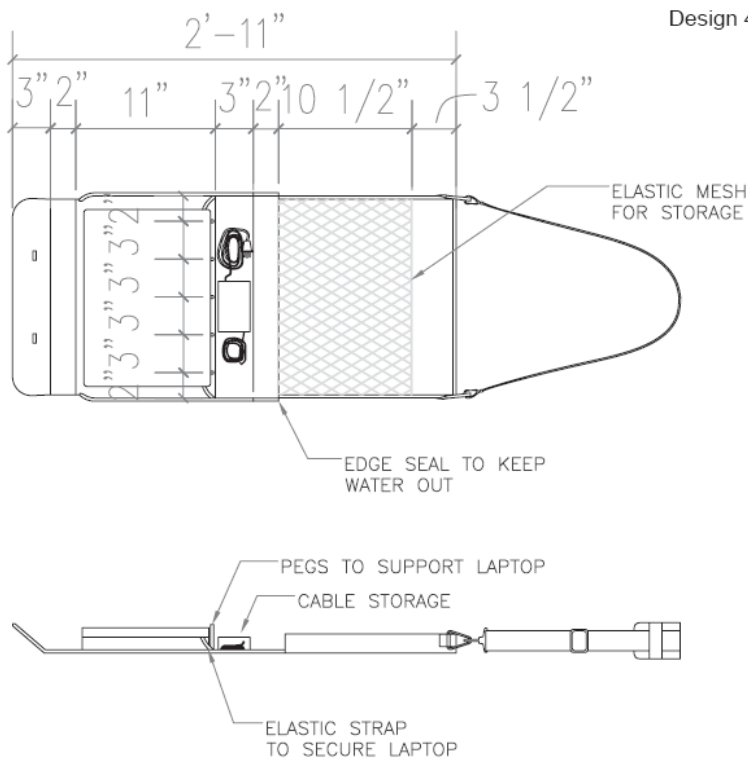
1. Users as the designers. Two of the five students on the design team were stroke survivors with aphasia, and a third member of the team was a speech pathologist from the Rehabilitation Institute of Chicago. The other two team members were an interior architect and a higher education professional. The team met twice a week for three hours to work on project ideas.

The benefits of the team composition were readily apparent from the beginning. Most of the team's ideas stemmed from problems and situations articulated by two team members with aphasia. The initial work was to listen carefully as the two team members with aphasia talked about the frustrations they faced on a daily basis. As ideas were incubated, it was clear and quick for the team to understand which ideas had merit and broad appeal, simply from the at-hand feedback from the stroke survivors.

For example, a particularly upsetting incident with an unsympathetic bus driver turned into an idea for an inexpensive, rerecordable fob that could be put on a key chain, a bracelet, or simply clipped on. A person with aphasia tries to speak or ask questions in a variety of situations and many times cannot speak clearly, quickly, or at all. Such a device would provide a tool for a person with aphasia to express certain things they need such as basic aphasia facts, emergency information, needs and wants, or personal/conversational information.



For example, oftentimes, someone with aphasia will also have a combination of other stroke effects, such as hemiparesis or paralysis on one side of the body. One of the team members, who has mild hemiparesis on her right side, expressed difficulty she had when moving or walking with her laptop. Out of this conversation began a project for laptop case which contains the laptop but does not need to be removed and allows the user to pick up the laptop with a handle or strap.



It was impossible for the group to stray far from the projects at hand, as the membership was a direct reminder of the team's work. In both examples, drawn from everyday difficulties of the team members, a solution was proposed that not only solved the matter at hand, but has broader appeal outside of the community of stroke survivors following universal design principles.

2. Creative approach to feedback. When ideas were out of incubation and ready for broader feedback, initial attempts at gathering data needed tweaking. The question was asked: how do you gather

quantitative feedback from individuals who have trouble communicating? The team had designed a simple Likert scale with icons for rating the prototypes and ideas that had come out of initial brainstorming sessions. Focus groups were conducted with aphasia support groups at the Rehabilitation Institute of Chicago's LIFE Center.



Communication Aids

DON'T LIKE

1



2

OKAY

3



4

LOVE IT

5



For some users with aphasia, numerical feedback was overwhelming. When the data was gathered and analyzed, it was clear another approach was needed: as some of the users had difficulty comprehending the scale due to the aphasia and language difficulties.

