Research In Focus: A Weekly Digest of
New Research from the NIDILRR Community

"Even people who cannot speak should be able to make their voices heard": Soliciting user feedback from people with severe speech and physical impairments

People with severe speech and physical impairments (SSPI) often have trouble communicating due to disabilities that affect their muscle control, such as cerebral palsy (CP), amyotrophic lateral sclerosis (ALS), or stroke. These individuals can benefit greatly from augmentative and alternative communication (AAC) devices and programs that can translate typed text to speech, like the computer system used by astrophysicist Stephen Hawking who has ALS. A brain-computer interface (BCI) is one new type of interface being developed that, in the future, will allow people to control their communication devices using only their brain waves. Although researchers have made great progress in developing BCI systems for people with SSPI, real user experience may be left out of the development process.

While people with SSPI have been included in the performance testing of BCI technology, few researchers have gathered feedback from users on how well these systems actually work for them. This feedback is important, since people with SSPI have the most to gain from these new communication systems. Getting feedback from users with severe communication disabilities can be challenging, since they may have trouble answering questions on a typical questionnaire or expressing their opinions verbally during testing. One recent NIDILRR-funded study looked at how developers can use AAC programs and techniques during testing to gather meaningful feedback from this key group and use their input for future development.

Researchers at the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication utilized a combination of technology and techniques to gather user feedback from 12 people with SSPIs who were testing a new BCI system. They tested a system called the Rapid Serial Visual Presentation (RSVP) Keyboard™, which flashes letters on a screen and then uses a combination of brain-wave detection and word prediction software to determine which letters the user wishes

to type. All participants had the capacity to answer yes/no questions, either verbally or using a communication device that they controlled with their fingers, feet, head, or eye gaze.

To get feedback on their BCI experience, the researchers had the participants complete brief questionnaires about how easy or difficult the device was to use, how comfortable they felt physically while using it, and how satisfied they were with the device. The researchers employed several AAC strategies to make communication easier. First, the researchers read questionnaire items aloud while also presenting them in large print. This ensured that participants with visual or auditory processing problems could understand the questionnaire questions. Second, each participant answered the questions using an AAC technique called partner-assisted scanning. The researcher read each answer choice aloud while simultaneously pointing to the corresponding print number on the screen. When the participants heard and saw the response choice that they wanted to choose, they gave a signal, such as a sound or an eye blink. The researcher then asked for yes/no confirmation from the participants before recording each questionnaire response. There were always two researchers present during the study, so one researcher would handle the equipment while the other focused on communicating with the participants. Finally, after the questionnaires were completed, the participants were invited to give free-response feedback using their preferred communication method, and to submit additional feedback by email if desired.

The researchers found that these AAC methods aided the participants in giving usable and relevant feedback without adding significant time to the overall testing plan. Participants were able to complete the questionnaires in five minutes or less. By using their preferred communication methods, participants were also able to ask questions during testing and offer narrative feedback, in addition to the data collected from the questionnaires.

The authors emphasized that people with communication disabilities have vital perspectives to offer on new communication systems that are being developed, such as BCIs. People with SSPI can be part of the development process and aid developers in creating quality products. This process is called User-Centered Design. Gathering this

feedback is not only important, but relatively easy to accomplish with communication supports such as partner-assisted scanning and AAC technology. In the future, BCI developers may want to use similar questionnaires and AAC methods to solicit feedback from product testers with SSPI, especially feedback about overall user satisfaction. The authors also suggested that opinion questionnaires could be used when selecting AAC and other assistive devices to provide an opportunity for each user to choose the one that works best for him/her. AAC devices and methods can give users a voice early in the BCI development process, creating a tool they can be comfortable using every day.

To Learn More

The RERC on AAC continues to develop and test BCI technology to improve communication access for people with minimal movement. Learn more about their current studies at https://rerc-aac.psu.edu/research/r1-investigating-use-of-a-bci-with-enhanced-language-modeling/

Melanie Fried-Oken, PhD, from the RERC on AAC shared exciting advances in BCI technology for people with ALS in a podcast with the Greater Philadelphia chapter of the ALS Society: http://alsphiladelphia.podbean.com/e/episode-25-bci-with-melanie-fried-oken/

As well as the InDATA podcast: http://www.eastersealstech.com/2015/10/30/atu331-brain-computer-interfaces-bci-with-dr-melanie-fried-oken/

The authors has published two other articles that include people with SSPI in the BCI development process that might interest you. They are:

Andresen, E. M., Fried-Oken, M., Peters, B., & Patrick, D. L. (2015). Initial constructs for patient-centered outcome measures to evaluate brain-computer interfaces. Disability and Rehabilitation: Assistive Technology, (0), 1-10.

Peters, B., Bieker, G., Heckman, S., Huggins, J. E., Wolf, C., Zeitlin, D., & Fried-Oken, M. (2015). Brain-computer interface users speak up: the Virtual Users' Forum at the 2013 International BCI Meeting. Archives of Physical Medicine and Rehabilitation, 96(3): S33-S37. This article is available from the NARIC collection under Accession Number J70939

To Learn More About this Study

Peters, B., Mooney, A., Oken, B., & Fried-Oken, M. (2016). Soliciting BCI user experience feedback from people with severe speech and physical impairments. Brain-Computer Interfaces, 3, 47-58. This article is available from the NARIC collection under Accession Number J73822.

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