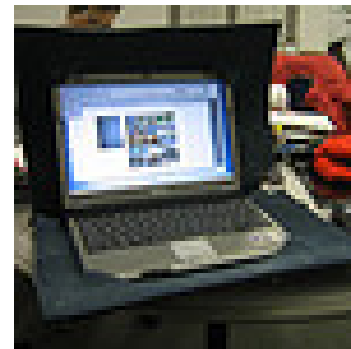
A redesign of the feedback sessions occurred. This time, when ideas and prototypes were presented, users were equipped with fake money (photocopied five dollar bills). Each user was asked to vote with their money, and was asked immediately thereafter why he or she had distributed their money as they did. When the directness of "voting with their wallet" was introduced, many users were able to clearly and straightforwardly articulate why they'd 'paid' more for a certain idea. This reduced the ambiguity encountered with using the symbolic scales for users who struggled with comprehension and expression, and was a method that effectively got to the bottom line—how much would you pay for a product.



\$110



\$10



\$90

3. Aggressive delegation of work. The class met in Chicago, host to a number of universities and colleges with design programs. While the team had an excellent sense of direction, the team had few

resources to create many of the mechanically-inclined ideas. It was decided to resource out ideas to as many other people outside of the group as possible. The team submitted two of its ideas, a one-handed nail clipper and spill-proof cafeteria tray, to the Engineering Design and Communication (EDC) program at Northwestern University. EDC is a two-quarter sequence of courses for first-year engineering students in Northwestern University's McCormick School of Engineering and Applied Science. The program routinely takes on a number of socially-oriented industrial design problems, and in this case, had 64 students working on the two projects for ten weeks. During the ten weeks students evaluated design goals and criteria for success, conducted in-depth research-including interviewing potential users and analyzing user needs, developed a design solution that met user needs, produced a prototype that demonstrated the features of the solution and prepared a final written report and oral presentation.



The connection to RIC allowed the team to provide many people with stroke and aphasia to be users for the student's EDC trials. From that connection, the team asked one of the instructors to discuss potential further development of the winning prototypes.

For the one handed laptop bag effort, the team partnered with two graduate students at the School of the Art Institute of Chicago (SAIC). Since both students were experienced in drawing and computer rendering, they were able to help render the bag designs quickly and professionally. Their work made it simple for the team to communicate the bag concept to potential bag manufacturers.

In the end, the team had the help of 3 professors from two universities, 64 industrial design students, 2 material designers, 3 professional industrial designers, and 2 children's books authors. This collaboration between disciplines made design solutions possible that would not have been realized without expanding the project team.

4. Reverse roles, became clients. The team outsourced the work on the ideas for a one-handed cafeteria tray and a one-handed nail clipper to the EDC, but continued to provide feedback and users for testing to the EDC groups. This decision effectively reversed the role as designers: the team became the client instead of the designer! The ten weeks spent assisting the EDC students allowed the team to experience a new design process and become more user-minded. This role reversal allowed the team to see another design group's process in motion. This in turn freshened the design team's perspective on its closely-held projects.

5. Frequent public presentations about work-in-progress. Over the eight months of the class, four public critiques of the work in progress were held. This allowed for feedback from a variety of professionals and students from all walks of life. The teammates, including those with aphasia, were

expected to present and discuss the work in progress. Moreover, the team took the opportunity during the public forum to ask for help with the product creation. Through this process, the team received contacts from many people including professors, writers, industrial designers and government workers.

6. A fully committed executive sponsor. The executive partner, the Rehabilitation Institute of Chicago, was an outstanding resource. RIC funded the project, selected the two teammates with aphasia and a speech pathologist, scheduled meetings with Elliot J. Roth, M.D. Senior Vice President for Medical Affairs every 6 to 8 weeks, and most importantly, provided many willing users to provide direct feedback. The speech-language pathologist's role was to provide support for the team members with aphasia and liaison with RIC on a regular basis. The Rehabilitation Institute of Chicago's Center for Aphasia Research runs a series of classes and groups for stroke survivors who have aphasia. The groups meet every week, and during the development of the projects, the team was able to meet with these groups to get extended feedback about the projects. Without this resource, the team may have otherwise struggled to find individuals outside of the immediate team to validate the work.

These six elements allowed the team to be focused, energized and successful in spite of the complex task at hand.

Designing-for-Aphasia Process as an Effective Model For Reintegrating Stroke Survivors

As stated earlier, the mission of the design team was to enable stroke survivors to reengage in dignified lives and begin their new lives through well-designed products. This well-crafted design effort turned out to be a therapeutic product itself.

The project had not been set up as a therapeutic effort. However, two of the teammates were dealing daily with the effects of stroke, specifically dealing with aphasia and the difficulty of communicating. These teammates were expected to participate fully in the design process which included:

1. A 3-hour studio twice a week
2. Four public critiques involving public speaking
3. Candid storytelling from their own lives
4. Idea generation for products
5. Assuming a tie-breaking role when the team could not decide on a direction
6. Monitoring daily habits for clues on products
7. Regular contact via email
8. Weekly classes on ethics of design and future studies of design
9. Weekly reading, research, and papers

Jan Novak reported being able to talk much more smoothly by the end of class. Moreover, prestroke, she had been a shy person when it came to public speaking. This design effort required her to discuss her stroke in public, which she discovered she could do quite well.

Yes I did find by talking to my teammates I came to realize that I can talk better because part of the therapy that the speech therapist would say to me was that I had to talk and that I can't sit back and not talk all day. So that is what I learned in the Archeworks experience . . . I discovered that I can talk better by interacting with other students and interacting with my teammates.

I have always been shy and giving presentations was always a . . . challenge for me . . . [S]o . . . doing the critiques for Archeworks and giving the presentations I could find that I could do it and if I presented real slow and not too quickly I could do it fluently and better than I had anticipated I could . . . I'm a self-conscious person but I even said something to my husband about that because he knows how self-conscious I am and I said once I got up to the microphone in the first critique I started feeling comfortable and started talking and nothing was going to stop me and I didn't feel self-conscious at all.

Because I learned something, a whole lot, just by this process of working and designing a product from the ground up and . . . because I don't think I would have ever been able to experience that in my life before the stroke

Andy Rizzuto reported staying in good mental shape, given the repeated work of problem solving.

Oh sure, just because it gives you something to do everyday, to think about subject to think about talking to think about expression otherwise you go alone you have to have people to talk to and use the brain. Because it's really like going to school to learn again this is a good subject talk about different subjects talk about different things, talk about life.

Well, because my brother had a stroke and my father died of a stroke, I already knew what a stroke is. So I helped my brother with his stroke, so I knew what kind of background is. so when I went through this I really knew what stroke is. So it's great that I talk to people new people because I saw what happened to my brother. It was a really positive thing. I wasn't self-conscious at all.

Edie, the speech pathologist, seldom had to function in her professional capacity. The design of the process consistently focused on talking and problem solving which in turn kept Jan and Andy 'in shape'. Edie was able to focus on other aspects of the design process, most notably the logistics of working with the EDC program.

However, Edie's presence was crucial for setting the tone for the entire 8-month design effort. On the first days of class, Edie encouraged Jan and Andy to be candid about their difficulties with expressing themselves and to be clear about how they wanted to be treated. Jan and Andy made it clear that they didn't want any special treatment. Both of them also made it clear that their pet peeve with aphasia was having their sentences finished by others or other general signs of impatience. Once these issues were out on the table, the other team members knew how to conduct themselves.

It is recommended that this designing effort, which includes stroke survivors and speech pathologists as full participants, become a model for aphasia therapy. This practice has the benefit of improving speech patterns, allowing survivors to improve the well-being of others with similar struggles, and encourage creative problem solving. Implementation details include:

1. A formal study of speech therapy techniques and product development techniques (including setting ground rules)
2. Creating a curriculum for such a class at the RIC LIFE Center.

Conclusion

The Archeworks/RIC design effort had as its goal enabling stroke survivors to re-engage in dignified lives and begin their new lives through well-designed products. It succeeded as a conventional product design effort due to many factors, as enumerated in this paper. More importantly, this design effort, which was radically user-centered, succeeded as a product in itself. It offered the team members who were also stroke survivors an opportunity to improve their speech and language skills in a supportive environment, to actively work to solve problems to benefit themselves and others living with stroke and aphasia, and to reintegrate into the community. This effort is a testament to thoughtfully conducted user-centered design.